

Integration of palliative care in African health systems: a systematic review



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Abstract

Millions of people need palliative care worldwide for symptoms associated with life-threatening illnesses, yet few receive it. This is particularly true in low-and-middle income countries, meaning that most are left without support and pain relief at the end of their life. Access to palliative care is now being understood as a human right and the ethical responsibility of health systems. This has resulted in increased international focus and a call to integrate palliative care into health systems to promote access, and inversely to strengthen health systems. Yet how to do this in low-and-middle income countries is unclear.

This study used scoping and systematic review methods to provide synthesised evidence on the approaches and interventions being used to integrate palliative care into African health systems, as well as describe lessons that can be learnt from these efforts. 40 articles were identified in the systematic review that described 51 different interventions that integrated palliative care into part of the health system in one or more African countries. The integration of palliative care services was rarely linked to health systems strengthening and concepts associated with integration were used inconsistently, if used at all. Core themes emerged on facilitators and barriers to the integration of palliative care into health systems. Facilitators included the use of a system-wide approach, the creation of sustainable partnerships, and making the patient central to integration interventions. The health system also needs to be able to support integration. This requires the presence of necessary policies and resources for palliative care, together with sufficient health workers who are trained and motivated to provide palliative care. Findings provide contextual evidence to guide implementors and decision makers seeking to integrate palliative care into health systems in Africa, as well as other low-and-middle income countries.

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Plagiarism declaration

I, Lara A. Court (CTRLAR001), hereby declare that the work on which this dissertation/thesis is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

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Abbreviations

APCA	African Palliative Care Association
CBO	Community-based organisation
CPC	Children's palliative care
HCBC	Home- and community-based care
HIC	Higher income countries
HPSR	Health policy and systems research
ICESCR	International Covenant on Economic, Social and Cultural Rights
LMIC	Low- and middle-income countries
NCD	Non-communicable disease
NGO	Non-profit organisation
PC	Palliative care
PHS	World Health Organisation's Public Health Strategy
PLWHA	People living with HIV and AIDS
SSA	Sub-Saharan Africa
TB	Tuberculosis
THP	Traditional Health Practitioner
UHC	Universal health coverage
WHA	World Health Assembly
WHO	World Health Organisation

Glossary of key terms

This glossary clarifies key terms – which are further described in Appendix 2.

Health system	A health system consists of all organisations, structures, people and efforts whose chief purpose is associated with health, whether it be to improve, promote or preserve health (Gilson 2012; World Health Organisation 2007).
Palliative care	“Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (World Health Organisation 2002).
Palliative care approach	The use of palliative care principles by all health professionals in a health care system, which allows for pain to be managed adequately in all settings, holistic assessment and support from the diagnosis of a life-threatening disease and referrals for more specialised palliative care in complex cases (Gomez-Batiste and Connor 2017).
Palliative care development	An increase in the processes, structures, policies, and resources that support delivery of palliative care in a given context, together with greater professional palliative care activity (i.e. palliative care research and the presence of palliative care associations) (Rhee <i>et al.</i> 2017).
Integration	“Managerial or operational changes to health systems to bring together inputs, delivery, management and organization of particular service functions as a means of improving coverage, access, quality, acceptability and (cost)-effectiveness” (Watt <i>et al.</i> 2017, p. iv15).
Integrated care	Integrated care is the end-product facilitated by integration processes. It refers to the delivery of coordinated health care services which aim to achieve better patient care (Brazil 2018; Shaw <i>et al.</i> 2011).
Integrated palliative care	“Integrated palliative care involves bringing together administrative, organizational, clinical and service aspects in order to realize continuity of care between all actors involved in the care network of patients receiving palliative care” (Hasselaar and Payne 2016, p. 8).
Systematic review	A type of literature review that uses pre-decided systematic research methods to search the literature, which are then analysed and reported on (Mulrow 1994). The aim is to synthesis and explain existing information around a topic or question to provide evidence for decision makers (Cronin <i>et al.</i> 2008; Dixon-Woods <i>et al.</i> 2016).
Health systems strengthening	The process of improving health systems functions to expand access to health services, improve coverage of health services and/or increase the quality and efficiency of the health system. This process involves understanding and evaluating how the different parts of the health system interact and perform, then intervening to change policy and practices of the health system. (World Health Organisation 2007; Gilson 2012; de Savigny and Adam 2009)
Intervention	“Combinations of technologies, inputs into service delivery, organizational changes and modifications in processes related to decision making, planning, and service delivery, as well as scaling up of interventions previously implemented in small scale using novel processes. These interventions are introduced into health systems as innovations, comprising new ideas, practices, objects or institutional arrangements.” (Atun <i>et al.</i> 2009)
Care-coordination	“The deliberate integration of patient care activities between two or more participants involved in a patient’s care to facilitate the appropriate delivery of health care services” (Bodenheimer 2008, p. 1064)

Part A - Protocol

Introduction

Worldwide every year, 20 million people need palliative care (PC) (Worldwide Palliative Care Alliance 2014), of which about 14 % actually receive it (World Health Organisation 2018). This means that most are left without access to care aimed at relieving physical, spiritual or psychosocial pain and suffering associated with life-threatening illnesses (Sepulveda *et al.* 2002). Two-thirds of these people not receiving PC are found in low-and-middle-income countries (LMIC) (World Health Organisation 2018) where access to PC is lowest, meaning that most are without pain relief and support at the end of their lives (Knaul *et al.* 2017). Given the rise in non-communicable diseases (NCDs) and aging populations, the demand for PC is set to rise in the near future (Hall *et al.* 2011), and will continue to outgrow the supply unless access to PC is urgently addressed (Grant *et al.* 2011a).¹

The lack of access to PC is now understood as a violation of human rights (Brennan 2007), and a responsibility of health systems (Blinderman 2009), and has recently come into international focus (Gómez-Batiste and Connor 2017). There has been a rising call for the integration of PC into all levels of the health system to ensure that PC needs are met (World Health Assembly 2014; Knaul *et al.* 2017). Integration of PC into health systems is not only seen as a mechanism to provide access to those who need it, but also as a strategy to improve the performance of health systems (World Health Assembly 2014). Health systems strengthening is of particular importance in LMICs where health systems are negatively affected by health worker shortages, insufficient health infrastructure and poor health outcomes (de Savigny and Adam 2009).

Defining palliative care

Palliative care is necessary to relieve pain and suffering at the end of life or due to problems associated with life-threatening illnesses (Sepulveda *et al.* 2002). It is best understood as an approach aiming to improve the quality of life of all patients, together with their families, who face problems related to life-threatening illness (World Health Organisation 2002). This is done through early identification, assessment and treatment of the range of physical, psychosocial and spiritual problems to prevent and relieve discomfort (Sepulveda *et al.* 2002). It is applicable at all stages of the disease, particularly early on when the patient is diagnosed (Worldwide Palliative Care Alliance 2014).

¹ The rise in the need for PC has been attributed largely to the world-wide rise of non-communicable disease, together with generations of people who are living longer and presenting with diagnoses that are more complicated at the end-of-life stage.

Palliative care has historically been linked to specific diseases such as cancer (World Health Organisation 1990) and HIV² (World Health Organisation 2004), only recently being identified as an integral component of the response to all non-communicable diseases (NCDs) (World Health Organisation 2013). Palliative care has also been shrouded in misunderstanding which has hindered its development (Hannon *et al.* 2016). It has often been used synonymously with end-of-life or hospice care, both of which are inaccurate and do not encompass the holistic nature of PC, nor the fact that PC is applicable over the course of a disease encounter (Worldwide Palliative Care Alliance 2014).

Palliative care in Africa

The need for PC in Africa is overwhelming (Grant *et al.* 2011a). Not only does Africa carry the greatest portion of global disease burdens for communicable diseases, such as HIV and Tuberculosis (TB) (Gysels *et al.* 2011), but NCD rates are also increasing and expected to outweigh communicable disease by 2030 (Mathers and Loncar 2006). Based on this, the amount of people needing PC in the continent annually has been estimated at being around 1.8 million people (Worldwide Palliative Care Alliance 2014). Most of these people will be unable to access appropriate service or care (African Palliative Care Association 2011).

Access to PC in Africa is acknowledged to be limited, but recently there has been an increase in attention to the development of PC services (Lynch *et al.* 2013). Clarke *et al.* (2007), reviewed that in 47 included African studies, 21 had no identifiable PC service.³ In a later global review, where an update on this information was provided and all African countries were reviewed, Africa showed the most significant gains in PC development (Lynch *et al.* 2013).⁴ Although this was encouraging, 28 countries still had no PC services, and only 8 countries had moved beyond having isolated pockets of PC provision (Lynch *et al.* 2013). In another recent scoping review of African countries, increased PC development (as reviewed in materials from 2005-2016) was identified in 26% of countries and the study noted that available services were predominantly found in Kenya, Uganda and South Africa (Rhee *et al.* 2017).

Despite these developments, there continues to be a chronic lack of adequate PC services in Africa. The continued limited provision of PC in Africa has been attributed to several factors. These include the general lack of resources for health (APCA 2011) and prioritisation of end of life care over curative care (Molyneux *et*

² Largely due the limited treatments available at the time of the rise of the disease.

³ This was a review of hospice and PC development to provide a base from which to measure further development and identify challenges to providing PC. The African countries were categorized according to four categories namely having 1) no identified hospice-PC activity, 2) a capacity building activity but no service, 3) localized PC provision, and 4) PC activities that are approaching integration with mainstream service providers (Lynch *et al.* 2013).

⁴ This review used the same categorization, but subdivided levels 3 and 4. This global mapping reviews used available peer-reviewed publications and books, grey literature and expert opinion.

al. 2013); the high burdens of disease and health worker shortages (Tropical Health and Education Trust 2015); the fact that PC is an emerging discipline on the continent, with a lack of robust evidence to guide PC development (Powell *et al.* 2014); negative attitudes towards PC and caring for dying patients (Ansary *et al.* 2014); limited funding available for PC and inefficient health worker knowledge about PC, together with a lack of access to PC medications (Rhee *et al.* 2018).

A lack of integration of PC into national health systems, including health policies and health worker educational curricula, has been cited as a particular challenge to the provision of PC (APCA 2011). Formal PC development began in Africa in the late 1970s with the creation of the Island Hospice service in Zimbabwe (Downing *et al.* 2010). Subsequent PC development was driven largely by private and international organisations, resulting in PC provision commonly occurring outside of national/public health systems (Clark *et al.* 2007). These included projects by the World Health Organisation (WHO) for cancer and HIV patients (World Health Organisation 2004); the Diana, Princess of Wales Memorial Fund⁵ and the Open Society Institute, who supplied funding to projects by the Foundation for Hospices in sub-Saharan Africa and other PC initiatives (Clark *et al.* 2007).

The presence of HIV dramatically changed the face of PC in Africa (Grant *et al.* 2011b), as it shifted focus onto PC when curative treatment was not available, requiring the alleviation of patients suffering being of primary focus (APCA 2011). During the HIV crisis there was a rush of donor funding to meet this need, and a rapid development of PC for people living with HIV and AIDS (PLWHA) (APCA 2011). However, increased international funding for HIV during this period increased the development of PC services outside of the national health system (Rhee *et al.* 2018), which could not provide enough care to meet the demand, and generally resulted in scattered services disconnected from public health structures (Uys 2003).

HIV changed the landscape of PC in Africa (APCA 2011), but other contextual issues have shaped what type of PC is needed in Africa. It has been argued that factors specific to the African context mean that PC provision there is different to the type of care recommended in high income countries (HICs).

Although the definition of palliative care is globally relevant, what constitutes palliative care needs and services in sub-Saharan Africa is continent-specific, particularly in the light of poverty and HIV disease. Necessary components include practical care, pain and symptom control, counselling/emotional/psychological support, income generation, financial support for food, shelter, funeral costs and school fees, respite, spiritual support and orphan care. (Harding and Higginson 2004, p. 6)

⁵ This fund closed in 2012, but legal ownership was taken over by The Royal Foundation of The Duke and Duchess of Cambridge and Prince Harry (<https://www.royalfoundation.com/the-diana-princess-of-wales-memorial-fund/>)

This has led to the development of varied models of PC in Africa (see Mwangi-Powell *et al.* 2013; Downing *et al.* 2015), including home-based care, hospital units, outreach teams, free-standing inpatient units and day care hospices (Gysels *et al.* 2011). Palliative care services in Africa often rely heavily on the use of volunteers (Harding and Higginson 2004), and the places of PC provision are often dictated by the resources available, with home- and community-based care (HCBC) models usually being the most sustainable option (Harding and Higginson 2005; Mwangi-Powell *et al.* 2013). Harding and Higginson (2005) conclude that in general, PC services in Africa typically involve a specialist service usually not integrated into the health system (Harding and Higginson 2005).

Problem statement and purpose of study

Poor access to PC has increasingly become an international priority, as PC has been understood as a necessary form of care for those with life-threatening illness, with the integration of PC into national health systems seen as a way to improve this. In a resolution by the World Health Assembly (WHA) in 2014 (Appendix 6, which called on member states to integrate PC into national health systems through providing policy, training and funding for PC, as well as through fostering necessary partnerships and ensuring adequate supply of essential medicines (World Health Assembly 2014). Amongst these member states were Ministers of Health from 26 African countries, who committed to providing governance in integrating PC into their context (Kimani *et al.* 2017).

Given this increased focus and commitment from African governments to integrate PC, evidence to guide these actions is more important than ever. Although building the research capacity on the continent has been targeted to provide the necessary evidence for integration (Volmink and Dare 2005; Radbruch 2008; Harding *et al.* 2013; Namisango *et al.* 2013; Powell *et al.* 2013; Ansary *et al.* 2014; Powell *et al.* 2014), the integration of PC into African countries has not yet been investigated in depth. Research has typically focused on PC development and describing models of care (Harding and Higginson 2005; Ncama 2005; Downing *et al.* 2010; Jang and Lazenby 2013; Mwangi-Powell *et al.* 2013; Harding *et al.* 2014), identifying the need for PC (Grant *et al.* 2003; van Niekerk and Raubenheimer 2014; Selman *et al.* 2015; Lazenby *et al.* 2016; Hamdi *et al.* 2017) or preferences with regards to PC (Alsirafy *et al.* 2010; Powell *et al.* 2014; Luyirika *et al.* 2016; Chisumpa *et al.* 2017). Reviews have been used to guide development through reviewing qualitative research on end-of-life care in sub-Saharan Africa, synthesising evidence on children's PC in Africa (Gysels *et al.* 2011; Harding *et al.* 2014) and updating the development of PC in African countries (Rhee *et al.* 2017), yet an in-depth and systematic review of the integration of PC has not been done.

A lack integration of PC into health systems is not only a problem experienced in Africa and has been recommended globally (World Health Assembly 2014). Even HIC countries fall short of providing full coverage with regards to PC (Lynch *et al.* 2013). Recent studies have also argued that although contextual differences are vital to consider in integration interventions and approaches, HICs and LMICs can learn from each other with regards to integrated care (Mounier-Jack *et al.* 2017). Therefore, reviewing the integration of PC into African countries could also support the integration of PC into other health systems (Hannon *et al.* 2016).

Using a health systems perspective or ‘systems thinking’ (de Savigny and Adam 2009) in reviewing this topic would be highly beneficial as health systems and the integration of PC are interlinked. The literature notes that in order to integrate PC health systems need to be strengthened (Luyirika *et al.* 2016; Knaul *et al.* 2017) and that integrating PC is a mechanism to strengthen health systems (Knaul *et al.* 2015; World Health Organisation 2018). Therefore, this topic would be best understood using a health systems approach, which has proved useful in understanding health systems strengthening, particularly in LMICs (Adam and de Savigny 2012).

Therefore, this systematic review will focus on investigating and analysing the approaches and interventions being used to integrate PC into African countries from a health systems perspective, to provide evidence to guide further interventions at this important time. This will entail investigating how the integration of PC is being conceptualised, together with the types and nature of integrative strategies being used, and finally to use this to attempt to draw out lessons to apply to the wider African context.

Research question

The primary research question that this systematic review aims to answer: “How is palliative care being integrated into African health systems and what lessons can be learnt from these approaches and interventions?”

Sub-questions include:

- How is the integration of PC being conceptualised globally and in the African context?
- What interventions and approaches are being used to integrate PC in African health systems?
- What were the facilitators and barriers to the integration of PC in these interventions?

Methodology

This systematic review study will take place in two phases: 1) a scoping review and 2) a systematic review. The scoping review will provide a backdrop on which to investigate the integration of PC by looking into the

concepts of integration and PC, both globally and in the African context. This will be followed by a systemic review, which will then investigate and analyse the approaches and interventions to integrate PC into African health systems in detail to draw out the barriers and facilitators of integration in these contexts (see Figure 1).

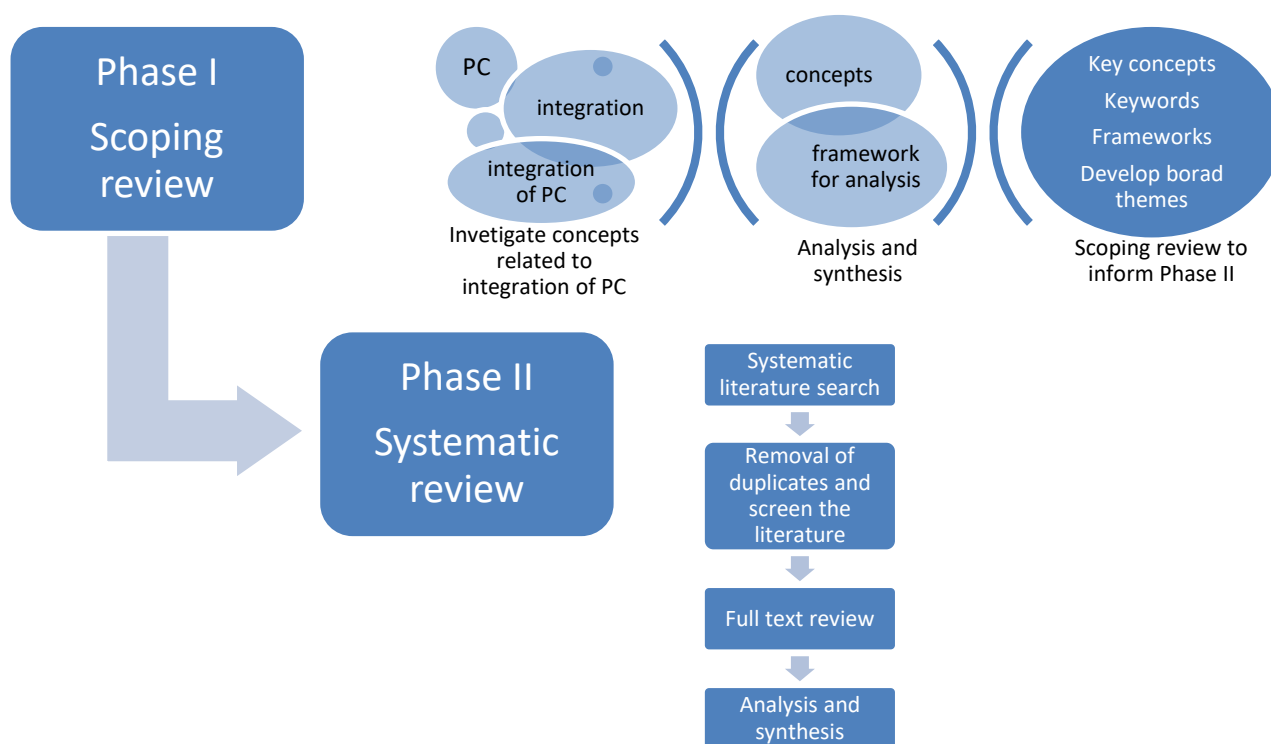


Figure 1. Overview of methodology

Phase I: Scoping review

On initial reading of the literature when developing this protocol, it was clear that many terms were used to describe and conceptualise the integration of PC and that this topic has only recently received attention in research. A scoping review is a useful way to review literature on a topic on which little is known (Arksey and O'Malley 2005) and is a mechanism through which to identify issues regarding terminology, the type and amount of literature available, determine gaps in the literature and refine a research question (Jones 2004; Arksey and O'Malley 2005). Therefore, a scoping review was found necessary in this topic to define search terms and key words and find or develop frameworks through which to analyse the interventions and approaches to PC that in the systematic review.

As discussed earlier, a health systems perspective is important when investigating the integration of PC, which is central element to health policy and systems research (HPSR). As such, this study is situated in this field which provides frameworks to conceptualise health systems strengthening through understanding the complex and dynamic nature of health systems, together with the relationships that influence them (Gilson 2012). Rapid scoping reviews are particularly suited for work in LMICs and are used in HPSR to synthesise

knowledge in a systematic, fast-tracked manner to provide evidence for policy makers, researchers and health workers and encourage informed decision making for health systems (Tricco *et al.* 2017). Therefore, this method was deemed suitable because it is situated within a health systems framework and allows for the rapid dissemination of results on the integration of PC.

Scoping reviews often include grey literature as well as the use of informants (Jones 2004). As such the scoping review will include a search and review of both grey and published literature, as well as informal consultations with experts in the field to gain a full understanding of the topic. The scoping review will include keyword searches in advised databases – Google Scholar, PubMed, Ebscohost, Africa-Wide, Scopus and Web of Science, as well as the use of a search engine, Google, to identify grey literature, such as reports or government documents. PC association websites will also be searched for relevant grey literature. Key search words will include ‘integration’, ‘palliative care’ and other related variants such as ‘end-of-life care’, ‘terminal care’, ‘hospice’ and ‘Africa’.

Phase II: Systematic review

Phase II will consist of the systematic review, which was found to be the most appropriate method as systematic reviews are necessary tools for organising the information available to give decision makers synthesised evidence to guide evidence-based decision making (Mulrow 1994).

A systematic review uses a rigorous and defined approach to reviewing literature on a certain topic (Cronin *et al.* 2008), of which the researcher provides an open account so that it could be reproduced (Dixon-Woods *et al.* 2016). Use of keywords to search for relevant literature for the topic is necessary and should be selected with care to ensure that relevant data is identified to answer the research question (Cronin *et al.* 2008). Therefore, a systematic search of published literature will then be conducted using key words, MeSH terms and search terms, informed by the scoping review (Cronin *et al.* 2008). After screening and removal of duplicates, all relevant articles will be included in the study using strict criteria and will be read in detail, then analysed and synthesised. Results from this analysis will be reported and discussed, after which conclusions will be made, together with recommendations on how to facilitate the integration of PC (Thomas and Harden 2008). Although it is not uncommon for the systematic review protocol to be modified during the study due to its interactive nature; if this occurs these changes will be described, giving explicit reasons for why this was the case (Moher *et al.* 2009).

This systematic review will focus on qualitative data. The value of reviewing and synthesizing qualitative research has been well recognised due to the ‘explanatory power’ of qualitative forms of data (Dixon-Woods

and Fitzpatrick 2001). Qualitative research was felt to be most valuable in attempting to answer this research question, which is seeking to understand the integration of PC into health systems and explain what facilitates or inhibits this. Due to this study focusing on qualitative research, it is imperative that the challenges associated with synthesising and reviewing qualitative data in a systematic review be recognised and considered to ensure rigour (Dixon-Woods *et al.* 2016).

The first part of the Phase II will entail searching the literature, which systematic reviews do primarily through searching electronic databases using keywords (Cronin *et al.* 2008; Dixon-Woods *et al.* 2016). It is important to ensure that these databases and key words are carefully selected to ensure that the relevant literature is found (Cronin *et al.* 2008) and to reduce database bias (Egger and Smith 1998). Therefore, when defining the search strategy for the systematic review, a Librarian from the University of Cape town library will be consulted to ensure that the relevant databases are searched and that the search terms are inclusive, allowing the electronic database search to be effective (Bown and Sutton 2010). The following databases will be included in this phase to allow for the discovery of the most relevant literature: Pubmed, Academic Search Premier, Africa-Wide Information; CINAHL; Health Source: Nursing/Academic Edition and Medline, as well as a complementary Google Scholar search.

Article selection

The process of systematically reviewing qualitative literature described by Moher *et al.* (2009) will be followed. After removing duplicates of research articles identified in the database search, records will be screened using the title of their abstract to determine their relevance (Moher *et al.* 2009). Those that do not meet the inclusion criteria will be excluded and those that do will undergo a full text review. Articles that are included following the full text review will be analysed and reported on.

Inclusion and exclusion criteria are important in a systematic review, as these influence the literature that undergoes analysis and, ultimately, the end results. These criteria need to be carefully considered as problems can be encountered if the inclusion and exclusion criteria are too narrowly defined, with the opposite also being true (Bown and Sutton 2010).

Phase II will only include published, peer reviewed journal articles to ensure the quality of the studies. Only English articles will be included (see below) and those reporting on interventions or approaches to integrating PC during and after 2002, when the most recent and holistic definition of PC was introduced by the WHO, which provides a useful 'watershed' moment for this review (World Health Organisation 2002).

The study aims to analyse interventions used to integrate PC into African health systems, therefore only research in African contexts will be considered. This study does *not* aim to evaluate the effectiveness of these interventions or whether interventions were ‘successful’ at integrating PC within the health system, but rather to understand what approaches are currently being used and how these relate to health system strengthening, how PC integration is being conceptualised in Africa and lastly, identify facilitators and barriers to integration described in the research. Therefore, in order for the study to be included it must be relevant to the topic and provide sufficient information to allow for this analysis. Articles will be only included that provide empirical evidence.

It is vital that the study selection process is accurately recorded, and a report is given on how records were retrieved and excluded and when full reviews took place, as this is central to the systematic review process and ensures rigour and reproducibility (Liberati *et al.* 2009).

Data extraction

Extracting the relevant data is an important part of the systematic review process to allow for analysis of the evidence (Liberati *et al.* 2009). Data extraction forms are a useful way to do so (Bown and Sutton 2010). The data extraction form below (Figure 2), will be developed further during phase I. This form will include the document details, as well as information about the nature of the intervention, together with elements of integration and PC identified in the scoping review.

Document details						Integration			Palliative care		Conceptualisation of integration	Relation of PC to health systems strengthening	Nature of intervention	Facilitators of integration	Barriers to integration
Country	Name of study	Authors	Date	Type of study	Aim	Level	Model	Dimensions	Model	Level					

Figure 2. Initial version of data extraction form (Source: author)

Data analysis and synthesis

Analysis and synthesis of the data will take place once all the relevant articles have been found using the systematic search. All literature will be analysed using the same process. Synthesis of qualitative data is somewhat more complex and contested than synthesising quantitative data (Thomas and Harden 2008). It involves summarizing findings to present conclusions on the whole body of included literature and can be

done using a quantitative or narrative approach (Popay *et al.* 2006). Narrative synthesis is an approach used in systematic reviews of qualitative literature. This brings together information from a variety of studies by using descriptive text to argue and expand on the results from the synthesis (Popay *et al.* 2006). This method was found to be suitable for the research question and design.

Thematic analysis, a type of narrative synthesis, can be used in different research approaches to give the researcher in-depth and detailed interpretations of qualitative data by recognizing, analysing and describing themes within the data (see Boyatzis 1998, Braun and Clarke 2006, Thomas and Harden 2008). A guide to thematic analysis is provided by Braun and Clarke (2006), which describes a six-step process. This consists of 1) familiarising yourself with data, 2) generating initial codes, 3) searching for themes, 4) defining and naming the themes, and lastly 6) producing the analysis report. During synthesis, it is important to check that the transfer from the themes of one study to the next is valid (Thomas and Harden 2008). In this study, themes and codes will be broadly developed for the systematic review from the literature identified in the scoping review.⁶ However, this will be a flexible process, and these will be adapted as new themes are identified during the systematic review. The research supervisor will assist in checking the themes produced.

Rigor

We have already highlighted several rigor issues relating to the scoping and systematic review methodologies above. For example, the use of a systematic review method will assist in minimizing bias, as this allows for literature to be selected through an open and systematic method. Data extraction forms will also be used to provide accurate record keeping and show how the research has developed. In addition, Mays and Pope (1995) presents suitable methods for ensuring rigour in qualitative research, which are applicable in this systematic review of qualitative literature. It is essential to ensure that a research design that is systematic in its approach is used and that the researcher is transparent throughout the research process through meticulous record keeping and descriptions as to why an action has been taken (Mays and Pope 1995). The latter part is vital in a systematic review, not only to ensure rigour, but also to allow for the process to be reproduced for another researcher – a key feature of a systematic review.

Ethics

This study consists of a scoping and systematic review which will use previously published journal articles that are available to the public. This is therefore a low (no) risk study, with few ethical considerations as no human

⁶ In Phase I literature on integration, PC and the integration of PC both globally and specifically in LMICs and Africa will be reviewed (reported in Part B).

subjects will be involved. The primary ethical consideration is related to how findings from the study might impact on future implementation and decision-making, which the researcher will seek to consider carefully.

Study limitations

This systematic review has some limitations, some of which have already been mentioned. Firstly, only reviewing English materials will exclude research from non-Anglophone African countries. The research undertaken in developing this protocol showed that published articles on PC is limited from Francophone and Lusophone countries (Rhee *et al.* 2017), so this is not expected to be a major limitation (and is a bias echoed in global health research generally). Secondly, although grey literature will be included in the scoping review, only published peer reviewed literature presenting empirical data will be included into the systematic review (for quality and rigor reasons), which will exclude some implementation experiences. Given the acknowledged lack of PC research capacity in Africa (Powell *et al.* 2014) this does remain a concern, and this review is likely to identify areas for future research. Thirdly, the literature search in the systematic review will only include databases that are accessible through the University of Cape Town’s subscriptions, which could limit access to some studies. In this event, identified authors will be contacted directly by email to attempt to gain access.

Dissemination of findings

This study aims to provide useful lessons to those attempting to integrate PC into health systems - whether they are health workers, policy makers or researchers. This is not only to assist in improving the ‘success’ of these integration interventions, but to increase access to PC, which is a vital and pressing need. This study will be published open access in thesis format, and as a journal article. Key findings will also be collated into a summary sheet to allow for easy dissemination. These materials will also be provided to the area experts that were consulted in Phase 1 of the study.

Timeline

Table 1. Timeline for study

Component	Activity	Date
Part A: Protocol	Subject formulation	October/November 2017
	Drafts	December 2017
	Edits	May 2017
Part B: Scoping review	Research	January/February 2018
	Drafts	March 2018
	Edits	June 2018
Part C: Systematic review	Research	April 2018
	Drafts	May 2018
	Edits	June 2018
	Intention to submit	June 2018
	Submission	July 2018

Budget

This study was done as a part of a completion of the Masters in Public Health degree. It was self-funded by the researcher and no conflicts of interest are present.

Table 2. Budget for the study

Item	Cost
Printing	R 600.00
Internet costs	R 1000.00
Materials (pen and paper)	R 100.00
Total	R 1700.00

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Part B - Literature Review

Frameworks to analyse the integration of palliative care into LMIC health systems: key themes in understanding integration

Introduction

Palliative care (PC) is increasingly seen as an important part of health care services, aiming to reduce suffering and support those with terminal illness, predominantly due to non-communicable disease (NCD), HIV and drug-resistant Tuberculosis (TB) (World Health Assembly 2014). The need for PC has historically been largely ignored, resulting in inadequate and inequitable access to this care in many parts of the world, particularly in lower-and-middle income countries (LMICs) and for vulnerable populations, including children (Worldwide Palliative Care Alliance 2014; Knaul *et al.* 2017). The need for PC in LMICs is great, due to lack of treatment options, and the need for PC is expected to rise alongside the projected increase in NCDs (Grant *et al.* 2011; World Health Organisation 2013). However, provision of PC in LMICs is limited (World Health Organisation 2015), with only one LMIC country, Uganda, identified as being at an ‘advanced’ stage of development and the vast majority of LMICs presenting with isolated provision of PC (Lynch *et al.* 2013) (Figure 1). There is a significant need for increased access to PC in LMICs.

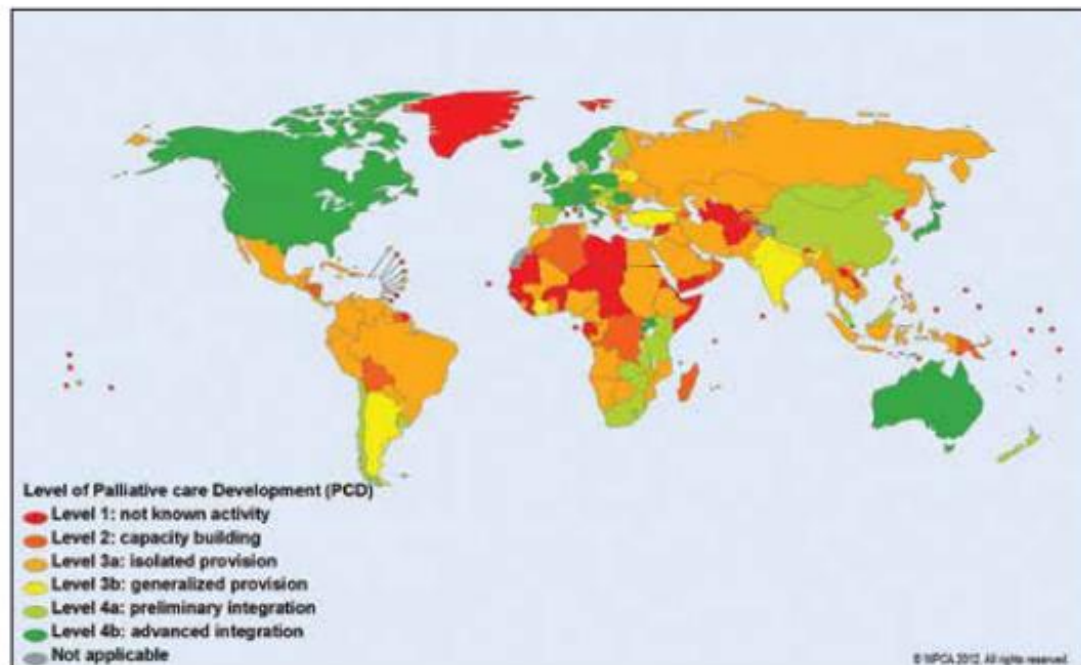


Figure 1. Levels of palliative care development (Source: Worldwide Palliative Care Alliance 2014)

The integration of PC into national health systems has been identified as a mechanism to increase access to PC (Stjernsward *et al.* 2007) and is beginning to receive international focus. Yet rigorous and contextually

appropriate research is limited (Hannon *et al.* 2016) and therefore further investigation is essential. This scoping review aims to provide a conceptual overview of PC and integration and to review the evidence on integration of PC in LMICs. This was necessary to develop search terms and key concepts to guide a future systematic review, as well as identify useful frameworks that could be used to analyse and conceptualise the integration of PC into health systems.

Method

Scoping reviews are useful to rapidly identify necessary key concepts, together with the sources and types of evidence that are available around a research topic (Davis *et al.* 2009) and are particularly relevant to the field of health policy and systems research (HPSR) (Tricco *et al.* 2017). This scoping review is necessary to examine the evidence around the topic of integration of PC to inform the systematic review. Specifically, it aimed to investigate the concepts of integration and PC; rapidly map the evidence on integration of PC in LMICs and how it relates to health system strengthening; and, lastly, to identify frameworks to analyse the integration of interventions in the systematic review. It was undertaken over three months in 2017. The rapid scoping review method was informed by Tricco *et al.* (2017) and which recommends the following steps: 1) identifying the research question, 2) identifying relevant studies, 3) selecting studies, 4) charting the data, and 5) synthesizing and reporting the results.

To answer the research question of *how* PC is being integrated into African health systems and further refine this question, a search strategy was designed to understand the areas of integration and PC in more detail. Grey and published literature were reviewed. Search platforms utilised included PubMed, Google and Google Scholar, together with searches of PC association websites (i.e. African Palliative Care Association (APCA), European Association for Palliative Care and International Association for Hospice & Palliative Care).¹ Use of these websites were integral to understanding how the integration of PC is advocated by these organisations, as well as sourcing relevant grey literature. No restrictions were made with regards to publication date (although materials not available in electronic format were less readily accessible), and only English literature was reviewed. Further articles were identified through citation tracking and discussions with experts in the field.

Search terms were grouped into three concepts: those relating to ‘palliative care’ (with variations such as ‘palliative’, ‘end-of-life care’, ‘terminal care’ and ‘hospice’); those relating to ‘integration’ (with variations around ‘integra*’, ‘integrated health care’, ‘coordination’, and ‘link’); and lastly those relating to ‘health

¹ APCA: <https://www.africanpalliativecare.org/>; EAPC: <http://www.eapcnet.eu/>; International Association for Hospice and Palliative Care: <https://hospicecare.com/home/>.

systems’ (with variations such as ‘health’, ‘health care’, ‘health system’, ‘health services’, ‘hospital’ and ‘clinic’).

The scoping review was approached in a staggered process, first covering the separate topics (PC, integration and health systems), and then merging these areas together, with specific searches run for materials on ‘integration of palliative care’ to gain an understanding of global trends. This was followed by a similar search with a focus on LMIC and African countries to investigate these areas in greater detail. Articles for full review were identified by scanning the titles and abstracts – and their reference lists were checked for further relevant materials. Key PC stakeholders were contacted informally by email to check the scope of literature gathered and to get feedback on recent developments in PC, that might not be showing in the published literature.

Palliative care

Definitions are important. They can serve as an impetus for changing practice, for introducing new programs and for working toward the allocation of more resources for palliative care. Moreover, the understanding of these concepts influences how medicine is practiced. (Kaasa 2001)

In the context of modern medicine, PC is still a relatively new concept (Box 1) and studies have highlighted that there are a variety of terms used to refer to PC and definitions of PC because of this (Kaasa 2001; Singer and Bowman 2002; Pastrana *et al.* 2008; Hui *et al.* 2013). This scoping review also found multiple terms used to refer to aspects of PC, but that the term ‘palliative care’ was most prevalent (Box 2).

Defining PC appropriately is important (Kaasa 2001). Alternative interpretations of PC act as a significant barrier to the provision of PC (Aldridge *et al.* 2016) and previous PC definitions have resulted in PC not being considered a public health priority, nor a responsibility of national health systems (Sepulveda *et al.* 2002; Gwyther *et al.* 2009).

The concept of PC has become more holistic over time (Gómez-Batiste and Connor 2017), as can be seen in the changes in the World Health Organisation (WHO) definitions

Box 1. Short history of PC

- 1960s: Provision of PC by medical facilities only began (initially PC services focused on patients with cancer)
- 1973: The term ‘palliative care’ first used
- 1987: PC becomes a medical speciality
- 1990s-2000s: HIV/AIDS epidemic increases need for PC in LMICs, particularly in Africa, and changes the way PC is understood

(Sources: Clark 2007; Pastrana *et al.* 2008; World Health Organisation 1990; Sepulveda *et al.* 2002; World Health Organisation 2004)

Box 2. Number of articles found containing terms associated with PC (from 230 articles)

- ‘palliative care’ = 167
- ‘end of life care’ or ‘end-of-life care’ = 80
- ‘hospice care’ = 48
- ‘terminal care’ = 45
- ‘supportive care’ = 36

(Source: author, from scoping review)

of PC depicted below (Figure 2), due to progression in medical knowledge (Sepulveda *et al.* 2002) and changes in perceptions of PC (Gómez-Batiste and Connor 2017), described under the later headings.

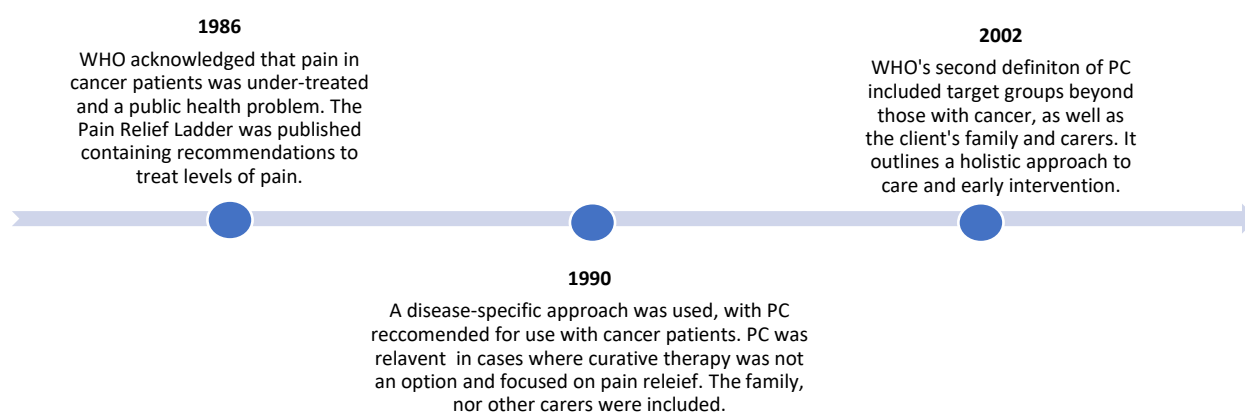


Figure 2. Primary changes in the WHO definitions of palliative care (Sources: World Health Organisation 1986; World Health Organisation 1990; World Health Organisation 2002)

Although studies have identified a lack of consensus on the definition of PC, the scoping study found that the 2002 WHO definition of PC was used in many articles (Table 1) and often referred to as the guiding definition, with only one other definition of PC referred to (Ferrell *et al.* 2017). It is also advocated for use in African countries by the APCA and used in their resources. (This study has primarily utilised this definition, as outlined in Box 3).

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.

Palliative care components:

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither to hasten nor postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patient's illness and in their own bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- Enhances quality of life, and may positively influence the course of illness;
- Applies early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Box 3. WHO definition of palliative care (Source: World Health Organisation 2002)

Table 1. Key documents using or referring to the WHO 2002 definition of palliative care (Source: author)

Author and Date	Study name	Context
Downing <i>et al.</i> 2013	The net effect: spanning diseases, crossing borders-highlights from the fourth triennial APCA conference and annual HPCA conference for palliative care	Africa
Harding and Higginson 2005	Palliative care in Sub-Saharan Africa	Africa
Kimani <i>et al.</i> 2017	Cancer and palliative care in Africa	Africa
Merriman and Harding 2010	Pain control in the African context: the Ugandan introduction of affordable morphine to relieve suffering at the end of life	Africa
Merriman and Kaur 2005	Palliative care in Africa: an appraisal	Africa
Sepulveda <i>et al.</i> 2003	Quality care at the end of life in Africa	Africa
Barros de Luca <i>et al.</i> 2017	Palliative care and human rights in patient care: an Armenia case study	Armenia
Brennan 2007	Palliative care as an international human right	Global
Gwyther <i>et al.</i> 2009	Advancing palliative care as a human right	Global
Gwyther and Krakauer 2011	WPCA policy defining palliative care	Global
Knaul <i>et al.</i> 2017	Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: the Lancet Commission report	Global
Stjernsward <i>et al.</i> 2007	The public health strategy for palliative care	Global
Webster <i>et al.</i> 2007	Palliative care: a public health priority in developing countries	Global
Worldwide Palliative Care Alliance 2014	Global atlas of palliative care at the end of life	Global
Breffni <i>et al.</i> 2016	Provision of palliative care in low- and middle-income countries: overcoming obstacles for effective treatment delivery	LMICs
Green and Horne 2012	Integrating palliative care into HIV services: a practical toolkit for implementers	LMICs
Sasaki <i>et al.</i> 2017	A scoping review of palliative care for children in low- and middle-income countries	LMICs
Downing <i>et al.</i> 2017	United against cancer: prevention to end-of-life care-highlights from the Uganda Cancer Institute-Palliative Care Association of Uganda Joint International Conference on Cancer and Palliative Care and the 7th Palliative Care Conference, 24-25 August 2017, Kampala, Uganda	Uganda
Sampson <i>et al.</i> 2005	A systematic review of the scientific evidence for the efficacy of a palliative care approach in advanced dementia	UK
Aldridge <i>et al.</i> 2016	Education, implementation, and policy barriers to greater integration of palliative care: A literature review	USA

Pain relief is a vital element of PC (Cousins *et al.* 2004; Brennan *et al.* 2007; Lohman *et al.* 2010) and the WHO 2002 definition explains that the need for PC will increase when curative care options decrease - but stresses that rather than PC replacing active treatment, both be provided in an integrated manner (Gómez-Batiste and Connor 2017) as depicted in Figure 3.

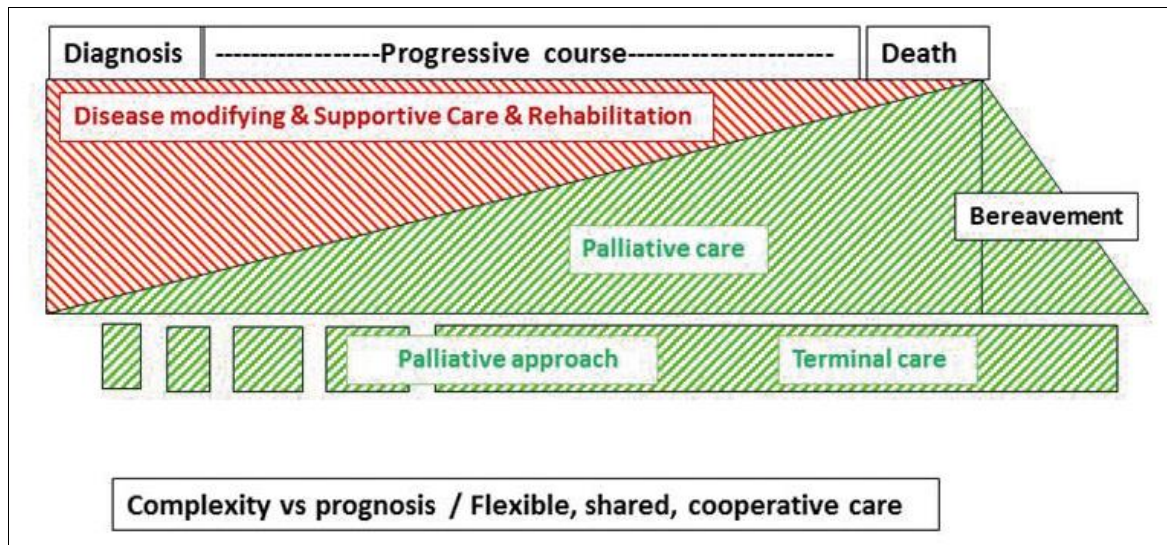


Figure 3. Integrated model of palliative care along disease evolution (Source: Gomez-Batiste and Connor 2017)

Arguments have been made questioning the ability of the WHO's definition to guide practice (Hasselaar and Payne 2016). Advocates have therefore clarified focal points in an attempt to do this (Gwyther and Krakauer 2011; Worldwide Palliative Care Alliance 2014; Gómez-Batiste and Connor 2017; Knaul *et al.* 2017), emphasising that PC should be available at all levels of care, clarifying what conditions would benefit from PC and discussing when PC should be initiated.

Palliative care as a human right and concern of health systems

... access to palliative care...is at the core of the right to health and is fundamental to health care.
(Knaul *et al.* 2015, p. 722)

Advocacy efforts have been made to ensure that PC is understood as a human right (Cousins *et al.* 2004; Brennan *et al.* 2007; Krakauer 2008; Selwyn 2008; Gwyther *et al.* 2009; Lohman *et al.* 2010; Brennan *et al.* 2016), a public health concern (Blinderman 2009) and ethical responsibility of health systems (Sharkey *et al.* 2017). Viewing PC this way is vital in order to increase access to PC within health systems (Gwyther *et al.* 2009), where historically health systems have typically targeted and resourced preventable and communicable disease (Grant *et al.* 2011; Powell *et al.* 2017), generally leaving PC provision to private non-governmental organisations (NGOs) and families of those in need (Blinderman 2009; Gwyther *et al.* 2009).

The argument that PC is a human right is summed up by Brennan (2007) who noted that access to PC is clearly seen in international human rights law, specifically under the right to health², as well as in General Comment 14³ (UN Economic and Social Council 2000), which noted that:

States are under the obligation to respect the right to health by, inter alia, refraining from denying or limiting equal access for all persons, including prisoners or detainees, minorities, asylum-seekers and illegal immigrants, to preventive, curative and palliative health services. (UN Economic and Social Council 2000, p. 12)

In recent years there has been an increased international focus on PC (World Health Assembly 2016) and greater advocacy efforts to improve access to PC. For example, an exploratory study has found a significant increase in declarations on PC, a common tool used by civil society and advocacy groups (Inbadas *et al.* 2016), particularly between 2011 and 2015, depicted below (Figure 4).

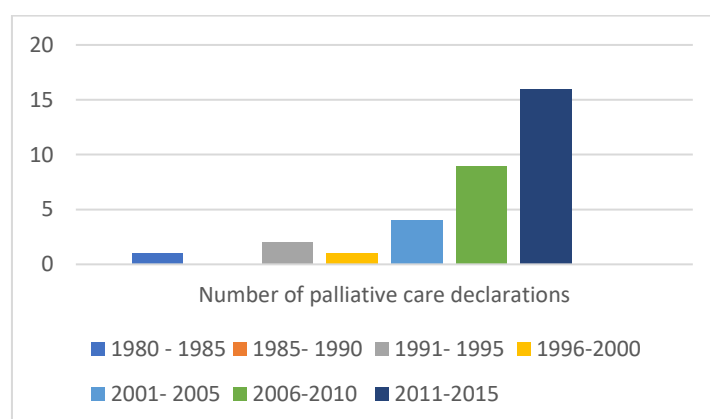


Figure 4. Number of palliative care declarations between 1980 and 2015 (Source: Adapted from Inbadas *et al.* 2016)

These advocacy efforts are understood to be seeing results in shifting international focus onto PC (Jackson 2016). For example, PC provision has been reframed as a vital component of public health by international bodies such as the WHO (Stjernsward *et al.* 2007), as a part of comprehensive health care services⁴ (World Health Organisation 2013) and integral in achieving of universal health coverage⁵ (UHC) (World Health Organisation 2017). Collective advocacy has also resulted in the recent release of key documents which place PC as an essential part of health care to be delivered through health systems (Jackson 2016; Knaul *et al.* 2017).

² Article 12.1 in the International Covenant on Economic, Social, and Cultural Rights (ICESCR).

³ The General Comment 14 describes the right to health in more detail.

⁴ Health systems should now offer promotive, preventive, curative, rehabilitative and palliative services to treat a population comprehensively.

⁵ Universal health coverage (UHC) means that all people and communities can use the promotive, preventive, curative, rehabilitative and *palliative health services* they need, of sufficient quality to be effective, while also ensuring that the use of these services does not expose the user to financial hardship (WHO 2013)

These documents make it clear than to increase access to PC, it needs to be integrated into health systems alongside other preventative, promotive and curative care services. These documents are laid out in Table 2 and discussed in more detail below.

Table 2. Key policy documents emphasising the integration of PC into health systems

Document title	Author and year	Direct extracts relating to integration
WHA67.19: Strengthening of palliative care as a component of comprehensive care throughout the life course	WHA 2014	[the WHA]...urges Member States to develop, strengthen and implement, where appropriate, palliative care policies to support the comprehensive strengthening of health systems to integrate evidence-based, cost-effective and equitable palliative care services in the continuum of care, across all levels, with emphasis on primary care, community and home-based care, and universal coverage schemes.
Cancer prevention and control in the context of an integrated approach	WHA 2014	[the WHA] ...urges Member States ... to develop and implement evidence-based protocols for cancer management, in children and adults, including palliative care... to provide pain relief and palliative care in line with resolution WHA67.19.
Alleviating the access abyss in palliative care and pain relief— an imperative of universal health coverage: the Lancet Commission report	The Lancet Commission on Palliative Care and Pain Relief 2017	Integration of palliative care and pain relief interventions, beginning with the Essential Package, will strengthen national health systems to meet the SDGs.

Two recent declarations by the World Health Assembly (WHA) in 2014 and 2017 show the increased international focus on integration of PC into health systems. Resolution WHA67.19 (2014), named ‘Strengthening of palliative care as a component of comprehensive care throughout the life course’ (World Health Assembly 2014), shows a deepening understanding of PC and how it relates to public health by recognising PC as a part of UHC and comprehensive health care, and provided recommendations for member states to integrate PC into health systems (World Health Assembly 2014)

A document building on this resolution was issued by the WHA in 2017 titled, ‘Cancer prevention and control in the context of an integrated approach’ (World Health Assembly 2017). Here, PC was clearly identified as a part of cancer services and signatory states were urged to provide PC within the context of cancer (World Health Assembly 2017).

Another important set of documents was the 2017 Lancet Commission on Palliative Care and Pain Relief (see Knaul *et al.* 2017). This also argued that PC is a public health concern and emphasised that access to PC needs to be addressed through integration of PC into health systems, to include it as a part of comprehensive care. This commission also identified and explained the anticipated health strengthening effects of universal access to PC:

The benefits of universal access to palliative care and pain relief spill into other parts of a health system and contribute to the quality of care... because the implementation of these interventions will strengthen the overall performance of health systems. (Knaul et al. 2017, p. 5)

Conversely, the commission stressed that health systems also need to be strengthened in order to provide universal access to PC (Knaul et al. 2015). A building blocks framework (Figure 5) is often used to portray the various functions of a health system⁶ and describe how these functions or blocks interlink and influence the whole system's performance, responsiveness and ability to be people-centred (World Health Organisation 2007). For health systems to provide enough PC for those who need it, it has been noted that most of these functions need to be strengthened (Grant et al. 2017). It is also useful to consider that integrated PC would not necessarily be a 'new' block, or be added only into 'service delivery', but would involve engagement with all these blocks and their interactions

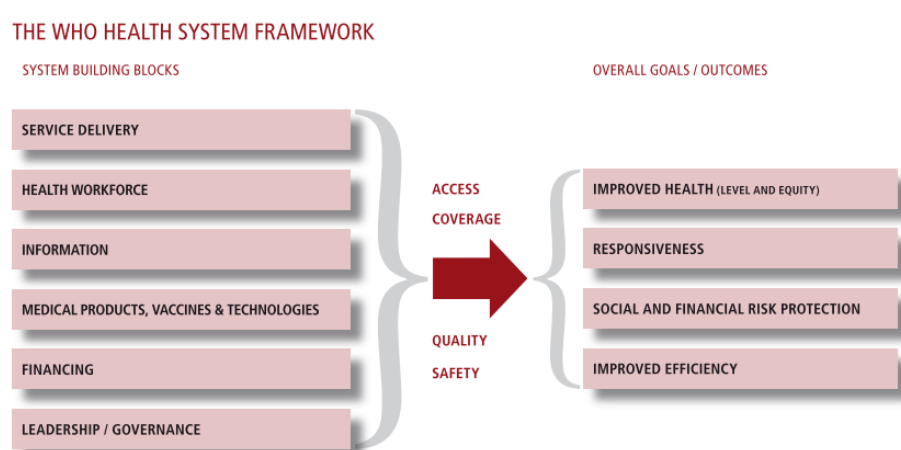


Figure 5. The WHO health system framework (Source: World Health Organisation 2007)

Access to palliative care in LMICs generally, and Africa in particular

Internationally, PC is described as a human right and the responsibility of the health system (as discussed above), however, in most LMICs, PC is limited or in many cases, non-existent (Lynch et al. 2013). The WHA resolution recommended that member states implement PC services, with an emphasis on primary care, home care and community-based care. However, in a recent study by the WHO, using government data, only 13% of LMICs provide PC in community-based facilities (World Health Organisation 2015), and only a third of low income countries had funding available for PC in national budgets. In a recent mapping of available PC services in forty-eight African countries, it was found that although service provision had increased in recent

⁶ Health systems functions are described as being related to governance, information, financing, service delivery, human resources, and medicines and technologies.

being a LMIC, namely Uganda.⁷ When PC is available in LMICs, it is usually provided for those with HIV⁸ and cancer, with PC services only recently being extended to people with other NCDs (Powell *et al.* 2017). This is of great concern as NCDs are the principle cause of death globally, with the highest incidences in LMICs (World Health Organisation 2013). Common barriers to PC access in LMICs have been summarized in Box 4 below.

Barriers to PC access in LMICs and Africa include:

- Lack of financial resources made available for PC
- Stigma placed on death and dying
- Incorrect understandings of the scope of PC
- Late referrals for PC
- Availability of trained health professionals
- Limited contextual research to guide development
- A lack of standardised implementation of PC
- Limited integration of PC into national health systems, policies and educational curricula
- Limited access to pain and symptom relieving medication

Box 4. Common barriers to PC access in LMIC's and Africa (Sources: Harding *et al.* 2008; African Palliative Care Association 2011; Ansary *et al.* 2014; Grant *et al.* 2015a; Tropical Health and Education Trust 2015; Fraser *et al.* 2017; Rhee *et al.* 2018)

Integration of palliative care into health systems in LMICs and Africa

As discussed, integration of PC into health systems was urged in the WHA resolution in 2014 (World Health Assembly 2014) and is seen as crucial in providing universal access to PC for those who need it (Knaul *et al.* 2017), strengthening health systems (Gómez-Batiste and Connor 2017) and providing continuity of care and comprehensive treatment for the patient (Gwyther 2005). There have been varied suggested approaches to integrating PC into LMIC and African health systems. For example, the promotion of a 'public health approach' is one such strategy. The WHO's Public Health Strategy for PC (Figure 7) has been identified as an 'effective and inexpensive' way of integrating PC into health systems in LMICs (Krakauer *et al.* 2007; Ddungu 2011; Harding *et al.* 2013).⁹ The Public Health Strategy aims to guide interventions to increase access to PC for a population (Stjernsward *et al.* 2007), and has been widely used as an integration approach in LMICs (Stjernsward 2002; Krakauer *et al.* 2007; McDermott *et al.* 2008) and is recommended for use in Africa by advocates and the APCA.¹⁰ This strategy has also been used to create evidence to support integration in LMICs,

⁷ This study found an association between the development of PC and human development (United Nations Human Development Index) worldwide, interestingly noting that African countries were often an exception, where PC development was occurring despite the country being described as having low human development.

⁸ Partly due to donor-funded PC initiatives targeting HIV care.

⁹ This model describes four pillars that need to be addressed 1) effective policies on PC provision, 2) education of health care workers and the community on PC, 3) implementation of PC services at all levels of health care and 4) appropriate drug availability. Contextually appropriate strategies need to be used, considering the resources available, disease demographics and functioning of the country's health care system.

¹⁰ The APCA is a pan-African organisation founded in 2003. The APCA's self-defined roles are to provide holistic relief and care to those with life-limiting illness and their families through increasing the PC knowledge base in all contexts, assisting

for example, to understand barriers to integration of PC (Aldridge *et al.* 2016) and map levels of PC development (Worldwide Palliative Care Alliance 2014; Rhee *et al.* 2017).

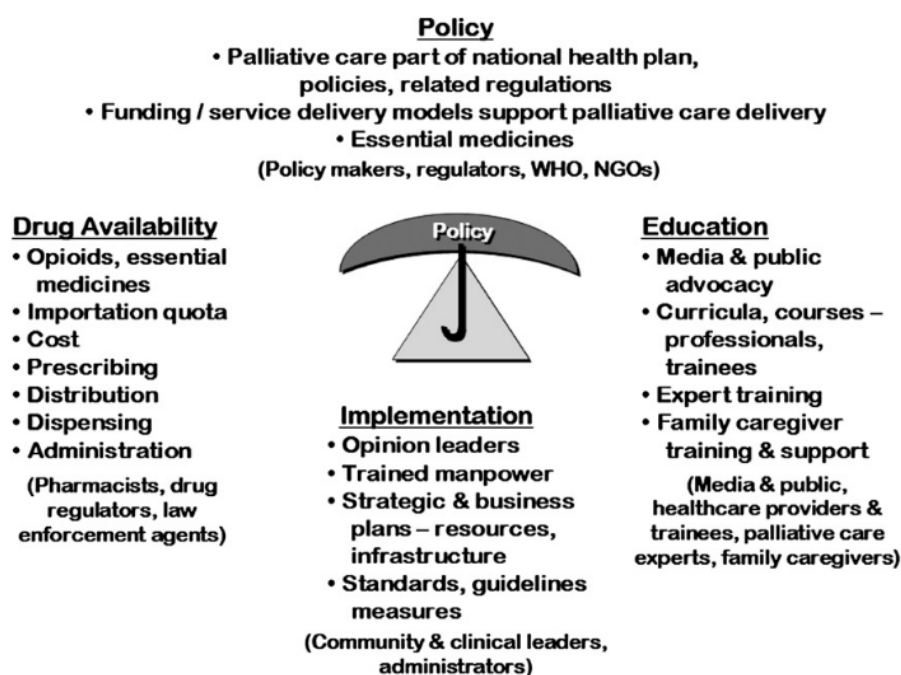


Figure 7. Detailed WHO Public Health Model (Source: Stjernswärd *et al.* 2007)

Although the Public Health Strategy offers guidance on how *to begin integrating* PC into a health system, emphasising the need for PC to be integrated¹¹ into all levels of the health system, it does not provide specific guidance on how to do so (Stjernswärd *et al.* 2007). There have been calls for further guidance and best practice models demonstrating *how* to integrate PC into different LMIC settings (Ddungu 2011). In response, models of PC in Africa have been reviewed, with a particular focus on sub-Saharan Africa (Harding and Higginson 2005; Downing *et al.* 2010; Mwangi-Powell *et al.* 2013; Downing *et al.* 2015), and on models of PC for people living with HIV and AIDS (PLWHA) (Harding *et al.* 2003; Ncama 2005).¹² Most models were described as ‘fluid’, often a composition of multiple models, allowing for adaptation to the needs of the population (Downing *et al.* 2015).

with integration of PC into all levels of care for health systems strengthening, together with ensuring the sustainability of these programs through collaboration.

¹¹ The model uses the term ‘implementation’ to describe integrating PC into health services at various levels of the health system.

¹² Successful models found included PC that is delivered through community home-based care, integrated community and home-based care and hospital-based care. These were then further expanded by Downing *et al.* (2015) which also identified hospital-based models (a specialist service and district hospital model) and community models (i.e. through a health centre and home-based care teams).

As a follow-up on the WHA resolution and to build on the Public Health Strategy, a practical guide describing how to establish PC services and integrate them into health systems was developed for PC program developers, with emphasis on LMICs (Krug and Kelley 2016).¹³ This emerged out of interventions which set out to integrate PC into four African health systems (Grant *et al.* 2017). Key elements for successful integration included: 1) taking account of the values, resources and structures within a health system where integration is aimed; 2) ensuring the approach is responsive to the population’s needs; 3) developing services in a cooperative manner using shared knowledge, and 4) realising that a PC approach needs to be integrated into all sectors for effective integration, not just into health care (Krug and Kelley 2016).

A Technical Advisory Group of the WHO Initiative for Palliative Care was also initiated to design a practical guide to integrate PC programs in LMICs using a public health approach (Gómez-Batiste and Connor 2017). Recommendations were made to integrate different levels of PC into the health system, including a PC approach, generalist and specialist PC or geographical PC networks. These levels are depicted visually (Figure 8) and described in greater detail in Table 3.

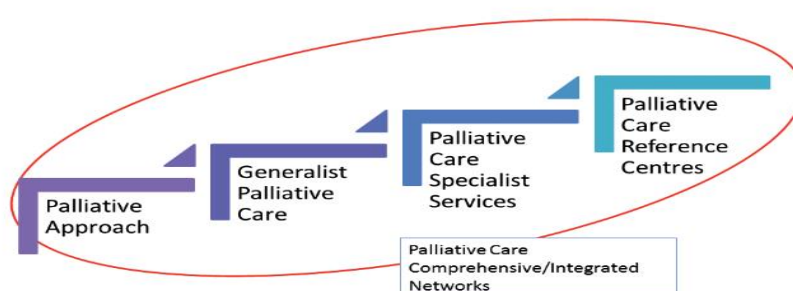


Figure 8. Levels of PC complexity (Source: Gómez-Batiste and Connor 2017)

¹³ The manual distinguished between the establishment and integration of services and although integration was not clearly defined, it was described as involving “... moving palliative care services from isolated “islands of excellence” and embedding these services within the infrastructure, resource chain and workforce planning of a district” and as linking or coordinating services between different levels of PC to allow for strong and effective PC provision (Krug and Kelley 2016, p. 43). This is different to the PHS where the terms ‘integration’ and ‘implementation’ of PC were often used interchangeably.

Table 3. Descriptions of the levels of PC (Sources: Harding and Higginson 2004; Spence *et al.* 2004; Grant *et al.* 2011b; True Colours Trust 2012; Hartwig *et al.* 2014; Rawlinson *et al.* 2014; Downing *et al.* 2016; Hannon *et al.* 2016; Gómez-Batiste and Connor 2017; Grant *et al.* 2017)

Level of PC	Description
PC approach	When PC principles are followed by all health workers for those with chronic or life-threatening conditions. Using a PC approach entails creating protocols to guide service provision, a cultural awareness around the need for PC, access to basic drugs and diagnostic equipment to assess and treat basic physical symptoms, together with the availability of basic spiritual, psychosocial and bereavement support structures. The use of volunteers or community based-health workers and the mentorship and support of staff are vital to using a PC approach. Using this approach in all services, particularly in primary health care and community-based structures, is perceived as a low-cost mechanism to ensure adequate quality of care and universal coverage for patients with PC needs.
Generalist PC	Provided by professionals with additional training to treat basic PC needs. Generalist PC professionals provide support and training to other facility staff working with the patients and facilitate referrals between the patient and other services, including specialist PC. This type of care is useful in areas where a high proportion of patients present with complex PC needs
Specialist PC	Provided by a team of professionals for those with complex PC needs which cannot be met through generalist PC or by using a PC approach. These teams can be multidisciplinary, including a doctor, nurse and other health care professionals (i.e. psychologist, social worker, spiritual counsellor, rehabilitation staff etc) or basic in nature, comprising of only a doctor and nurse. Basic teams are often directed by nurses and supported by doctors in and volunteers are used to link the team to the community.
PC network	PC networks are models of integrated and organised PC provided in to those within a geographical area with care pathways between all services, often led by a leading PC team or through an agreement between the different services.

Interventions to integrate palliative care into health systems

A rapid review of interventions to integrate PC in HICs, where access to PC services is better (Lynch *et al.* 2013), revealed that although some focus is given to increasing access to PC through integration (Aldridge *et al.* 2016), more emphasis is placed on integrating PC with specific health services, such as cancer care (Hui and Bruera 2015; Ferrell *et al.* 2017), and on integrating different PC services so as to improve the continuum of care and coordination (Bainbridge *et al.* 2010; Ewert *et al.* 2016; Garralda *et al.* 2016; Brazil 2018). The InSuP-C research project is good example of the latter, which aimed at identifying best practices of delivering integrated PC in European settings to improve continuity of care (van der Eerden *et al.* 2014; Ewert *et al.* 2016). This project provided a definition of integrated PC:

*Integrated palliative care involves bringing together administrative, organisational, clinical and service aspects to realise continuity of care between all actors involved in the care network of patients receiving palliative care. It aims to achieve quality of life and a well-supported dying process for the patient and the family in collaboration with all the caregivers (paid and unpaid). (Van der Eerden *et al.* 2014, p. 3)*

Examples of similar intervention approaches can be found in LMICs – for example interventions to integrate PC services with specific services such as HIV and cancer (World Health Organisation 2004; Krakauer *et al.* 2007; Green and Horne 2012; Simms *et al.* 2012); or interventions to increase access to PC through integration (Khosla *et al.* 2012). In the LMIC studies, there was a similar variation in definition and conceptualisation of

integrated PC – but few provided clarity. In fact, this scoping review found only two LMIC-focused studies in which integrated PC was clearly defined (Table 4).

Table 4. Definitions of integration of PC found in documents on the integration of PC in LMICs

Date and author	Definition of integration of palliative care
Green and Horne (2012), p. 6	The aim of integration is to enable people living with HIV to access different but connected health and psychosocial care services from one point of access, rather than via many fragmented services and providers. By doing this, HIV healthcare workers are better able to improve patient outcomes with efficiency for both the client and the healthcare system.
Rhee <i>et al.</i> (2018), p. 6	Integration was defined as availability of PC services through all levels of the health care system, including in different types of services provided, such as public hospitals vs. faith-based and private hospitals.

Integration

In health systems around the world ‘integration’ and ‘integrated care’ has become a major area of focus, particularly in primary health care (Frenk 2009). This has come from an awareness, particularly in LMICs, that health outcomes have not necessarily improved through health systems organised around a specific health problem or primarily targeting curative care (Dudley and Garner 2011). Changes in health care needs have also sparked this shift (back to) integrated care, as health systems are not orientated to providing care for chronic and multimorbid health care needs (World Health Organisation Regional Office for Europe 2016). These are more prevalent globally and related to NCDs, the leading causes of death worldwide (World Health Organisation 2013).

Defining integration in health services and systems

As discussed, there is a lack of consensus how integration (as it relates to health) should be defined – and in fact, a systematic review found 175 different definitions relating to integration (Armitage *et al.* 2009). Others have noted that this lack of consensus frustrates efforts to provide integrated care (Kodner 2009; Mayhew *et al.* 2017) and hampers research (Leutz 1999; Atun *et al.* 2009; Valentijn *et al.* 2015).

Table 5. Most popular definitions of ‘integration’ identified in this scoping review

Source	Definition/Description
WHO Regional Office for Europe 2016	Integrated health services delivery is defined as an approach to strengthen people-centred health systems through the promotion of the comprehensive delivery of quality services across the life-course, designed according to the multidimensional needs of the population and the individual and delivered by a coordinated multidisciplinary team of providers working across settings and levels of care.
Briggs and Garner 2006	...a variety of managerial or operational changes to health systems to bring together inputs, delivery, management and organisation of particular service functions.
Atun and Menabde 2008	...the extent, pattern, and rate of adoption and eventual assimilation of health interventions into each of the critical functions of a health system.

Leutz 1999	The search to connect the healthcare system (acute, primary medical and skilled) with other human service systems (e.g., long-term care, education and vocational and housing services) to improve outcomes (clinical, satisfaction and efficiency).
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One of the reasons for the variety of definitions around integration is that it has relevance to, and can be understood from different disciplinary perspectives, which are often not complementary (Waddington and Egger 2008; Shaw *et al.* 2011).¹⁴ Another reason for this lack of consensus is that integrated services can look different in various contexts, depending on why services were integrated and for whom. A WHO technical brief reported that integrated health services are most commonly referred to as: (1) a package of integrated health interventions for a particular population; (2) the use of multiservice delivery points to provide a range of integrated services for a geographical population; (3) continuity of care over time; (4) vertical integration over levels of service provision; (5) integrated policy making and management and, lastly, (6) working between sectors (Waddington and Egger 2008). The most relevant and frequently used definitions of integration identified in this scoping review are laid out in Table 5 above.

It is important to differentiate between ‘integration’, ‘integrated care’ and ‘continuity of care’ which are related, but different concepts. We have already unpacked ‘integration’ above. ‘Integrated care’ generally refers to health care delivery that aims to achieve better patient care by providing coordinated services, which is achieved through integration and integrative processes (Shaw *et al.* 2011; Brazil 2018). ‘Continuity of care’ - also described as an outcome of integration - has been defined as being “the method by which patients experience the cohesiveness and connectedness of the health system” (Kodner 2009, p. 10).

In the broader health literature there have been several attempts made to describe integration conceptually (Leutz 1999; Waddington and Egger 2008; Kodner 2009; Dudley and Garner 2011; Shaw *et al.* 2011; Goodwin 2013; Valentijn *et al.* 2015). The *breadth* of integration (also called orientation of integration (Martínez-González *et al.* 2014) has been said to refer to whether *horizontal*¹⁵ or *vertical*¹⁶ integration has taken place (Shaw *et al.* 2011). *Types or dimensions* of integration have also been discussed and the most common identified being (1) functional integration (also called administrative integration (Shaw *et al.* 2011), (2) organisational integration, (3) professional integration, (4) clinical integration, (5) normative integration and (6) systemic integration (Leutz 1999; Delnoij *et al.* 2002; Contandriopoulos *et al.* 2003; Fulop *et al.* 2005). The *degree* of integration has also been described, mainly referring to the influential framework by Leutz (1999)

¹⁴ For example, for a health care user, an integrated health service would be one that is easy to navigate, require fewer facility visits and provide continuity of care. But for a health care worker, integration could mean that technical services and support functions are managed, funded and provided together and integration could have negative impacts on their workload.

¹⁵ The joining or working together of similar organisations, networks or groups at the same level of care.

¹⁶ Coordination over different levels or stages of care, common in disease funded programs.

which describes the extent of integration along a continuum, where services are integrated through *linkages* to *coordination* to *full integration*, described in more detail below (Table 6).

Table 6. Intensity of integration (Source: Shaw *et al.* 2011, adapted from Leutz 1999)

Intensity Level	Description
Linkage	Taking place between existing organisational units with a view to referring patients to the right unit at the right time, and facilitating communication between professionals involved in order to promote continuity of care. Responsibilities are clearly aligned to different groups with no cost shifting.
Coordination	Operating through existing organisational units so as to coordinate different health services, share clinical information and manage transition of patients between different units (for example chains of care, care networks).
Full integration	Formally pooling resources, allowing a new organisation to be created alongside development of comprehensive services attuned to the needs of specific patient groups.

Only limited attempts have been made to conceptualise the full complexity of integration interventions (Goodwin 2013; Bautista *et al.* 2016). One prominent framework identified that uses a health systems perspective to analyse integration approaches was developed by Atun (2010). It allows the user to analyse the integration of health interventions into health system functions and determine the nature and degree of integration (Atun *et al.* 2010). Valentijn and colleagues (Valentijn *et al.* 2013; Valentijn *et al.* 2015) also developed a conceptual framework to analyse integration from a health systems perspective, called the Rainbow Model of Integrated Care (Figure 9). This framework acknowledges the complex nature of providing integrated care in a health system and demonstrates how different integrative processes are related across the levels of care. It recognises that integration requires inputs at all levels of the health system and includes a range of actors and/or organisations (Grooten *et al.* 2018). The value of the Rainbow Model of Integrated Care framework has gained popularity in recent studies (see (Bautista *et al.* 2016; van Rensburg and Fourie 2016; Chuah *et al.* 2017; Mounier-Jack *et al.* 2017), owing to its ability to comprehensively analyse integration interventions within the context of a dynamic health system.¹⁷

¹⁷ This model has been used to measure integrated care in three countries to analyse the integration of mental health services and HIV, investigate different integration approaches used in LMICs compared to HICs, study the types of integrated mental health care in specific African and review instruments that measure integrated care.

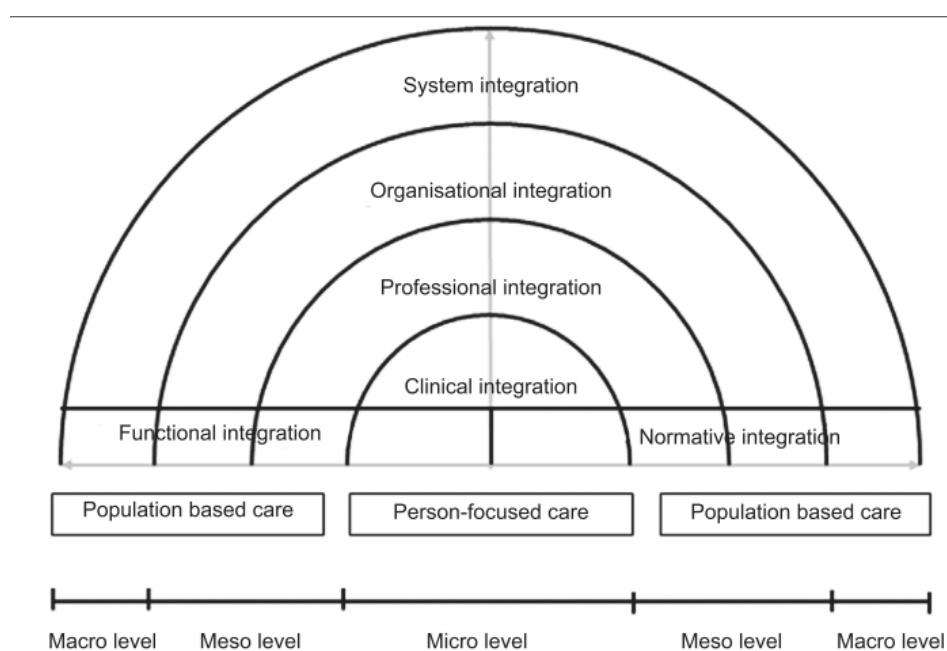


Figure 9. The Rainbow Model of Integrated Care (Source: Valentijn *et al.* 2013)

Health service/system integration approaches in LMICs and Africa

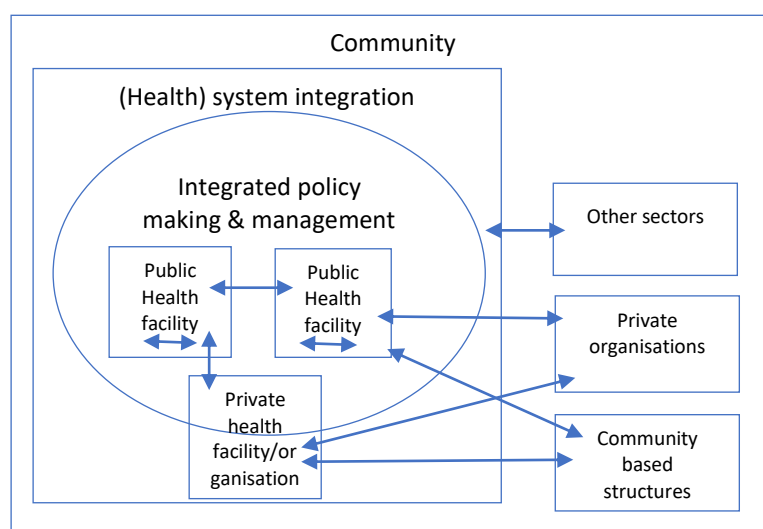
Arguments exist both for and against integration of health care services in LMICs, which can be seen by the great variety of integrated programs that exist (Waddington and Egger 2008). Integration is seen as leading to more user satisfaction and a healthier population as it is perceived as a part of the solution to allow health systems to adapt to changing needs (Grooten *et al.* 2018), overcome health system problems such as lack of financial resources (Briggs and Garner 2006) and shortages of skilled health care workers (Sweeney *et al.* 2014), and, lastly, improve the quality and access to health care services (Dudley and Garner 2011). Integration is also thought to reduce fragmentation with the health system caused by health care orientated around specific health problems and curative care (de Pinho *et al.* 2005). However, there are also concerns that integration of services can influence the quality of the services provided, or compromise the value of single-focus programs that are functioning well, by joining them with others that are not (Waddington and Egger 2008; Dudley and Garner 2011).

There are claims that the integration of health services in LMICs have improved the quality and access to health care services. However, review work has found few high-quality studies that measure this, making such claims poorly evidenced (Briggs and Garner 2006; Dudley and Garner 2011). The evidence from these reviews have suggested that ‘adding’ services to others can improve the use of the service and healthcare delivery outputs, but that the opposite often occurs in instances of ‘fuller’ health service integration (Dudley and Garner 2011).

Interventions and approaches to integration in LMICs have typically focused on the creation of packages of health services for specific groups at a service delivery point (i.e. a clinic or hospital), usually around the priorities of international funders (Mounier-Jack *et al.* 2017). LMICs have also targeted the integration of disease-specific programs, such as the integration of TB and HIV services (Legido-Quigley *et al.* 2013), to reduce health expenditure and improve efficiency (Ekman *et al.* 2008; Atun *et al.* 2010). Integration interventions in LMICs rarely focus on integration between health and other non-health sectors (Briggs and Garner 2006; Mounier-Jack *et al.* 2017) and are not often viewed from a holistic health systems perspective, where the effect on the intervention on the system as a whole is taken into account (Mayhew *et al.* 2017). A systematic review of the integration strategies used in LMICs by Briggs *et al.* (2006) found that three main integration models were used, including: 1) adding on a new service to an existing service; 2) creating a new integrated service instead of multiple facilities ('one-stop shop') or 3) developing a package of services for a particular group of people. Chuah *et al.* (2017) found that in LMICs models of integration often involved integration within a single facility, between multiple facilities or through task shifting and case managers, with little evidence of systems integration.¹⁸ These approaches correlate with the different meanings of integrated health care services found by Waddington and Egger (discussed earlier), summarized conceptually below (Box 5).

¹⁸ Study investigated approaches to integrate mental health and HIV services globally using Valentijn *et al.*'s (2013) framework.

- **Integration at the point of service delivery:**
 - Developing a package of integrated services for a population or particular group.
 - Integration within one facility:
 - Providing an integrated service combining two previously separate services or a multipurpose delivery site.
 - Adding an additional component, or linked a new component, to an existing service.
 - Integration through task shifting.
- **Integration between organisations:**
 - Integration between multiple facilities:
 - Provision of lifelong care or prolonged care over a life stage (i.e. a person with HIV or a child from the birth through to child care.) or for a particular population.
 - Coordination between public and private facilities/organisations and/or community structures/organisations.
 - Integration between different levels of care.
- **Integration between different sectors**
- **Integrated policy making and management**
- **System integration**



Box 5. Integration approaches to integrating health care services in LMICs (Sources: Adapted from Briggs and Garner 2006; Waddington and Egger 2008; Chuah *et al.* 2017)

Conclusion: Frameworks for the integration of PC into African health systems

The aim of this scoping review was to investigate the concepts of integration and PC; the evidence on integration of PC in LMICs, and how this relates to health system strengthening; as well as to identify frameworks that would be useful in analysing interventions and approaches to integrating PC in the African context. This scoping review shows that both PC and integration are defined in a variety of ways, represented by numerous terms and definitions in the literature¹⁹, with little consensus on either (Armitage *et al.* 2009), although the WHO's definition of PC has gained some traction. Although the underlying concepts relating to integration have been defined (Shortell *et al.* 1996; Leutz 1999; Delnoij *et al.* 2002; Curry and Ham 2012), there

¹⁹ Such as 'hospice care', 'terminal care', 'supportive care' or 'end of life care'.

are limited examples of frameworks that explain the complex, dynamic nature of integration *in relation to health systems* (Goodwin 2013).

Therefore, it is no surprise that the integration of PC is inconsistently conceptualised, with this scoping review showing that in LMICs literature on the integration of PC rarely refers to the integration of PC into health systems as they are now globally understood (including areas such as health policy or health worker education); and/or integration of PC services with other health services. This inconsistent conceptualisation is of great concern, as this can inhibit the integration of PC into LMIC health systems, which is vital to increasing access to this care and strengthen health systems in contexts where the need for PC is greatest and increasing (Knaul *et al.* 2017). With the recent call by the WHA, and commitment by members to integrate PC into health systems, a clear understanding of integration of PC is urgent to guide this process.

Further research is also needed to guide such efforts (Harding *et al.* 2003; Ncama 2005; Mwangi-Powell *et al.* 2013). Although mapping of the development of PC in African countries has been recently undertaken (Rhee *et al.* 2017), the approaches to integrating PC have not been reviewed.

This scoping review also aimed to identify or develop a framework that could be useful in guiding such an investigation. Although the WHO's Public Health Strategy is useful to analyse barriers to the integration of PC and map the development of PC, more detailed guidance is required to analyse approaches to integrating PC in health systems. Investigating the integration of PC from a health systems perspective will be beneficial, with PC being recently understood as a primary responsibility of health systems (Webster *et al.* 2007), and the integration of PC into health systems seen as a key approach for increasing access to PC, and for strengthening health systems (Knaul *et al.* 2017). There are some examples of such frameworks from HICs (see Bainbridge *et al.* 2010; Hui *et al.* 2015; Hui and Bruera 2015). However, these are applicable only to specific HIC contexts and were not developed to analyse a variety of interventions, as is necessary in the suggested required systematic review. For example, Hui and Bruera's (2015) framework is applicable to investigate the integration of PC and oncology in small hospitals; or Bainbridge *et al.*'s (2010) framework is used to evaluate regional PC networks, both of which are from HICs.

Therefore, a framework has been developed by the author (see Table 7), drawing on models of integration being used in LMICs identified in other studies (Briggs and Garner 2006; Waddington and Egger 2008; Chuah *et al.* 2017), and the levels of PC, drawing information from studies from this review (see (Harding and Higginson 2005; Ncama 2005; Mwangi-Powell *et al.* 2013; Gómez-Batiste and Connor 2017). This framework

will be adapted further during the systematic review. The Rainbow Model of Integrated Care (Valentijn *et al.* 2013) will also be used to allow explore the types and level of integration.

Table 7. Initial framework to investigate the models of integration and level of palliative care used in interventions (Source: author)

Mode of integration		Level of palliative care			
		PC approach	Generalist PC	Specialist PC	PC Network
	Integrated policy-making (only)				
	Integrated training (only)				
	Single facility integration				
	Multi facility integration				
	Sectoral integration				
	System integration				

The integration of PC into African health systems requires complex and multi-faceted interventions that take health systems into account (Grant *et al.* 2017). An analysis of the current interventions and approaches to integrating PC would be highly beneficial in identifying facilitators and barriers to integration to provide guidance for future interventions.

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Part C - Journal Article

Journal targeted: *Health Policy and Planning (HPP)*¹

Approaches to integrating palliative care into African health systems: a systematic review

Lara Court²

Abstract

Africa is characterised by a high burden of disease and health system deficits, with an overwhelming need for palliative care. The demand for palliative care is expected to increase, yet only one African country is assessed to have fully integrated palliative care into their health system - and generalised palliative care is said to be available in a mere handful of others. The integration of palliative care into all levels of a health system has been called for to increase access to palliative care, and to strengthen health systems. Contextually appropriate evidence to guide integration is vital, yet limited. This qualitative systematic review analyses interventions to integrate palliative care into African health systems to provide insight into the 'how' of palliative care integration - what approaches are currently being used, common facilitators and barriers to palliative care integration and how palliative care integration is being conceptualised and related to health systems strengthening in the African context. 40 articles were identified, describing 51 different interventions. This study found that a variety of different integration models are being used, with limited trends of best practice being evaluated and repeated in other contexts. Most interventions focused on integrating specialised palliative care services into individual or multiple health facilities, such as hospitals, clinics or home-based care programs; with few examples of palliative care being integrated at a national- or population-level. Four themes were identified that could either promote integration (by being present), or block integration (by their absence). These include the provision of palliative care at all levels of the health system alongside curative care; the development and presence of sustainable partnerships; the ability of the health system and health workers to support integration; and lastly, placing the client, their family and community at the centre of integration. These echo what is found in broader literature on the integration of health services. There is currently a prominent suggestion that the integration of palliative care contributes to health system strengthening, however this is not well evidenced in the literature and future interventions would benefit from

¹ Instructions for authors are in Appendix 5. Authors' contribution and information are excluded.

² For the purpose of the thesis, the student is the sole and first author of this article.

placing health systems strengthening at the forefront, as well as situating their work within the context of integration of health services more generally.

Key words: Palliative care, integration, Africa, health systems strengthening.

Key Messages

- More specialised palliative care is predominantly being integrated into health care facilities, with a limited focus on integrating palliative care at a national- or population-level, or facilitating the use of a 'palliative care approach'.
- As would be expected, integration of palliative care into health systems is occurring mostly in a sub-set of southern and eastern African countries where palliative care development levels are higher.
- The concept of 'integration' is rarely defined in the literature on palliative care integration, and is not yet associated with work on the integration of health services generally. Commonalities exist between the two, so lessons can be shared.
- Few interventions linked the integration of palliative care to health system strengthening, or assessed this as an outcome, making this difficult to claim in the African context. Evidence on this is vital to strengthen arguments to integrate palliative care into resource-constrained health systems.

Introduction

...palliative care is an ethical responsibility of health systems, and that it is the ethical duty of health care professionals to alleviate pain and suffering, whether physical, psychosocial or spiritual, irrespective of whether the disease or condition can be cured... (World Health Assembly 2014, p. 2)

Palliative care (PC) has recently been understood as a human right, as a lack of access to PC leaves patients without relief from pain at the end of their life or when facing life-threatening illness (Brennan 2007), negatively effecting patients and their families, as well as health system performance (World Health Assembly 2014). Provision of PC is vital in improving patients' quality of life and allowing for a responsive health system (Knaul *et al.* 2017). This shift in the understanding of PC has resulted in health systems being made responsible for providing this care (World Health Assembly 2014) and a greater focus on PC development (Inbadas *et al.* 2016), particularly in subset of African countries such as Kenya, Malawi, South Africa, Tanzania, Uganda, Zambia and Zimbabwe (Rhee *et al.* 2017a). However, with 16 African countries assessed as having no identifiable PC service (Rhee *et al.* 2017a), a significant lack of PC remains a concern (Reid *et al.* 2018) and further provision and access is urgently needed (Powell *et al.* 2013). Therefore, African health systems characteristically have an urgent need for palliative care (PC) in the face of limited health care resources and high burdens of death from communicable and non-communicable diseases (NCDs) (Grant *et al.* 2011b). Following World Health Organisation (WHO) estimates that 1% of a population require PC, approximately ten million people in Africa need PC annually (African Palliative Care Association 2018). Yet most Africa countries

typically have less than two PC services³ available per million people and even one of the most developed African countries, South Africa, has approximately only 160 PC services which assisted 40 000 people in 2017 (Rhee *et al.* 2017c).

The HIV/AIDS crisis also greatly increased the demand for PC in Africa (Uys 2003) and dramatically reshaped the way in which PC services were provided (African Palliative Care Association 2011). Modern PC was historically provided by non-governmental organisations (NGO), independent of the public health system (Powell *et al.* 2013). During the HIV/AIDS crisis, the responsibility for PC provision fell largely on the patient's families and NGOs funded by external donors, who were still unable to effectively provide enough care (Uys 2001). The provision of PC services outside public health systems not only led to limited access to PC, but also created fragmented PC provision and separated PC services from disease-modifying health services (Grant *et al.* 2011a). The further shifting of HIV/AIDS from crisis to chronic disease, based on the increasing availability of antiretroviral medicine, has further shaped PC services in Africa (Herce 2014) and led to challenges relating to funding (Rhee 2018).

The integration of PC into health systems has been urged by the World Health Assembly (WHA)(World Health Assembly 2014; World Health Assembly 2017) and the WHO (World Health Organisation 2013; Gómez-Batiste and Connor 2017; Knaul *et al.* 2017). This is based on the understanding that universal access to PC can only be achieved by integrating PC into health systems (Knaul *et al.* 2017). Advocates of this have argued that integrating PC into health systems does not only hold benefits for the user by increasing access to PC, but also has the potential to *strengthen* health systems. For example, providing PC and pain relief is thought to result in benefits that 'spill' into and strengthen other health system functions and improve quality of care (Knaul *et al.* 2017). These benefits include supporting the development of responsive and patient-centred health systems, where patients' needs guide treatment (Green and Horne 2012; Gwyther *et al.* 2018), and enabling staff to provide the care needed by those with life-threatening illness, which motivates them and improves the quality of care (Grant *et al.* 2017). Integration of PC has also been found to reduce the number of end-of-life hospital admissions, which has potential cost-saving benefits and can relieve congestion in health facilities (Hongoro and Dinat 2011).

The call to integrate PC into health systems comes within a broader impetus towards the integration of health care services (Waddington and Egger 2008), as integrated care is seen as a way to support health systems in

³ For the purposes of this study, a PC service refers to a health service whose aim is to provide PC to those with life-threatening illness, through professionals trained in aspects of PC. It includes, but is not limited to, any kind hospice, home care teams (who provide PC), support teams in hospitals and other health facilities, palliative care units and outpatient clinics, as well as paediatric palliative care hospices and services.

adapting to changing population needs and improve health outcomes (World Health Organisation Regional Office for Europe 2016). However, few attempts have been made to understand the complex nature of integrated care initiatives (Goodwin 2013), and there is lack of consensus on what integration means (Armitage *et al.* 2009), how integrated care should be provided and measured (Kodner 2009; Dudley and Garner 2011), as well as whether integration actually achieves the expected positive results as described above (Briggs and Garner 2006). Recognising this, recent frameworks have been developed to investigate the complexities of integration interventions (see Atun *et al.* 2009; Valentijn *et al.* 2013; Part B and Methods section).

The WHO published a *Public Health Strategy* to guide the integration of PC into health systems (Stjernsward *et al.* 2007). This document describes four key ‘pillars’ needed, including: the development of appropriate PC policies, adequate drug availability, education of health care workers and the public on PC, together with specialised training of professionals, and, lastly, implementation of PC at all levels of the health system. Although this strategy provides guidance on embedding PC within a health system, more specific guidance has been called for (Harding and Higginson 2005; Ncama 2005; Hasselaar and Payne 2016). Models of PC have been reviewed and found that a variety of models of PC provision exist in Africa, at different levels of care, with home-based care often being most practical due to the available resources and context (Harding and Higginson 2005; Ncama 2005; Downing *et al.* 2010; Jang and Lazenby 2013; Mwangi-Powell *et al.* 2013; Harding *et al.* 2014). Other practical guidance has been provided, such as describing key elements for successful integration, together with strategies to develop different levels of PC within a health system (Krug and Kelley 2016; Gómez-Batiste and Connor 2017). These ‘levels of PC’ described by Gómez-Batiste and Connor (2017) (Table 3) include: the use of a PC approach by all health workers working with patients with life-threatening disease to manage their general pain and other symptoms, as well as generalist and specialist PC provided by specially trained health workers and PC teams to patients with more complex PC needs.

This systematic review of the interventions and approaches to integrating PC into health systems in the African context was undertaken to provide further insight into how the integration of PC is being conceptualised in Africa and being related to health systems strengthening, together with what approaches are being used to integrate PC.⁴ Learning from the approaches and experiences currently being used to integrate PC into African health systems can guide future interventions at this time of increased PC development and increased focus on integration of PC. Although reviews on PC development in Africa have been done (Jang and Lazenby 2013; Rhee *et al.* 2017a), a specific review on the integration of PC into African health systems is still needed.

⁴ This study was not evaluative – and as such did not assess whether the intervention had effectively or successfully integrated PC into the health system. The available evidence was descriptive, rather than evaluative in nature, and studies did not provide enough information to allow for this type of assessment.

Methods

A qualitative systematic literature review method⁵ was chosen because of its ability to synthesize the evidence available on a given topic in a rigorous and transparent manner and to assist with evidence-based decision making (Dixon-Woods *et al.* 2016). A scoping review was done as an initial phase of the systematic review due to the complexity and understudied nature of the topic (Arksey and O'Malley 2005, see Part B).⁶ The evidence on PC integration from the scoping review was primarily qualitative in nature, consisting predominantly of grey literature, descriptive articles, program descriptions and systematic reviews of qualitative research. Very limited published evidence described failed integration interventions. This, together with the 'explanatory power' of qualitative data (Dixon-Woods and Fitzpatrick 2001), guided the focus on qualitative data in the systematic review, as this is the predominant type of available data and would best answer the descriptive question of *how* PC is being integrated into African health systems. The systematic review process is described in more detail below.

This systematic review used a health systems approach to analyse interventions, to help in understanding how the intervention influenced the health system as a whole, and to conceptualise the potential health systems strengthening effect of the intervention (Gilson 2012). Systematic reviews are frequently used in health policy and systems research to allow for the provision of synthesised results on a topical subject for decision makers and implementers (Tricco *et al.* 2017). Methods used in other related systematic reviews also informed this study, to further increase the generalisability of the results (Legido-Quigley *et al.* 2013). This included studies which analysed the integration of health care services using a health systems perspective (Legido-Quigley *et al.* 2013; Chuah *et al.* 2017) and explored the integration of PC in high income country (HIC) settings (Garraalda *et al.* 2016).

Systematic literature search

The search strategy was developed collaboratively between the researcher and study supervisor, and checked with a Librarian from the University of Cape Town (see Appendix 3). Search terms and MeSH terms were grouped in three categories (see Appendix 3). The first category related to 'Africa', which included all 55 countries recognised by the United Nations, together with the variations of individual country names (i.e. Ivory Coast and Cote d'Ivoire) (see Appendix 3 for the complete list of countries). To manage the search results the first category search was restricted to titles and abstracts. The second group of search terms related to

⁵ The qualitative systematic review method was chosen to analyse and interpret qualitative data obtained in the analysed studies

⁶ The results from the scoping review were presented in Part B and used to refine the research question and methods used for the systematic review. The results were drawn in again in the Discussion sections of this Part C paper to allow for a deeper understanding and interpretation of the results from the systematic review.

‘integration’ and the third to ‘palliative care’. The search terms within these two categories were informed by the scoping review, and were searched using Boolean terms. Articles with the words ‘African American’ were frequently identified during trial searches – but were excluded. A variety of databases were searched in order to ensure that all relevant articles were found, as well as reduce bias (Bown and Sutton 2010). To identify integration interventions from economic, implementation science and health care fields the databases searched included Pubmed, Academic Search Premier; Africa-Wide Information; Cumulative Index of Nursing and Allied Health Literature (CINAHL); Economic Literature (EconLit); Education Resources Information Center (ERIC); Health Source: Nursing/Academic Edition; Medline and Humanities International Complete databases. A complementary Google Scholar search was conducted to identify articles from specific African countries that were not identified in the other databases.⁷

Article selection

The inclusion and exclusion criteria are summarized in Box 1. This review was restricted to articles that addressed specific interventions or approaches to integrating PC into the health system in an African country between 2002 and 2018. *Integration* was understood as any “Managerial or operational changes to health systems to bring together inputs, delivery, management and organization of particular service functions as a means of improving coverage, access, quality, acceptability and (cost)-effectiveness” (Watt *et al.* 2017, p. iv15). A *health system* was defined using the WHO definition (World Health Organisation 2007) and HPSR theory (Gilson 2012) to extend beyond the public system delivering care to the population, to include both public and private organisations, people and actions whose main goal is to improve, promote and maintain health. Interventions that

integrated PC into an already existing program were included; however, articles describing interventions to integrate another type of care, for example HIV care, into PC programs, without any aim of linking this PC program to the health system were excluded. Only articles in English were considered, from the year 2001 (when PC was more clearly defined by the WHO and related partners to ensure conceptual clarity) to present-day. Only published, peer-reviewed articles were included to ensure quality, as well as excluding non-empirical, editorial and opinion pieces

Box 1: Inclusion and exclusion criteria

Inclusion criteria:

- Empirical research articles describing an intervention that integrated palliative care into a part of a health system in an African country between 2002 and 2018 according to the way these terms are understood in the study (see Glossary of key terms)

Exclusion criteria:

- Not in English
- Not in an African country
- Intervention completed before 2001
- Articles that did not describe an intervention to integrate palliative care in the health system
- Editorials, opinion or narrative articles; grey literature and articles not published in a peer-reviewed journal

⁷ The first 200 articles were included, and the articles were ranked according to relevance.

This review did not aim to evaluate the interventions' effectiveness or how successful the intervention was at integrating PC, but explored the nature of the interventions, to draw out facilitators and barriers to integration. Therefore, studies were not excluded based on study design or outcome measures. Articles which generally addressed integration of PC or that focused on supporting the integration of PC were excluded if they did not also describe an intervention to integrate PC into a health system. These included studies identifying the need and preferences for PC, primarily focusing on the provision of drugs used in PC provision or mapping the development of PC - although some are referenced in the discussion and conclusion section. The search identified multiple articles referring to the same intervention, such as a published study protocol and outcomes article. In such instances, only the most relevant article was included - the one providing the most information regarding the intervention or approach.

Data extraction, analysis and synthesis

Once relevant articles were identified for review, data was extracted into a data extraction form (Appendix 1),⁸ to reduce bias and error, and improve rigour by providing an audit trail. The various categories were initially informed during the scoping review and refined during the systematic review.

Following data extraction, data analysis and synthesis took place. This involved analysing how integration of PC was conceptually understood and related to health system strengthening within the identified studies; identifying the 'level of integration' (Table 1) and 'dimensions of integration' or integrative processes (Table 2) used by the interventions; and mapping the 'model/mode of integration' and 'level of PC' used in the interventions. Lastly a thematic analysis of the facilitators and barriers to integration was undertaken (see below).

The 'level of integration' was analysed using the conceptual framework developed by Valentijn *et al.* (2013), (Figure 1), previously applied to integrated health care. This helped to determine if targeting a specific level of integration could facilitate or hinder integration of PC into a health system, as well as to trace the type of integration being used in interventions. Others have used this framework to better understand integration in African countries (for example, to explore how integrated care is outlined in government policy to understand the forms of integrated mental health care, see Van Rensburg and Fourie 2016); and elsewhere (for example, to measure integrated care in Singapore, see Nurjono *et al.* 2016, and for mapping levels of integration of HIV

⁸ Extracted variables included, study details (i.e. date, name, authors, methodology, country and study aim); how integration was conceptualised in the study; how the intervention related to health systems strengthening; aspects related to integration (including the level, model and dimensions of integration used in the intervention) and the nature of the intervention (including the partners, type of facility, level of PC, team members and intervention description). Lastly themes related to the barriers and facilitators to integration of PC into the health system were identified.

and mental health services globally, see Chuah *et al.* 2017). In this model, person-centred population-based care is understood as the guiding principle by which to achieve integration across levels of care, where integrative processes are seen as playing inter-connected roles. These levels include the macro- (system integration), meso- (organisational, professional) and micro-level (clinical integration). Functional and normative integrative processes act across these levels to support coordination (see Appendix 2 and Table 2).

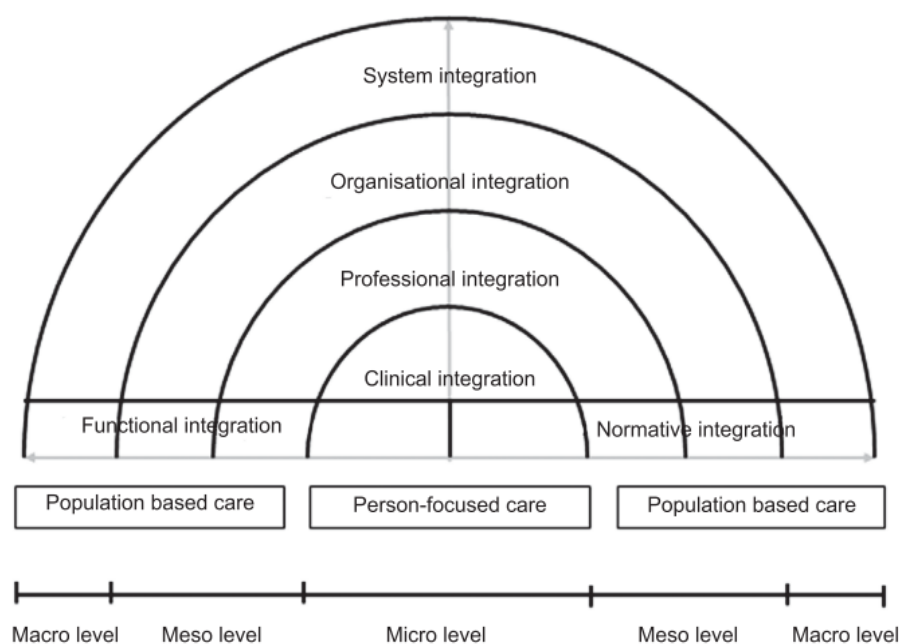


Figure 1. Conceptual framework for integrated care (Source: Valentijn *et al.* 2013)

Table 1. Levels of integration (Source: Valentijn *et al.* 2013)

Integration Level	Description
Macro level	Whole system level interventions to deliver integrated care to the population served, often at a national level. Systems need to be tailor made to match the needs of the people and to do so both vertical and horizontal integration is required, together with partnerships between professions and organisations.
Meso level	Interventions that seek to deliver integrated care for a particular group or populations with the same disease or conditions.
Micro level	Interventions seeking to deliver integrated care for individual service users and their carers through care coordination.

The 'dimensions of integration' (or integrative processes) used by the interventions were analysed, focusing on whether these were reported to act as a facilitator or barrier to integration (Table 2). These dimensions were identified in the scoping review (Part B), framed according to the work of other reviews and empirical studies (Shortell *et al.* 1996; Kodner 2009; Shaw *et al.* 2011; Curry and Ham 2012; World Health Organisation Regional Office for Europe 2016).

Table 2. Dimensions of integration. (Sources: Adapted from Shaw *et al.* 2011; Curry and Ham 2012; Valentijn *et al.* 2013; World Health Organisation Regional Office for Europe 2016; Watt *et al.* 2017)

Integration Dimension	Description
System integration	Coordinating the rules and policies within a health system.
Vertical integration	Vertical integration focuses on integration across different levels of care, such as between tertiary, secondary and primary care facilities. For example, between a hospital (offering specialist palliative care services) and community structures (providing primary or home-based care) or creation of a network across different levels of care.
Horizontal integration	Horizontal integration focuses on integration between organisations, networks or groups within the health sector, usually at the same level of care
Organisational integration	Organisational integration can be described as bringing together different organisations or facilities through mergers, networks and partnerships.
Professional integration	Integration that is led by professionals within or between organisations (compared to entire organisations as above) through shared responsibility, problem solving or decision making for common patients.
Clinical integration (service integration)	Coordinating the care process for individual patients across different services and organisations in a system.
Functional integration (administrative integration)	This involves the coordination of non-clinical or support functions to support system, organisational, professional and clinical integration and includes quality improvement, financial management and funding, information management (i.e. shared electronic patient records), shared practices and referral forms
Normative integration	Supports integration at different levels by developing a common frame of reference, mission, vision, values and culture between organisations, professional groups and individuals.

An analytical framework was developed from the scoping review to analyse the interventions in greater depth by investigating the 'level of PC' and 'models of integration' used in the intervention, and this was further developed in the systematic review process (see Part B and Figure 2). The 'levels of PC' were identified according to the WHA resolution (2014) and work by Gómez-Batiste (2017), described below (Table 3).

Table 3. Palliative care levels (Sources: Adapted from Gomez-Batiste and Connor 2017; World Health Assembly 2014)

Palliative care levels	Description
Palliative care approach	Use of palliative care principles by all health professionals within health care system/facility allowing for timely referrals for specialised care, pain management and support from diagnosis.
Generalist/basic palliative care	Care provided by specifically trained professionals who typically attend patients with life-threatening diseases and more complex palliative care needs, train other staff in providing a palliative care approach and act as reference points for patients and other hospital services.
Specialised palliative care	Care is provided by a specialist multidisciplinary team to patients with complex palliative care needs that cannot be attended to with generalist care. These teams are either basic (doctor and nurse) or more complex with professionals from other health services.
Palliative care network	A model of integrated palliative care provision in a geographical area involving integrated care pathways between services at different levels of care.

The scoping review revealed different approaches to integration and these were used to inform the 'models of integration' in the framework, specifically using work by the authors Waddington and Egger (2008), Briggs *et al.* (2006) and Chuah (2017). These included integration between single and multiple facilities, between organisations, between sectors or within policy and system wide integration. As the articles were reviewed in

the systematic review it became clear that these needed to be adapted to be relevant specifically to the models of integration of PC, therefore these were adjusted to include integration into policy (only), integration into training (only), single facility integration, multiple facility integration, intersectoral integration and system integration. Included studies underwent a consistent coding process, after which the codes were grouped by theme.

Results

To summarise, in order to answer the research question of how PC is being integrated into African health systems and what lessons can be learnt, the literature was analysed to determine how the integration of PC was being conceptualised in the African context; what different types of interventions and approaches are being used to integrate PC; how these integration interventions related to health systems strengthening and lastly, what the facilitators and barriers to the integration were in these interventions.

In total, 2028 articles were identified across all databases, imported into EndNote citation manager (removing duplicates). The title and abstracts of the remaining 1216 articles were reviewed, excluding those not relevant to the research topic⁹, which left 98 articles that addressed the integration of PC in Africa. Three further articles were identified through citation tracking, so 101 articles underwent full text review. After full text review¹⁰, 40 articles met the criteria, and were included in the data extraction sheet. This process is outlined in Figure 2 below. (Note, these 40 articles represent 51 interventions, see Appendix 4).

Included articles consisted primarily of descriptive studies. Limited evaluative studies were available. Evaluative studies typically provided outcomes that were related to patient health outcomes (patient pain, quality of life), length of hospital stay, numbers and types of patients seen within the program or the impact of a PC training program, rather than outcomes related to the extent of integration. No articles reported on 'failed' integration interventions or situations where integration did not occur, most likely due to publication bias, however difficulties within the intervention were described. Four review articles were included, where interventions were described as a part of a review of PC development in a country. Quantitative research designs were scarce, with only five studies identified (Jameson 2007; Harding *et al.* 2009; Tapsfield and Bates 2011; Harding *et al.* 2013b), including one cost evaluation (Hongoro and Dinat 2011). Mixed methods study designs were common.

⁹ Articles not related to PC, not in English, not in Africa and prior to 2001. Of articles that discussed the integration of PC in an African country, only empirical peer-reviewed studies that described an integration intervention were included.

¹⁰ Articles were excluded when full texts were inaccessible (after searching the University's library and journal subscriptions, and contacting authors directly).

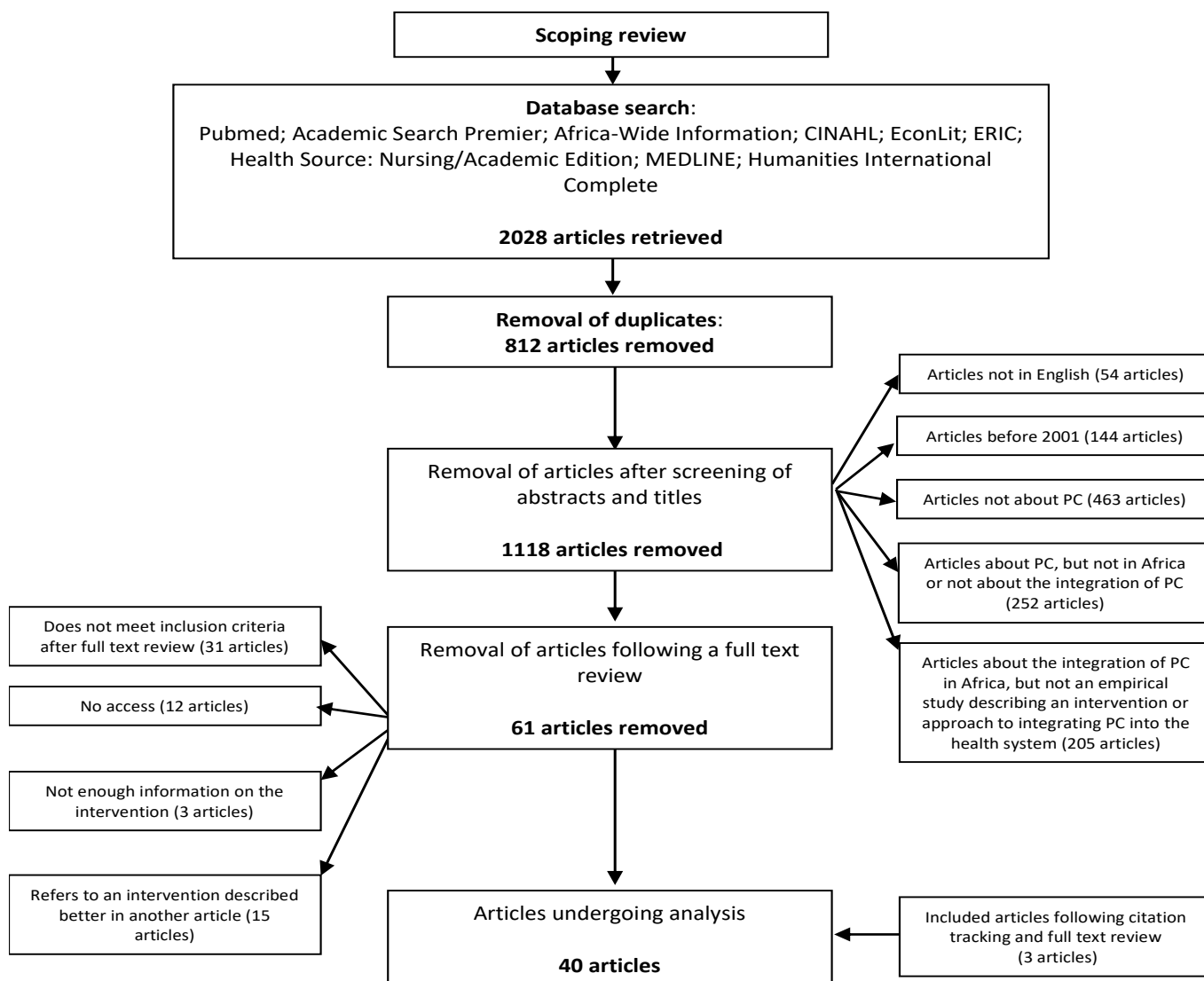


Figure 2. Systematic search process (Source: author)

Just under half of the articles (47%) describing or evaluating an integration intervention had been published in or since 2014 when the WHA resolution 67.19 was released (Figure 3) – demonstrating the increased interest in PC integration evidenced in the scoping review (Part B).

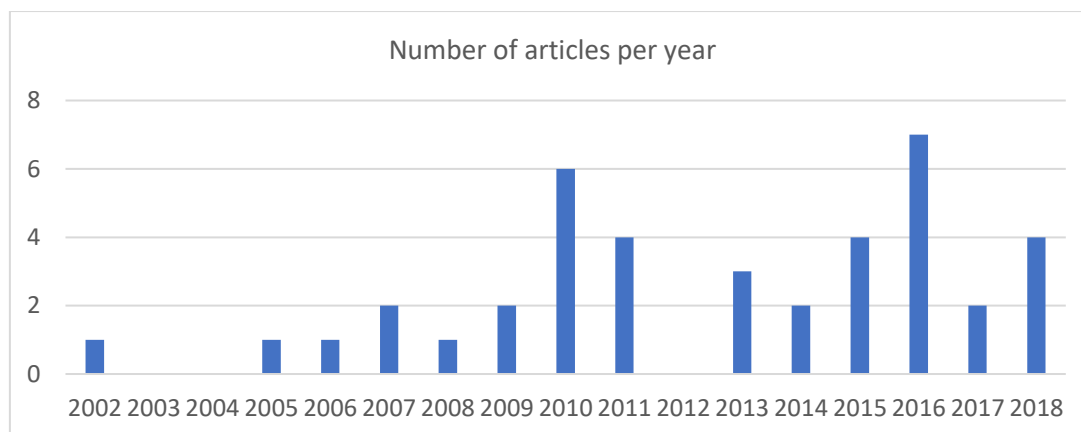


Figure 3. Number of included articles sorted by publication year, out of a total of 40 articles (Source: Author)

Two thirds of the interventions came from four countries (South Africa, Uganda, Kenya and Malawi), with just under a third of the published interventions taking place in South Africa. The number and level of included interventions found in each country are depicted below in Figure 4. The level of each intervention will be described in more detail later in this section (see 'Levels of integration and integrative processes').

Macro or macro/meso level interventions	
Uganda (3), Kenya (2), Zambia (2), Namibia (1), Rwanda (1) ●	
Meso and meso/micro interventions	
Training ●	South Africa (4), Tanzania (1), Cameroon (1), Kenya (1), Uganda (1)
Single facility integration ●	Malawi (4), Kenya (4), South Africa (3), Uganda (2), Botswana (1), Tanzania (1)
Multiple facility integration ●	South Africa (8), Malawi (5), Kenya (2), Tanzania (2), Uganda (2), Ethiopia (1), Zimbabwe (1)

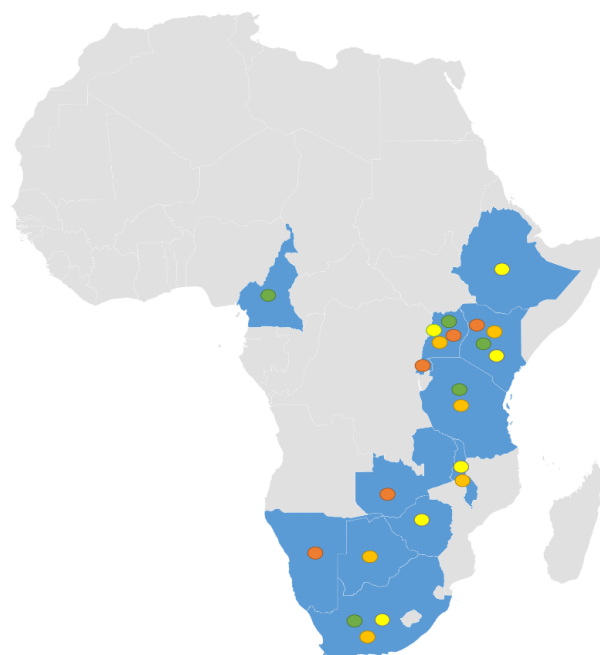


Figure 4. Number and level of interventions by country (Source: Author)

The different models of integration identified in the scoping review were refined during the systematic review (newly identified models tested our current understanding of 'types' of interventions currently being applied to integrate PC into health systems, facilities and services). Figure 5 maps the included interventions against these criteria – noting that many interventions displayed multiple features and two interventions were not mapped (see Appendix 4 for numbers, categorisations and descriptions of the interventions).

		Level of palliative care			
		PC approach PC principles used by all health professionals across health system	Generalist PC PC trained professionals attend patients with complex PC needs and refer for specialist care	Specialist PC Care provided by specialist multidisciplinary team to patients with complex PC needs	PC Network Organisation of PC provision in a geographical area to provide integrated PC
Models of integration	Integration of PC into policy-making (only) Integration of PC into national policy		1		
	Integration of PC into/through training (only) Integration of PC into the education curricula of health workers or using training to integrate PC into health worker practice		9 14 38 39 40 46	4	
	Single facility integration Integration of PC into one facility or organisation, with or without informal linkages with other facilities or organisations at the same or different level of care to facilitate integrated PC		15 21 22 27 28	3 18 19 24 29 31 30 35 41 44	
	Multi facility integration Integration of PC into more than one facility or organisation at the same or different level of care; integration between two organisations to facilitate integrated PC		10 12 16 17 25 32 49 11 34	8 5 13 7 20 33 42 50 51 2	
	Inter-sectoral integration Integration of PC into a non-health sector or Integration between health and other sectors				
	System integration Integration of PC into the health system at a primary health care or national level to ensure PC provision for the population		23 36 43 45	26 37	

Figure 5. Models of PC compared to models of integration in the identified 5 interventions (Source: Author)

Note: Numbers in this figure indicate the intervention number, located in Appendix 4. Larger image file will be inserted pre-publication.

Conceptualisations of the integration of palliative care

The scoping review revealed that integration is an inconsistently defined concept, confirmed in the systematic review. None of the included articles explicitly defined ‘integration’ or ‘integrated PC’ at the outset of the article, despite these being concepts being core and referred to continually. Multiple terms, other than integration, were used to refer to integration of PC within a health system as it is understood in this review, namely as “Managerial or operational changes to health systems to bring together inputs, delivery, management and organisation of particular service functions as a means of improving coverage, access, quality, acceptability and (cost)-effectiveness” (Briggs and Garner 2006). When the term ‘integration’ was used it often referred to a variety of different concepts, often in the same article.¹¹

Terms used to refer to integration included ‘joining’, ‘inclusion’, ‘development’, ‘implementation’ or ‘embedding’. Interventions aimed to ‘incorporate’ PC, to “connect and relate with palliative care” (Downing et al. 2015, p. 367) or to ‘link’ or create ‘linkages’ with PC services. The terms ‘development’ and ‘integration’ were often used interchangeably to refer to provision of PC by a public health system, often in instances where there were no PC services previously. In these cases, there is both the development of a PC service where there was none, as well as integration or embedding of PC into a public health system, which could be resulting in the mixed use of the terms. The term ‘coordinated’ PC services was also used to describe what we would identify as integrated PC (DesRosiers et al. 2014; Grover et al. 2017; Krakauer et al. 2018). These different conceptualisations are not surprising given the multi-faceted nature of integration (Kodner 2009), its different dimensions (Valentijn et al. 2013), and the many disciplinary perspectives applied to PC integration (Hui et al. 2013; Worldwide Palliative Care Alliance 2014).

Levels of integration and integrative processes

The levels of integration and integrative mechanisms as depicted in the included studies, were further investigated applying the Rainbow Model of Integrated Care (Figure 1) by Valentijn et al. (2013). The included interventions typically involved integration at more than one level.

Approaches to integration at a macro or macro/meso level

Six articles described interventions targeting the whole population at a national (and macro) scale (Stjernsward 2002; Freeman et al. 2016; Grant et al. 2017; Kamonyo 2018; Krakauer et al. 2018). Notably, three of these interventions were in Uganda, the African country where PC is said to be most integrated (Lynch

¹¹ In one study integration was used to describe the provision of PC by a public health system; PC being addressed in national policy and educational curricula of health professionals; PC being integrated with curative care; coordinating PC across different levels of care, as well as within and between facilities at the same level of care (i.e. horizontal integration).

et al. 2013). One analytical study described a three-year intervention to integrate PC into hospitals and the greater health systems in Uganda, Rwanda and Zambia, which is an example of an intervention involving integration at macro and meso levels as it integrated PC into national policy (macro level) and built partnerships, capacitated staff and integrated PC services into hospitals (meso level).

Four interventions applied the WHO public health strategy (Stjernswärd 2007), through collating the results around the model's 'pillars' (namely policy, drug availability, training and implementation (see Kamonyo 2018; Krakauer *et al.* 2018) or using it as a guiding principle (Freeman *et al.* 2016). Only one of the 51 interventions explicitly used a (self-declared) health systems approach (Grant *et al.* 2017), and has been highlighted by the WHO as an example of how to integrate PC in low-resource countries (World Health Organisation 2016).

Approaches to integration at a meso and micro level

The use of education as a mode to integrate PC at meso and micro levels was prominent in the literature. Although capacity building formed a part of many interventions, certain interventions solely applied a focused training approach to integrate PC into a health system, (with the understanding that the trainee would return to their setting and integrate PC into their systems or routine work).¹² The training was inserted into health worker curricula (Bassah *et al.* 2016) or provided as a separate PC training program (Gwyther and Rawlinson 2007; Downing and Kawuma 2008; Paice *et al.* 2010; Malloy *et al.* 2011; Downing *et al.* 2013), with two training programs provided by international organisations and the remainder implemented by local training institutions with international affiliations or assistance from international academics (Gwyther and Rawlinson 2007; Downing and Kawuma 2008; Downing *et al.* 2013; Bassah *et al.* 2016). These studies used innovative strategies and catered for varied types of health professionals.¹³

Four of the intervention studies used training to integrate PC into community-based organisations (all in South Africa) – all using training as the mode of integration, but differently from those above (Defilippi 2005; Di Sorbo *et al.* 2010; Wube *et al.* 2010; Jack *et al.* 2011). The previous group aimed to integrate PC into health worker training at academic institutions (Gwyther and Rawlinson 2007; Malloy *et al.* 2011; Bassah *et al.* 2016) or provide training to different cadres of health care workers from a variety of organisations, whereas this subset used training to integrate PC into the community setting by targeting a specific community-based

¹² Transfer of skills into practice was investigated using self-report measures (Paice *et al.* 2010; Bassah *et al.* 2016), observation (Downing and Kawuma 2008), or sometimes not at all (Malloy *et al.* 2011).

¹³ Programs trained trainers to educate others in PC (Downing *et al.* 2013; Paice *et al.* 2010); trained nursing faculty members together with their students (Bassah *et al.* 2016) or separately (Paice *et al.* 2010) or trained varied health professionals (Rawlinson 2007; Downing and Kawuma 2008; Paice *et al.* 2010; Gwyther and Malloy *et al.* 2011). Techniques included mobile training teams in rural areas (Downing and Kawuma 2008), classroom-based (Paice *et al.* 2010; Malloy *et al.* 2011) or long-distance learning (Gwyther and Rawlinson 2007) and mentorship (Downing *et al.* 2013).

organisation (CBO) or cadre working at the community level. One innovative intervention trained Traditional Health Practitioners (THP) (Drenth *et al.* 2018) and the other three trained community health workers (CHWs) in CBOs providing home-and community-based care (HCBC) (Defilippi and Cameron 2010; Campbell and Baernholdt 2016; Naicker *et al.* 2016). THPs are often identified as being external to health systems, however THPs are influential in communities as traditional medicine is often sought alongside bio-medical measures.

Five studies described seven more complex interventions to integrate PC into HCBC programs using training together alongside other methods. These included setting up a PC home-based care service (Wube *et al.* 2010; Downing *et al.* 2015); creating a PC network focused on PC provision in the community (Defilippi 2005), or adding PC to a package provided by already existing CBOs providing home-based care (Di Sorbo *et al.* 2010; Grant *et al.* 2011a; Downing *et al.* 2015). These interventions were led by NGOs (Grant *et al.* 2011a; Downing *et al.* 2015; Wube *et al.* 2010), such as Hospices (Defilippi 2005; Di Sorbo *et al.* 2010).

The remaining articles, and largest subset, described interventions to integrate PC services into health facilities. These services often comprised of similar elements, outlined in Box 2.

- *Provision of care to inpatients:* Most interventions provided PC services to in-patients, except where PC was integrated into an outpatient setting (Harding *et al.* 2013b). This was facilitated using referrals and members from the PC team attending ward rounds or offering consultations on symptom management.
- *Out-patient clinics:* Many interventions used this mechanism to integrate PC into a facility, (Molyneux *et al.* 2013; DesRosiers *et al.* 2014; Cornetta *et al.* 2015; Lowther *et al.* 2015; Zipporah 2016; Gwyther *et al.* 2018). Usually individuals were seen together with their care-giver, however group outpatient clinics were also described (DesRosiers *et al.* 2014).
- *Drop in clinics:* Two interventions (Hongoro and Dinat 2011; Molyneux *et al.* 2013) used drop in clinics, for which the patient did not need to make an appointment but could attend when they were at the hospital for other treatments.
- *Outreach visits:* Outreach visits were used to provide specialist PC services away from the facility, to reduce hospital admissions in one study (Hongoro and Dinat 2011). These were often home visits (Herce *et al.* 2014), according to set criteria, such as those whose mobility is heavily effected (Hongoro and Dinat 2011) and children whose caregivers could not carry them in (Amery *et al.* 2009). Also found in the form of mobile clinics (Herce *et al.* 2014), visits to other facilities, such as children homes (Amery *et al.* 2009) and other health centres (Tapsfield and Bates 2011).
- *Telephonic advisory service:* Telephonic consultations were used to manage patients' symptoms at home (Hongoro and Dinat 2011; Cornetta *et al.* 2015) and to provide follow up and bereavement calls (Gwyther *et al.* 2018).
- *Treatment plans:* Specialist PC teams often developed care plans that would be used while the patient is in the facility and following discharge. Good examples of these are in the intervention discussed by Gwyther *et al.* (2018) where a care plan was developed to guide treatment for patients being discharged to home based care, as well the inpatient unit described by Jameson *et al.* (2007) which developed treatment plans for symptom control to be used by the staff tending to the patient (Jameson 2007).
- *Referrals to external community structures:* Part of the service run by hospital-based PC services is to advocate on the behalf of the patient with community-based support, external to the public health system, such as hospice referrals or placement with a home-based care organisation.

Box 2. Common elements of PC services integrated into health facilities in the literature (Source: Author)

A limited number of these interventions created a PC network through the development and linking of PC services in a geographic area using horizontal and vertical integration (Defilippi 2005; Nanney et al. 2010; Molyneux et al. 2013; Herce et al. 2014; Zipporah 2016; Krakauer et al. 2018). Others developed a hospital-based PC team (Kirk and Collins 2006; Herce et al. 2014; Gwyther et al. 2018) which provided specialist PC, usually to hospital inpatients, or functioned as consultants for symptom management. They also performed an education and supervisory role to health workers in the community (Nanney et al. 2010) and other staff members, such ward staff within the hospital (Downing et al. 2016; Zipporah 2016; Gwyther et al. 2018) or in other health facilities (Molyneux et al. 2013; Herce et al. 2014). In certain interventions the hospital-based team developed treatment plans for care coordination and acted as links between hospital departments or between the hospital and external community resources, such as Hospices. Sometimes hospital-based teams were created together with in-patient PC wards or clinics to provide space for the team to work (Jameson 2007; Hongoro and Dinat 2011). One intervention described the provision of a ward within a government hospital that was staffed by Hospice (Gwyther et al. 2018).

Training, mentorship and/or support of staff to provide generalist care was a key component of many interventions to integrate generalist PC or a PC approach into the facility. Innovative interventions provided PC training for nurses in an HIV outpatient clinic attached to a hospital (Harding et al. 2013b) specific training of 'link-nurses', supported by the PC team, who acted as a local resource in the wards, and provided generalist PC, referring patients to the specialist PC team when necessary (Tapsfield and Bates 2011; Downing et al. 2016).

Less common components included the creation of a multi-disciplinary clinic, including PC, for gynaecologic cancer care at Botswana's national referral facility (Grover et al. 2017).¹⁴ Another was the provision of PC 'beds' in a hospital emergency unit as a means of integrating PC into a tertiary hospital in South Africa, which then led to integration with other hospital services (Gwyther et al. 2018).

Relating palliative care integration to health systems strengthening

One included study noted that that health systems need to be strengthened in order to integrate PC effectively (Molyneux et al. 2013). However, it was rare for interventions to investigate outcomes related to health systems strengthening, or to integrate PC with the aim of strengthening health systems, with only two studies explicitly mentioning this (Freeman et al. 2016; Grant et al. 2017).

¹⁴ This strategy was found to assist with care coordination and reducing delays in terms of starting PC treatment.

Sixteen of the 40 articles did not relate the described interventions to the broader health system.¹⁵ Another subset of articles briefly noted that interventions should aim to strengthen health systems (Brown *et al.* 2016), or that integration of PC can increase health system responsiveness (Gwyther *et al.* 2018), and influence the performance of the whole system (Defilippi and Cameron 2010; Nanney *et al.* 2010; Downing *et al.* 2015; Zipporah 2016). However, outcomes were not described, nor were these claims robustly made. Other articles described in more detail how the health system influenced integration interventions and vice versa (Box 3), although health systems strengthening was not the study's main aim.

Two interventions did aim to strengthen health systems through integrating PC (Freeman *et al.* 2016; Grant *et al.* 2017), however only the study by Grant *et al.* (2017) described health system effects as outcomes. As noted, the intervention described by Grant *et al.* (2017) used a health systems approach and provided outcomes and recommendations relating to this. They concluded that integration *can* result in a stronger health system, as staff give better, more comprehensive care and are more motivated to do so. Findings also suggested that using a PC approach facilitated health system responsiveness through increased cooperation and communication between patient, families and health workers. Cost savings were also shown due to earlier pain control resulting in shorter admission periods (Grant *et al.* 2017).

Health system influences on intervention:

- Lack of health infrastructure;
- Limited availability of health professionals.

Intervention effects on the health system:

- Improved accessibility and sustainability of health care services
- Cost-saving for hospitals due to reduced admissions;
- Assists in addressing health worker shortages;
- Provided a strategy to increase access to health care services;
- 'Freeing up' of space in hospital wards due to reduced admissions and provision of PC at home.

Box 3. Synthesised descriptions from included articles on how the health system influenced the interventions and vice versa (Sources: Paice *et al.* 2010; Wube *et al.* 2010; Hongoro and Dinat 2011; Malloy *et al.* 2011; DesRosiers *et al.* 2014; Herce *et al.* 2014; Campbell and Baernholdt 2016; Downing *et al.* 2016; Naicker *et al.* 2016; Krakauer *et al.* 2018)

Facilitators and barriers to the integration of palliative care into health systems

Themes identified in the scoping review were refined into four analytical themes in the systematic review process, that could either promote integration by being present or block integration by their absence. These include 1) the provision of PC at all levels of the health system alongside curative care, 2) the development

¹⁵ They aimed to provide guidance on the implementation of a PC service, improve the quality and comprehensiveness of patient care or improve clinical and treatment outcomes increase access to PC within a specific setting.

and presence of sustainable partnerships, 3) the ability of the health system and health workers to support integration, and lastly, 4) placing the client, their family and community at the centre of integration.

Provision of palliative care at all levels of care alongside curative care

Across the included studies, it was shown that integrating PC with curative or disease-specific treatment facilitated integration, and integrating PC into all levels of care, including the community, through vertical integrative mechanisms promoted full integration of PC. The provision of PC alongside disease orientated or curative treatment is a key principle of PC to allow for comprehensive care of the patient (World Health Organisation 2002). This review found that providing PC together with other types of care also facilitates integration of PC into facilities. Studies showed how PC can be integrated using relatively simple techniques, and that, although developing a separate PC team is necessary to provide specialist PC and oversee PC programs, integrating PC principles into existing health programs is highly beneficial. Some interventions integrated PC with other treatment through the creation of PC teams who worked alongside other services, but more success was found in providing PC together with other types of disease-modifying treatment, for example through multipurpose clinics, which also held substantial benefits for patients (Amery *et al.* 2009; Tapsfield and Bates 2011; Herce *et al.* 2014; Brown *et al.* 2016; Grover *et al.* 2017). Provision of PC with other treatment shortened the time before treatment commenced (Grover *et al.* 2017) and significantly improved patient care (Harding *et al.* 2013b). Provision of PC as a stand-alone program was seen to result in frustration for health workers and patients, hindering integration of PC. For example, in a study where PC was provided separately to other types of treatment, patients' needs could not be managed properly, and financial strain was placed on patients, who needed to travel to different service sites for treatments (Grant *et al.* 2011a).

Linking different types of PC across and within levels of care was identified as being either a barrier or facilitator. Creation and linking of PC at different levels of care through vertical integration (i.e. integration across different levels of care) was found to embed PC into a health system, as well as provide coordination of care or integrated PC.¹⁶ Identified studies vertically integrated PC in a variety of ways, often through scaling up successful models of PC.¹⁷ As earlier described, a key feature identified by these studies was the need to

¹⁶ "Integrated palliative care involves bringing together administrative, organizational, clinical and service aspects in order to realize continuity of care between all actors involved in the care network of patients receiving palliative care. It aims to achieve quality of life and a well-supported dying process for the patient and the family in collaboration with all the caregivers, paid and unpaid." (Hasselaar and Payne 2016, p. 8).

¹⁷ One study in South Africa, led by Hospice, described the creation of the Integrated Community Home Care program where PC provision between the district hospital, clinic and HCBC organisations was coordinated (Defilippi 2005). Other interventions linked primary and secondary levels of care by setting up specialist PC teams in district hospitals, who were linked to volunteers providing generalist PC in the community (Nanney *et al.* 2010; Herce *et al.* 2014). Further studies targeted the provision of care in and between tertiary and secondary levels of care (Zipporah 2016; Grant *et al.* 2017) or created networks where PC was integrated into and between provincial, district and community levels (Molyneux *et al.* 2013; Krakauer *et al.* 2018).

consider the health system at a community level and include the community in integration interventions to facilitate timely referrals of patients with complex PC needs and the use of a PC approach (Grant *et al.* 2011a). The inclusion of health workers that are often seen as ‘external’ to the health system (i.e. community health workers (CHW), care givers, volunteers, THPs and spiritual leaders), facilitated integration of PC principles due to their close links with the community (Jack *et al.* 2011). Volunteers were essential to the integration of PC principles into the community as they performed “much of the day-to-day care and building of relationships between patients, the palliative care team, and the community” (Grant *et al.* 2011a, p. 8). As discussed earlier, the inclusion of THPs in training programs is an important way of integrating PC, as in Africa patients will often seek help from THPs prior to seeking care from other health structures (Grant *et al.* 2011a) and can encourage timely referrals for patients with complex PC needs (Drenth *et al.* 2018). Interventions which included churches (Murray *et al.* ; Bassah *et al.* 2016; Freeman *et al.* 2016) found that this was integral to integrating PC into communities.

The development and presence of sustainable partnerships

Collaboration and the development of partnerships through organisational¹⁸ and professional¹⁹ integrative mechanisms were clear facilitators to integrating PC into a health system, as well as allowing for the provision of integrated PC. A variety of different types of relationships were evident in the literature which varied in complexity and nature. Partnerships varied in intensity²⁰, with examples of PC organisations working in a segregated manner, with others having created informal links and other more formally coordinating their efforts. Greater integration was found where professionals formally coordinated their efforts compared to those that created informal linkages.

Partnerships were developed as a mechanism to share information and provide mentorship, often with an international organisation or NGO with international affiliations. (Downing *et al.* 2013; Herce *et al.* 2014; Brown *et al.* 2016; Gwyther *et al.* 2018). Those built on co-learning and mutual respect (Drenth *et al.* 2018) and encouraged leadership by the local partner or the Ministry of Health (MoH) were seen to be favourable:

The way in which the STEP UP programme worked with the district is important. The programme did not seek to mandate changes that should be made, but rather to work in partnership and suggest

¹⁸ The bringing together several organizations through the creation of networks and partnerships.

¹⁹ Integration that is led by professionals within or between organisations (compared to entire organisations).

²⁰ 1) Segregated: Autonomous organisations/professions working separately with limited to no communication. 2) Linkages: Integration between organisations or professionals that is limited to referrals and informal communication, with no cost-sharing and clearly aligned separate responsibilities given to the separate groups. 3) Coordination: Separate professionals or organisations operating through existing structures to coordinate care, share clinical information, manage transition between the different parts of the organisation or between organisations. 4) Full integration: Full incorporation of the one organisation into the other or the creation of a new organisation with pooled funds and resources allowing for the provision of comprehensive services for specific groups of people.

potential ways forward. Ownership and control was placed with the district themselves, rather than being imposed by an external body... (True Colours Trust 2012, p. 9)

Collaboration between professionals within an organisation or between organisations were key. Linkages formed between PC team members and other health workers within a facility or with those outside it was used to integrate PC with other types of care, coordinate PC provision, encourage referrals of PC patients and to facilitate the transfer of PC knowledge in a facility. A variety of strategies were used to do this, such as combined ward rounds and assessment between PC team members and other staff, locating a PC team close to wards in which they frequently work, creating multi-disciplinary teams and clinics or the use of a PC coordinator to liaise with other staff.

Macro-level²¹ interventions often involved more complex relationships, with a greater number of partners at different levels of care to promote system-wide integration. These interventions also typically involved the APCA (Freeman *et al.* 2016; Grant *et al.* 2017; Kamonyo 2018) which was recognised as an influential organisation (Paice *et al.* 2010), vital in facilitating the development of national PC associations (Molyneux *et al.* 2013) and increasing the capacity for PC and assisting PC development in Africa (Rhee *et al.* 2018).

The same was found for other PC associations. Participation of government and hospital staff in PC associations was noted to be a facilitator of integration, as this linked the staff with a broader network of PC (Molyneux *et al.* 2013). Partnerships and the involvement of PC associations promoted integration as PC associations often led interventions to integrate PC (Sithole and Dempers 2010; Freeman *et al.* 2016; Zipporah 2016; Krakauer *et al.* 2018) or assisted in implementing it through providing advocacy (Downing *et al.* 2013), technical support (Lohman and Amon 2015) and training (Cornetta *et al.* 2015; Lowther *et al.* 2015; Gwyther *et al.* 2018). Sustainability was also encouraged through PC associations ensuring accountability once the intervention was complete (Drenth *et al.* 2018).

A similar effect was noted with the presence of local champions for PC, who formed strategic partnerships with key government officials to advocate for the integration of PC into the health system (Stjernsward 2002; Malloy *et al.* 2011; Lohman and Amon 2015; Zipporah 2016).

Partnerships with international donors was also a key facilitator to the initiation of integrated PC due to the lack of nationally provided resources.²² Public-private engagements or collaboration between government and

²¹ Interventions targeting the health system at a national level to attempt to provide PC for the whole population.

²² Donors included USAID (Nanney *et al.* 2010; DesRosiers *et al.* 2014; Campbell and Baernholdt 2016; Freeman *et al.* 2016), PEPFAR (Nanney *et al.* 2010; Downing *et al.* 2013; Krakauer *et al.* 2018), Open Society Foundation (Drenth *et al.*

NGOs also encouraged integration, such as partnerships between government departments with NGOs with international funding or affiliations (Whyle and Olivier 2016) or health workers from public organisations with professionals in NGOs (Gwyther *et al.* 2018). There was limited evidence of the MoH leading an intervention to integrate PC with one study standing out as an example where the Rwandan MoH led and coordinated the integration of PC into the health system, albeit with significant donor funding and technical support (Krakauer *et al.* 2018).²³

Although public-private engagements and partnerships with donors are very helpful in initiating integration, many authors noted that sustainable integration occurs when governments take the lead and ownership over the programs (Sithole and Dempers 2010; Wube *et al.* 2010; Grant *et al.* 2017). One article stated that “ownership of the program by each hospital and district health service bred success.” (Grant *et al.* 2017, p. 8). This view that global and local partnerships are necessary, but that local leadership is vital was also highlighted in a recent review of PC in LMICs, showing that this facilitator extends beyond the borders of Africa (Hannon *et al.* 2016).

The ability of the health system and health workers to support integration

The ability of the health system and actors within it to support integration was expressed extensively in the literature as being either a facilitator or barrier when integrating PC (Downing *et al.* 2015). This theme comprised of three major sub-themes: the acceptability and desire for PC by the health system actors, the presence of supportive PC policy, and resources for PC.

Firstly, the value placed on PC by actors within the health system can promote or inhibit the integration of PC. Misconceptions and negative health worker attitudes towards PC can present a major obstacle to integration (Grant *et al.* 2011a; Downing *et al.* 2013; Bassah *et al.* 2016; Grant *et al.* 2017) and studies noted that if PC is not desired nor valued, it will not be prioritised, making integration a challenge. Intervention staff reported that they could positively change health system actors’ awareness and attitudes to PC, through normative integrative mechanisms²⁴ such as advocacy or awareness creation, which facilitated integration. Advocacy was used primarily as a mechanism to integrate PC in two studies (Lohman and Amon 2015; Freeman *et al.* 2016),

2018; Kamonyo 2018) and the Diana Princess of Wales Memorial Fund (Downing and Kawuma 2008; Grant *et al.* 2011a ; Malloy *et al.* 2011; Downing *et al.* 2013; Harding *et al.* 2013b; Molyneux *et al.* 2013; Herce *et al.* 2014; Lowther *et al.* 2015; Downing *et al.* 2016; Naicker *et al.* 2016).

²³ This resulted in significant progress over a short period of time and goals in place to make PC universally accessible.

²⁴ Normative integrative mechanisms involve strategies to develop a common understanding on the importance of PC between organisations and health workers to allow and support integration across the health system.

with the latter using a human rights advocacy approach²⁵, and was described as a key and strategic part of other interventions (Lohman and Amon 2015; Kamonyo 2018). It was found to bolster other programs aiming to integrate PC (Downing *et al.* 2016), lay the foundation for concrete advances in the integration of PC (Lohman and Amon 2015; Grant *et al.* 2017) and encourage sustainability by helping governments to realise their role in PC provision (Molyneux *et al.* 2013).

The use of innovative and appropriate strategies was found to be particularly successful (True Colours Trust 2012; Freeman *et al.* 2016; Grant *et al.* 2017). Although advocacy was usually initiated by PC associations (Sithole and Dempers 2010), champions or PC teams (Gwyther *et al.* 2018), success was also found in advocacy through senior health workers within the MoH who had the respect of other staff (Downing *et al.* 2016; Grant *et al.* 2017), patients and patient groups (2012; Freeman *et al.* 2016) and faith-based community structures (Nanney *et al.* 2010).

The effectiveness of multi-level advocacy (at community/regional/national levels) was also described, with an emphasis on how senior officials, implementers and the community need to all be targeted to raise the awareness and value of PC in the whole health system (Downing *et al.* 2013; Freeman *et al.* 2016):

...it is important to generate as much interest and support from the wider community of leaders and members of the public as possible so a 'bottom up' groundswell of demand is created alongside a 'top down' mandate from government and managers. (True Colours Trust 2012, p. 14)

The use of normative integrative strategies facilitates integration across the health system by ensuring that PC is prioritised, desired and accepted by the health system actors. Another key facilitator is the presence of national PC policies and the inclusion of PC in other related health policies (i.e. NCD, HIV or cancer policies) (Kamonyo 2018). Policies are important as they serve as mandates, paving the way for the integration of PC or limiting it. For example, the presence of national policy supporting PC in Kenya is reported to have resulted in rapid integration of PC into hospitals, whereas the lack of this in Malawi hindered the same (2012). Krakauer *et al.* (2018) described how the Rwandan MoH started integrating PC into the health system initially through the creation of national policy, but then continued to mandate integration through the issue of directives to referral and provincial hospitals (Krakauer *et al.* 2018).

It is not only the presence of supportive policy that plays a role, but also the type of policies developed and the initiators of the policy development and implementation process. An intervention focusing on the creation

²⁵ Advocacy was used to encourage holistic and positive views towards PC, demonstrate the need for PC in a population, encourage the inclusion on PC in policy and training, and the availability of drugs necessary for pain relief.

of PC policy in Uganda noted that policies need to be specific in terms of how PC services will be integrated, with set objectives and priorities, and need to be based on a contextual assessment on the PC needs of the population (Stjernsward 2002). The influence of local governments leading integration of PC into policy was also described, where integration was promoted when nominated persons or champions within the MoH drove the policy development process (Stjernsward 2002; Grant *et al.* 2017), whereas the lack a national coordinating body was found to hinder integration (Freeman *et al.* 2016).

Interventions found that although national policies are needed to facilitate integration, they are also important at the local facility level (Downing *et al.* 2013; Grant *et al.* 2017; Krakauer *et al.* 2018). The importance of this was clearly seen in a study in Cameroon, where the lack of a local hospital PC policy made it challenging to integrate PC into practice (Bassah *et al.* 2016), and another study in Kenya (Zipporah 2016) which found that integration was hindered due to PC not being included in local health plans. Conversely, the creation of quality control measures (Defilippi and Cameron 2010), as well as monitoring and evaluation structures (Molyneux *et al.* 2013) were important in facilitating integration. The use of protocols to mandate the inclusion of PC in the treatment of life-threatening disease, such as cancer (Brown *et al.* 2016) and describe how pain and other symptoms associated with life-threatening disease should be adequately treated facilitated integration (Hongoro and Dinat 2011; Downing *et al.* 2016).

The development of other functional integrative mechanisms, such as communication techniques, also facilitated integration between professionals and organisations. These included novel mobile phone strategies (Grant *et al.* 2011a; Drenth *et al.* 2018), the creation of standardised forms to facilitate referrals (Cornetta *et al.* 2015; Krakauer *et al.* 2018), multi-dimensional record forms that include aspects of PC (Harding *et al.* 2013b), referral forms for PC teams, the development of care plans that travel with the patient to facilitate coordinated PC (Gwyther *et al.* 2018). One study found that the development of a categorisation system, which characterised the PC needs of patients, allowed for correct referral for specialist PC. The creation of early identification systems and referral pathways were a crucial element for successful integration (Nanney *et al.* 2010; Grant *et al.* 2011a; Tapsfield and Bates 2011; Lowther *et al.* 2015; Grant *et al.* 2017; Gwyther *et al.* 2018). The creation of referral pathways between different sectors also allowed for PC to be integrated with support from other sectors such as social services (Herce *et al.* 2014).

Although the presence of policies at a national and local level to integrate PC is a start, as one study pointed out, it does not always mean that integration occurs (Harding *et al.* 2013b). Funds also need to be available for PC, and there need to be adequate amounts of sufficiently trained staff. The importance of government funding in providing sustainable integration of PC into health systems was a common theme in the studies.

The lack of funding was frequently mentioned as a barrier to the integration of PC (Molyneux *et al.* 2013; Cornetta *et al.* 2015; Freeman *et al.* 2016; Zipporah 2016; Grant *et al.* 2017; Drenth *et al.* 2018). Conversely, the use of government funds to provide PC was found to facilitate integration:

This project has been successful and sustainable, since services are provided in government hospitals, making it accessible, affordable, and sustainable since services are maintained using hospital funds. (Zipporah 2016, p. 2)

An acceptance of the importance of PC was key – especially within the MoH providing finances for PC within health budgets, as well as the presence of policy mandating PC (Grant *et al.* 2017). Demonstrating the cost-effectiveness of integrating PC has also been focused on to provide evidence to encourage government funding (Hongoro and Dinat 2011; Grant *et al.* 2017; Drenth *et al.* 2018).²⁶

Another significant facilitator of integration was the presence of sufficient numbers of adequately trained staff members to provide PC (hence all the interventions relating to training). This can influence integration in two ways, firstly the generally limited human resources for health found in most African contexts can severely limit integration (APCA 2011), and secondly, the limited knowledge of PC in the existing health workforce also presents a problem. As discussed earlier, the training of health professionals in PC has been identified as a key mechanism to overcome these two barriers and to promote integration (Stjernsward *et al.* 2007; World Health Assembly 2014). In the literature, training of a large proportion of health care workers was found to be essential to ensuring that all those within the system are using a PC approach²⁷ (Grant *et al.* 2017), and instrumental in integrating PC. Training of existing staff was described as a relatively cost-effective way to embed PC into the health system, as it uses existing resources to provide PC (Defilippi and Cameron 2010; Di Sorbo *et al.* 2010; Campbell and Baernholdt 2016), and integrating PC into curricula of health professionals currently in training was important to ensure that future cadres are equipped (Gwyther and Rawlinson 2007; Bassah *et al.* 2016). Training of all health workers was discussed as being important in facilitating integration (Freeman *et al.* 2016; Grant *et al.* 2017), as well as the presence of different types of training (Gwyther and Rawlinson 2007) that include a practical element, such as a clinical placement, together with ongoing support such as supervision or mentorship. The creation of sustainable training was also described as important

²⁶ Hongoro and Dinat's study found that hospital-based outreach services have the ability to avert facility admissions and that the costs per patient seen by the outreach service were less than hospitalization costs, therefore presenting as a cost-saving measure for the hospital. Following this finding the government took over most of the funding for the program. Grant *et al.*'s study found that one setting showed notable cost savings by controlling pain early on through PC and shorter hospital stays, as well as by integrating PC into the health system at a low cost.

²⁷ Where palliative care principles are used by all health professionals within the health care system allowing for timely referrals for more specialised care, adequately managed pain and holistic support from the time of diagnosis.

through using local resources and training local trainers, as well as using appropriate training methods to provide contextual information.

The client, their family, and community at the heart of integration of PC

The importance of the needs and preferences of the patient, together with the understanding that the patient should direct their own care are principles that are central to PC (Worldwide Palliative Care Alliance 2014), and recognition of this is also a clear facilitator of integration. Understanding and responding to the needs of patients and communities is a key element of health system responsiveness (dRobone *et al.* 2011), which is understood as a priority of national health systems, to allow systems to adapt to changing health needs and promote improved health outcomes (Mirzoev and Kane 2017). Therefore, the prioritization of the needs of patients and treating patients with respect and dignity not only fits in well with the principles of PC and enhances integration, but would also assist in improving health system responsiveness (and therefore health system development).

In the included literature the need to provide appropriate, acceptable and desirable PC was shown to be central to the uptake of PC and to facilitating integration. It was noted that when PC was integrated into the community in a contextually appropriate way, responsive to the patient's needs, the community integrated PC principles more readily and there was less stigma attached to PC (Nanney *et al.* 2010; Grant *et al.* 2011a; Herce *et al.* 2014), illustrated in the quote from Grant *et al.*'s (2011a) study "Much of this community acceptance was due to the work with local churches and village chiefs ... where pastors included time during worship to talk about palliative care." This was a common characteristic of interventions to integrate PC into home-and community-based facilities or organisations, but was also found to facilitate integration in meso and macro level interventions (Freeman *et al.* 2016). Some noted how the type of service provided needed to be adapted to suit the needs of the patients and families, which enhanced integration (Di Sorbo *et al.* 2010).

A large additional literature was identified in the scoping review that confirms these findings, emphasising PC preferences relating to the needs of populations (Harding and Higginson 2004; Barnard 2006; Harding *et al.* 2008; Selman *et al.* 2009; Alsirafy *et al.* 2010; Gysels *et al.* 2011; Harding *et al.* 2013a; Powell *et al.* 2013; Powell *et al.* 2014; van Niekerk and Raubenheimer 2014; Selman *et al.* 2015; Luyirika *et al.* 2016; Chisumpa *et al.* 2017; Lewis *et al.* 2017; Kimani *et al.* 2018; Reid *et al.* 2018). Although these do not address the integration of PC specifically, they support PC integration by guiding what type of PC is needed and preferred by a population.

Discussion

This study reviewed and investigated approaches and interventions being used to integrate PC into African health systems, and identified potential facilitators and barriers to this. The integration of health care services is a topic which is receiving renewed attention (Waddington and Egger 2008), particularly in relation to the integration of HIV into routine maternal health services in Africa health systems (Dabis and Ekpini 2002; Horwood *et al.* 2010; Pfeiffer *et al.* 2010), and has a growing literature base (Briggs and Garner 2006; Legido-Quigley *et al.* 2013; Chuah *et al.* 2017). Certain findings from this review study echo those from this broader literature, discussed below, which has implications for those attempting to integrate PC with other health services and health systems.

It is clear that the literature on the integration of PC suffers from the same problem as in the broader integration literature, namely a lack of consensus around what integration means and entails (Kodner 2009) and inconsistent use of different terms to describe similar concepts (or the same term for different concepts) (Armitage *et al.* 2009). Integration is a multifaceted and dynamic concept; therefore, the multiple terms and perceptions are understandable (Shaw *et al.* 2011), however, it is of concern that no included article explicitly defined integration of PC. Although its meaning could sometimes be inferred through textual analysis, the articles lacked a clear description of how integration was being understood and the integrative mechanisms being used. Although beyond the scope of this review study (and requiring integration *and* PC expert input), PC integration needs to be defined with some urgency, as a lack of conceptual clarity has been found to hinder development of integrated programs (Valentijn *et al.* 2013). For implementors, clearly outlining integration at the outset can also help to guide intervention development and assist in interpreting the results to create evidence to support integration of PC. This would allow researchers to compare results from different PC integration interventions with greater ease and enable other implementors to learn from the integration intervention (Chuah *et al.* 2017), or imitate the intervention more effectively in other settings. Policy and guidance on PC integration for health workers to practically integrate PC into their work and contexts also needs to have conceptual clarity to discourage confusion, which could affect implementation.

The literature on PC integration is similar to broader literature on integration in some respects, but also presents with other unique features. For example, limited intersectoral integration and integration at a macro level are features common to integration interventions in LMICs (Mounier-Jack *et al.* 2017) and similarly in this review, PC was rarely integrated into non-health sectors, with limited examples found of integration between health and non-health sectors. Integrative mechanisms²⁸ used by PC interventions were also similar in some ways to those described in general health service integration literature from LMICs (Mounier-Jack *et*

²⁸ I.e. systemic, functional, normative, professional, organisational and clinical/service integration.

al. 2017). However, what stood out, was the strong use of normative or cultural integrative mechanisms, which seems a distinctive focus of PC integration interventions. The focus on the integration of PC principles and values into a health system is not surprising, given the negative attitudes and myths around PC, which present as a significant barrier to integration. Studies on integration have found that health care services were integrated through a variety of models (Waddington and Egger 2008; Legido-Quigley *et al.* 2013; Chuah *et al.* 2017). Similar models were identified in this review, where PC was frequently integrated into single facility or between multiple facilities (Chuah *et al.* 2017); however, the creation of networks is rarely mentioned in the broader health integration literature, but to be a characteristic feature of PC integration interventions. The creation of networks was a characteristic of more complex interventions and not highly used, possibly because of this. In resource-poor contexts with limited resources available for PC and limited PC services (Rhee *et al.* 2017a), the development of a PC network could be a challenging task. Even some HICs are only now focusing on the creation of PC networks to provide coordinated PC in geographical areas (Bainbridge *et al.* 2010; Garralda *et al.* 2016; Hasselaar and Payne 2016). The integration of PC into policy and through training were other models that appear specific to the integration of PC, possibly due to the influence of WHO's Public Health Strategy, which recommends that PC be integrated into education, policy, implementation of PC services and ensuring necessary drug availability. The Public Health Strategy provides guidance on how to establish the necessary initial structures to integrate PC into African health systems; however, more practical, context specific examples are needed to fully integrate PC (Harding and Higginson 2005; Ncama 2005; Hasselaar and Payne 2016).

This review also identified facilitators and barriers to the integration to PC, some similar to those found to facilitate in broader integration literature. For example, the creation of partnerships, supportive organisational culture and placement of the client and families as central to integration also promote broader integration and conversely a lack of the skilled health workers and resources can inhibit integration (Watt *et al.* 2017; Topp *et al.* 2018).

The similarity of some of the findings from this study to the broader literature on integration is important, as it would indicate that lessons can be drawn from this evidence base, and across different topics and experiences. Yet, from the information provided by the included articles, it would appear that this is not being utilised. The integration of PC into health systems in Africa is largely being addressed by PC advocates and service providers to increase PC service provision and improve the quality of patient care. This has resulted in the body of literature on PC integration in Africa being somewhat detached from research from other fields. Separation from research on broader health service integration limits the ability to use the knowledge from other types of integration interventions and reduces the impact of arguments to support PC integration.

Although urgings to integrate PC from an ethical and human rights perspective has proved fruitful, currently this is coming from PC advocates, and arguments to integrate PC could be further strengthened by using the available evidence that promotes integrated care in general. PC integration into health systems is also not yet being linked with health policy and systems research (HPSR), as reflected in the included studies, despite research into health systems and health systems strengthening being primary objectives of the field. Networking and collaboration have been called for to enhance research into PC (Harding *et al.* 2013a; Powell *et al.* 2013) and closer collaboration and interdisciplinary engagement between HPSR and PC researchers would certainly be a good fit.

This study also adds to the growing body of literature on the integration of PC into African health systems by verifying and providing additional detail on previous findings. Where in the past PC was frequently integrated into home- and community-based care structures (Downing *et al.* 2010; APCA 2011), this review highlights how hospital or facility-based PC is an area that is receiving specific attention and provides some insights into the components of these programs (Box 2). With the integration of PC into the primary care level being recommended by the WHA (World Health Assembly 2014), it is vital that these new PC services being integrated into hospitals be linked to services at lower levels of care or include the development of PC services at the primary care and community level.

It is evident that much of the evidence on integration is coming from a sub-set of countries, typically where PC development is more robust such as Uganda, South Africa and Kenya. Although this is understandable, this puts countries with limited PC development at a disadvantage as contextually appropriate evidence to guide integration is lacking. This needs to be addressed, possibly by using these countries as sites for integration interventions. Northern African countries are all at very early stages of PC development and research from this area is extremely limited (Ansary *et al.* 2014), with even more disparaging situations found in West Africa (African Palliative Care Association 2017). In the recent scoping review of PC development in African countries certain fragile, conflict or post-war states, such as South Sudan, Somalia, Libya and Mali, did not respond to the study or had no any PC services or key informants (Rhee *et al.* 2017c). No evidence came from these areas in the review, indicating that fragile and conflict states need to be directly targeted, as there is limited published evidence to guide PC integration. It is encouraging to note that this has also been identified by the APCA, who has now started focusing on developing and integrating PC services in certain West African countries together with international funders (APCA 2017).

The application of a health systems perspective in the study revealed that 'systems thinking' (while mentioned in some included studies), was uncommon, despite the fact that PC integration interventions is so strongly

influenced by the health system. Although some interventions did do some form of assessment prior to initiation to determine the influence of health system characteristics (i.e. number of health workers available, the level of PC development or resources available), it was rare for interventions to link their impact to health system functioning. There is a rising call to integrate PC into health systems to strengthen health systems; however, the results from the included articles makes this challenging to claim in the African context, not because it is untrue, but as health systems strengthening is not being clearly linked with the integration of PC nor investigated as such. Although it is useful to show how providing PC benefits the client, in African countries, which are often resource-poor, and the integration of PC must compete with other prioritised communicable disease programs (Ansary *et al.* 2014), it is vital to show how integrating PC can improve health system functioning. In order to do this implementors would need to assess how integrating PC improves service delivery, motivates and improves the performance of the health workforce, provides cost-savings and efficient use of resources, enables the health system to be more responsive or provides risk protection for clients, just to name a few examples (World Health Organisation 2007). This would need to be done as a primary aim of the intervention so that clear evidence is provided. Linking integration of PC to health systems strengthening is not only important for implementors and research, but also for health workers. Integration of health services often comes with extra responsibilities for health workers and can be perceived as a burden (Waddington and Egger 2008), if health workers could be shown how providing PC could improve their efficiency, make their work more effective and motivate them, this could improve the acceptance of the integration intervention.

Approaches currently being used to integrate PC in Africa have been highlighted. Valentijn *et al.*'s Rainbow Model of Integrated Care (Valentijn *et al.* 2013) was useful in identifying the focus of the intervention and classifying the types of integrative mechanisms being used. Use of the framework revealed the complex and interrelated nature of integration, with most interventions taking place over more than one level and employing a variety of integrative mechanisms. This proved typical, as there was little evidence of PC integration at a macro level. The majority focused on integrating PC into facilities, home or community-based programs, where PC services were often integrated as a separate program, rather than integrated with other types of care. Although embedding a PC service within a health system or service is highly beneficial, provision of PC alongside other curative treatment proved to be a cost-effective way of integrating PC, the potential of which was not always used in interventions and needs to be further explored. The levels of PC were identified using the framework developed by Gómez-Batiste and Connor (2017), which showed that services often consisted of generalist and/or specialist PC, with limited emphasis on the use of a PC approach within the facility. To fully integrate PC into health systems, approaches need to use a macro and population-based approach where PC is not only implemented at service level but also nationally. Examples of this do exist in

resource-poor contexts (Kamonyo 2018; Krakauer *et al.* 2018), but notably these were highly complex interventions taking place over a long time period, with the involvement of many partners and strong leadership by the government or MoH. The integration of a PC approach into the training of *all* health care professionals, as well as the culture and values in these sectors is vital in order to successfully integrate PC into health systems. This would provide health workers with the awareness and elementary skills needed to assess and treat the basic physical and psychosocial symptoms of those with life-threatening illnesses, as well as create a system that is supportive of the delivery of PC, both important facilitators of integration.

Limitations

There were limitations to this study, predominantly the exclusion of grey literature and articles that were not in English. Excluding non-English articles after 2001 at the outset of the study resulted in a mere 7% of the articles being rejected, representing, amongst other things, the lack of PC development and research coming out of non-Anglophone countries (Rhee *et al.* 2017b). This confirms that Francophone and Lusophone countries would greatly benefit from being the target of future PC development and integration interventions in an effort to remediate this gap. The use of published articles on interventions to integrate PC was a method used to strengthen the study by ensuring that only good quality evidence was used, however this did result in certain narratives, reports and evaluations on interventions not being included in the study as they had not yet made their way into scientific literature. Where possible, grey literature identified in the scoping review prior to the systematic review was used to understand and validate the interventions. Reports of interventions were also sourced, where available, to supplement the published article. Therefore, it is believed that the study comprehensively reached its aim of providing a picture of current interventions to integrate PC to draw lessons to guide further integration interventions. Focus on increasing PC research in Africa is vital in ensuring that relevant interventions reach publication, allowing the results to be used to inform a wider audience.

Conclusion

The integration of PC into African health systems is vital to provide access to PC to those who need it, around 10 million people every year. PC is a human right and an ethical responsibility of health systems, yet it is still being denied to most who need it, even in vulnerable populations such as children. In this context, where only four countries have more than 20 PC services to meet the need of their entire population and many of these are not linked to national health systems, the integration of PC must be prioritised. At this time of increased PC development on the continent, the focus needs to not only be on creating these services, but also integrating them into health systems. From this study the following recommendations are made to the different actors involved in integrating PC into African health systems.

This study revealed key strategies for implementors attempting to integrate PC into African health systems. Firstly, the factors that inhibit and promote integration should be considered and included in intervention design, practically described in Box 4 below.

- *Make the patient central to integration* by providing responsive care and investigating the PC needs of patients, as well as what type of care is culturally appropriate and desired.
- *Foster partnerships between professionals and organisations both within and between levels of care*, using formally coordinated relationships and encouraging local ownership where possible.
- *Integrate PC into other types of care*, rather than only focusing on stand-alone PC services, and *across different levels of care*, ensuring to include the community and primary care level to sustain and enhance integration.
- Strategies to increase *the acceptability and desire for PC* by the range of health system actors are vital, with innovative and multi-level advocacy and training often proving useful.
- *Functional integrative mechanisms* are key and need to be considered at all stages of the intervention (i.e. local and national policies; standardized forms, clinical guidelines and protocols; communication, categorization and referral systems).

Box 4. Top five tips for implementors to facilitate integration (Source: author).

Secondly, situating interventions within the broader context of integrated care is necessary not only to allow for better knowledge translation between the two fields, which share commonalities, but also to draw out lessons from this body of work to facilitate integration. Practically, this could be done by defining and conceptualising *integration*, as well as defining the *dimensions of integration* to be targeted within the intervention. Ideally this would be done at the outset so that these concepts could guide development. Attention needs to be paid to the use of *normative* and *functional* integrative mechanisms in interventions. These mechanisms facilitate integration through embedding PC principles into the health system and through the creation of ‘back office’ functions to support integration across various levels.

Thirdly, the use of a health systems approach by implementors would be highly beneficial in terms of identifying how the health system being targeted would influence the intervention and vice versa and would be the first step in allowing interventions to provide evidence on how PC integration strengthens health systems. This is vital in bolstering the argument to integrate PC in resource-poor contexts, where other communicable disease programs compete for funding and prioritisation. The implementation of integration interventions that specifically aim to improve health systems functions and gather data around this are also imperative if PC integration is truly to be associated with health systems strengthening in Africa, as this claim currently remains unsubstantiated.

Health ministries and policy makers are integral to PC integration and where possible need to lead the process. For PC to be fully integrated into a health system, this study found that a system-wide approach needs to be

used and the health system needs to be able to support the integration. This supports the WHO public health strategy and entails the availability of adequately trained health professionals, funding and resources for PC, as well as the presence of policies to guide the integration of PC into standard care and care of those with life-threatening illness, including NCDs. For these policies to be implemented by health workers, PC principles and values need to be integrated into the health system and 'integration' should be clearly conceptualised within policies and guidelines so that health workers have a clear idea of what the integration of PC entails, enabling easier implementation.

Further research is needed from a wider variety of academic fields, including those involved in HPSR. Research on PC integration is currently being led by PC advocates in the field, academia and PC associations. However, different views and perspectives would greatly support arguments to integrate PC and widen the influence of the body of work, as well as allow for collaboration between the fields of HPSR and PC to support research development. Further emphasis needs to be placed on researching the integration of PC in countries where PC is less developed, such as west or northern Africa and fragile, conflict or post-war states, so that contextually approximate evidence is available to guide PC integration. Further research on how PC integration strengthens health systems is necessary, as well as research on macro or national level approaches that have been used to integrate PC. There is a significant gap in evaluative research that assesses the 'success' and system level impact of integration interventions which needs to be addressed to determine best practices.

Funders play a vital role in integrating PC in the African context, where funds are often not available through national budgets. This study highlighted this, but also described how integration of PC was facilitated by local ownership. It is recommended, that as far as possible, local partners and the MoHs have an active role in guiding, developing and implementing integration interventions to increase sustainability.

PC associations were found to be pivotal actors in integration interventions and should be initiated if they are not already present. PC associations would benefit from continuing to focus on training health workers in all levels of PC, advocating and integrating PC principles and values into all levels of the health system (particularly the community), as well as providing an accountability function with local governments, as these facilitate the integration of PC into health systems.

As described by Pope Benedick XVI, "This (palliative care) is a right belonging to every human being, one which we must *all* be committed to defend." (Pope Benedick XVI 2006), the integration of PC to provide people with access to care that is rightfully theirs is a necessary and worthwhile goal, one that will take action from the range of actors across the system.

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Appendices

Appendix 1: Data extraction table

Key to this table

Dimensions of Integration: PROF (professional), ORG (organisational), CLIN (clinical), NORM (normative), FUNC (functional), VER (vertical), HOR (horizontal)
PC level: PCA (palliative care approach), GEN (generalist), SPEC (specialist)
Mode of integration: PO (policy only), SF (single facility, MF (multiple facility), SW (system-wide approach), TO (training only)
Other acronyms: PC (palliative care), HS (health system), community (COMM), CHW (community health worker), CBO (community-based organisation), health professional (HP)

Document details						Integration				Integration of PC for HSS	Nature of the intervention				Facilitators and barriers to integration of PC into HS	
Locat	Name of study	Author and date	Type	Aim	Lvl	Mode	Dimensions	Conceptualization		Partners	Type of facility	PC Level	Intervention Description	Facilitators	Barriers	
Uganda	Uganda: initiating a government public health approach to pain relief and palliative care	Stjernsward, 2002	Descriptive	Use Uganda as an example of how to implement the WHO's PHS to integrate PC cost effectively	Macro	PO	FUNC, NORM	'Coordination' (btw policies, teaching and services; btw AIDS PC and cancer services); 'Integration' (cultural solutions should be integrated with medical PC approaches); 'implementation' of PC services (using WHO PHS)	Not specifically mentioned	WHO, MoH, Hospice Uganda, clinicians, doctors, nurses, pharmacists, Drug Commissioner, Dean Makerere University, nursing school directors	n/a	PCA, GEN and SPEC PC	Integration of PC into national health policy and health frameworks through an intervention driven by the WHO	Policy, training, system wide approach	HS's ability to support integration	
South Africa	Integrated community-based home care: striving towards balancing quality with coverage in SA	Defilippi, 2005	Descriptive/Evaluation	To describe program development, implementation and outcomes	Meso and micro	MF	ORG, VER, HOR, CLIN, NORM	'Continuum of care', 'integration'	Strengthening HSS to deliver good PC at all levels and to strengthen the service delivery capacity of hospices	Hospice, MoH, home care team.	Hospice, clinics and hospitals (diff settings)	PC network, SPEC and GEN PC	Hospice led ICHC program provides integrated PC through creation of networks btw private and public sectors, and across/btw levels of care	System-wide approach, partnerships, patient at the centre of integration	HS's ability to support integration, COMM attitudes to PC	
South Africa	Difference in quality of life of referred hospital patients after hospital palliative care team intervention	Kirk and Collins, 2006	Evaluation	To evaluate the difference in quality of life of referred hospital patients after PC intervention	Meso and micro	SF	HOR, PROF, CLIN, NORM	'Developing' a PC service, team is a 'link' to other services	Not mentioned	Government	Tertiary public hospital	SPEC and some GEN PC	The development of a SPEC hospital PC team to advise hospital staff, created linkages btw other professionals and referrals to external COMM structures	Partnerships	Lack of system wide approach	
South Africa	Palliative medicine teaching program at the University of Cape Town: Integrating palliative care principles into practice	Gwyther and Rawlinson, 2007	Descriptive	To describe the development of the postgraduate palliative medicine programs at University of Cape Town	Micro	TO	ORG	'Integrate' PC knowledge into their health care settings	Not specifically mentioned. Discussed how HSs are based on a curative model and how PC can address this, but no links made.	Hospice Association of South Africa (HPCA), UCT, University of Wales College of Medicine Diana Princess of Wales Memorial Fund	University	GEN and SPEC PC	Integrated PC into the HS by training qualifying and qualified HPs through long distance programs - a postgraduate diploma and Mphil in Palliative medicine for doctors, as well as an "Introduction to PC" course and mentorship for all HPs.	Training	Training	

5	South Africa	The role of a palliative care inpatient unit in disease management of cancer and HIV patients	Jameson, 2007	Observational study	Evaluation of inpatient PC unit for private and state patients for patients with cancer and AIDS	Meso and micro	MF	ORG, PROF	'Implementation' of a PC service	PC eased burden for patients and provide quality care, limited consideration of PC for HSS.	Service organisation (Rotary), Private partners, MoH (public partner)	COMM hospital	SPEC PC	Integration of PC into a hospital through development of hospital-based PC unit in a public-private partnership. Follow up done by hospice at discharge. Formal coordination btw the two organisations	Partnerships	Training
6	Uganda	The impact of a modular HIV/AIDS palliative care education programme in rural Uganda	Downing and Kawuma, 2008	Evaluation	To evaluate the HIV/AIDS PC education programme	Meso	TO	PROF, NORM	Education is to allow for 'increased provision' of PC; 'integrated' into the nursing program; 'integrated' with HIV services	Not mentioned	Midmay, MoH	Health facility and hospitals	GEN and SPEC PC	Mobile training team providing modular, face-to-face training for qualified nurses	Training	Training, HS's ability to support integration
7	Uganda	The beginnings of children's palliative care in Africa: evaluation of a children's palliative care service in Africa	Amery <i>et al.</i> 2009	Evaluation	To evaluate a children's PC service designed specifically for a resource-poor SSA setting	Meso	MF	ORG, NORM	None	Not mentioned	Developed by Hospice Uganda, no mention of MoH but it provides care in an inpatient ward in public oncology ward	Public hospital, children's homes, outpatient t HAU site	SPEC and limited GEN PC	Provides SPEC PC to patients in hospital inpatient ward, outpatient hospice clinic and children's home. Children's PC (CPC) is integrated with cancer care.	Partnerships, training	HS's ability to support integration
8	South Africa	Palliative care in correctional centres-HPCA making progress in South Africa	Sithole and Dempers 2010	Descriptive	To describe how to integrate PC in correctional facilities	Meso and micro	MF	ORG; FUNC, NORM, CLIN, HOR	integrate' PC into health service	Not mentioned	Department of Correctional Services; HPCA	Correctional facility	SPEC and GEN PC	An innovative project integrating PC into health services in national prisons. Included building partnerships, training trainers, creation of SPEC PC teams in the prison health service and training specific inmates in GEN PC to support SPEC team. Piloted in one prison, then scaled up to another seven prisons.	Partnerships	HSs ability to support integration
9	Tanzania	Living and dying in east Africa: implementing the End-of-Life Nursing Education Consortium curriculum in Tanzania	Paice <i>et al.</i> 2010	Descriptive/Evaluation	To provide nurses with the knowledge and skills to care for the dying and to educate others	Meso	TO	PROF, ORG	'Develop', 'implement'	Not mentioned. Mentions some HS barriers to delivering PC, but not phrased this way	The faculty of ELNEC-International: Tanzania, MoH and APCA, hospice	Not specified	GEN PC	International trainers invited to train oncology nurses in PC. Trainers spent time in Tanzania prior to the training to understand context	Training, HS's ability to support integration	
10	South Africa	Expanding the reach of palliative care to community-based home care programs	Defilippi and Cameron, 2010	Descriptive/ Evaluation	To describe the development, implementation and outcomes of a pilot supportive supervision and training program	Meso and micro	MF	CLIN, ORG	'Integration', 'expanding'	Showed how to expand professional PC supervision outside hospice - strategy to strengthen a HS at the subdistrict level	Elton John Aids Foundation, HPCA, hospice	Four CBOs	GEN PC	CHWs from four CBOs given training, mentorship and supervision to integrate PC into routine practice.	Training, HS's ability to support integration, partnerships, system-wide approach	Training
11	Zimbabwe	The Zimbabwe Rural Palliative Care Initiative: PCI-Z	Di Sorbo <i>et al.</i> 2010	Evaluation	To describe program development, implementation and outcomes	Meso and micro	MF	CLIN, VER, PROF	'Integrate' PC into communities; 'integrate' PC home-based care into hospitals	Not mentioned. Limited linking of aims to general HS	The Foundation for Hospices in Sub-Saharan Africa, US hospice programs, Island Hospice, DFID	home-based care teams and facilities	PCA and GEN PC	Led by Hospice. Integrated PC into existing CBOs. The PCI-Z program trains HPs and provides supplies and infrastructure	System-wide approach, partnerships, training	HSs ability to support integration, training

12	Ethiopia	Building a palliative care program in Ethiopia: the impact on HIV and AIDS patients and their families	Wube <i>et al.</i> 2010	Descriptive/ Evaluation	To describe program development, implementation and outcomes	Meso and micro	MF	VER; HOR, ORG, CLIN	'Incorporate' PC into home-based care	Recommended COMM-based PC programs used nationally to increase access to PC and improve health outcomes	Family Health International (FHI), MoH, NGOs and CBOs.	Health facility and home-based care NGO's	PCA and GEN PC	Led by FHI. COMM-based PC service introduced, loosely coordinated with health centres and COMM supports. Used comprehensive approach through volunteers and links with COMM	Partnerships,	
13	Tanzania	Scaling up palliative care services in rural Tanzania	Nanney <i>et al.</i> 2010	Descriptive	None given	Meso and micro	MF	VER, CLIN, ORG	'Integration' of PC teams into hospitals; 'developed access' to PC	HS strengthened to link PC services to other pre-existing hospital resources, allowing for a greater continuum of care	The U.S. President's Emergency Plan for AIDS Relief (PEPFAR), United States Agency for International Development (USAID); MoH, faith-based organisations	District hospitals and home-based teams (rural)	PC network providing GEN and SPEC PC, encouraging a PCA	Scaled up PC model into 11 rural district hospitals. Consists of hospital-based PC SPEC team supervising trained volunteers (who refer patients with complex PC) and collaborate with local churches to support COMM and PC patient's families	FUNC integration, System-wide approach.	Training
14	Kenya	Advancing palliative care in Kenya	Malloy <i>et al.</i> 2011	Descriptive	To develop PC by increasing knowledge and skill in PC of nursing faculty members, then integrate this into nursing curricula	Meso and micro	TO	PROF, CLIN	Develop' PC service, 'integrate' PC into curricula	Training to address health worker shortage (recognises HS deficit influence)	KHPCA, Kenyatta National Hospital, End-of-Life Nursing Education Consortium, Funder (OSF)	Medical college	GEN PC	Training program run by international trainers with faculty staff from nursing schools, to integrate PC training into the nurse's training	Training, advocacy, partnerships	Training, the HS's ability to support integration.
15	South Africa	A cost analysis of a hospital-based palliative care outreach program: implications for expanding public sector palliative care in South Africa	Hongoro and Dinat, 2011	Cost-evaluation	To find the costs and cost drivers for a hospital outreach PC service and explain possible quality-of-life improvements and potential cost savings	Meso and micro	SF	PROF, CLIN	Integration' of in-hospital PC team; 'implement', 'establish'	PC program reduced hospital costs and benefits the HS by reducing congestion in wards, allowing beds to be available for acute cases	MoH; academia, external funders (Irish Aid, DFID)	Tertiary public hospital	SPEC PC and PCA	PC team integrated into hospital. Team treated inpatients through drop-in clinics, in-hospital consultations and facilitated PC at home using a telephonic advisory service and outreach teams, who referred to SPEC PC team. Provided training to staff and research on PC	Partnerships, system-wide integration.	Lack of system wide integration
16	Malawi	Hospital based palliative care in sub-Saharan Africa; a six-month review from Malawi	Tapsfield and Bates, 2011	Case review	To review six months of in-patient PC services at Tiyanjane Clinic	Meso and micro	MF	PROF, VER	'Develop'	Not mentioned	District health services, local medical school, Palliative Care Support Trust (PCST) and the Malawi government	Tertiary public hospital	SPEC and GEN PC	PC clinic developed in a hospital. Hospital-based PC team provided SPEC PC to inpatients and outpatients, home visits and weekly clinic that integrated PC and cancer care*. COMM volunteers provide home-based PC and 'link' nurses used to provide GEN PC in hospital (refer patients with complex PC needs to SPEC PC team). Coordinated with COMM structures	Partnerships, system wide approach, client at the centre of integration	Ability of the HS to support integration
17	Malawi	Palliative care making a difference in rural Uganda, Kenya and Malawi: three rapid evaluation field studies	Grant <i>et al.</i> 2011	Rapid field evaluation	To describe patient, family and local COMM perspectives on the impact of three COMM-based PC interventions in	Meso and micro	MF	ORG, PROF, CLIN	'Integration' (lack of integration btw the HIV services and HBC services), 'embedding' PC into the HS, 'integrating' PC with curative care. A public health approach with 'integration' of PC into policy and health sectors; PC 'integrated' with	Study discusses how health services were not designed to offer integrated care for chronic disease and how patients bear this burden.	MoH, independent clinic	Independent voluntary health organisation	GEN PC	PC clinic run out of two public health centres using volunteers in the COMM and nurses at the health centres, with home-based carers providing home visits. Good referral links with hospital and clinic, but limited integration with other types of treatment.	Client and COMM at the centre of integration, training, system wide approach	Lack of system wide approach, FUNC integration, HS's ability to support integration

18	Uganda				sub-Saharan Africa	Micro	SF	CLIN	local health and social care through referral pathways btw and across services		Faith based COMM programme, no explicit links to the MoH mentioned	Freestanding mobile clinic.	SPEC PC	Freestanding mobile PC clinic, part of a HIV program run by a private CBO. Consisted of SPEC PC team who received referrals from volunteers. Good integration of PC and HIV care, limited integration with public HS and other diseases	Client at the centre of integration, partnerships	
19	Kenya					Meso	SF	VER			Hospice, MoH, home care team	Rural area. COMM hospital	GEN and SPEC PC	PC program integrated with department in hospital. Hospital-based SPEC PC team and unit, with volunteers in the COMM. Used mobile clinics to provide integrated HIV and PC using primary health care	Client at the centre, training, partnerships	Ability of the HS to support integration
20	South Africa, Uganda and Tanzania	Developing children's palliative care in Africa through beacon centres: lessons learnt	Downing <i>et al.</i> 2013	Descriptive	To develop children's PC (CPC) through the development of Beacon sites to provide training and clinical experience in CPC	Meso and micro	MF	Normative, CLIN, FUNC	Develop' CPC to support students in 'integrating' CPC into their workplace. To ensure the 'integration' of PC into HSs resulting in PC being available to a greater number of people in SSA	Not mentioned	The Diana, Princess of Wales Memorial Fund, Pefpar, Mildmay, PASADA, HPCA		SPEC PC	Training of 'champions' in CPC, who would then deliver a training program on CPC, provide mentorship and support at three diff sites to students to assist in integrating CPC into their work places. The champions would also advocate for CPC together with PC associations	Training, partnerships, advocacy	Ability of the HS to support integration, partnerships
21	Tanzania	Can palliative care integrated within HIV outpatient settings improve pain and symptom control in a low-income country? A prospective, longitudinal, controlled intervention evaluation	Harding <i>et al.</i> 2013	Observational study	To determine whether PC delivered from within an existing HIV outpatient setting improves control of pain and symptoms compared to standard care	Meso and micro	SF	PROF, CLIN	'Integration' used to refer to provision of a HIV PC service. Described as 'integrated' PC	Not mentioned	Donor (DPWMF) and authors of the study.	District hospital	GEN and SPEC PC facilitated PCA in COMM	An intervention integrated PC with routine HIV care at an HIV outpatient facility in a hospital, through training of the facility staff and creating a PC team. Village health workers were also giving lay training on PC	System-wide approach	HS's ability to support integration
22	Malawi	Developing a palliative care service for children in the Queen Elizabeth Central Hospital, Blantyre, Malawi	Molyneux <i>et al.</i> 2013	Descriptive	To describe how a PC service developed and expanded	Meso and micro	SF	NORM, CLIN; PROF; VER; ORG	Development' of a PC service, 'integration' used to refer to team's role in coordinating care for clients within the hospital, 'embedding'	The HS needed to be strengthened to provide PC services.	MOH, Champions, PACAM, authors	Tertiary public hospital	SPEC PC and PCA	Development of a hospital-based SPEC PC team ("Umodzi") providing CPC to inpatients, outpatients (through limited outreaches), as well as training to paediatric staff to encourage a PCA. Acted as a coordinating mechanism for patients within the hospital.	Advocacy, local leadership, partnerships	Ability of the HS to support integration, desire for PC
23							SW	ORG, PROF, VER, HOR, NORM								

24	South Africa	A hospital-based palliative care service for patients with advanced organ failure in sub-Saharan Africa reduces admissions and increases home death rates	DesRosiers <i>et al.</i> 2014	Evaluation	To determine whether the PC service reduces admissions and increases home death rates compared with the same fixed time period of standard hospital care	Meso and micro	SF	PROF	develop'; provided 'coordinated care'	Lack of PC services impacts on HS, as long and frequent hospital visits place a high demand on limited resources and drive up costs. Providing PC can result in cost savings	Public hospital in Cape Town, no mention of funding for program	Public hospital	SPEC PC	Multi-disciplinary PC team who conducted group outpatient clinics with patients and their families who have advanced organ-failure, together with a multi-disciplinary team (MDT) consultation, who used a care-coordination model	Placing patient at the centre)	Lack of data
25	Malawi	Assessing and responding to palliative care needs in rural Sub-Saharan Africa: results from a model intervention and situation analysis in Malawi	Herce <i>et al.</i> 2014	Descriptive/Evaluation	To integrate pain, symptom relief and psychosocial support with disease modifying treatment for patients with serious chronic illnesses	Meso and micro	MF	VER, PROF, ORG	'Integration' of PC into policy, 'implementation' of PC services in hospitals, 'coordination' btw diff sectors and levels of care, 'integrate' PC with NCD treatment	Identified how the HS influenced the intervention by noting that in rural settings limited health infrastructure and human resources and high rates of HIV and NCDs strain the capacity of the HS to deliver PC	Partners In Health (PIH) (USA), Abwenzi Pa Za Umoyo (APZA) (Malawian sister organisation), Malawi MoH	District hospital	PC network with GEN and SPEC care, with a PCA	PC network developed, involving specialist MDT (who receive mentorship from an international trainer), a PC coordinator, volunteers and CHWs from both the MoH and NGOs. Services are provided at a district hospital, outpatient clinics and through a mobile district wide clinic. Also includes referrals to a separate program to support basic and socio-economic needs	Partnerships, system-wide approach, training,	Ability of the HS to support integration
26	Kenya	Evaluating a human rights-based advocacy approach to expanding access to pain medicines and palliative care: global advocacy and case studies from India, Kenya, and Ukraine	Lohman and Amon, 2015	Case study	To examine the impact of human rights research and advocacy efforts	Macro	SW	Normative	Integration' of PC into the public health care system. 'Integrate' PC into HIV/AIDS strategy and programs	Not mentioned	KHPCA, the Pain and Policy Studies Group, American Cancer Society's 'Treat the Pain' project; Kenyan government, Human Rights Watch (HRW)	Not specified	GEN and SPEC PC	This intervention, led by Human Rights Watch, used an advocacy approach to draw attention to the lack of CPC. Following research and dissemination of findings, steps to integrate PC into the public HS were taken	Advocacy, partnerships	Lack of a system wide approach
27	Kenya	Nurse-led palliative care for HIV-positive patients taking antiretroviral therapy in Kenya: a randomised controlled trial	Lowther <i>et al.</i> 2015	RCT	To test the effectiveness of integrating PC into existing outpatient care for people with HIV taking ART	micro	SF	CLIN	PC can be effectively delivered by 'integrating' it into existing HIV services	Not mentioned	KHPCA; DPWMF; researchers from both International and local universities	COMM hospital (privately funded)	GEN PC	This intervention, led by researchers, integrated PC into routine HIV care in an outpatient HIV clinic	System-wide approach, training	
28	Kenya	Integration of palliative care into comprehensive cancer treatment at Moi Teaching and Referral Hospital in Western Kenya	Cornetta <i>et al.</i> 2015	Descriptive	To review the implementation of a PC service and describe the scope and challenges of providing PC in an East African tertiary public hospital	Meso and micro	SF	FUNC, PROF	'Integration' of PC into a hospital, 'implementation' of a PC service	Not mentioned	Moi university School of Medicine, Moi Teaching and Referral Hospital (MTRH), and donors, Hospice (KEHPCA), other civil society organisations	Tertiary public hospital	SPEC PC and PCA	Hospital-based SPEC PC team was developed, led by a University and MoH, to integrate PC into cancer treatment. It initially began as a cancer treatment program, however PC services were added as patients with incurable cancers were seen	System-wide integration, FUNC integration	Negative attitudes towards PC, ability of the HS to support integration
29	Malawi (1)	Understanding models of palliative care delivery in Sub-	Downing <i>et al.</i> 2015	Mixed methods	To investigate how diff models of PC work within diff HSs		SF	FUNC, PROF, ORG	New referral pathways created 'linkages' btw levels of care, organisations, professionals (including specialist clinical	Investigating models of PC provision helps to strengthen health services as	Funded through an international project and government	National referral hospital	SPEC PC	A CPC service running from a public referral hospital providing care to inpatients and home-based PC through national outreach visits	System wide integration, partnerships, placing clients	Policy

30	Malawi (2)	Saharan Africa: learning from programs in Kenya and Malawi				SF		areas, diff cadres of staff within the facility and linkages btw professionals in diff sectors)	what is happening in PC can be transferred to the whole HS with the aim of improving quality of care		District hospital (faith based)	GEN and SPEC PC	A PC unit was developed inside a rural faith-based hospital which sees outpatients and inpatients, as well as provides HCBC.	at the centre of integration, training		
31	Malawi (3)					SF					Rural faith-based organisation	SPEC PC	A HCBC team, a part of a faith-based organisation, which provides PC in patient's homes or in a PC clinic.			
32	Malawi (4)					MF					Urban, home-based care NGO	GEN PC	A PC program run by NGO, providing HCBC, integrated PC and HIV treatment. Good links with COMM organisations to provide socio-economic and nutritional support.			
33	Kenya (1)					MF				Government funded	National tertiary referral hospital	SPEC PC	Hospital-based PC team targeted adults in hospital, with good links to Hospice for continuity of care. No PC unit.			
34	Kenya (2)					MF					MoH district hospital linked with hospice	GEN PC	PC team in hospital, with formal links to Hospice. Team was integrated within a HIV care program, but also provided care to other inpatients and outpatients, as well as through home visits			
35	Kenya (3)					SF					Faith-based district level hospital	SPEC PC	PC program run from faith-based hospital. PC team provided care to inpatients, outpatients, home visits and through provision of a day centre without the use of an inpatient PC unit			
36	Namibia	Interventions geared towards strengthening the health system of Namibia through the integration of palliative care	Freeman <i>et al.</i> 2016	Descriptive (short commentary)	To illustrate how a country can implement the WHO's public health strategy (PHS) for developing PC service	Macro and meso	SW	Normative, FUNC, ORG	'Implementation', 'integration', 'developing' services. Integration used to describe inclusion of PC in HS. Study discusses how intervention created 'supportive environment' for PC integration.	Interventions aimed at strengthening the HS of Namibia through integrating PC for people living with HIV, AIDS and cancer. (no further information)	USAID, APCA, the Ministry of health (MoH) and Social Services and local partners (i.e. CBOs)	Non-governmental home- and community-based care programs	PCA and GEN PC	Intervention aimed at national level advocacy, policy change and capacity building to develop skills, knowledge and research capacity for PC. Specific interventions aimed to integrate PC into 3 HCBC programs and education curricula for health workers, as well as other sectors. Led by APCA and showed integration btw health and social sector	Partnerships advocacy training	HS's ability to support integration, not using a system wide approach
37	Kenya	Kenya Hospices and Palliative Care Association: integrating palliative care in public hospitals in Kenya	Zipporah, 2016	Descriptive (short commentary)	To describe the interventions by the Kenya Hospice and Palliative Care Association (KHPCA) to integrate PC into the public HS to increase access to PC	Macro and meso	SW	PROF, CLIN, ORG	'Integration' (specifically integrating PC services), also used to refer to integration of PC into the HS more broadly and mentions that hospitals have 'integrated PC'	Integration is to improve access. Briefly mentions that integrating PC improves access and affordability of health care and helps to hold a government responsible	KHPCA; MoH, international donor funding	Public provincial hospitals	PC network with GEN and SPEC PC	Intervention led by HPCA to integrate PC into HS nationally. Components included advocacy at all HS levels, training of HPs and setting up hospital-based PC services.	Partnerships Advocacy	Lack of a system wide approach HSs ability to support integration
38	Cameroon	A qualitative evaluation of the impact of a	Bassah <i>et al.</i> 2016	Mixed	To examine how nursing students, report transfer of	Meso	TO		'Integration' of PC principles into all settings and 'integration' of PC	Not mentioned	University of Nottingham (UK) and Author	University	GEN PC	This intervention used a PC training program to integrate PC into nursing students' work setting, through	Training, partnerships, supportive	Ability of the HS to support

		palliative care course on preregistration nursing students' practice in Cameroon			learning into practice and the barriers and facilitators to this in a resource-poor country				competencies into daily practice					embedding a PC course into the nurses usual training using local facilitators	work environment	integration, partnerships staff attitudes, values and organisational culture
39	South Africa	Community health workers' palliative care learning needs and training: results from a partnership between a US university and a rural community organisation in Mpumalanga province, South Africa	Campbell and Baernholdt, 2016	Descriptive	To increase the capacity of CHWs to deliver PC	Micro	TO	CLIN	None	Not mentioned - but did discuss how the HS affected the CHW roles and has resulted in task-shifting	Partnership btw a faculty at a United States (U.S.) university and the leaders of a local NGO	Rural COMM organisation	GEN PC	A US agency planned a training with a CHWs in a South African NGO to integrate PC into their practice. This was done through training the CHWs, training strong CHW's to become future trainers, providing 'top up' sessions and continued access to PC educational materials	Training	Ability of the HS to support integration
40	South Africa	Development and pilot evaluation of a home-based palliative care training and support package for young children in southern Africa	Naicker <i>et al.</i> 2016	Descriptive/Evaluation	To develop and evaluate a training and support package to assist home-based care workers in providing PC for children at home in the southern African context	Meso and micro	TO	CLIN,	integrate' PC into HBC to provide a continuum of care	Intervention aimed to relieve burden on HSs due to HIV (full wards). Alluded to how package can use HBC to target children needing PC to assist burden on HS and increase access to PC	The Diana, Princess of Wales Memorial Fund, Human Sciences Research Council, Wits University, University of Oxford, University of KwaZulu-Natal, International Children's Palliative Care Network, CBOs	Not specified - CHWs from rural areas in KwaZulu-Natal, South Africa.	GEN PC	This intervention developed holistic and locally relevant training package for CHW's to integrate PC into work with children and support parents. It aimed to facilitate links btw the professional health workers and CHWs	Training, partnerships	Ability of the HS to support integration
41	Uganda	A palliative care link nurse programme in Mulago Hospital, Uganda: an evaluation using mixed methods	Downing, 2016	Evaluation	To evaluate the impact of a PC link nurse programme at Mulago Hospital	Meso and micro	SF	FUNC, PROF	'Integration' of PC into national HSs and facilities and to facilitate further PC development	Integration of PC services into existing HSs increases accessibility and sustainability of services. Hospital based PC teams with link-nurses can do this and influence overall HS.	MoH, Mulago hospital, Makerere University, University of Edinburgh (funder)	Tertiary public hospital	PCA, GEN and SPEC PC	Training of ward nurses as 'link' nurses, supervised by a coordinator, to provide GEN PC in the wards to encourage referrals to the SPEC PC team and facilitate a PCA (by training other ward staff in PC principles)	System-wide approach, FUNC integration, training, partnerships	FUNC integration, negative attitudes towards PC, partnerships
42	Malawi	The Edinburgh Malawi Cancer Partnership: helping to establish multidisciplinary cancer care in Blantyre, Malawi	Brown <i>et al.</i> 2016	Descriptive	To develop an integrated cancer and PC unit at a tertiary hospital for people with cancer.	Meso and micro	MF	FUNC, CLIN, PROF	When referring to the unit, it is described as an 'integrated' PC and oncology unit	Health care partnerships should look to strengthen established HSs, but no real link to PC, more about partnership.	Edinburgh Cancer Centre and the Queen Elizabeth Central Hospital, donors (Scottish Malawi development program)	Tertiary and district public hospital	SPEC PC	Development of partnership btw local and international PC and oncology units to facilitate the provision of comprehensive cancer care, which included PC	Partnerships; system-wide approach, FUNC integration	
43	Kenya, Rwanda, Uganda and Zambia	Integrating palliative care into national HSs in Africa: a multi-country intervention study	Grant <i>et al.</i> 2017	Evaluation	To integrate PC into national HSs.	Macro and meso	SW	ORG, FUNC, PROF, NORM	Integration of PC into education (in terms of practicing habits)	Used an HSS approach, referring to the building blocks WHO document. Results described in terms of HSS.	University of Edinburgh Global Health Academy, APCA, Makerere University Palliative Care Unit; National	Public referral hospitals, regional hospitals and	PC network which included SPEC PC,	Complex intervention to integrate PC into HS, specifically hospitals. Included advocacy, increasing staff capacity (which also facilitated the use of a PCA in the COMM and facilities), service delivery (through setting up SPEC and GEN PC	Policy and information systems, partnerships advocacy; training system wide approach	HSs ability to support integration, partnerships, training

										Palliative Care Associations, MoH	district hospitals	GEN PC and PCA	services in hospitals) and facilitating partnerships btw referral hospitals to form PC network.			
44	Botswana	Multidisciplinary gynaecologic oncology clinic in Botswana: a model for multidisciplinary oncology care in low- and middle-income settings	Grover <i>et al.</i> 2017	Evaluation	To describe implementation and outcomes of newly established gynaecologic multi-disciplinary clinic	Micro	SF	CLIN, PROF	'Care coordination'	Streamlining care through multidisciplinary clinics improve cancer care coordination and clinical outcomes	Government (public hospital)	Public hospital	SPEC PC	An intervention aimed at improving care coordination for pregnant women with cancer by establishing an MDT clinic, which included PC	Partnership	HS's ability to support integration
45	Rwanda	Palliative care in Rwanda: aiming for universal access	Krakauer <i>et al.</i> 2018	Review article	To describe how Rwanda is integrating PC into their national HS	Macro and meso	SW	FUNC, VER, PROF, ORG, NORM	'Develop'/'development'/'developing' PC services; 'integration' of PC into HS and all levels of care	No specifically mentioned. PC described as improving patient outcomes, giving financial risk protection for families and save money for HS by reducing hospital admissions near the end of life. (not tested in the intervention)	University of Wisconsin, University of Edinburgh, Makerere University, Tropical Health and Education Trust, Open Society Foundation, Pefpar, Intrahealth international, Massachusetts General Hospital, Hospice Without Borders, Mildmay international, DFID, Roros foundation	Hospitals	SPEC, GEN, PCA, PC network	National level intervention over at the last 7 years, led by the MoH. Involved the creation PC policies (including guidelines, frameworks) that were followed up with directives; mechanisms to facilitate integration across the system (referral forms; PC training at all levels of the HS; innovative prescribing mechanisms and the creation of PC networks, which included home-based PC services	Funding Policy Partnerships Training System wide approach	HS's ability to support integration
46	South Africa	Palliative care in South Africa	Drenth <i>et al.</i> 2018	Review article	Review of Hospice Palliative Care Association of South Africa (HPCA) projects in South Africa.	Micro	TO	CLIN	'Integration' of PC into education, 'integrated services', 'integrated' PC into prison setting	Not mentioned	Hospice, Traditional Health Practitioners (THP)	COMM based structure (THP)	GEN PC	Interventions funded by Open Society Foundation PC initiative to integrate PC into practices of THPs through training and communication technique.	Client and COMM at the centre of integration, partnerships, training.	HSs ability to support integration, negative perceptions of PC.
47	Kenya	The palliative care journey in Kenya and Uganda	Kamonyo, 2018	Review article	To examine PC achievements and challenges in Kenya and Uganda and the role of various actors in PC	Macro	SW	FUNC, NORM, ORG, HOR	'implementation', 'integration', 'development'.	HSs are strengthened by integrating PC at all levels.	MoH, OSF for East Africa, International Palliative Care Initiative (IPCI), Kenya Hospice and Palliative Care Association (KHPCA).			Provision of financial grants from the OSF to support local organisations to work with MoH to integrate PC into HS. Funds received by the KHPCA, individual hospices and local champions to target policies, drug availability, training of HPs and integrate PCs.	Partnerships, training	Ability of the HS to support integration

48	Uganda				establishment in the region.	Macro	SW	ORG			APCA, MoH, IPCI, Palliative Care Association of Uganda, Hospice Africa Uganda, Makerere University, Uganda Network on Law Ethics and HIV/AIDS, National Medical Stores, National Drug Authority, Joint Medical Stores.			Intervention involved the provision of funding to local partners to integrate PC into the national HS. Integration efforts targeted improving provision of PC in policy, improving drug availability, training HPs in PC and implementation of CPC services at diff levels of the HS		
49	South Africa	The development of hospital-based palliative care services in public hospitals in the Western Cape, South Africa	Gwyther <i>et al.</i> 2018	Review article	To describe models for PC at tertiary, provincial and district hospital level, which could inform development of hospital-based PC in South Africa	Meso and	MF	ORG; CLIN; HOR, FUNC, VER	'Integration', 'development'	PC is essential to universal health coverage and improving quality of care for individuals. Integration of PC	Government, Hospice and the Hospice Palliative Care Association of SA and University	Tertiary public hospital	GEN and SPEC PC, with a PCA	Hospital-based PC team provided SPEC PC and provided integrated PC through strong links with CBO's, strong referral system and training program for ward nurses	FUNC integration, training	FUNC integration
50						Meso	MF	ORG			Hospice, government	District hospitals	SPEC PC	Integration of PC hospital. Ward provided in hospital and medication by MoH, staffed by Hospice, who provides SPEC PC.	Partnerships	
51						Meso	MF	ORG, HOR			Hospice, public hospital	Provincia l public hospital	SPEC PC	Coordination btw two organisations facilitated through MDT meetings and the development of care plans. Hospice staffs ward in hospital and formal referral pattern btw hospital and Hospice PC program	Partnerships, placing the client at the centre of integration, FUNC integration	

Appendix 2: Key concepts

Table 1. Models of PC (Source: Adapted from Gomez-Batiste and Connor, 2017)

Palliative care approach	Referring to a situation where palliative care principles are used by <i>all health professionals within the health care system or facility</i> allowing for timely referrals for more specialised care, adequately managed pain and holistic support from the time of diagnosis.
Generalist/basic palliative care	This is a model of providing care where <i>specifically trained professionals</i> (usually nurses) attend patients with more complex palliative care needs, train other staff in providing a palliative care approach and act as reference points for patients and other hospital services.
Specialised palliative care	This type of care is usually provided by a <i>specialist multidisciplinary team</i> to patients with complex palliative care needs that cannot be attended to with generalist care. These teams are either basic (doctor and nurse) or more complex with professionals from other health services.
Palliative care comprehensive network	This refers to the model of <i>integrated organisation of palliative care provision in a geographical area</i> in which there are integrated care pathways between all services. This involves a leading team which works in all settings and/or a service agreement between organisations or services to provide integrated care.
Palliative care national program	<i>Provision and planning of palliative care in a region or country</i> , using a public health approach and usually led by the Ministry of Health.

Table 2. Concepts relating to integration (Sources: Adapted from Leutz 1999; Shaw *et al.* 2011; Curry and Ham 2012 Valentijn *et al.* 2013, and World Health Organisation Regional Office for Europe 2016; Watt *et al.* 2017)

Integration	<p>The “managerial or operational changes to health systems to bring together inputs, delivery, management and organisation of particular service functions as a means of improving coverage, access, quality, acceptability and (cost)-effectiveness.” (Briggs and Garner 2006, p. 2)</p> <p>Integration is conceptualised at occurring at different levels to integration services for a whole population (macro); for specific populations or group (meso) and to coordinate care for individual clients within a setting (micro).</p> <p>Different models of integrating palliative care were considered including integrated management and policy making; integration at service delivery points, between different levels of the health system and between organisations/health facilities at the same level of care; as well as integration of palliative care into education and training.</p>
Dimensions of integration (also referred to as integrative processes)	
At a macro level	Whole system level interventions to deliver integrated care to the population served, often at a national level.
System integration	Coordinating the rules and policies within a health system.
Vertical integration:	Vertical integration focuses on integration across different stages of care. For this paper vertical integration is considered being between different levels or stages of care such as, between tertiary, secondary and primary care facilities; between a hospital (offering specialist palliative care services) and community structures (providing primary or home-based care); creation of a network across different stages or levels of care.
Horizontal integration	Horizontal integration focuses on integrating organisations, networks or groups within the health sector, usually at the same level of care. For this paper horizontal integration is considered being between hospices and other NGO’s providing the similar type of care; between a hospice and a hospital providing the same types of care; collaboration between different health facilities at the same level of care.
At a meso level	Interventions that seek to deliver integrated care for a particular group or populations with the same disease or conditions.
Organisational integration	Organisational integration can be described as bringing together several organisations through the creation of mergers, networks and partnerships.
Professional integration	Integration that is led by professionals within or between organisations (compared to entire organisations as above). This involves shared responsibility, problem solving or decision making for a group of people.

Organisational and professional integration occur along a continuum and for the purpose of this paper is understood as follows:	
Segregated	Autonomous organisations/professions working separately with limited to no communication
Linkages	Integration between organisations or professionals that is limited to referrals and informal communication, with no cost-sharing and clearly aligned separate responsibilities given to the separate groups
Coordination	Separate professionals or organisations that operate through existing structures to coordinate care, share clinical information, manage transition between the different parts of the organisation or between organisations.
Full integration	Full incorporation of the one organisation into the other or the creation of a new organisation with pooled funds and resources allowing for the provision of comprehensive services for specific groups of people
At a micro level	Interventions seeking to deliver integrated care for individual service users and their carers through care coordination.
Clinical integration (service integration):	Coordinating the care process for individual patients across different services and organisations in a system. Interventions include shared guidelines and protocols, developing extended clinical roles, guidelines and inter-professional education and enabling patients to help coordinate their own services.
Linking the macro, meso and micro levels	
Functional integration (administrative integration)	This involves coordination of non-clinical or support functions to support system, organisational, professional and clinical integration and include quality improvement, financial management and funding, information management (i.e., shared electronic patient records), shared policies and practices and referral forms.
Normative integration	This supports integration at different levels by developing a common frame of reference, mission, vision, values and culture between organisations, professional groups and individuals to allow coordination. Interventions include those that aim to shift health worker or community attitudes to death or the need for palliative care; that aim to adapt the culture of an organisation to value palliative care. Interventions include advocacy, training, shared goal development or local events. Normative integration is vital to ensure that implementation is successful 'on the ground'

Appendix 3: Search strategy for systematic review

Database	Date final search	No. of articles found	Key word and search history
Pubmed	09/03/2018	618	((((((Palliative Care[MeSH] OR Palliative Medicine[MeSH] OR Hospice and Palliative Care Nursing[Mesh] OR Terminal Care[MeSH]))) OR ((Palliative OR "end of life" OR "life limiting" OR life-limiting OR end-of-life OR "terminal care" OR "terminally ill" OR hospice)))) AND (((Delivery of Health Care, Integrated[Mesh] OR Delivery of Health Care[MeSH] AND Health Services[MeSH] OR Health Planning[MeSH])) OR ((Developing OR embed* OR implement OR implements OR implementation OR development OR develop OR integrated OR integrate OR integration OR integrating OR coordinated OR coordinating OR coordination OR co-ordinate OR co-ordination OR co-ordinating OR linking OR linkage OR link)))) AND ((Africa[Text Word] OR African[Text Word] OR Algeria[Text Word] OR Angola[Text Word] OR Benin[Text Word] OR Botswana[Text Word] OR "Burkina Faso"[Text Word] OR Burundi[Text Word] OR Cameroon[Text Word] OR "Canary Islands"[Text Word] OR "Cape Verde"[Text Word] OR "Central African Republic"[Text Word] OR Chad[Text Word] OR Comoros[Text Word] OR Congo[Text Word] OR Democratic Republic of Congo[Text Word] OR Djibouti[Text Word] OR Egypt[Text Word] OR Eritrea[Text Word] OR Ethiopia[Text Word] OR Gabon[Text Word] OR Gambia[Text Word] OR Ghana[Text Word] OR Guinea[Text Word] OR Ivory Coast[Text Word] OR "Cote d'Ivoire"[Text Word] OR Jamahiriya[Text Word] OR Kenya[Text Word] OR Lesotho[Text Word] OR Liberia[Text Word] OR Libya[Text Word] OR Madagascar[Text Word] OR Malawi[Text Word] OR Mali[Text Word] OR Mauritania[Text Word] OR Mauritius[Text Word] OR Mayotte[Text Word] OR Morocco[Text Word] OR Mozambique[Text Word] OR Namibia[Text Word] OR Niger[Text Word] OR Nigeria[Text Word] OR Principe[Text Word] OR Reunion[Text Word] OR Rwanda[Text Word] OR "Sao Tome"[Text Word] OR Senegal[Text Word] OR Seychelles[Text Word] OR "Sierra Leone"[Text Word] OR Somalia[Text Word] OR "St Helena"[Text Word] OR Sudan[Text Word] OR Swaziland[Text Word] OR South Africa[Text Word] OR Tanzania[Text Word] OR Togo[Text Word] OR Tunisia[Text Word] OR Uganda[Text Word] OR "Western Sahara"[Text Word] OR Zaire[Text Word] OR Zambia[Text Word] OR Zimbabwe[Text Word])))) NOT ("African American" OR "African Americans" OR "African american")
Ebscohost: Academic search premiere, Africa- wide information, CINAHL, EconLit, ERIC, Humanities International complete, MEDLINE, Health Source: Nursing/ Academic Edition	09/03/2018	1210	AB (Africa OR African OR Algeria OR Angola OR Benin OR Botswana OR Burkina Faso OR Burundi OR Cameroon OR Canary Islands OR Cape Verde OR Central African Republic OR Chad OR Comoros OR Congo OR Democratic Republic of Congo OR Djibouti OR Egypt OR Eritrea OR Ethiopia OR Gabon OR Gambia OR Ghana OR Guinea OR Ivory Coast OR Cote d'Ivoire OR Jamahiriya OR Kenya OR Lesotho OR Liberia OR Libya OR Madagascar OR Malawi OR Mali OR Mauritania OR Mauritius OR Mayotte OR Morocco OR Mozambique OR Namibia OR Niger OR Nigeria OR Principe OR Reunion OR Rwanda OR Sao Tome OR Senegal OR Seychelles OR Sierra Leone OR Somalia OR St Helena OR Sudan OR Swaziland OR Tanzania OR Togo OR Tunisia OR Uganda OR Western Sahara OR Zaire OR Zambia OR Zimbabwe) AND AB (Palliative OR end of life OR life limiting OR life-limiting OR end-of-life OR terminal care OR terminally ill OR hospice) AND (Developing OR embed OR implement OR implements OR implementation OR development OR develop OR integrated OR integrate OR integration OR integrating OR coordinated OR coordinating OR coordination OR co-ordinate OR co-ordination OR co-ordinating OR linking OR linkage OR link) NOT African American
Google Scholar	10/03/2018	First 200	Palliative OR terminal care OR terminally ill AND integration OR service OR develop* OR implement AND Africa OR Malawi OR Tanzania OR South Africa OR Uganda

Appendix 4: List of interventions and approaches to integrate palliative care into health systems included in the systematic review

No.	Country	Mode of integration and level of PC	Short description of the intervention	Name of study	Author & date
1.	Uganda	Policy only; PC approach, generalist & specialist PC*	Integration of PC into national health policy & health frameworks in Uganda through an intervention driven by the WHO.	Uganda: initiating a government public health approach to pain relief and palliative care	Stjernsward, 2002
2.	South Africa	Multiple facility; PC network, specialist & generalist PC	The Integrated Community-based Home Care (ICHC) program is led by Hospice, in partnership with other CBOs providing PC & the Ministry of Health (MoH). It attempts to provide integrated PC through the creation of networks between the private & public sector (i.e. Hospice & MoH), as well as across & between levels of care (i.e. HCBC – clinic – hospital).	Integrated community-based home care: striving towards balancing quality with coverage in South Africa	Defilippi, 2005
3.	South Africa	Single facility; Specialist & some generalist PC	The development of a specialist hospital-based PC team which advises other health professionals, created linkages between other HPs in the hospital & referrals to external community structures.	Difference in quality of life of referred hospital patients after hospital palliative care team intervention	Kirk <i>et al.</i> 2006
4.	South Africa	Training only; specialist & generalist PC.	This intervention aims at integrating PC into the health system by training qualifying & qualified health professionals through long distance programs - a postgraduate diploma & Mhil in Palliative medicine for doctors, as well as an "Introduction to PC" course and mentorship for all health professionals.	Palliative medicine teaching program at the University of Cape Town: Integrating palliative care principles into practice	Gwyther <i>et al.</i> 2007
5.	South Africa	Multiple facility; Specialist PC	Integration of PC into a hospital through the development of a hospital-based PC unit in a joint public-private partnership between Hospice, hospital & local donors. Follow up was done by hospice upon discharge, with formal coordination between the two organisations.	The role of a palliative care inpatient unit in disease management of cancer and HIV patients	Jameson, 2007
6.	Uganda	Training only; Generalist & specialist PC	This innovative training program that involved a mobile training team providing modular, face-to-face training for qualified nurses.	The impact of a modular HIV/AIDS palliative care education programme in rural Uganda	Downing <i>et al.</i> 2008
7.	Uganda	Multiple facility; Specialist & limited generalist PC	A program that provides specialist PC to patients in a national public hospital inpatient ward, outpatient hospice clinic & children's home. Children's PC (CPC) is integrated with cancer care.	The beginnings of children's palliative care in Africa: evaluation of a children's palliative care service in Africa	Amery <i>et al.</i> 2009
8.	South Africa	Multiple facility; Specialist & generalist PC	An innovative project integrating PC into health services in national prisons. Components included building partnerships, training trainers, creation of specialist PC teams in the prison health service & training specific inmates in generalist HCBC with PC to support specialist team. This intervention was piloted in one prison, then scaled up to another seven prisons* in South Africa.	Palliative care in correctional centres - HPCA making progress in South Africa	Sitholi <i>et al.</i> 2010
9.	Tanzania	Training only; Generalist PC	International trainers were invited to deliver training to oncology nurses in delivering PC effectively. Trainers spent a short amount of time in Tanzania prior to the training to understand the context.	Living and dying in east Africa: implementing the End-of-Life Nursing Education Consortium curriculum in Tanzania	Paice <i>et al.</i> 2010

* The information on the type of PC to be provided through the policy in intervention 1 was not available in the study, therefore it was supplemented by reading the Ugandan Health Sector Strategic Plan (2000/1 – 2004/5) (accessed at http://siteresources.worldbank.org/INTPRS1/Resources/383606-1201883571938/Uganda_HSSP.pdf).

*Supplementary information on the roll-out of intervention 8, following the pilot was attained from another article reviewing PC in South Africa (Drenth *et al.* 2018)

10.	South Africa	Multiple facilities; Generalist PC	Community health workers (CHW) from four CBOs were provided training, mentorship & supportive supervision to integrate PC into their routine practice*.	Expanding the reach of palliative care to community-based home care programs	Defilippi <i>et al.</i> 2010
11.	Zimbabwe	Multiple facilities, generalist PC & PC approach.	The intervention, PCI-Z program, led by a Hospice organisation (FHSSA), in partnership with local private & public organisations, aimed to integrate PC into existing HCBC organisations. The PCI-Z program trains health professionals & provides physical support in terms of supplies & infrastructure. *	The Zimbabwe Rural Palliative Care Initiative: PCI-Z	Di Sorbo <i>et al.</i> 2010
12.	Ethiopia	Multiple facility, generalist PC & PC approach.	Intervention led by an international organisation (FHI), in partnership with other private & public partners. A HCBC PC service was introduced, which was loosely coordinated with the clinic/health centres & other community supports. It needed to use a comprehensive approach to provide socio-economic support, which was possible through community-based volunteers & establishing strong links with the community.	Building a palliative care program in Ethiopia: the impact on HIV and AIDS patients and their families	Wube <i>et al.</i> 2010
13.	Tanzania	Multiple facility; PC network providing specialist, generalist PC & encouraging a PC approach	This intervention scaled up a successful PC model into 11 rural district hospitals* in Tanzania. The model consists of a hospital-based PC specialist team who supervise trained volunteers (who refer patients with complex PC needs to the hospital-based PC team) & collaborate with local churches to support the community & families of PC patients.	Scaling up palliative care services in rural Tanzania	Nanney <i>et al.</i> 2010
14.	Kenya	Training only; generalist PC	A training program run by US trainers with faculty staff from nursing schools, with the aim that PC training would be integrated into the nurses' training.	Advancing palliative care in Kenya	Malloy <i>et al.</i> 2011
15.	South Africa	Single facility; specialist PC & PC approach.	This intervention, led by university & MoH with support from donor funding & international trainers, created a hospital-based PC team in a large referral hospital. The team treated inpatients through drop-in clinics, in-hospital consultations & facilitated PC at home using a telephonic advisory service & outreach teams, who referred to the specialist team if needed. The team also provided training to staff & research on PC.	A cost analysis of a hospital-based palliative care outreach program: implications for expanding public sector palliative care in South Africa	Hongoro <i>et al.</i> 2011
16.	Malawi	Multiple facility; Specialist & generalist PC.	A PC clinic, supported by the Palliative Care Support Trust & the MoH, was developed in a referral hospital. It consisted of a hospital-based PC team that provided specialist care to inpatients & outpatients, through home visits & a weekly clinic at a government health centre, which integrated PC & cancer care*. Community volunteers provide home-based PC & 'link' nurses are used to provide generalist care within the hospital, who refer patients with complex PC needs to the specialist PC team. The program is coordinated with community structures.	Hospital based palliative care in sub-Saharan Africa; a six month review from Malawi.	Tapsfield <i>et al.</i> 2011

*Although no. 10 is not an intervention that integrates PC into a public health system, it is a good example of integrating PC into home-based care, which is a part of the health system.

*The hospitals in intervention 13 were run by a faith-based organisation (Evangelical Lutheran Church of Tanzania); however, in 2012 these hospitals were transferred to the government system.

*Intervention 16 was supplemented by another study by Mukhula *et al.* (2017) to understand the program run by Tiyanjane Clinic in greater depth. (Mukhula V, Sibale D, Tarmahomed L, *et al.* 2017. Characterising cancer burden and quality of care at two palliative care clinics in Malawi. *Malawi Medical Journal*, 29: 130-5.)

17.	Malawi	Multiple facility; Generalist PC	A PC clinic is run out of two public health centres consisting of volunteers in the community & nurses at the health centres, with home-based carers providing home visits. Good referral links with hospital & clinic were evident, but with limited integration with other types of treatment.	Palliative care making a difference in rural Uganda, Kenya and Malawi: three rapid evaluation field studies*	Grant <i>et al.</i> 2011
18.	Uganda	Single facility; Specialist PC	A freestanding mobile PC clinic is a part of a HIV program run by a private CBO. The clinic consisted of a specialist PC team who received referrals from volunteers. Good integration of PC & HIV care, but limited integration with the public health system & other diseases.		
19.	Kenya	Single facility; Generalist & specialist PC	This PC program was integrated with the Community health department in a rural hospital. It consisted of a hospital-based PC specialist team & unit, with volunteers in the community, using mobile clinics to provide integrated HIV & PC using a primary health care approach.		
20.	South Africa, Uganda & Tanzania	Multiple facilities; specialist PC	The Beacon Centres program aimed to integrate CPC into the health system by training 'champions' in CPC. These champions would then deliver a training program on CPC, provide mentorship & support at three different sites to students to assist in integrating CPC into their work places. The champions would also advocate for CPC together with PC associations.	Developing children's palliative care in Africa through beacon centres: lessons learnt	Downing <i>et al.</i> 2013
21.	Tanzania	Single facility: Generalist & specialist PC, facilitated PC approach in community	An intervention, led by researchers, which integrated PC with routine HIV care at an HIV outpatient facility in a hospital, through training of the facility staff & creating a PC team. Village health workers were also giving lay training on PC.	Can palliative care integrated within HIV outpatient settings improve pain & symptom control in a low-income country? A prospective, longitudinal, controlled intervention evaluation	Harding <i>et al.</i> 2013
22.	Malawi	Single facility; Specialist PC & a PC approach	Development of a hospital-based PC specialist team ("Umodzi") providing CPC. It provided care to inpatients, outpatients (through limited outreaches), as well as training to paediatric staff to encourage a PC approach. Acted as a coordinating mechanism for patients within the hospital.	Developing a palliative care service for children in the Queen Elizabeth Central Hospital, Blantyre, Malawi	Molyneux <i>et al.</i> 2013
23.	Malawi	System wide; PC network providing specialist & generalist PC, encouraging a PC approach.	Program built off intervention (above) as method to extend PC services to adults and children. The Palliative Care Support Trust developed the STEP UP programme, led by Umodzi (above), funded and supported by international PC organisations and African Palliative Care Association (APCA). Advocacy was a significant component at a district and local level to ensure funding for PC and use of a PC approach in the community. A district wide PC network was set up, led and supported by the tertiary hospital-based PC team. Training and funds were provided to train PC teams and volunteers in the supported district hospitals and set up PC units.		
24.	South Africa	Single facility; specialist care.	A novel hospital-based PC service consisted of a multi-disciplinary PC team who conducted group outpatient clinics with patients & their families who have advanced organ-failure, together with a multi-disciplinary team (MDT) consultation, who used a care-coordination model.	A hospital-based palliative care service for patients with advanced organ failure in sub-Saharan Africa reduces admissions & increases home death rates	DesRosiers <i>et al.</i> 2014

*Information on interventions 17-19 was supplemented by information from the original evaluation report written by the authors of the study and supplied on the APCA's website (<https://www.africanpalliativecare.org/resources-centre/partners-resources/>).

25.	Malawi	Multi-facility; PC network with specialist, generalist & PC approach	International NGO led intervention, in partnership with local NGOs & MoH, where a PC network was developed, involving specialist MDTs (who receive mentorship from an international trainer), a PC coordinator, volunteers & CHWs from both the MoH & NGOs. Services are provided at a district hospital, outpatient clinics & through a mobile district wide clinic. Also includes referrals to a separate program to support basic and socio-economic needs.	Assessing & responding to palliative care needs in rural sub-Saharan Africa: results from a model intervention & situation analysis in Malawi	Herce <i>et al.</i> 2014
26.	Kenya	System wide; Specialist & generalist PC	This intervention*, led by Human Rights Watch in partnership with other local & international partners, used an advocacy approach to draw attention to the lack of CPC. Following research & dissemination of findings, steps to integrate PC into the public health system were taken.	Evaluating a human rights-based advocacy approach to expanding access to pain medicines & palliative care: global advocacy & case studies from India, Kenya, & Ukraine	Lohman <i>et al.</i> 2015
27.	Kenya	Single facility; generalist PC	This intervention, led by researchers, integrated PC into routine HIV care in an outpatient HIV clinic.	Nurse-led palliative care for HIV-positive patients taking antiretroviral therapy in Kenya: a randomised controlled trial	Lowther <i>et al.</i> 2015
28.	Kenya	Single facility; Specialist PC & PC approach.	A hospital-based PC specialist team was developed, led by a University & MoH and with donor & mentorship support from the United States (US), to integrate PC into cancer treatment. It initially began as a cancer treatment program, however PC services were added as patients with incurable cancers were seen.	Integration of palliative care into comprehensive cancer treatment at Moi Teaching & Referral Hospital in Western Kenya	Cornetta <i>et al.</i> 2015
29.	Malawi (1)	Single facility; Specialist care	A CPC service running from a public referral hospital, privately funded through a project & providing care to inpatients & home-based PC through national outreach visits.	Understanding models of palliative care delivery in Sub-Saharan Africa: learning from programs in Kenya & Malawi*	Downing <i>et al.</i> 2015
30.	Malawi (2)	Single facility; Specialist & generalist PC	A PC unit was developed inside a rural faith-based hospital which sees outpatients & inpatients, as well as provides HCBC.		
31.	Malawi (3)	Single facility; Specialist PC	A HCBC team, a part of a faith-based organisation, which provides PC in patient's homes or in a PC clinic.		
32.	Malawi (4)	Multiple facility; Generalist PC	A PC program run by an NGO in an urban area, providing HCBC providing integrated PC & HIV treatment. Good links with community organisations to provide socio-economic & nutritional support.		
33.	Kenya (1)	Multiple facility; Specialist PC	A hospital-based PC team targeted adults in a public referral hospital, with good links to the Nairobi Hospice to enhance continuity of care. The MDT saw patients in the wards as it has no PC unit.		
34.	Kenya (2)	Multiple facility; Generalist PC	The development of a PC team in a public hospital, with formal links to their local Hospice. The team was integrated within a HIV care program, but also provided care to other inpatients & outpatients, as well as through home visits.		
35.	Kenya (3)	Single facility; specialist PC	A PC program being run from a faith-based hospital in a rural area, where a PC team provided care to inpatients, outpatients, home visits & through provision of a day centre without the use of an inpatient PC unit.		

*Intervention no. 26 was also supported by the True Colours Trust and supplementary information was also found from the report on the program written by the True Colours Trust (Accessed from <http://www.truecolourstrust.org.uk/wp-content/uploads/2012/12/Developing-palliative-care-short-summary.pdf>).

*In this study seven different projects in Malawi & Kenya (no.'s 29 – 35) were evaluated to identify different models of PC provision. Specific details such were not provided by the study and a report providing further information was not available (the author was contacted directly), therefore the studies were included only using the information provided.

36.	Namibia	System wide; generalist & PC approach.	Intervention aimed at national level advocacy, policy change & capacity building to develop skills, knowledge & research capacity for PC. Specific interventions aimed to integrate PC into 3 HCBC programs & education curricula for health workers, as well as other sectors. Led by the APCA and showed integration between health & social sectors.	Interventions geared towards strengthening the health system of Namibia through the integration of palliative care	Freeman <i>et al.</i> 2016
37.	Kenya	System wide; PC network with specialist & generalist PC.	Intervention led by Kenyan Hospice and Palliative Care Association (KHPCA) to integrate PC into health system nationally. Components included advocacy at all health system levels, training of health professionals & setting up hospital-based PC services. Predominantly donor funded & supported by a coalition made up of the APCA & international funders & PC organisations.	Kenya Hospices & Palliative Care Association: integrating palliative care in public hospitals in Kenya	Zipporah, 2016
38.	Cameroon	Training only; Generalist PC	This intervention used a PC training program to integrate PC into nursing students' work setting, through embedding a PC course into the nurses usual training using local facilitators.	A qualitative evaluation of the impact of a palliative care course on preregistration nursing students' practice in Cameroon	Bassah <i>et al.</i> 2016
39.	South Africa	Training only; Generalist PC.	A US agency planned a training with a CHWs in a South African NGO to integrate PC into their practice. This was done through training the CHWs, training strong CHW's to become future trainers, providing 'top up' sessions & continued access to PC educational materials.	Community health workers' palliative care learning needs & training: results from a partnership between a US university & a rural community organization in Mpumalanga province, South Africa	Campbell <i>et al.</i> 2016
40.	South Africa	Training only; Generalist PC.	This intervention developed a holistic & locally relevant training package for CHW's to allow them to integrate PC into their work with children and support parents. It aimed to facilitate links between the professional health workers & CHWs.	Development & pilot evaluation of a home-based palliative care training & support package for young children in southern Africa	Naicker <i>et al.</i> 2016
41.	Uganda	Single facility; Specialist, generalist & PC approach	An innovative program which involved training ward nurses as 'link' nurses, supervised by a coordinator, to provide generalist PC in the wards to encourage referrals to the PC specialist team & facilitate a PC approach (by training other ward staff in PC principles).	A palliative care link nurse programme in Mulago Hospital, Uganda: an evaluation using mixed methods	Downing, 2016
42.	Malawi	Multiple facility; Specialist PC	This intervention consisted of the development of a partnership between local & international PC & oncology units to facilitate the provision of comprehensive cancer care, which included PC.	Edinburgh Malawi Cancer Partnership: helping to establish multidisciplinary cancer care in Blantyre, Malawi	Brown <i>et al.</i> 2016
43.	Kenya, Rwanda, Uganda & Zambia	System wide; PC network which included specialist PC, generalist PC & PC approach	This complex intervention worked both nationally & locally to integrate PC into the health system, specifically targeting hospitals. The components included advocacy, increasing staff capacity (which also facilitated the use of a PC approach in the community & facilities), service delivery (through setting up specialist & generalist PC services in hospitals) & facilitating partnerships. The last component facilitated links with referral hospitals to create a loose PC network.	Integrating palliative care into national health systems in Africa: a multi-country intervention study	Grant <i>et al.</i> 2017
44.	Botswana	Single facility; Specialist PC	An intervention aimed at improving care coordination for pregnant women with cancer by establishing an MDT clinic, which included PC.	Multidisciplinary gynecologic oncology clinic in Botswana: a model for multidisciplinary oncology care in low- & middle-income settings	Grover <i>et al.</i> 2017
45.	Rwanda	System wide;	A national level intervention over at the last 7 years, led by the MoH. It involved the creation PC policies (including guidelines, frameworks) that were followed up with directives; mechanisms to facilitate integration across the system (referral forms; PC	Palliative care in Rwanda: aiming for Universal Access	Krakauer <i>et al.</i> 2018

		PC network with a PC approach, generalist & specialist PC	training at all levels of the health system; innovative prescribing mechanisms & the creation of PC networks, which included home-based PC services.		
46.	South Africa	Training only; generalist PC	Interventions funded by Open Society Foundation (OSF) PC initiative & led by Hospice & Palliative Care Association of South Africa (HPCSA). The intervention to integrate PC into the practices of THPs* through training & a novel communication technique.	Palliative care in South Africa	Drenth <i>et al.</i> 2018
47.	Kenya	System wide integration	This intervention involved the provision of financial grants from an international donor, the OSF, to support local organisations in Kenya to work with their MoH to integrate PC into their health system. Funds were received by the KHPCA, individual hospices & local champions & used to target policies, drug availability, training of health care professionals & integrate PC into hospitals.	The palliative care journey in Kenya & Uganda*	Kamonyo, 2018
48.	Uganda	System wide integration	This intervention involved the provision of funding to the APCA, the Palliative Care Association of Uganda (PCAU), Hospice Africa Uganda (HAU) & Makerere University to integrate PC into the national health system. Integration efforts targeted improving provision of PC in policy, improving drug availability, training health professionals in PC & implementation of CPC services at different levels of the health system.		
49.	South Africa	Multiple facility; General & specialist PC, with some PC approach.	Intervention into a tertiary public hospital where a hospital-based PC team was established providing specialist care. Program aimed at providing integrated PC through strong links with CBO's and included development of a referral system & training program for ward nurses to promote a PC approach.	The development of hospital-based palliative care services in public hospitals in the Western Cape, South Africa	Gwyther <i>et al.</i> 2018
50.	South Africa	Multiple facility; Specialist PC	Integration of PC into a district public hospital where a ward was provided in the hospital by the MoH, together with medication, which is staffed by Hospice, who provides specialist PC.		
51.	South Africa	Multiple facility; Specialist PC	Coordination between two organisations, Hospice & public tertiary hospital facilitated through MDT meetings & the development of care plans. Hospice staffs a ward in the hospital & there is a formal referral pattern between the hospital & Hospice PC program.		

*Although THP are not conventionally identified as being a part to the public health system, they have a significant role to play on integrating PC into the health systems through referring patients who need PC, as THP are often the first point of call for patients in the community as found in intervention 46.

*This is a review article which describes the development of PC in Kenya and Uganda through funding provided by the Open Society Foundation to local organisations and the APCA. It has been included as interventions 47 and 48, however due to its characteristics it cannot be mapped on the devised framework.

Appendix 5: Journal style guide

Instructions for Authors

Health Policy and Planning improves the design, implementation and evaluation of health policies in low- and middle-income countries through providing a forum for publishing high quality research and original ideas, for an audience of policy and public health researchers and practitioners. *HPP* is published 10 times a year.

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- Addressing *HPP*'s readership: national and international policy makers, practitioners, academics and general readers with a particular interest in health policy issues and debates.
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- Acknowledgements
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Baker and Watts (1993) found...

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- '10 best resources' [for example, see David & Haberlen, HPP, 20(4): 260-3].

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- Always include a leading zero before the decimal point (e.g., 0.32 not .32).
- Do not report tests statistics (such as chi-2, T, F, etc.)."

For acknowledgements, figures and measures see above.

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Reviews may be invited. They generally address recent advances in health policy, health systems and implementation. **Systematic reviews are particularly welcomed**, but may not be appropriate for every topic. If authors are submitting a review article that is not a systematic review then the paper should explain why a systematic review was not feasible/desirable, and the review methods should be described in a way that is as clear and as replicable as possible.

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Appendix 6: World Health Assembly Resolution 67.19

SIXTY-SEVENTH WORLD HEALTH ASSEMBLY WHA67.19

Agenda item 15.5 24 May 2014

Strengthening of palliative care as a component of comprehensive care throughout the life course

The Sixty-seventh World Health Assembly,

Having considered the report on strengthening of palliative care as a component of integrated treatment throughout the life course;

Recalling resolution WHA58.22 on cancer prevention and control, especially as it relates to palliative care;

Taking into account the United Nations Economic and Social Council's Commission on Narcotic Drugs' resolutions 53/4 and 54/6 respectively on promoting adequate availability of internationally controlled licit drugs for medical and scientific purposes while preventing their diversion and abuse, and promoting adequate availability of internationally controlled narcotic drugs and psychotropic substances for medical and scientific purposes while preventing their diversion and abuse;

Acknowledging the special report of the International Narcotics Control Board on the availability of internationally controlled drugs: ensuring adequate access for medical and scientific purposes, and the WHO guidance on ensuring balance in national policies on controlled substances: guidance for availability and accessibility of controlled medicines;

Also taking into account resolution 2005/25 of the United Nations Economic and Social Council on treatment of pain using opioid analgesics;

Bearing in mind that palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual;

Recognizing that palliative care, when indicated, is fundamental to improving the quality of life, well-being, comfort and human dignity for individuals, *being an effective person-centred health service that values patients' need to receive adequate, personally and culturally sensitive information on their health status, and their central role in making decisions about the treatment received;*

Affirming that access to palliative care and to essential medicines for medical and scientific purposes manufactured from controlled substances, including opioid analgesics such as morphine, in line with the three United Nations international drug control conventions, contributes to the realization of the right to the enjoyment of the highest attainable standard of health and well-being;

Acknowledging that *palliative care is an ethical responsibility of health systems, and that it is the ethical duty of health care professionals to alleviate pain and suffering*, whether physical, psychosocial or spiritual, irrespective of whether the disease or condition can be cured, and that end-of-life care for individuals is among the critical components of palliative care;

Recognizing that more than 40 million people currently require palliative care every year, foreseeing the increased need for palliative care with ageing populations and the rise of noncommunicable and other chronic diseases worldwide, considering the importance of palliative care for children, and, in respect of this, acknowledging that Member States should have estimates of the quantities of the internationally controlled medicines needed, including medicines in paediatric formulations;

Realizing the urgent need to include palliation across the continuum of care, especially at the primary care level, recognizing that inadequate integration of palliative care into health and social care systems is a major contributing factor to the lack of equitable access to such care;

Noting that the availability and appropriate use of internationally controlled medicines for medical and scientific purposes, particularly for the relief of pain and suffering, remains insufficient in many countries, and highlighting the

need for Member States, with the support of the WHO Secretariat, the United Nations Office on Drugs and Crime and the International Narcotics Control Board, to ensure that efforts to prevent the diversion of narcotic drugs and psychotropic substances under international control pursuant to the United Nations international drug control conventions do not result in inappropriate regulatory barriers to medical access to such medicines;

Taking into account that the avoidable suffering of treatable symptoms is perpetuated by the lack of knowledge of palliative care, and highlighting the need for continuing education and adequate training for all hospital- and community-based health care providers and other caregivers, including nongovernmental organization workers and family members;

Recognizing the existence of diverse cost-effective and efficient palliative care models, acknowledging that palliative care uses an interdisciplinary approach to address the needs of patients and their families, and noting that the delivery of quality palliative care is most likely to be realized where *strong networks exist between professional palliative care providers, support care providers (including spiritual support and counselling, as needed), volunteers and affected families, as well as between the community and providers of care for acute illness and the elderly;*

Recognizing the need for palliative care across disease groups (noncommunicable diseases, and infectious diseases, including HIV and multidrug-resistant tuberculosis), and across all age groups;

Welcoming the inclusion of palliative care in the definition of universal health coverage and emphasizing the need for health services to provide integrated palliative care in an equitable manner in order to address the needs of patients in the context of universal health coverage;

Recognizing the need for adequate funding mechanisms for palliative care programmes, including for medicines and medical products, especially in developing countries;

Welcoming the inclusion of palliative care actions and indicators in the WHO comprehensive global monitoring framework for the prevention and control of noncommunicable diseases and in the global action plan for the prevention and control of noncommunicable diseases 2013–2020;

Noting with appreciation the inclusion of medicines needed for pain and symptom control in palliative care settings in the 18th WHO Model List of Essential Medicines and the 4th WHO Model List of Essential Medicines for Children, and commending the efforts of WHO collaborating centres on pain and palliative care to improve access to palliative care;

Noting with appreciation the efforts of nongovernmental organizations and civil society in continuing to highlight the importance of palliative care, including adequate availability and appropriate use of internationally controlled substances for medical and scientific purposes, as set out in the United Nations international drug control conventions;

Recognizing the limited availability of palliative care services in much of the world and the great avoidable suffering for millions of patients and their families, and *emphasizing the need to create or strengthen, as appropriate, health systems that include palliative care as an integral component of the treatment of people within the continuum of care,*

1. URGES Member States:

- (1) to develop, strengthen and implement, where appropriate, palliative care policies *to support the comprehensive strengthening of health systems* to integrate evidence-based, cost-effective and equitable palliative care services in the continuum of care, across all levels, with emphasis on primary care, community and home-based care, and universal coverage schemes;
- (2) to ensure adequate domestic funding and allocation of human resources, as appropriate, for palliative care initiatives, including development and implementation of palliative care policies, education and training, and quality improvement initiatives, and supporting the availability and appropriate use of essential medicines, including controlled medicines for symptom management;
- (3) to provide basic support, including through multisectoral partnerships, to families, community volunteers and other individuals acting as caregivers, under the supervision of trained professionals, as appropriate;
- (4) to aim to include palliative care as an integral component of the ongoing education and training offered to care providers, in accordance with their roles and responsibilities, according to the following principles:
 - a. basic training and continuing education on palliative care should be integrated as a routine element of all undergraduate medical and nursing professional education, and as part of in-service training of caregivers

at the primary care level, including health care workers, caregivers addressing patients' spiritual needs and social workers;

- b. intermediate training should be offered to all health care workers who routinely work with patients with life-threatening illnesses, including those working in oncology, infectious diseases, paediatrics, geriatrics and internal medicine;
 - c. specialist palliative care training should be available to prepare health care professionals who will manage integrated care for patients with more than routine symptom management needs;
- (5) to assess domestic palliative care needs, including pain management medication requirements, and promote collaborative action to ensure adequate supply of essential medicines in palliative care, avoiding shortages;
 - (6) to review and, where appropriate, revise national and local legislation and policies for controlled medicines, with reference to WHO policy guidance, on improving access to and rational use of pain management medicines, in line with the United Nations international drug control conventions;
 - (7) to update, as appropriate, national essential medicines lists in the light of the recent addition of sections on pain and palliative care medicines to the WHO Model List of Essential Medicines and the WHO Model List of Essential Medicines for Children;
 - (8) to foster partnerships between governments and civil society, including patients' organizations, to support, as appropriate, the provision of services for patients requiring palliative care;
 - (9) to implement and monitor palliative care actions included in WHO's global action plan for the prevention and control of noncommunicable diseases 2013–2020;

2. REQUESTS the Director-General:

- (1) to ensure that palliative care is an integral component of all relevant global disease control and health system plans, including those relating to noncommunicable diseases and universal health coverage, as well as being included in country and regional cooperation plans;
- (2) to update or develop, as appropriate, evidence-based guidelines and tools on palliation, including pain management options, in adults and children, including the development of WHO guidelines for the pharmacological treatment of pain, and ensure their adequate dissemination;
- (3) to develop and strengthen, where appropriate, evidence-based guidelines on the integration of palliative care into national health systems, across disease groups and levels of care, that adequately address ethical issues related to the provision of comprehensive palliative care, such as equitable access, person-centred and respectful care, and community involvement, and to inform education in pain and symptom management and psychosocial support;
- (4) to continue, through WHO's Access to Controlled Medicines Programme, to support Member States in reviewing and improving national legislation and policies with the objective of ensuring balance between the prevention of misuse, diversion and trafficking of controlled substances and appropriate access to controlled medicines, in line with the United Nations international drug control conventions;
- (5) to explore ways to increase the availability and accessibility of medicines used in palliative care through consultation with Member States and relevant networks and civil society, as well as other international stakeholders, as appropriate;
- (6) to work with the International Narcotics Control Board, the United Nations Office on Drugs and Crime, health ministries and other relevant authorities in order to promote the availability and balanced control of controlled medicines for pain and symptom management;
- (7) to further cooperate with the International Narcotics Control Board to support Member States in establishing accurate estimates in order to enable the availability of medicines for pain relief and palliative care, including through better implementation of the guidance on estimating requirements for substances under international control;
- (8) to collaborate with UNICEF and other relevant partners in the promotion and implementation of palliative care for children;
- (9) to monitor the global situation of palliative care, evaluating the progress made in different initiatives and programmes in collaboration with Member States and international partners;
- (10) to work with Member States to encourage adequate funding and improved cooperation for palliative care programmes and research initiatives, in particular in resource-poor countries, in line with the Programme budget 2014–2015, which addresses palliative care;
- (11) to encourage research on models of palliative care that are effective in low- and middle-income countries, taking into consideration good practices;
- (12) to report back to the Sixty-ninth World Health Assembly in 2016 on progress in the implementation of this resolution.

Ninth plenary meeting, 24 May 2014 A67/VR/9

Appendix 7: Summary sheet for dissemination

A systematic review was done of published, English literature describing interventions to integrate palliative care (PC) into African health systems from 2001 to date. This was done to understand what approaches are being used to integrate PC into health systems and to identify possible facilitators and barriers to this to develop robust and contextually appropriate evidence to guide implementors.

Specific factors were found that could either promote integration by their presence or block it in their absence. These included:

- **The provision of PC at all levels of care alongside curative care:** To fully integrate PC into a health system, services need to be available at all levels of care and PC needs to be integrated with other types of curative care.
- **Sustainable partnerships:** Partnerships between a variety of different actors within and outside the health system are key to facilitate coordinated care and integrate PC fully into the health system. This includes developing relationships between professionals and organisations at different levels of care (i.e. primary, secondary and tertiary) and at the same level of care, private-public partnerships and partnerships between health and other sectors. Formalised partnerships with clear referral pathways and open communication that prioritized local ownership were recommended.
- **A health system that can support integration:** For PC to be fully integrated into health systems a number of health system factors need to be present including 1) Supportive policy and guidelines at all levels (i.e. national and facility level), 2) sufficient funding for PC, 3) enough health workers trained in the different levels of PC (i.e. using a PC approach, generalist or specialist PC) and lastly 4) a culture both within the health system and community that will support the integration of PC into their daily practice. The last point entails the use of advocacy and training on the principles of PC to debunk any myths or negative attitudes around PC.
- **Placing the client, their family and communities as central to integration:** This not only facilitates the integration of PC but is also central to the principles of PC and also promotes health system responsiveness. This entails ensuring that the client's needs and preferences guide the types of services integrated and that services adapt or respond to the changing needs.

The following recommendations are made from the results of the study:

- **Implementors:**
 - Situating interventions within the broader context of integrated care would allow for better knowledge translation between those aiming to integrate PC and others focusing on other types of health service integration. Practically, this could be done by describing how integration is being defined and conceptualised, as well as the dimensions of integration being used within the intervention and using these concepts to guide development.
 - The use of a health systems approach would be highly useful in terms of identifying how the health system being targeted would influence the intervention and vice versa and would be the first step in allowing interventions to provide evidence on how the integration of PC strengthens health systems. This is vital in bolstering the argument to integrate PC in resource-poor contexts, where other communicable disease programs compete for funding and prioritization. The second would be to design interventions that specifically aim to improve health systems functions and gather data around this. This is imperative if PC integration is truly to be associated with health systems strengthening in Africa, as this claim currently remains unsubstantiated.
- **Health ministries and policy makers:**
 - Ensuring that 'integration' is clearly conceptualized in policies and guidelines would assist health workers in having a clear idea of what the integration of PC entails, enabling easier implementation.
 - For PC to be fully integrated into a health system, a system-wide approach needs to be used and the health system needs to be able to support the integration. This entails the availability of adequate trained health professionals, funding and resources for PC as well as the presence of policies to guide

the integration of PC into standard care and care of those with life-threatening illness, including NCDs. For these policies to be implemented by health workers, PC principles and values need to be integrated into the health system.

- **Researchers:**
 - Further research is needed from a wider variety of academic fields. This is currently being led by PC advocates both in the field, academia and PC associations, however different views and perspectives would greatly support the arguments to integrate PC and widen the influence of the body of work.
 - Further emphasis needs to be placed on researching the integration of PC in those where PC is less developed such as west or northern Africa and fragile, conflict or post-war states so that contextually approximate evidence is available to guide PC integration.
 - Further research on how PC integration strengthens health systems is necessary, as well as research on macro or national level approaches that have been used to integrate PC.
- **Funders:** It is recommended, that as far as possible local partners and Ministries of Health have an active role in guiding, developing and implementing integration interventions to increase sustainability.
- **PC associations:** PC associations should be initiated if they are not already present and would benefit from continuing to focus training health workers in all levels of PC and advocating and integrating PC principles and values into all levels of the health system, particularly the community and provide an accountability function with local governments, as these facilitate the integration of PC into health systems.