

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

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#### **Abstract**

Africa is characterized by a high burden of disease and health system deficits, with an overwhelming and increasing demand for palliative care (PC). Yet only one African country is currently considered to have advanced integration of palliative care into medical services and generalized PC is said to be available in only a handful of others. The integration of PC into all levels of a health system has been called for to increase access to PC and to strengthen health systems. Contextually appropriate evidence to guide integration is vital yet limited. This qualitative systematic review analyses interventions to integrate PC into African health systems to provide insight into the 'how' of PC integration. Forty articles were identified, describing 51 different interventions. This study found that a variety of integration models are being applied, with limited best practices being evaluated and repeated in other contexts. Interventions typically focused on integrating specialized PC services into individual or multiple health facilities, with only a few examples of PC integrated at a population level. Four identified issues could either promote integration (by being present) or block integration (by their absence). These include the provision of PC at all levels of the health system alongside curative care; the development and presence of sustainable partnerships; health systems and workers that can support integration; and lastly, placing the client, their family and community at the centre of integration. These echo the broader literature on integration of health services generally. There is currently a strong suggestion that the integration of PC contributes to health system strengthening; however, this is not well evidenced in the literature and future interventions would benefit from placing health systems strengthening at the forefront, as well as situating their work within the context of integration of health services more generally.

Keywords: Palliative care, integration, intervention, implementation, Africa, health systems strengthening

#### 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).

A lack of access to palliative care (PC) leaves end-of-life patients without pain and symptom relief when facing life-threatening illness, which is a human right (Brennan, 2007). This negatively effects

both 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 ensuring responsive health systems (Knaul *et al.*, 2017). 'Health systems' are increasingly seen as responsible for PC provision (World Health Assembly, 2014), and there is greater focus on PC development within health systems (Inbadas *et al.*, 2016), particularly in low- and middle-income countries (LMICs) (Rhee *et al.*, 2017a). Despite this, Rhee *et al.* (2017a) showed that 16 of the African countries they assessed had no identifiable PC service at the time. There is therefore a major need to

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#### **Key Messages**

- Specialized palliative care (PC) is predominantly being integrated into healthcare facilities, with a limited focus on integrating PC at a national or population level, or facilitating the use of a 'palliative care approach'.
- As would be expected, integration of PC into health systems is occurring mostly in a subset of southern and eastern African countries where PC development levels are higher.
- The concept of 'integration' is rarely defined in the literature on PC 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 PC into 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 PC into resource-constrained health systems.

improve access to PC in LMICs (Powell et al., 2013; Reid et al., 2018), which characteristically balance the need for PC against limited resources and high burdens of death from communicable and non-communicable diseases (NCDs) (Grant et al., 2011b). Following World Health Organization (WHO) estimates that 1% of a population require PC, ~10 million people in Africa need PC annually (African Palliative Care Association, 2018). Yet most African countries typically have less than two PC services available per million people and even one of the most developed African countries, South Africa, had approximately only 160 PC services assisting only 40 000 people in 2017 (Rhee et al., 2017c).

The human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS) crisis greatly increased the demand for PC in Africa (Uys, 2003) and dramatically reshaped PC service provision (African Palliative Care Association, 2011). Modern PC was historically provided by non-governmental organizations (NGO), independent of the state-run health system (Powell et al., 2013). During the HIV/AIDS crisis, the responsibility for PC provision fell largely on the patients' families and NGOs funded by external donors, who were unable to provide enough care to meet the demand (Uys, 2001). The provision of PC services outside public health systems led to limited PC access, fragmented PC provision and separated PC services from disease-modifying health services (Grant et al., 2011a). The 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 et al., 2014), with PC providers now having being responsible for orphans and survivors for example, which has led to funding challenges (Rhee et al., 2018).

The integration of PC into health systems has been urged by many including the World Health Assembly (WHA) and the WHO (World Health Organization, 2013, World Health Assembly, 2014; Gómez-Batiste and Connor, 2017; Knaul et al., 2017; World Health Assembly, 2017). Advocates of this have argued that integrating PC into health systems benefits the user by increasing access to PC and can also 'strengthen' health systems. For example, providing PC is thought to result in benefits that spill into and strengthen other health system functions and improve the quality of care (Knaul et al., 2017). These benefits include supporting the development of responsive, patient-centred health systems, where patients' needs guide treatment (Green and Horne, 2012; Gwyther et al., 2018), and enabling and motivating staff to be able to provide the care needed by those with life-threatening illness (Grant et al., 2017). Integration of PC is also thought 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 is linked to the broader drive towards integrated health services (Waddington and Egger, 2008)—which is seen as a way to support health system

adaptation towards changing population needs and improving health outcomes (World Health Organization Regional Office for Europe, 2016). However, the complex nature of integrated care initiatives is not well understood (Goodwin, 2013) and there is a 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); and whether integration achieves the expected positive results (Briggs and Garner, 2006). Recent frameworks have been developed to support investigation into the complexities of integration interventions (see Atun *et al.*, 2010; Valentijn *et al.*, 2013; Court, 2018).

The WHO published a 'Public Health Strategy' to guide the integration of PC into health systems (Stjernsward et al., 2007), which describes four key pillars, including: the development of appropriate PC policies, adequate drug availability, education of healthcare workers and the public on PC, together with specialized training of professionals, and the implementation of PC 'at all levels' of the health system. However, more specific guidance has been called for (Harding and Higginson, 2005; Ncama, 2005; Hasselaar and Payne, 2016). Reviews reveal a variety of PC provision models in Africa, at different levels of care, with home-based care often seen as most pragmatic (Harding and Higginson, 2005; Ncama, 2005; Downing et al., 2010; Jang and Lazenby, 2013; Mwangi-Powell et al., 2013; Harding et al., 2014). Practical elements for successful integration have been described, 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: a 'PC approach' used by all health workers working with patients with lifethreatening disease to manage their symptoms; 'generalist PC'; 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 Africa was undertaken to provide clarity on how the integration of PC is being conceptualized in Africa, how it is being related to health systems strengthening and what approaches are being used to integrate PC. Although reviews on PC development in Africa have been done (Jang and Lazenby, 2013; Rhee *et al.*, 2017a), no reviews on the integration of PC into African health systems currently exist. Lessons can guide future interventions at this time of increased PC development and increased focus on integration of PC.

## Methods

A qualitative systematic literature review was applied, enabling the synthesis of diverse forms of evidence in a rigorous and transparent manner (Dixon-Woods *et al.*, 2006). An initial scoping review phase was conducted due to the complexity and understudied nature of

the topic (reported elsewhere in Court, 2018). The evidence on PC integration found in the scoping review was diverse and primarily 'grey' and qualitative in nature. Qualitative review enabled the descriptive question of 'how' PC is being integrated into African health systems to be explored. In addition, a health systems lens was applied to help understand how PC integration interventions influenced the health system (Gilson, 2012). Other related systematic reviews informed this review to further increase the generalizability of the results (Legido-Quigley *et al.*, 2013).

The search strategy was developed collaboratively between the authors and checked by a search Librarian from the University of Cape Town. Search terms and MeSH terms were grouped in three categories (Supplementary Table S4). The first category related to 'Africa', which included all 55 countries recognized by the United Nations, together with the linguistic variations in individual country names ('African American' was excluded). The second group of search terms related to 'integration', and the third related to 'palliative care'. The search terms within these latter two categories were informed by the scoping review. Various databases were searched to ensure that all relevant articles were found, to reduce bias and to identify integration interventions across economic, implementation science and healthcare fields. The databases (and related database platforms) searched included Google Scholar; EBSCOhost; PubMed; Academic Search Premier; Africa-Wide Information; Cumulative Index of Nursing and Allied Health Literature; Economic Literature; Education Resources Information Center; Health Source: Nursing/Academic Edition; Medline; and Humanities International Complete databases. The first category search was restricted to titles and abstracts.

#### 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 Organization, 2007) and health policy and systems research (HPSR) theory (Gilson, 2012) to extend beyond the public system delivering care to the population, to include both public and private organizations, people and actions whose main goal is to improve, promote and maintain health. Interventions that integrated PC into an existing program were included; however, articles describing interventions to integrate another type of care (i.e. HIV care) into PC programmes, without any aim of linking this PC programme to the health system, were excluded. Only articles in English were considered, after the year 2001 (when PC was more clearly defined by the WHO and related partners to ensure conceptual clarity) to end 2018. A further checking search was conducted in 2019 prior to the publication of this article, but no further publications were included. Only published, peer-reviewed articles were included to ensure quality, as well as excluding non-empirical, editorial and opinion pieces.

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 understand them and draw out facilitators and barriers to integration. Therefore, studies were not excluded based on study design or outcome measures. Articles generally addressing integration of PC or supporting the integration of PC

**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.

#### 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.

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, focusing primarily on drugs used in PC provision or mapping the development of PC generally. In instances where the search identified multiple articles referring to the same intervention, such as a published study protocol and outcomes article, only the most relevant and substantive article was included.

#### Data extraction, analysis and synthesis

Once relevant articles were identified for review, data were extracted into a data extraction form (Supplementary Table S1) to reduce bias and error and improve rigour by providing an audit trail. The categories were informed by the scoping review and then refined. Following data extraction, data analysis and synthesis took place. This involved analysing how integration of PC was framed 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.

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 the integration of PC into a health system and trace the type of integration being used in interventions. Others have used this framework to better understand integration in African countries (e.g. 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 (e.g. to measure integrated care in Singapore, see Nurjono et al., 2016, and to map levels of integration of HIV 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 play interconnected roles. These levels include the macro (system integration), meso (organizational, professional) and micro (clinical integration) levels. Functional and normative integrative processes act across these levels to support coordination (Supplementary Table S2 and Table 2).

#### Table 1 Levels of integration

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 organizations.		
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.		

Source: Valentijn et al. (2013).

Table 2 Dimensions of integration

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 organizations, networks or groups within the health sector, usually at the same level of care.				
Organizational integration	Organizational integration can be described as bringing together different organizations or facilities through mergers, networks and partnerships.				
Professional integration	Integration that is led by professionals within or between organizations (compared with entire organizations 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 organizations in a system.				
Functional integration (administrative integration)	This involves the coordination of non-clinical or support functions to support system, organizational, 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 organizations, professional groups and individuals.				

Sources: adapted from Shaw et al. (2011), Curry and Ham (2012), Valentijn et al. (2013), World Health Organization Regional Office for Europe (2016) and Watt et al. (2017).

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 (Court, 2018) and 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 Organization Regional Office for Europe, 2016).

An analytical framework was developed in the scoping review to analyse 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 Court, 2018; Figure 2). The 'levels of PC' were identified according to the WHA resolution (2014) and work by Gómez-Batiste and Connor (2017), described below (Table 3).

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 Waddington and Egger (2008), Briggs and Garner (2006) and Chuah et al. (2017). During the iterative process of the systematic review, these were adapted to match specific models of integration of PC more closely—in particular, adjusted to include integration into policy (only), integration into training (only), single facility integration, multiple facility integration, intersectoral integration and system integration. Included

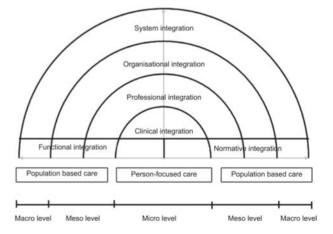


Figure 1 Conceptual framework for integrated care (source: Valentijn *et al.*, 2013).

studies underwent a consistent coding process, after which the codes were grouped by theme.

#### Results

A total of 2028 articles were identified across all databases, imported into EndNote citation manager (removing duplicates). The

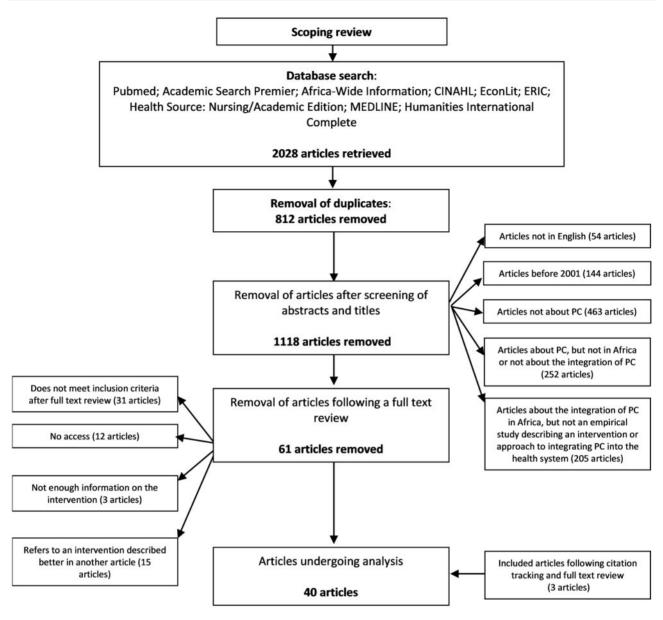


Figure 2 Systematic search process (source: authors).

Table 3 Palliative care levels

Palliative care levels	Description		
Palliative care approach	Use of palliative care principles by all health professionals within healthcare system/facility allowing for timely referrals for specialized 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.		
Specialized pal- liative 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 form 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.		

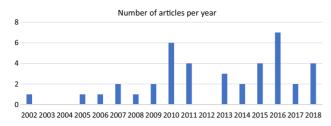


Figure 3 Number of included articles sorted by publication year, out of a total of 40 articles (source: authors).

title and abstracts of the remaining 1216 articles were reviewed to exclude those not immediately relevant to the research topic, which left 98 articles that addressed the integration of PC in Africa. Three further articles were identified through citation tracking, resulting in 101 articles that underwent full-text review. After full-text review of accessible articles, 40 articles met the criteria and were included in the data extraction sheet. This process is outlined in Figure 2 (note that these 40 articles describe 51 interventions, see Supplementary Table S5).

Included articles were mainly empirical descriptive studies—with limited evaluative studies. Evaluative studies typically provided outcomes that were related to patient health outcomes, length of hospital stay, numbers and types of patients seen within the programme or the impact of a PC training programme, rather than outcomes related to the extent of integration in the system. No articles reported on 'failed' integration interventions or situations where integration did not occur, most likely due to publication bias; however, difficulties within interventions were sometimes described. Four review articles were included, where case descriptions of interventions were described as a part of a review of PC development in a country. Only five of the included studies had a quantitative design (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 the most common.

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 an increased interest in PC integration.

Two-thirds of the interventions came from just four countries (South Africa, Uganda, Kenya and Malawi), with just under a third of the interventions taking place in South Africa. The number of interventions and their level of targeted integration are depicted by country below (Figure 4) (see below for more on the level of each intervention).

As noted, the models of integration identified in the scoping review were further refined, as 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 Supplementary Table S5 for numbers, categorizations and descriptions of the interventions).

#### Conceptualizations of the integration of palliative care

Both the scoping and systematic review confirmed that 'integration' is inconsistently defined. None of the included articles explicitly defined 'integration' or 'integrated PC', despite these being core concepts of the studies. Even when the term 'integration' was used, it often referred to very different concepts, often in the same article.

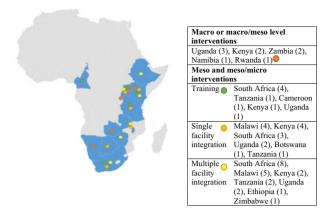


Figure 4 Number and level of interventions by country (source: authors).

For example, in one study, 'integration' alternately described 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; and coordinating PC across different levels of care, as well as within and between facilities at the same level of care (i.e. horizontal integration). In addition, multiple other terms were used to refer to what we have framed as 'integration of PC within a health system'—such as 'joining', 'inclusion', 'incorporation', 'implementation' or 'embedding'. Interventions aimed to 'connect and relate with palliative care' (Downing et al., 2015, p. 367), 'link' or create 'linkages' with PC services or 'coordinate' PC services (DesRosiers et al., 2014; Grover et al., 2017; Krakauer et al., 2018). The terms 'development' and 'integration' were often used interchangeably—usually referring to newly mandated provision of PC by a public health service—sometimes where there was no previous PC service at all, and sometimes as a shifted accountability from a different part of the health system [e.g. from community-based organizations (CBOs)]. These different conceptualizations are not surprising given the multifaceted 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 on a national 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, where PC is said to be the most integrated in Africa (Lynch *et al.*, 2013). One analytical study described a 3-year intervention to integrate PC into hospitals and the greater health systems of Uganda, Rwanda and Zambia, exemplifying integration at macro and meso levels.

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

			T 1 C	11. 4.		
	Level of palliative care  PC approach Generalist Specialist PC P					
		PC approach PC principles used by all health professionals across health system	PC PC trained professionals attend patients with complex PC needs and refer for specialist care	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	
	Integration of PC		•			
Models of integration	into policy-making (only) Integration of PC into national policy		1			
	Integration of PC into/through training (only) Integration of PC into		9 14 38	4		
	the education curricula of health workers or using training to integrate PC into health worker practice		39 40 46			
Mod	health worker practice					
	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	3 18		
			22 27 28	29		
		-		30 6 41		
			10	44 5		
	Multi facility			8		
	integration Integration of PC into more than one facility		12	13		
	or organisation at the same or different level of care; integration between two organisations to facilitate integrated PC		17 25	20		
			11 34	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			26		
	the health system at a	36	43	37		
	primary health care or national level to ensure PC provision for the population		45			

Figure 5 Models of PC compared with models of integration in the identified five interventions (source: authors). Numbers in this figure indicate the intervention number, located in the Supplementary Material. Larger image file will be inserted pre-publication.

(Grant *et al.*, 2017) and has been highlighted by the WHO as an exemplar of how to integrate PC in LMICs (World Health Organization, 2016).

#### Approaches to integration at meso and micro levels

Education was prominent as a mode to integrate PC at meso and micro levels. Although capacity building formed a part of many interventions, certain interventions 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 work). Training was inserted into health worker curricula (Bassah et al., 2016) or provided separately (Gwyther and Rawlinson, 2007; Downing and Kawuma, 2008; Paice et al., 2010; Malloy et al., 2011; Downing et al., 2013). Two training programmes were provided by international organizations, with the remainder implemented by local training institutions with international assistance (Gwyther and Rawlinson, 2007; Downing and Kawuma, 2008; Downing et al., 2013; Bassah et al., 2016). Innovative strategies such as mobile training teams in rural areas targeted training at academic institutions (Gwyther and Rawlinson, 2007; Malloy et al., 2011; Bassah et al., 2016), and to different cadres of healthcare workers, from varied organizations.

Four interventions used training to integrate PC into CBOs, all in South Africa. Although training was the mode of integration, it differed from the above interventions as these aimed to integrate PC into the community setting by targeting a CBO or cadre working at the community level. These included Traditional Health Practitioners (THPs) (Drenth *et al.*, 2018) and 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).

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

The other largest subset of articles described interventions to integrate PC services into 'health facilities'. These often comprised similar elements (Box 2). Training, mentorship and/or support of staff to provide generalist PC were the key components of many that aimed to integrate generalist PC or a PC approach into a health facility. Innovative interventions provided PC training for nurses in an HIV outpatient clinic attached to a hospital (Harding *et al.*, 2013b) or through training of 'link-nurses', who provided generalist PC and referred patients to the specialist PC team when necessary (Tapsfield and Bates, 2011; Downing *et al.*, 2016).

Some 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) providing specialist PC, usually to hospital inpatients, or functioning as consultants for symptom management. They also performed a supervisory role to CHWs (Nanney et al., 2010), hospital ward staff (Downing et al., 2016; Zipporah, 2016; Gwyther et al., 2018) or

**Box 2**: Common elements of palliative care (PC) services integrated into health facilities in the literature (source: authors)

- 'Provision of care to inpatients': most interventions provided PC services to inpatients, 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.
- 'Outpatient 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 caregiver; 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), and 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 as the inpatient unit described by Jameson (2007) that 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 communitybased support, external to the public health system, such as hospice referrals or placement with a homebased care organization.

staff 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.

Less common intervention strategies involved the creation of a multidisciplinary clinic which for gynaecologic cancer care, which included PC (Grover *et al.*, 2017), and provision of PC 'beds' in a hospital emergency unit (Gwyther *et al.*, 2018).

# Relating palliative care integration into health systems strengthening

One included study noted that health systems need to be strengthened 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).

Sixteen of the 40 articles did not relate the described interventions to the broader health system. Rather, they provided 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. Another subset of articles 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 their 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 an intervention using a health systems approach and had health system effects as outcomes. They concluded that PC 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).

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

Themes identified in the scoping review (Court, 2018) 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 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

Provision of PC alongside disease-orientated treatment is a principle of PC to allow for comprehensive care of the patient (World Health Organization, 2002). Included studies showed that, although developing a separate PC team is necessary to provide specialist PC and oversee PC programmes, integrating PC principles into existing health programmes is highly beneficial and can be done using

Box 3 Synthesized 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)

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

relatively simple techniques. This was done through the creation of PC teams who worked alongside other services, but integration occurred best when PC was provided together with other types of care, e.g. 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). Conversely, provision of PC as a stand-alone programme resulted in frustration for health workers and patients, hindering integration of PC, as 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).

Integration of PC into all levels of care, including the community, through vertical integrative mechanisms was identified as being either a barrier or a facilitator. This was found to embed PC into a health system, as well as provide coordination of care or integrated PC. Identified studies vertically integrated PC in a variety of ways, often scaling up successful models of PC. As mentioned, an identified feature was the need to consider the health system at a community level and include the community in integration interventions to facilitate the use of PC and timely referrals of patients (Grant *et al.*, 2011a). The inclusion of community structures, such as churches (Murray *et al.*, 2009; Bassah *et al.*, 2016; Freeman *et al.*, 2016), or health workers that are often seen as 'external' to the health system (i.e. CHWs, care givers, volunteers and THPs) facilitated the integration of PC principles due to their close links with community (Grant *et al.*, 2011a; Jack *et al.*, 2011).

#### The development and presence of sustainable partnerships

Collaboration and the development of partnerships through organizational and professional integrative mechanisms (such as networks, partnerships, or professional-led institutional change) were clear facilitators to integrating PC into a health system. Different types of relationships were evident in the literature with macro-level

interventions often involving more complex relationships. Partnerships varied in intensity, and 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 organization or NGO (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 favoured:

The way in which the STEP-UP programme worked with the district is important ... [it] did not seek to mandate changes that should be made, but rather to work in partnership and suggest 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 organization or between organizations was key. Linkages formed between PC team members and other health workers within/without a facility were leveraged to integrate PC with other types of care, coordinate PC provision, encourage referrals of PC patients and facilitate the transfer of PC knowledge in a facility. Various 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 multidisciplinary teams and clinics or the use of a PC coordinator to liaise with other staff.

Collaboration with 'PC associations' was key. Macro-level interventions typically involved the APCA (Freeman et al., 2016; Grant et al., 2017; Kamonyo, 2018), recognized as an influential organization that supported PC development in Africa (Paice et al., 2010; Rhee et al., 2018) and initiated national PC associations (Molyneux et al., 2013). PC associations often led PC integration interventions (Sithole and Dempers, 2010; Freeman et al., 2016; Zipporah, 2016; Krakauer et al., 2018) or supported implementation by 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), and ensuring accountability once the intervention was complete, improving sustainability (Drenth et al., 2018). Participation of government and hospital staff in PC associations facilitated integration by linking staff with a broader network of PC (Molyneux et al., 2013).

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 were also the primary facilitators to the initiation of integrated PC due to the lack of local resources. (Donors represented in the included studies were: the U.S. Agency for International Development (USAID), the U.S. President's Emergency Plan for AIDS Relief (PEPFAR), The Open Society Foundation and the Diana Princess of Wales Memorial Fund.) Public–private engagements between government and NGOs also encouraged integration. These included partnerships between government departments and NGOs with international funding or affiliations (Whyle and Olivier, 2016) or between health workers from public organizations and professionals in NGOs (Gwyther et al., 2018). There was limited evidence of the MoH leading an intervention to integrate PC, with only one study showing the Rwandan MoH leading and coordinating the integration of PC into

the health system, albeit with significant donor funding and technical support, and reporting significant uptake over a short time (Krakauer et al., 2018). Although public-private engagements with donors are helpful in initiating integration, many noted that sustainable integration occurs when governments take the lead and ownership over the programmes (Sithole and Dempers, 2010; Wube et al., 2010; Grant et al., 2017). Grant et al. (2017) noted 'ownership of the program by each hospital and district health service bred success' (p. 8). This view was also highlighted in a recent review of PC in LMICs, showing that this facilitator extends beyond Africa (Hannon et al., 2016).

#### The health system and health workers supporting integration

The ability of the health system and actors within it to support integration was expressed extensively—as either a facilitator or a barrier when integrating PC (Downing et al., 2015). Three sub-themes emerged: the acceptability and desire for PC by the health system actors, the presence of supportive PC policy and resources for PC. First, 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 (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 prioritized, making integration impossible. Intervention staff reported positively changing health system actors' awareness and attitudes towards PC, through normative integrative mechanisms (strategies to develop a common understanding) such as advocacy—which facilitated integration across the health system by ensuring that PC was prioritized, desired and accepted by health system actors. Advocacy was used to integrate PC in two studies (Lohman and Amon, 2015; Freeman et al., 2016), the latter using a human rights advocacy approach—also a strategic part of other interventions (Lohman and Amon, 2015; Kamonyo, 2018). Advocacy was usually initiated by PC associations, champions or PC teams, but success was also found through advocacy by senior health workers within the MoH who had the respect of other staff (Downing et al., 2016; Grant et al., 2017); by patients and patient groups (Freeman et al., 2016); and by faith-based community structures (Nanney et al., 2010). Advocacy was found to bolster other programmes 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 realize their role in PC provision (Molyneux et al., 2013). The use of innovative, appropriate strategies (True Colours Trust, 2012; Freeman et al., 2016; Grant et al., 2017) was recommended, as well as multi-level advocacy, with emphasis on the need to include actors at all levels of the health system to raise the value of PC throughout the 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).

Another key facilitator was the presence of national PC policies and the inclusion of PC in related health policies (i.e. NCD, HIV or cancer policies) (Kamonyo, 2018). Policies 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 was reported to have resulted in rapid integration of PC into hospitals, whereas the

lack of this in Malawi hindered the same (True Colours Trust, 2012). Krakauer *et al.* (2018) described how the Rwandan MoH started integrating PC into the health system through the creation of national policy but then continued to mandate integration by issuing directives to referral and provincial hospitals (Krakauer *et al.*, 2018).

The basic presence of supportive policy plays a role, but so too does the type of policies developed and the initiators of the policy development and implementation. An intervention focusing on the creation of PC policy in Uganda showed that policies need to be specific (on how PC services will be integrated), with set objectives and priorities, and need to be based on a contextualized assessment on the PC needs of the population (Stjernsward, 2002). The influence of local governments leading integration of PC into policy was highlighted, 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).

Studies found that policies at the local facility level are also important (Downing et al., 2013; Grant et al., 2017; Krakauer et al., 2018). This was seen in studies in Cameroon where the lack of a local hospital PC policy made it challenging to integrate PC into practice (Bassah et al., 2016) and in Kenya where integration was hindered as PC was not addressed in local health plans (Zipporah, 2016). Conversely, integration was facilitated by creating quality control measures (Defilippi and Cameron, 2010), developing monitoring and evaluation structures (Molyneux et al., 2013) and applying protocols to mandate the inclusion of PC in the treatment of life-threatening disease (Brown et al., 2016) and to describe the treatment of symptoms associated with life-threatening disease (Hongoro and Dinat, 2011; Downing et al., 2016). The creation of early identification systems and referral pathways was a crucial element for successful integration of PC into a health system (Nanney et al., 2010; Grant et al., 2011a; Tapsfield and Bates, 2011; Lowther et al., 2015; Grant et al., 2017; Gwyther et al., 2018), as well as integration between different sectors (Herce et al., 2014).

Functional integrative mechanisms not only helped integrate PC into a health system but also facilitated integration between professionals and organizations. These included novel mobile phone strategies (Grant *et al.*, 2011a; Drenth *et al.*, 2018), creating standardized forms to facilitate referrals (Cornetta *et al.*, 2015; Krakauer *et al.*, 2018), using multidimensional record forms that included aspects of PC (Harding *et al.*, 2013b), developing referral forms for PC teams and care plans that travel with the patient to facilitate coordinated PC (Gwyther *et al.*, 2018).

Although the presence of policies at national and local levels to integrate PC is a start, as one study pointed out, integration did not always follow (Harding *et al.*, 2013b). The importance of government funding for sustainable integration of PC into health systems was a common concern. The lack of funding was seen as a major barrier to PC integration (Molyneux *et al.*, 2013; Cornetta *et al.*, 2015; Freeman *et al.*, 2016; Zipporah, 2016; Grant *et al.*, 2017; Drenth *et al.*, 2018)—and conversely the availability of government funds a facilitator:

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).

It was noted that MoH first needed to value PC to provide finances for PC within health budgets and develop policies mandating PC (Grant *et al.*, 2017). A common intervention to encourage government funding was to demonstrate the cost-effectiveness of integrating PC (Hongoro and Dinat, 2011; Grant *et al.*, 2017; Drenth *et al.*, 2018).

Another significant facilitator of integration was the presence of sufficient numbers of adequately trained staff to provide PC (hence all the interventions focusing on training). This can influence integration in two ways: first, the generally limited human resources found in most African contexts can severely limit integration (African Palliative Care Association, 2011) and, second, 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 large proportions of healthcare workers was found to be essential in ensuring that those within the system are using a PC approach (Grant et al., 2017), instrumental in integrating PC. Training existing staff was described as a relatively cost-effective way to integrate PC, 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 ensured that future cadres are equipped (Gwyther and Rawlinson, 2007; Bassah et al., 2016). To facilitate integration, all cadres of health workers need to be trained (Freeman et al., 2016; Grant et al., 2017) and different types of training need to be available (Gwyther and Rawlinson, 2007), which includes a practical element, together with ongoing support, such as supervision or mentorship. Training also needs to be sustainable through using local resources, training local trainers and using appropriate training methods to provide contextual information.

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

The needs and preferences of the patient, together with an understanding that the patient should direct their treatment (Worldwide Palliative Care Alliance, 2014), are central principles to PC and also found to be a facilitator of integration. Understanding and responding to the needs of patients is also a key element of health system responsiveness (Robone *et al.*, 2011), a priority of national health systems, which allows systems to adapt to changing health needs and promote improved health outcomes (Mirzoev and Kane, 2017). Therefore, prioritizing the needs of patients fits the principles of PC and enhances integration and also assists 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. PC principles were integrated more readily, and less stigma was attached to PC, when PC was integrated into community in a contextually appropriate way, that was responsive to patients' needs (Nanney et al., 2010; Grant et al., 2011a; Herce et al., 2014). Grant et al.'s (2011a) note '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 also illustrated interventions that integrated PC through HCBC, as well as in meso- and macro-level interventions where integration was enhanced when the provided services were adapted to suit patient/family needs (Di Sorbo et al., 2010; Freeman et al., 2016).

A large additional literature base was identified in the scoping review that confirms these findings, emphasizing 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; Kimani et al., 2018; Lewis 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 interventions being used to integrate PC into African health systems and identified potential facilitators and barriers to this. Health service integration is receiving renewed attention (Waddington and Egger, 2008), particularly in relation to the integration of HIV into routine maternal health services in Africa (Dabis and Ekpini, 2002; Horwood *et al.*, 2010; Pfeiffer *et al.*, 2010), an area of growing evidence (Briggs and Garner, 2006; Legido-Quigley *et al.*, 2013; Chuah *et al.*, 2017). Main findings from this review echo those from this broader literature (below) and have implications for those seeking to integrate PC.

Literature on the integration of PC suffers from the same problem found in 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 use of multiple terms and perceptions is 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 (and requiring integration and PC expert input), 'PC integration' needs to be defined with some urgency, as a lack of conceptual clarity can hinder the development and integration of PC (Valentijn et al., 2013). For implementors, clearly outlining integration at the outset could help to guide intervention development and assessment, assist in interpreting the results (to create evidence to support integration of PC) and allow researchers to compare results from different PC integration interventions. This would enable others to learn from and transfer lessons to other interventions and settings more effectively.

Other similarities with the broader literature included limited intersectoral integration (e.g. between health and on-health sectors) and limited integration interventions at a macro level—both common features in integration interventions in LMICs generally (Mounier-Jack et al., 2017). Integrative mechanisms (i.e. systemic, functional, normative, professional, organizational and clinical/service) applied in PC interventions were also similar to those described in general health service integration efforts in other LMICs (Mounier-Jack et al., 2017).

However, the literature on PC integration in Africa does present some unique considerations. For example, there was strong application 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 healthcare services were integrated through a variety of models (Waddington and Egger, 2008; Legido-Quigley et al., 2013; Chuah et al., 2017)—and these 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 literature but appears to be characteristic of PC integration interventions. Network creation was also characteristic of more complex PC interventions, although not often used, possibly because of the limited resources available for PC in resource-poor contexts (Rhee et al., 2017a). Higher-income countries 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 was other models that had specific characteristics in PC integration, 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. Although the Public Health Strategy provides guidance on how to establish the necessary initial structures for PC integration, it was noted that more practical, context-specific examples are needed (Harding and Higginson, 2005; Ncama, 2005; Hasselaar and Payne, 2016).

This review also identified facilitators and barriers to the integration of PC—also similar to those suggested in broader integration literature. For example, the creation of partnerships, supportive organizational 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).

There is therefore potential for lessons to be drawn across integration experiences, within and without the specificity of PC interventions. Yet, from this analysis, it would appear that this is rarely being done—with PC integration being treated in a siloed way—mainly addressed by PC advocates, focusing on PC service provision. This has resulted in the literature and experiences of PC integration in Africa becoming somewhat 'detached' from the broader research and lessons on health service/systems integration. This limits PC interventions from learning from integration practices more broadly and, conversely, prevents broader health service/system integration efforts from learning from (often innovative) PC integration experiences.

Although urgings from PC advocates to integrate PC from an ethical and human rights perspective have proved fruitful, arguments to integrate PC could be bolstered by supportive evidence on the need to integrate systems more broadly. PC integration into health systems is also not yet being linked into or profiled within HPSR. 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 recommended.

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 HCBC structures (Downing et al., 2010; African Palliative Care Association, 2011), this review highlights how hospital or facility-based PC is an area that is receiving specific attention and provides useful insights (Box 2). With the integration of PC into primary care being recommended by the WHA (World

Health Assembly, 2014), it is vital that the new PC services being integrated into hospitals be linked to services at lower levels of care.

Much of the evidence on integration in Africa is coming from a subset 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 that integration is lacking. This needs to be addressed, possibly by prioritizing these countries as sites for PC integration interventions (since PC development and integration are so closely related). 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 concerning situations found in West Africa (African Palliative Care Association, 2017). In a scoping review of PC development in Africa, no evidence came from some fragile, conflict or post-war states, such as South Sudan, Somalia, Libya and Mali (Rhee et al., 2017c), indicating that such states need to be directly considered, as there is almost no evidence to guide PC integration in such settings. It is encouraging to note that the APCA has recognized this and is now focusing on developing and integrating PC services in certain West African countries together with international funders (African Palliative Care Association, 2017).

The application of a health systems perspective to this review shows that 'systems thinking' (while mentioned in some studies), was uncommon, despite it seeming obvious that PC integration is strongly shaped by health systems. Although some PC integration interventions did 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 outcomes 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 make this challenging to claim in the African context, not because it is untrue, but as health systems strengthening is currently not being clearly linked with PC integration. Although it is useful to show how providing PC benefits the client, in African countries, the integration of PC must often compete with other prioritized communicable disease programmes for resources (Ansary et al., 2014), it is therefore vital to show how integrating PC can improve health system functioning. To show 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 Organization, 2007). These might also need to be among the primary aims of the intervention so that clear causation evidence is found. Linking integration of PC to health systems strengthening is also for health workers as 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 their acceptance of the integration intervention.

Approaches currently being used to integrate PC in Africa have been highlighted. Valentijn *et al*'s (2013) Rainbow Model of Integrated Care was useful in identifying the focus of the intervention and classifying the types of integrative mechanisms being used. Use of this 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, with little evidence of PC integration at a macro level. The majority

focused on integrating PC into facilities, home or community-based programmes, where PC services were often integrated as a separate programme, 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 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' healthcare professionals, as well as the culture and values in these sectors, is vital 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. However, excluding non-English articles after 2001 at the outset of the study resulted in a mere 7% of the articles being rejected, representing, among 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 to remediate this gap. The quality check on peerreviewed publications did result in certain narratives, reports and evaluations on interventions being excluded from the review. However, these were gathered during the initial scoping review phase and were checked against the collected studies. In this process, no major new interventions or findings were surfaced. Most grey reports had complementary published articles, so it is believed that the review was comprehensive. However, increasing PC research in Africa is vital to ensure relevant interventions reach publication, enabling lessons to reach a wider audience.

## Conclusion

The integration of PC into African health systems is vital to provide access to PC to the 10 million people who need it every year. PC is a human right and an ethical responsibility of health systems, yet is still being denied to most who need it, even in vulnerable populations such as children. In this context, where only four African countries have >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 prioritized. At this time of increased PC development on the continent, the focus needs to not only be on creating more PC services but also integrating them into health systems in a way that ensures their functioning, sustainability and the development of the health system as a whole.

**Box 4** Top five tips for implementors to facilitate integration (source: authors)

- '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 organizations 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 levels 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).

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

Second, situating interventions within the broader context of integrated care is vital to allow for better knowledge translation between the fields and to draw out lessons from this body of work to facilitate PC integration. Practically, this could be done by (collaboratively) defining and conceptualizing 'integration' and the 'dimensions of integration' to be targeted within the intervention. Ideally this would be done at the outset so that these concepts could guide intervention development and implementation. Attention needs to be given 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.

Third, use of a health systems approach by implementors (to identify how the targeted health system would influence the intervention and vice versa) 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. PC integration interventions that specifically aim to improve health systems functions and gather data around this are imperative if PC integration is truly to be associated with health systems strengthening in Africa, which currently remains unsubstantiated.

Health ministries and policymakers are integral to PC integration and need to lead the process wherever possible. For PC to be integrated into a health system, this review found that a system-wide approach needs to be applied and the health system needs to be able to support the integration process. 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 conceptualized 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 from within HPSR. 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 and providing contextual evidence for the integration of PC in countries where PC is less developed. There is a significant gap in evaluative research that assesses the 'success' and system-level impact of integration interventions, which also needs to be addressed to determine best practices.

Funders play a vital role in integrating PC in the African context, but integration of PC is facilitated by local ownership; therefore, as far as possible, local partners and MoHs need to have an active role in guiding, developing and implementing integration interventions to increase sustainability. PC associations are pivotal actors in integration interventions and should be initiated if they are not already present. Focus on training all types of health workers, advocating and integrating PC principles and values into all levels of the health system (particularly the community) and providing an accountability function with local governments would 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, 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.

## Supplementary data

Supplementary data are available at Health Policy and Planning online.

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