

## **Title Page**

**Developing evidenced based practice for palliative care through strategic planning and thus influencing health systems: a case study from Makerere University Palliative Care Unit, Uganda, Africa.**

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**Running Title:** Developing evidenced based practice

## **Abstract**

Influencing and strengthening health systems is a key part of integrating palliative care using a public health approach. Makerere Palliative Care Unit (MPCU) aims to be a centre of excellence improving access to quality, evidence-based palliative care for patients and families through developing an integrated clinical service, research, training and capacity-building in collaboration with partners. Strategic planning, which focuses not only on outputs but also outcomes, is missing in many palliative care programmes. We developed a research agenda supported by an outcomes focused 5-year strategic plan that embeds a coherent and integrated approach allowing evidence based practice to become routine. Small action based research projects are owned and developed by staff members at a local level, while contributing to the Unit's overall research themes. Outcomes are presented to stakeholders and donors as part of the ongoing evidence based strategy. Credibility and ownership is raised through evaluation, and publication helps the sharing of experiences.

## **Key Words**

Africa

Evidence based

Health Systems

Integration

Palliative care

## **Main Text**

### **Introduction**

Palliative care is still a relatively new concept within health and social care in most of the world. Significant recent advances have been made in India, other parts of Asia, the Arab world and Africa as well as continued advances in Europe, the Americas and Australasia.<sup>[1]</sup> Models of care have been established and evaluated<sup>[2,3]</sup> and current service provision mapped with a clear emphasis on the need for a public health approach.<sup>[4,5]</sup> However much remains to be achieved. Few countries have palliative care national policies and few demonstrate integrated models of sustainable service provision. Integrated planning for health and social care capacity linked to educational programmes and competency based training remains scanty with some significant exceptions. Models of service often have developed through non-governmental systems and while these may have significant and important partnerships with government services they may also be seen as external to the core health system. This can result in islands of excellence reaching significant numbers but without integration and sustainability.<sup>[6]</sup> Access to essential palliative care medications remains an international scandal<sup>[7]</sup> with as many as 5 billion people globally lacking access to pain control and oral morphine<sup>[8]</sup> arguably a denial of the right to health.<sup>[9-11]</sup> Indeed the first internationally agreed national indicator for access to palliative care is morphine-equivalent consumption of strong opiates per death from cancer.<sup>[12]</sup>

Palliative care services have often concentrated on a few disease entities but increasing awareness of the need for palliative care for those with life-limiting, chronic illness and their families necessitates planning for the rising numbers of non-communicable diseases which account for two thirds of current global mortality.<sup>[13]</sup> This is in addition to the continuing burden of communicable diseases such as HIV/AIDS and TB. Adding to this challenge is the

relative scarcity of an effective and convincing evidence base particularly for palliative care in low and middle income countries.<sup>[14, 15]</sup> This can mean that important aspects of holistic and culturally relevant care needs, and evaluation of the models used, are largely unexplored and are not available to those designing policy, ensuring implementation and influencing health systems. Where services have been developed, clear strategic planning which focuses not only on outputs (activity based indicators) but also on outcomes has been missing in many programmes. Outcomes which focus on the impact of the model and interventions are essential to evaluation, ensuring effective implementation and maintaining quality. Furthermore, an understanding of the transformational factors in health systems development allows us to integrate and generate evidence to support change in a public health and academic system.<sup>[16]</sup>

## **Context**

Palliative care in Uganda has been at the forefront of developments in palliative care in Africa largely due to the visionary leadership of key stakeholders such as: Hospice Africa Uganda which founded a clinical and educational service in 1993; key partners in developing clinical and educational models focussed on HIV/AIDS care such as Mildmay Uganda and Kitovu Home Care; the Ugandan Ministry of Health who were the first to extend opiate prescribing to nurses and clinical officers and have included palliative care in their policy and planning documents; and the Palliative Care Association of Uganda (PCAU), established in 1999 which is the umbrella organization for services across the country. While emphasis was placed on building community programmes a need for new models of integrated hospital and academic palliative care became evident with the consistently late presentations of disease. This led to the establishment in 2008 of the Makerere Palliative Care Unit (MPCU), incorporating the Mulago Hospital Palliative Care Unit established in 2006. MPCU aims to operate a centre of excellence which improves access to quality, evidence-

based palliative care for patients and families in need by delivering an integrated clinical service within the national referral hospital site in Uganda; carrying out research, training and capacity-building in collaboration with partners; and developing leaders in Palliative Care. Essential to this aim is health systems integration and strengthening within the national government hospital setting and university, fostering a culture of evidenced based practice to improve access to quality palliative care for those most vulnerable and in need. In seeking to integrate and influence a health system it is essential to work at a values base so that good practice is strengthened and changes are owned and championed by the personnel within the system. <sup>[17]</sup>Identifying, emphasizing and even challenging values are inextricably linked to change in practice<sup>[18]</sup> and sustainable service delivery.

The development of a 5-year strategic plan<sup>[19]</sup> was an important component in implementing this vision for all in need in Uganda, and for sharing this vision in sub-Saharan Africa and beyond. Essential to evaluating the effectiveness of this approach is establishing not only outputs but also outcomes. The latter looks more at the impact of the model and interventions and is essential to evaluation.

## **Method**

In order to instil an integrated systems-based and outcomes process we first developed a research agenda. Working with our key partner, the Primary Palliative care team at the University of Edinburgh, we launched a research network in March 2009 with key stakeholders, academic colleagues and palliative care professionals asked to participate. Using a consensus method we explored the priorities and key research questions and then grouped and prioritised these to determine an overall research agenda. This was then included in the strategic planning process led by an external consultant to link outcomes to the

developed research agenda within a monitoring and evaluation framework and establish a relevant data capture system. All members of the MPCU are expected to participate in data collection and other research activities and have been given significant research capacity training. This training has also been extended to key partners and stakeholders. National, regional and international collaborations were developed to extend the scope of evidence and widen impact. Regular review evaluates the success of this approach. Research projects contributing to the outcome and impact assessments are subjected for prior ethics approval, results presented at national and international forums and submitted for peer review publication.

## **Results**

The overall vision is to support, develop, deliver and evaluate palliative care in a hospital setting and ensure its integration into the community with 3 main strands emerging from the research agenda setting process (Table 1). Review of research activity reveals that 35 projects are ongoing or completed with 11 in strand one and 14 and 10 in strands two and three respectively. To illustrate this process we will outline an example from each strand with a focus on integration.

Integrating palliative care and influencing the values of a health system firstly involves an understanding of the needs and experiences of patients and their families. A point prevalence assessment revealed 45% of the inpatients in the medical and surgical wards at Mulago Hospital had evidence of unmet palliative care needs<sup>[20]</sup> and this was further emphasized by a census of Mulago Hospital revealing 37%<sup>[21]</sup> of all patients had palliative care needs. Further research revealed the lack of effective information support and the type of information desired by patients.<sup>[22]</sup> Influencing system change entails building relationships and an

understanding of the expectations and experiences of the human resource. A survey of the attitudes and beliefs about morphine among health care staff revealed widespread fears and wrong beliefs as well as a dearth of education and clinical modelling (Table 2).<sup>[23]</sup> Further research revealed significant fears amongst medical staff about breaking bad news (Table 3).

Training programmes and implementation frameworks supported the development and mentoring of nurse links (Table 4),<sup>[24]</sup> pharmacy interns,<sup>[25]</sup> undergraduate and postgraduate nurses and medical staff (Table 5).<sup>[26]</sup> This was supported by a tool to aid identification of patients with generalist and specialist palliative care needs<sup>[27]</sup> and shared clinical guidelines.<sup>[28]</sup> The impact of training as assessed through qualitative in depth interview and proxy indicators such as morphine consumption and utilisation mapping.<sup>[29]</sup> Regular use of a validated outcome tool allowed for patient feedback as did audit of referral pathways and assessment of discharge experience.<sup>[30]</sup> A volunteer programme to support social and pastoral care was developed and implemented.<sup>[31]</sup> Training and support for abstract writing and publication is showing initial results which need to progress to further peer reviewed publications (Table 6). Fundamental to this model is the integration of palliative care with support for generalist colleagues to deliver quality palliative care as part of their practice and clear referral pathways within and outwith the institution to the wider health care system. Crucially, there is evidence of ownership for palliative care, value for the role palliative care has in changing beliefs and changes in practise.

## **Discussion**

Since the research agenda setting process by the MPCU research network there have been further developments in the region. The African Palliative Care Research Network (APCRN) has been established by the African Palliative Care Association (APCA) and a prioritisation

and consensus process confirmed similar priority areas.<sup>[32]</sup> Makerere University has also been identified as a regional hub for the APCRN. MPCU also supported PCAU to develop research workshops along with a prioritized research agenda for Uganda, which is currently being finalised. Building capacity is crucial and MPCU had led the development and delivery of short workshops on qualitative methodology, modules on research theory and research projects within the BSc in Palliative Care led by the Institute of Palliative care in Africa (IHPCA). Along with national and international partners MPCU delivered the first Advanced Research School for Palliative care in Africa in 2012.<sup>[33]</sup> A facilitated approach to the use of strategic planning which ensures a research agenda is integral to model development and service implementation ensures evidenced based practise and quality review is at the core. Although this paper focuses on a Ugandan case study with much of the evidence from sub-Saharan Africa, one of the authors has extensive experience in India. A health systems approach embedding research is appropriate in any setting and has particular relevance where palliative care is not integrated and research evidence is scarce. It has therefore been suggested research should be the 5<sup>th</sup> pillar of the public health approach to palliative care.<sup>[34]</sup>

## **Recommendations**

Developing a strategic plan that has embedded within it a coherent and integrated approach to research allows evidence-based practice to become routine. Small projects can be owned and developed by staff members that contribute to the overall research culture. Outcomes can be presented to stakeholders and donors as part of the on-going research agenda. Credibility is raised through evaluation and publication and allows for the sharing of experience. Funding requirements for separate research are reduced and collaborations nationally and internationally enhanced. Crucially, palliative care with its foundations in enhancing quality of life for patients and their families and focus on holistic needs of the chronically ill can

offer a transformational element to educational initiatives to change individual practice but also provide a pivotand impetus for health systems change.<sup>[35]</sup>

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**Table 1. Summary of MPCU network research agenda**

**1. Patient needs and perspectives;** documentation of illness trajectories, cultural expectations and issues toward the end of life, holistic needs, decision making and the choice of place of care.

**2. Staff needs and perspectives;** identification of the gaps in confidence, knowledge and skills for the delivery of palliative care, exploring key strengths and challenges including beliefs, systems, culture

**3. Frameworks and models of care;** identification of patients with palliative care needs, provision of care, barriers and blocks for quality and continuity of care, and influences on decision making.

**Table 2: Attitudes and beliefs about morphine amongst health care staff**

*"...the users tend to be physically and psychologically dependent, so they think they need the substance.... I haven't seen it but it is something I have read about, it is well documented in motion pictures and is widely publicized'*

*'I would want to know more, I would want to know more if given a chance, I think it is not really enough.....So if we could have more of the training like an intense training maybe a week, it would do good.'*

*'Accessibility or availability because if not mistaken, when you go to surgical ward right now you may not find any oral morphine there not even I.V, even if you go to emergency right now still not there.'*

**Table 3: Fear of breaking bad news**

*“it is not easy for the doctor and the patient.....doctors suffer significant stress when faced with the task of breaking bad news”*

*“when you have the skills it takes away the fear”*

**Table 4: Development and training of link-nurses**

*“Excellence is not a skill it is an attitude. I had a negative attitude towards palliative care thinking it was care for the dying patients only. But after training I developed a positive attitude because palliative care improves the quality of life of patients and their families.”*

*“As a link nurse I have come to know that patients are individuals with different problems, so I handle them at the individual level. Also the concept of team work has made me get very close to the palliative care team so we work hand in hand. Patients have become ours not theirs.’*

**Table 5: Impact of training undergraduate health professionals**

*“It helped me to understand patients strongly from their perspective, you know, you wear a patient’s shoes, you understand what a patient is going through, so you are able to treat them more empathetically”*

*“It changed my practice. When I see a patient very sick I don’t give up, I know there is still something I can do for that patient, it was not like that before”*



**Table 6: Conference Presentations 2012/13**

Conferences			Concurrent Abstract Sessions	Workshops and Plenary Sessions
National	PCAU	Palliative Care Association of Uganda Conference, Kampala, 2013	6 (1 prize)	3
	KEHPCA	Kenya Hospice and Palliative Care Association Conference, Nairobi, 2013	6	-
	NQI	National Quality Improvement Conference, Ministry of Health, Uganda, 2013	5	1
	Makchs	Mackere College of Health Sciences Conference, Kampala, 2013	2	-
International	APCA	African Palliative Care Association Conference, Johannesburg, South Africa, 2013	9	1
	AORTIC	African Organisation for Research and Training in Cancer Conference, Durban, South Africa, 2013	6	-
	IAPC	Indian Association for Palliative Care Conference, Bangalore 2013 and Bhubaneswar 2014	12 (4 prizes)	2

	EAPC	European Association of Palliative Care Conference, Prague, Czech Republic, 2013	6 (1 prize)	-
	ECTMIH	European Congress on Tropical Medicine and International Health, Copenhagen, Denmark, 2013	-	1
	PCC	Palliative Care Congress, Harrogate, United Kingdom 2014	4	-
	PCN	Palliative Care Network, web conference 2013	4 (1 prize)	-