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Barriers and mechanisms to the development of palliative care in Aceh, Indonesia

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The aim of this study was to identify barriers and mechanisms in the development of palliative care in the province of Aceh, North West Indonesia. Several factors, including an ageing population, have increased palliative care needs in the region; however, as with many low to middle income countries (LMICs), palliative care is not well established or integrated into mainstream health care services. Consequently, many people may experience serious health-related suffering (SHRS) at the end-of-life. Qualitative semi-structured interviews and focus groups were conducted with key stakeholders in Aceh, Indonesia and a semi-structured interview guide prompted an exploration of palliative care provision, including barriers and enablers. Interviews were digitally recorded, transcribed, and analysed using the principles of thematic analysis. Eight interviews and two focus groups were conducted with medics ($n = 6$), nurses ($n = 7$), hospital management ($n = 1$) and religious/cultural leaders ($n = 2$). The findings indicate that all participants recognise a need to reduce SHRS and a growing impetus to embed a culturally salient and sustainable model of palliative care within the Aceh healthcare system. The following four themes indicate key areas for further focus: (1) Local vision and leadership, (2) Prioritisation of palliative care policy and funding, (3) Access to palliative care in community and public services, and (4) supporting palliative care in the cultural context of Sharia law, family, and faith. Future expansion requires the identification of a culturally and socioeconomically salient package of palliative care which operates across rural community and acute care settings and is informed by further evaluation and evidence.

Keywords: Palliative care, End-of-life, Accessibility, Indonesia, Qualitative, Culture, Policy, Community

Introduction

Palliative care has been identified as one of the most significant public health challenges of the twenty-first century, especially in low to middle income countries (LMICs). A recent report from the Lancet Commission highlighted an ‘access abyss’ in the relief of pain and other suffering at end-of-life, caused by life-limiting and life-threatening health conditions.[1]

It has been estimated that by 2060, around 47% of all deaths globally will experience serious health-related suffering. Of these deaths, 83% will occur in LMIC’s.[2] In response, calls for global action have been made to integrate palliative care into existing health systems, as an ethical and economic imperative.[2] Evidence suggests that palliative care in LMIC’s can be an effective and acceptable approach to relieving serious health-related suffering and may also be considered as a poverty reduction strategy that mitigates the high costs of illness which are otherwise absorbed by the individual, family and local community.[3] However, the need for palliative care and pain relief has been largely ignored by the global health community, most notably in the Sustainable Development Goals which do not include any goals or indicators relating to palliative care.[4] This is despite recognition that palliative care and pain relief are essential elements of universal health coverage.[4]

Indonesia is a multi-religious country in South–East Asia with a population of more than 250 million.[5] Indonesia’s health system has public and private sectors, with the government funding public hospitals and Pusat Kesehatan Masyarakat (Puskesmas-Primary Healthcare Units). The private health system is comprised of private insurance organisations, particularly faith-based Islamic and Christian organisations.[6–8] Wealthy residents often travel abroad, most often to Singapore or Malaysia to access high-quality healthcare. There is a growing recognition of palliative care need which reflects

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societal change including an ageing population, management of long-term conditions, changing family structures and technological advances. In Indonesia, palliative care services were initiated in 1990 through the establishment of pilot palliative services in existing healthcare institutions.[5,6] Since then, a national guideline for palliative care has been published but in general, the development of palliative care has been slow and has been hampered by poor understandings of palliative care, the challenging geography of Indonesia, and limited access to opioid medication.[7,8] In 2020, the Global Atlas of Palliative Care classified palliative care development in Indonesia as level 3a: 'isolated provision with only localised hospice-palliative care development'.[9]

Research addressing palliative care in Indonesia is limited, a recent literature review on the provision of palliative care in Indonesia concluded that palliative care progress was slow. Nonetheless, several factors were found to contribute to the development of palliative care, including family involvement and local and national government acknowledgement.[5] Whilst the research evidence is sparse, other studies have identified both barriers (lack of resources, geography, limited education and lack of understanding of palliative care) and facilitators (family involvement, religion and spirituality) to the development of palliative care.[5,10] Across all of these studies, researchers have recognised the need for more research to underpin service developments.

Therefore, the aim of our study was to identify barriers and mechanisms to the development of palliative care in the province of Aceh, Indonesia.

Method

Study design

Given the limited existing evidence base and the exploratory nature of the research, a qualitative study design was adopted using reflective thematic analysis.[11] Face to face semi-structured interviews and focus groups were used to elicit the views of a range of health care professionals, academics and spiritual leaders from the Aceh province, Indonesia.

Setting

Aceh is the westernmost province of Indonesia, located on the northern end of Sumatra. Granted special autonomous status, Aceh is a religiously conservative Islamic territory and the only Indonesian province practising Sharia law. Banda Aceh is the capital and largest city in the province. Banda Aceh was the closest major city to the epicentre of the earthquake which caused the 2004 Boxing Day tsunami. It suffered significant damage and around 167 000 people died as a result.[12] The aftermath of the tsunami had a devastating impact on the region which had already endured civil war for a number of years. Nonetheless, resilience, local activism, in combination with international aid funding has led to an effective health care system being reinstated in the region.[12]

Study population and recruitment

Participants in this study comprised health care professionals, academics, and spiritual/cultural leaders with an interest in palliative care, based in and around the city of Banda Aceh. Participants were recruited using convenience sampling; a local researcher (EW) identified and approached (face-to-face or via e-mail) individuals with an interest in palliative care and invited them to participate. Recruited participants were also asked to identify additional suitable participants and recruitment was further extended using snowball sampling. Potential participants were given an information sheet about the study, if they agreed to take part an interview/focus group was arranged at a convenient time. Participants were invited to participate in an individual interview, however, where several members of an existing team agreed to participate, we offered to hold a focus group. This was in order to capitalise on existing team interactions and communication, and in acknowledgement of their close collaborative working practices.[13]

Data collection

A question guide was developed by consensus, taking account of previous evidence on palliative care in Indonesia, (for example, Rochmawati.[5] The question guide is provided in Table 1. Interviews and focus groups were conducted in a place of the participants choosing, this included hospital and university offices, hotels and cafes. Whilst it was our intention to hold all interviews and focus groups in private

Table 1 Question prompts for qualitative interviews and focus groups

- Please can you tell me about your role(s) in Banda Aceh?
- What do you think is meant by the term palliative care?
- Who are the main providers of care for people who are approaching the end of life? [prompts: doctors, nurses, family members, communities]
- Are you aware on any local or national policy on palliative care? Or research that is ongoing in palliative care?
- What do you think are the good things about palliative care provision in the city and province?
- How do you think palliative care has evolved in recent years?
- What factors have helped in this development?
- What aspects of palliative care need to develop in the city and the province?
- What factors do you think are hindering this development?/ What are the main problems you face in delivering palliative care in this region? [prompt: lack of expertise/ medication/opiates, poor infrastructure, lack of education]
- What do you consider to be the most important research questions in the field of palliative care in the province?
- Is there anything else you would like to add?

locations, for practical reasons this was not always possible and in some instances they were held in public areas of cafes and hotels. Where an interview/focus group was held in a public location we ensured that it was done in a quiet space with limited interruptions. Interviews were undertaken by FW, TR, EW and CG who are all experienced academics trained in qualitative methods. Interviews were led by one or two researchers, with another researcher taking extensive field notes. All interviews were conducted in English; where translation was required this was provided in real time by EW, an Indonesian speaker.

Data analysis

Interviews were recorded digitally in audio format and lasted between 20–60 minutes. Researchers recorded field notes during and following interviews; interviews were conducted in September 2019. Written consent was given at the beginning of each interview and ethical approval was approved by the University of Sheffield Research Ethics Committee (UK) (Application Number 030619)with reciprocal permission agreed by the Universitas Syiah Kuala in Banda Aceh (Indonesia).

Interviews were transcribed verbatim by a professional transcription service, transcripts were not returned to participants for checking due to language differences. To ensure rigour and trustworthiness, transcripts were read by three of the authors (FW, CG, TR), and core thematic categories were identified by tagging groups of words with similar meanings. An initial coding framework was developed by consensus. Although sample size was not dictated by data saturation, we found that after eight interviews no new themes were identified, indicating data saturation was achieved. The software programme NVivo was used to aid analysis.

Results

In total 16 participants were invited to participate in an interview or focus group, all of these agreed to participate. Eight participants took part in an individual interview and a further eight participants took part in two focus groups (with four participants in each). See Table 2 for demographic details of participants.

Thematic analysis

Our findings indicate that palliative care is an evolving concept within the Aceh care system. How palliative care might be embedded within the health care systems is unclear however, the following four themes capture key areas for consideration: (1) local vision and leadership, (2) policy and funding, (3) community and public services, access, and prioritisation, and (4) Sharia law, family, and faith.

Table 2 Demographics details of participants ($N = 16$)

	N	%
Total participants	16	100
Gender (female)	9	56%
Role		
Doctor	6	38%
Nurse	6	38%
Spiritual/cultural leader	2	13%
University academic	2	13%

Theme 1: local vision and leadership

Commitment and vision to achieve spread and access to palliative care was observed within a relatively small group of motivated clinicians and had emerged from exposure to palliative care practices in other regions of Indonesia and other countries around the world. As a result, ‘early shoots’ of palliative care practice were emerging within particular care settings. Critical care was one such setting, where leaders were increasingly confronted by decisions around transition from acute care to end of life and use of palliative care interventions. Palliative care within the hospital setting was therefore primarily focused on critical care, nevertheless, the difficult decisions regarding transition from curative to palliative care were routinely experienced and prompted clinical staff to nurture palliative care practices within and beyond the immediate critical care setting.

> One of the innovation is to build palliative unit. Why? Because a lot of patients, a lot of palliative patients come to our hospital and sometimes it affects our, I mean it’s a being a burden to ICU. So, the hospitals, we give useless therapy for that patient which will cost not be cost effective. (BA3 Focus Group)

However, a narrow conceptualisation of palliative care was evident and limited to the care of the dying patient in the last few days of life and often conflated with resuscitation decisions:

> No, only few people talking about palliative care. Like I told you, not many people had worked with us in [hospital] who understand about palliative care, what they need to, what they do, to deliver palliative care. They say, “ok this palliative care - DNR you know, ‘do not resuscitate.’ (BA1 Medic)

It was notable that nursing leaders, especially those with strong links to the local University were promoting palliative care and capacity building as a pivotal feature within nurse education. The nurse education programme had been recently revalidated and included a palliative care study module with a broader conceptualisation of palliative care which attempted to address palliative care in the context of long-term conditions and the community setting. Significantly, several barriers were identified including access to opioid management and the challenges of supporting palliative care needs within a highly rural setting. In addition, some visionaries from medical disciplines sought to promote a conceptualisation of palliative care consistent with a holistic approach. Those who had sought to 'import' this broader notion were clear that palliative care invoked a set of practices beyond the final days of life. An anaesthetist spoke of one such local 'visionary':

> One of his [XX] missions is that hopefully really do we want to realise it, he wants to make people aware, raise the awareness that one day, all of us we will need the palliative care, the hospice care so not, it's not only treating the disease but trying to humanise the care and really looking at us as human. (BA4 Medic)

Theme 2: policy and funding

Medical leaders were concerned with how palliative care was classified and funded. The national and social security system was established in Indonesia in 2004 and provides a social health insurance system. Palliative care is not provided as a distinct speciality and as a result palliative care currently does not receive a tariff within the insurance system. As such, this system provides a particular fiscal and organisational set of conditions, which mitigate against the development of formal palliative care services. This tendency to relegate palliative care provision was viewed as a source of frustration within local clinical teams, especially as those practices and interventions regarded as overly aggressive at the end of life were unlikely to be cost ineffective:

> The funny thing is that the government is always talking about cost effective and trying be cost effective as much as you can, but in the other way [aggressive interventions in the final days of life], in the other way we do something that is completely not suitable or not necessarily done to the patients, it's wasting resources (yeah) and actually for the hospice care and home care visit, we can do the cost effective in that way (mm) yeah but, but again, the government don't see this (ok) when we mention about end of life care; it's not a priority for them. (BA4 Medic)

The absence of palliative care as a distinct speciality or funding tariff prompted a 'creative' approach when costing palliative care interventions. Respondents reported the widespread practice of classifying palliative care under a range of activities such as hospital-based pain management, psychological support or rehabilitation. For local palliative care leaders these negotiated procedures allowed patients to receive appropriate care through legitimate financial means, described as '*palliative care without the label*'.

Theme 3: Community and public services: access and prioritisation

Community based palliative provision remains underdeveloped. Within the Aceh province, palliative care need is most prevalent in the community setting. The geography of the region impacts upon access to acute care services, with travel time of up to two days for those living in very remote areas. Participants highlighted the pressures placed upon families, who are therefore tasked with providing care. Community practitioners also noted a reluctance for families to use acute hospital services, especially when there was a clear need for palliative care and where families wished for an emphasis upon quality of life:

> There is one patient come in and the condition get poorer and poorer, so but the family decided please not, don't refer my, the patient to hospital. So, they prefer, because they are afraid that they are going to do a lot of intervention to the patient with all the incubators and everything. (BA10 Focus Group)

In addition, community based (Puskesmas) respondents described a public health focus to their work (families, adolescents, maternal health), with the care of older people experiencing long term and chronic conditions relatively low on the agenda. This 'vacuum' in the provision of care in later life had resulted in a culture focused on 'self-care' especially in the use of traditional medicines (reflecting poor access to opiates), but also unpaid volunteers working alongside families as counsellors and social workers. Family and community structures therefore supported a community approach to supporting death and dying but structured palliative care approaches were less discernible.

Theme 4: sharia law, family and faith

Religious involvement in the provision of care and decision making at the end of life is an essential feature of family life in the region. Underpinned by the distinct values of Islamic faith, often described as 'local wisdom', involvement extends to a genuine involvement in discussions around withdrawal of treatment and end-of-life care. It is a mainstay of community life and as such is an important mechanism for care.

> Part of the tradition and also the culture of Aceh is family connectiveness, family togetherness, it's not only when we say family it means my cousin, my auntie or my nephews but also the neighbourhood [ok] yes. So the connectiveness between all the members of the community, for example my neighbour is sick but actually I have no family, family, like have no like blood connection with my neighbour, but she, or he is my neighbours so I have to visit, we make a visit, all the neighbourhood [mm] and we also spread the message, "please visit her, please visit her, she is sick". (BA9 Spiritual leader)

The significance of Islamic faith, culture and Sharia law to determine practice and development of health services within the region cannot be underestimated. Sharia law pervades all aspects of life, including influencing health care policy and service provision and providing a legal framework that health services must operate within. As noted above, 'local wisdom' helps to connect families and communities in providing care and was fundamental to the context of death and dying within Banda Aceh where families provided the mainstay of care but also underpinned nursing curriculum:

> Palliative care is being connected to being Muslim. We really encourage end of life care, it is really something that all Muslims need to pay attention to (BA5 Dean of Nursing School)

However, advancing palliative care as a distinct speciality was viewed by clinicians as work still to be done. The development of palliative care particularly with regard to symptom management was also impeded by uncertainty regarding the use of opioids in accordance with Sharia Law, where usage is bounded by circumstances and criteria:

> So, the basic rule actually it [use of opioids] is forbidden (yeah) but since the special, very, very special circumstances, we are, Islam (allowed) allow (yeah, yeah) us to do that. For example, in like cancer patients (yeah) who are in very bad pain (mm) so it's allowed. (BA8 Religious/Cultural Leader)

Discussion

Our findings contribute to previous research undertaken in Indonesia, but also offer further insights into understanding progress that is being made and how this could be extended. Importantly, a culturally and socioeconomically salient model of palliative care will be central to embedding accessible palliative care across both rural community and acute care settings, and in supporting opiate access. Our findings indicate that socioeconomic sustainability as well as the centrality of the family and Islamic faith will be pivotal in shaping future directions, particularly regarding family caregiving support.[14–17] Such a model is likely to reflect that in common with many other Islamic countries, family caregiving and Islam are central to cultural practices and health care within Aceh.[18]

Family involvement in caregiving requires a specific focus on integrating community and acute care sectors as well as how to support and empower caregivers, particularly given the rurality of the area.[17] Sani *et al.*[19] argue that the covid-19 pandemic has stimulated greater calls for increased government funding and capacity building, particularly around family care giver support and integrated care models. It is likely that the pandemic has escalated palliative care needs and increased the imperative for an integrated community based palliative model.[19,20] Covid-19 may therefore serve to reframe palliative care as a public health concern with increased opportunities for the advancement of palliative care in Aceh. Community palliative care initiatives in comparable health systems ((or example, the Neighbourhood Network in Palliative Care (NNPC)) maybe particularly relevant models in the context of Aceh.[21]

Previous research has highlighted the challenges of situating palliative care within existing funding systems, but our findings have added knowledge around how this can be navigated, in particular using creative approaches to classifying palliative care under other care approaches. It is suggested that lack of access to palliative care within LMICs can be constructed as 'serious health related suffering' and a human rights issue.[1] National governments have been called upon to integrate palliative care as an essential component within all levels of health systems[1,22,23] and there is an argument that even a minimal package of palliative care can impact positively on quality of care, economic productivity and care costs across the life course.[1] Our findings indicate that palliative care funding can be creatively accounted for in the current system however, further visibility may facilitate further development.

This research was initiated by key professional leads within Banda Aceh suggesting a keen vision drive to develop and support sustainable palliative care initiatives. Clark *et al.*[4] discuss 'tipping points' within the context of LMICs in which palliative care provision becomes more pressing than life extending interventions, and this shift reflects the growing number of local palliative care advocates. The development of palliative care within Indonesia requires professional competency and practice in which palliative care presents as a distinct approach within both nursing and medical curricula.[24] Our findings indicate that progress was evident particularly within the nursing curricula in which palliative care was emerging as a pivotal element of provision. However, whilst leadership and vision are driving forward palliative care within the Aceh region, a robust evidence base is required to underpin momentum. Clark *et al.*[22] suggests that strategies at both macro (global), meso (national) and micro levels (professional, patients, religious leaders) should focus on integrating palliative care practice with clear measurable outcomes which can be clearly costed in terms of human health and financing of care. Our findings highlight that a firm evidence base, utilising local, national and international research networks will be important in assessing outcomes and costs with which to inform policy and curricula and drive forward the momentum for an accessible package of palliative care within Aceh.

Strengths and limitations of the study

This study was conducted in collaboration with key leads in Banda Aceh who facilitated access to those working in both the acute and community sectors. It is acknowledged that participants were selected by those advocating palliative care nevertheless, the range of roles and professional groups reflect a range of contexts and practice. Where possible interviews were conducted in English but where this was not the case, EW acted as an interpreter. Despite this, some meaning may have been lost in the translation process. The findings reflect wider literature around palliative care and LMICs, including the wider Indonesian context which suggest that our findings, whilst particular to the province of Banda Aceh are also generalisable to similar contexts.[22]

Conclusion

There is a growing impetus to embed a culturally salient and sustainable model of palliative care within the Banda Aceh healthcare system. However, a review of both wider meso level organisational and governmental systems, including opiate access, funding, and education as well as micro-level approaches involving key stakeholders within both community and hospital settings is required. Priorities for future research include identifying an appropriate and culturally acceptable minimum package of palliative care, with a particular focus on community and family, as well as the need to evidence interventions and increase research capacity utilising national and international networks and funding.[25]

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Data availability statement The participants of this study did not give written consent for their data to be shared publicly, so due to the sensitive nature of the research supporting data is not available.

Notes on contributors

Dr Fiona Wilson, PhD, MA, BA, is a course lead and lecturer. She joined the University of Sheffield in May 2016. She has a clinical nursing background having worked in the areas of critical care, palliative care and the care of older people. She is an experienced researcher having worked on several studies exploring issues around service delivery and quality of life for older people, exploring the impact of reminiscence as well as exploring participatory research approaches with older people and hard-to-reach groups. Her most recent research has focussed on access and care decisions in the context of palliative and end-of-life care.

Dr Elly Wardani, MA PhD, recently joined the Higher Colleges of Technology-United Arab Emirates on January 2022. She was an assistant professor at the University of Syiah Kuala, Banda Aceh-Indonesia. She has been involved in multidisciplinary research with medical and nurses team in building their capacity in communication, safety, and leadership. Her current research has focussed on curriculum development for nurses, diversity and quality of care, and how these impact on overall patients' safety and satisfaction.

Professor Tony Ryan, PhD, MA, PGCert, BSc (Hons), work in the field of older people and family care spans 25 years having worked on a number of large-scale research studies and service development projects in the field of dementia, stroke, palliative and supportive care and healthcare workforce. He led a major strand of the South Yorkshire CLAHRC (2009-2013) and most recently co-led the Strategic Research Alliance, a five-year research partnership between the Royal College of Nursing and the University of Sheffield (2017-2022).

Professor Clare Gardiner, PhD, BSc (Hons), joined the University of Sheffield in 2015 as a Vice-Chancellor's Fellow, undertaking a Fellowship project on the costs of palliative care in the last six months of life. She previously worked as a senior lecturer at The University of Auckland, New Zealand, before which she was a lecturer and research fellow at the University of Sheffield. She has been involved in palliative and end-of-life care research for over 10 years, and have published over 80 papers in peer review journals. She has been involved in a number of international research projects, totalling over £5 million of funding to date.

Dr Ashfaque Talpur, PhD, MPH, BSc (Hons), completed his PhD in the Division of Nursing and Midwifery in 2019 under the supervision of Prof. Tony Ryan and Dr. Sharron Hinchliff. His thesis was a constructive grounded theory of elder mistreatment among older people from Pakistani communities living in the UK. Since 2019, he has worked as a research associate in the Division of Nursing and Midwifery.

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