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ORIGINAL ARTICLE

Implementation science of pediatric palliative care in lower-middle-income countries in Southeast Asia: An integrative review

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ABSTRACT

There is an ongoing development in the pediatric palliative care (PPC) program in Southeast Asia (SEA). However, the implementation process has not been clearly understood among lower-middle-income countries (LMICs) in this region. The purpose of this paper is to review and synthesize research about the implementation process of 7 identified LMICs in the SEA: Cambodia, Indonesia, Myanmar, Lao PDR, Philippines, Timor-Leste, and Vietnam. An integrative review utilizing Whittemore and Knafi's five-stage process was employed. Electronic searches of CINAHL, Web of Science, ProQuest, and Google Scholar (no year restriction) were conducted. From 7,599 articles retrieved, only 11 met the eligibility criteria. Each article was appraised for methodological quality (QualSyst tool and AACODS checklist), and constant comparison methods were used. Two overarching themes emerged in this review - the gaps in PPC standards, practice framework and guidelines and the PPC challenges and implementation strategies. Understanding the implementation science of PPC among LMICs in the SEA region addresses the gap between idealism and realism. It provides reliable information in the development of strategic work plans that will improve the implementation process and promote the translation of EBIs into practice significant to the quality of pediatric patient outcomes.

Keywords: adoption; innovation; health science; knowledge translation; patient care

BACKGROUND

Pediatric palliative care (PPC) is an emerging worldwide development in the care of children and refers to the "prevention and relief of suffering of pediatric patients and their families facing the problems associated with life-threatening illness".[1-3] These problems include the physical, psychological, social, and spiritual suffering of patients and the psychological, social, and spiritual suffering of family members. According to World Health Assembly, ensuring access to PPC is "an ethical responsibility of health systems", and should be integrated into public health care to achieve the Sustainable Development Goal on universal health coverage.[4] Although there were initiatives and efforts from the international community, access to PPC is still not evident to some countries especially those that belong to lower-middle-income countries (LMICs).

The younger population constitutes 35% of the total population worldwide and almost 50% of this group belongs to LMICs.[5-6] The range of life-limiting conditions that need PPC for this group of population is estimated to cost as high as 21 million each year.[7] As a result, millions of vulnerable children from LMICs suffer and die each year with serious health conditions.[8]

Notably, there is an immense need for PPC in LMICs. However, PPC has not been understood by most of these countries as a priority to their health care system. Most of these countries have very limited PPC services,[9] have access to only a few institutions, and have not yet realized that PPC is an integral part of the health care system. Connor et al. found that less than 1% of Kenyan children and 5% of South African and Zimbabwean children have access to PPC services. Nearly 50% of the need for PPC services is in the African region.[5]

Southeast Asia (SEA) region is ranked 2nd for the distribution of children in need of PPC services (24%).[5] Although there are shreds of evidence among these countries of keeping with the recent development of PPC in the world, there is still inadequate recent PPC literature in SEA countries especially those LMICs with limited resources, which may suggest the underdevelopment of the implementation of these services.[10] In the SEA region, 7 countries belong to this economy with only USD1,026 to USD3,995 gross national income (GNI) per capita: (a) Cambodia, (b) Indonesia, (c) Lao People's Democratic Republic, (d) Myanmar, (e) the Philippines, (f) Timor-Leste and (g) Vietnam.[11] The implementation of PPC among these LMICs in SEA is largely unknown; and issues remain unclear and unresolved particularly understanding the involvement of pediatric patients, their families, and health care practitioners.

Implementation science is a careful investigation of the methods and strategies of evidence-based interventions (EBIs) that aim to improve population health.[12] Understanding the implementation of palliative care services to children will systematically address the gap between idealism and realism by identifying the barriers and facilitators that may affect implementation fidelity and translation of evidence-based interventions into practice. A comprehensive literature review like this will facilitate the aggregation of diverse literature from a variety of contexts about PPC implementation science. As a result, this rising need to consider relevant researches to facilitate uptake of evidence-based practice into the utilization and application by health care practitioners and policymakers.

OBJECTIVES

This integrative review aimed to systematically examine in literature and integrate key findings from various sources to better understand the implementation science of PPC in LMICs in the SEA region. Understanding these concepts will promote the implementation science of

PPC to propose pragmatic strategies towards further research, policy formulation, and sustainability.

METHODOLOGY

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Design: This integrative review followed five stages based on the methodology proposed by Whittemore and Knafi in 2005 with some updates and modifications.[13-15] The five stages included (1) problem identification, (2) literature search, (3) data evaluation and extraction, (4) data analysis, and (5) presentation of results. We particularly focused on the development of review question, search strategy, critical appraisal for quality, identification of common aspects, and construction of themes for presentation. The entire review process from conceptualization to reporting took twelve months (March 2019 to March 2020). PICO framework and search strategy were presented in Tables 1and 2 respectively, while the search flow process is illustrated in figure 1.

Ethical considerations: This integrative review critiqued and reviewed the information from various sources – both from published and grey literature related to PPC implementation and quality metrics. There are no ethical issues identified in the conduct of this integrative review. Hence, an exemption letter (UPMREB 2019-507-EX) from our Research Ethics Board was secured.

RESULTS

Eleven studies met the inclusion criteria and were recorded, organized by theme, and analyzed based on resemblances and variances. As to the quality of the literature, we assessed the title, abstract, problem statement, review of literature, methods, design, data analysis, discussion, and overall style.[16] Based on the evaluation result using the QualSyst tool,[17] 10 studies were included because they all had relatively high-quality scores. Also, one doctoral thesis was included after critical appraisal using the AACODS checklist.[18]

The quality score for the 11 papers was presented in Table 3.

LMIC in SEA citations: From the 11 studies included in this integrative review, LMICs in SEA were cited 23 times from various sources. The citations from highest to lowest were: Indonesia (n=6; 26.08%), Philippines (n=5; 21.74%), Lao PDR (n=3; 13.04%), Myanmar (n=3; 13.04%), Vietnam (n=3; 13.04%), Cambodia (n=2; 8.69%), and Timor-Leste (n=1; 4.35%). All of the principal authors of these studies were not affiliated from any of the LMICs mentioned in SEA. Majority of the principal authors (n=4; 36.36%) came from USA. Other studies have principal authors from UK (n=2; 18.18%), Korea (n=2; 18.18%), Japan (n=1; 9.09%), Malaysia (n=1; 9.09%), and Singapore (n=1; 9.09%).

PPC outcome measures: We attempted to identify the PPC outcome measure as an important aspect of implementation science. However, none of the available literature presented any evidence of the quality metrics or outcome measurement of the interventions provided or the success of implementation strategies in LMICs in the SEA region.

Research findings based on themes: This integrative review was presented under the two major themes which were referred to as:

Gaps in PPC standards, practice framework and guidelines: Nine out of 11 studies included in this review highlighted topics related to emerging standards, practice framework and guidelines.[9-10,19-25] These topics which pertains to the essential domains of a so called standards and practice guidelines refer to 'service models',[9,20,22-23,25] 'management of symptoms',[10,21,24] 'structural environment',[10,19-20,23-25] and 'regulations'.[23-24]

PPC barriers and challenges, and implementation strategies: This theme originated from all 11 studies. [9-10,19-27] This theme has two categories were synthesized: 'barriers and challenges', [10,19-23,27] and 'strategies of implementation'. [9-10,19,21-27]

Table 1 : PICO Framework Formulating the Literature Review Question

Type of participant (P)	This review will investigate the PPC implementation among nurses and other members of the PPC interdisciplinary team.
Types of phenomena of interest (I)	This review will explore (1) methods and strategies; (2) facilitators and barriers; (3) structural environment of PPC implementation; and (4) PPC quality metrics.
Types of contexts (C)	This review will investigate PPC implementation in LMICs in SEA particularly in (1) Cambodia, (2) Indonesia, (3) Lao People's Democratic Republic, (4) Myanmar, (5) Philippines, (6) Timor-Leste and (7) Vietnam.
Outcome measure (O)	This review will consider PPC quality metrics in LMICs in SEA.

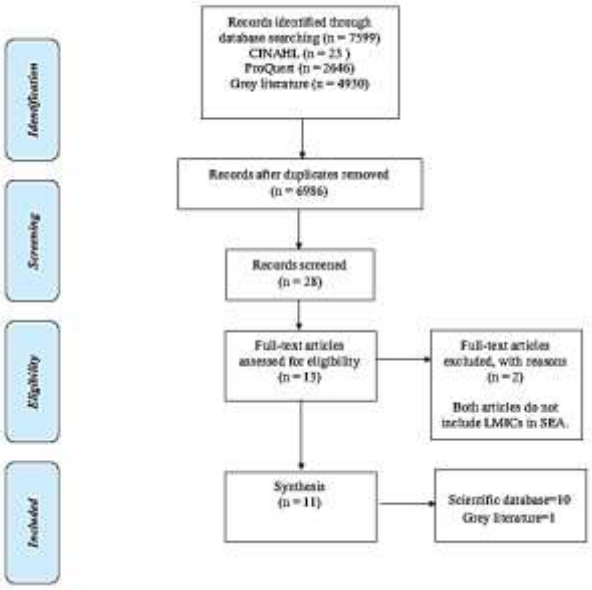
Table 2 : Systematic Search Terms Referring to PICO

Search 1 (Participants)	nurs* AND pediatric* AND palliative
Search 2 (Phenomenon of interest)	method* OR strateg* OR facilitator* OR barrier* OR environment OR implementation
Search 3 (Context)	Cambodia OR Indonesia OR Lao People's Democratic Republic OR Lao PDR OR Laos OR Myanmar OR Philippines OR Timor-Leste OR East Timor OR Vietnam OR Southeast Asia
Search 4 (Outcome)	quality OR palliative metrics OR outcome OR measure
Search 5 (Combine)	Search 1 AND Search 2 AND Search 3 AND Search 4

Table 3: Quality Scores

Title of the Study	**Quality Score (QualSyst tool)**
Downing et al. (2016)	22/22
Downing et al. (2018)	22/22
Knapp et al. (2011)	22/22
Chong et al. (2017)	20/22
Sasaki et al. (2017)	20/22
Park et al. (2018)	20/22
Celiker et al. (2017)	20/22
Chong et al. (2018)	19/22
Krauker et al. (2007)	19/22
Carter and Lee (2018)	19/22
Title of the Doctoral Thesis	**Quality Score (AACODS checklist)**
Pasaol (2019)	34/34

Figure 1. Search Flow Process.



DISCUSSION

This integrative review aims to understand the implementation science of PPC among LMICs in the SEA region to identify the implementation process, related policies, enforcement gaps, and recommend guidelines for wide-spread adoption of effective PPC programs. Two major themes emerged and discussed in this section. Furthermore, this review only presents concepts that are within the scope of implementation science.

The implementation of PPC among these LMICs was guided by EBIs and emerging standards and practice guidelines. The care standards are set by the individual PPC facilities rather than an overarching system.[19] Also, it was presumed that these countries are likewise utilizing their respective countries' professional standards of practice, and standards of practice and guidelines recommended by the ICPCN and APHN. Among these standards and guidelines were: Standards of practice for pediatric palliative care and hospice;[28] Standards for pediatric palliative care in Europe;[29] Standards of practice for pediatric palliative care and hospice;[30] End of life care for infants, children, and young people with life-limiting conditions;[31] and National pediatric palliative care clinical guidelines.[32] ICPCN and APHN are leaders in developing children's palliative care programs for its member associations in the Asia Pacific region. Although upon checking in their official membership directories, only 3 organizations (Yellow Ribbon Foundation, Rachel House - Yayasan Rumah Rachel, and Pediatric Palliative Care Unit "Dharmais" Cancer Hospital) from Indonesia were active members of ICPCN; and 3 organizations (Dharmais Cancer Hospital, Rachel House - Yayasan Rumah Rachel, and Persahabatan General Hospital) from Indonesia, and 3 organizations (Davao Regional Medical Center Section of Hospice and Palliative Medicine, Southern Philippines Medical Center Section of Palliative Medicine, and Makati Medical Center) from the Philippines were registered members of APHN.

Records suggest that some of these countries have integrated EBIs into their national implementation of PPC. These interventions were presented as a program, process, pharmacologic management, and policies that help improve the provision of quality service.[9-10,19-26] Although, there is a lack of evidence of quality metrics among these countries to quantitatively measure the target outcomes, narrative reports from some records implies implementation of the desired programs.[19,22,24,26] We found out that the existing reference map from the Global Atlas of Palliative Care at the End of Life needs to be updated based on the developments and EBI integration of each country in this region.[9] The updating of the map may reflect significant development of PPC provision among these countries but still needs further discussion among experts in this field.

The service model varies among each country, but almost half of the services in this region are mixed services and are dedicated to adult palliative care that has been asked to provide the needs of sick and dying children.[20] Downing et al. and Sasaki et al. have mentioned the Rachel House (Yayasan Rumah Rachel) in Indonesia as one of the best service models of PPC provision from an LMIC.[22,25] Rachel House is home-based palliative care and trains the community to engage in palliative care services such as pain and symptom management, and psychosocial and spiritual management. Although further research is still needed to examine the organizational process and level of evidence integrated into the practice, the existing framework may guide other countries in the region to adopt the service model or innovate practices that will ensure implementation.

There is evidence of integrating EBIs in the pharmacological management of symptoms in children with life-limiting conditions at the end of life. Some of the medications which are being prescribed are comparable to other countries with advanced palliative care provision. Some offer treatment options and adjuvants to modify the effect of other medications. Vietnam has documented information about pediatric dosing for these palliative medications.[24] However, the use of most of these drugs, including routes of administration lacks an evidence base and remains a challenge to implementers.[21]

The structural environment in this kind of palliative care setting should also be evidence-based. The majority of these countries have records of collaboration from physicians, allied health specialists, administrative support, and volunteers. Although most of them hold concurrent appointments and were directly involved in adult palliative care, an alternative novel way to harness a wide range of palliative skills in this kind of resource-limited setting is to employ part-time staffing arrangements.[20] In this way, every member of IDT could be employed in various ratios of full-time equivalents. But, interesting to note that, these countries are still working on having a specialist qualification training and certification specific to PPC.[23.25]

PPC implementation should be a national concern. Just like adult palliative care, policies should also include those services for children with life-limiting conditions. Policies and guidelines concerning palliative care should

not only be directed to adult care needs but should also include care of pediatric patients and their families. There is a lack of discussion about regulations about PPC. In this review, for instance, only one study presented the availability of a national policy (national opioid policy in Vietnam).[24] Although not part of the studies reviewed, additional readings suggest that there were ongoing national movements to establish and/ or strengthen the laws and regulations of PPC among these LMICs in the region. The Philippines, for example, have already integrated PPC in their national policy on palliative and hospice care.[33] The Kingdom of Cambodia has developed their health strategic plan for 2016-2020 and is still reviewing and updating the Minimum Package of Activities (MPA) and Complementary Package of Activities (CPA) Guidelines which includes palliative care as one of its health problem priorities.[34] Timor-Leste, as the newest sovereign state in SEA, aims to have palliative health care services to be available at their national hospital by the year 2020.[35] These initiatives and policies ensure government support in the implementation of PPC.

Barriers to the implementation of PPC are expected among LMICs. [9-10,19-27] However, it is presumed that despite limited resources, effective palliative care can still be implemented. This is why we have presented challenges in the implementation of PPC to look into implementation strategies or innovations that will forge success in the implementation process. Limited capacity development programs and availability of financial and human resources to support its implementation are the major challenges encountered among the implementers.[9-10,19-27]

The capacity building becomes problematic if the training does not meet the needs of its implementers. For instance, there was only a few qualified personnel who had specific training on PPC like bereavement and social works,[20,22-23,25,27] and child psychology.[19] This is a critical aspect of implementation because, with a lack of qualified implementers, the provision of PPC services will be limited.

The source of funding to implement PPC is expected to a resource setting like this.[20-21,23] Although it is claimed that financial issues may result in absence of PPC services among LMICs,[25] another factor that has been observed to hamper implementation is funding allocation.[22] Much has been allocated to adult palliative care services compared to PPC services. It is important to revisit the government budget plans allocated for palliative care, taking into consideration that palliative care is not only for adults at the end of life but likewise for children with the same situation.

There were shreds of evidence of establishing and strengthening the laws and regulations about palliative care, specific PPC policy still needs to be mainstreamed on the national level.[23] Besides, standards of care are set by the individual health centers rather than an overarching system. This results in significant variability of PPC services provided to patients.[19]

Public awareness will enable the community to understand what PPC is all about, how it can support them when it is needed and can serve as their guidance on how they can be involved in the implementation process.[22-23] In Lao PDR for instance, establishing a PPC system for difficult cases of pediatric cancers was deemed important in changing the perception of childhood cancers.[26] Organizations such as the APHN and ICPCN are committed to lead advocacy activities and establish collaboration in PPC development in the region. More so, it is also important to work with multi-lateral organizations such as the World Health Organization (WHO), United Nations Children's Fund (UNICEF), and the Human Rights Watch to ensure that PPC is being included within issues such as Universal Health Coverage (UHC), Sustainable Development Goals (SDGs), medication access, and human right.[22]

Training and education were essential components of capacity building.[25] Organizations may focus their training activities on specific palliative care demands of their country to optimize the available resources. Chong et al. work is a good reference regarding PPC training needs in the region.[20] The group identified the following according to demand: bereavement care; spiritual care; pain and other symptom management; counseling and psychosocial support; communication skills; end-of-life care in children; nursing issues; management of central lines; care of a critically sick child at home; cultural aspects of care; and self-care. Also, Downing et al. stipulated that the need for education in PPC at three levels (palliative care approach, general palliative care, and specialist palliative care) is a barrier in the implementation because such training is not available in these countries.[23]

Besides active family participation in program implementation and service provision, stakeholders' involvement and community ownership were recognized as drivers of a successful PPC model.[9,23] The part-time staffing arrangement wherein every member of the IDT could be employed in various ratios of full-time equivalents is also a novel strategy to optimize the service of trained PPC providers in similar low resource settings.[20] Furthermore, the setting of specific guidelines on PPC will also serve as an effective strategy to provide essential information such as special PPC needs at each developmental stage and pediatric dosing for palliative medications.[24]

Research has been suggested to determine evidence-based practice,[27] and identify the factors affecting medication access and possible knowledge gaps among care providers in the region.[21] It will be beneficial to establish the direction of research in this area and to prioritize topics that will improve service provision. One of the priority topics that need to be addressed is the application of existing standards of practice. Since it was intended to guide PPC practitioners in developed countries, the application of these standards may create gaps or issues in the implementation process despite the realization of universal health coverage (UHC). Future research may be intended to develop clinical practice guidelines that are more applicable and appropriate to LMICs in this region. Perinatal palliative care as part of PPC should be contextualized in these countries, and clinical practice guidelines should also be developed. Another priority topic is the PPC outcome measure. At present, there was no existing PPC outcome measure developed in the SEA region.[22-23] The government and other stakeholders, including patients and families, are insisting on the provision of outcomes data.[36] Without the

measurement of outcomes in PPC, the field will fall further behind in demonstrating its effectiveness, the impact it can have on children and their families, its role in UHC, and its role in health systems strengthening.

Implementation science in this specific field of palliative care can be better understand using various models and frameworks. According to Rabin et al., we can classify the different stages or phases in implementation and later describe the factors affecting its success.[37] Findings from this review suggest that the implementation among these countries is still in its developing phase which is also reflected in the proposed map of PPC provision in the SEA region. Moreover, the PARHis (Promoting Action on Research Implementation in Health Services) framework provides a formula that may determine a successful implementation (SI) of a program, and that is SI=f (E, C, F). SI is a function that depends on the "type and nature of evidence (E), the social and organizational context (C), and the elements that facilitate the process (F)".[38] Lack of research and evidence-based practice along with the identified challenges such as capacity building and availability of financial and human resources to support its implementation in the implementation process may explain why there is a poor or unsuccessful provision of PPC among LMICs in the SEA region. The PRISM (Practical, Robust Implementation and Sustainability Model) is another model that can describe the enablers of successful implementation.[39-40] Using this implementation science model to understand the PPC service model of Rachel House can guide the implementer and researchers during the development and implementation of PPC programs in other LMICs. Another model which can be used during the development is the CFIR (Consolidated Framework for Implementation Research). This model is composed of five themes: "intervention characteristics, outer setting, inner setting, characteristics of the individuals, and process".[41-42] Lastly, the RE-AIM (Reach Effectiveness Adoption Implementation Maintenance) framework can also be used to evaluate the success of implementation process.[43-45]

The findings from this review have certain limitations. First, other relevant studies may have been missed despite the inclusiveness and exclusiveness of the search strategy. The use of summary scores to evaluate the quality of sources from published and grey literature which can potentially introduce bias in the review of the literature. Since records for this review were geographically limited to LMICs in the SEA region, the inclusion of fully published articles only written in English may affect the generalizability of results as research papers from these countries were also published in their mother-tongue languages.

On the other hand, our search process has been validated, taking into consideration the inputs and comments of other researchers. The search strategy for all databases is shared with them to assess reproducibility and detect any variations from the protocol. Hence, we believe that this procedure increases the practicality of the research findings.

CONCLUSION

Despite the integration of EBIs in the PPC practice and the use of models and frameworks to explain implementation science, it was still difficult to understand and evaluate PPC among these countries in the SEA region because of two main reasons. The first reason is that the standards and practice guidelines are not clear and concretized and it was only theorized to be on its way to development. The second reason is related to outcome measurements or quality metrics that are not yet available among LMICs in the SEA region.

Standards and practice guidelines are necessary to establish the "how-to" of the procedures or processes to be done or implement the knowledge. In this way, implementation science will take its role by filling in the gaps between what the implementers know about the standards of practice and what they do in real practice. Moreover, with various evidence-based practices throughout the world, we can develop a more structured way of ensuring implementation by integrating evidence-based care bundles in the palliative care provision for children. This will not only apply to the implementation process but more so to the improvement of patient outcomes.

The lack of outcome measurement or quality metrics in this region is one of the reasons for the lack of robust evidence in this specific field of palliative care. This can also explain why none of the records included in this review have looked at outcomes for children and their families. Having relevant and validated tools to measure the outcomes may forge successful implementation of evidence-based PPC programs.

Although there is an ongoing improvement of palliative care services in LMICs, children did not always benefit from these developments. Much attention has been given to palliative care for adults compared to children, indicating greater attention and support are needed in capacity building, clinical practice, funding, and research on PPC. A PPC model that can maximize available resources and appropriate for the country's health care setting should be adopted for implementation to provide PPC services for those children and families in need especially those who lack access, realizing the ultimate goal of universal health coverage. The Rachel House in Indonesia can serve as a model for other LMICs in SEA to adopt their innovations and strategies in implementing PPC programs in their respective countries.

In this review, we refer to the standards of practice among LMICs in the SEA region as on its a developing stage, which guides the practice of providing the necessary PPC services to children and their families. Although more integration of EBIs is still needed, using these available standards as a guide to service provision programs may develop best practices to deliver safe, effective, high-quality care for pediatric patients and their families; respond to family needs; improve knowledge, skills, and support for care providers; and identify unmet needs in the delivery of care so that organizations can resolve the issues and address the challenges in caring for pediatric patients and their families situated in a low-resource setting.

Records included in this review gave us a hint of what is PPC in this region in terms of social and organizational context. However, there is still a need to explore the other elements that facilitate the implementation process. This

review is a call to action for implementers, stakeholders, funding agencies, researchers, and implementation scientists to revisit if not to establish their country's research agenda on palliative care. There is much more research that needs to be conducted in this field of palliative care, specifically in this area of implementation science and evidence-based practice.

With regards to the methodology employed in this study, we found those records from grey literature useful in answering the background question since most of the widely-used scientific databases contain journals from Western countries and information that were available from conference proceedings, guidelines, and social media. Grey literature has helped in understanding emerging concepts or ideas especially in limited-resource settings where implementers are still learning to adapt EBIs.

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