

# An agenda to develop Pediatric Palliative care programs to serve children with life-threatening and life-limiting conditions in the Gulf Cooperation Council countries

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Palliative Care & Social Practice

2023, Vol. 17: 1–7

DOI: 10.1177/  
26323524231201868

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**Abstract:** Medical advances have increased the number of children living with life-threatening/life-limiting illnesses worldwide, including in Gulf Cooperation Council (GCC) countries. Pediatric palliative care (PPC) is a relatively young subspecialty that cares for children with life-threatening/life-limiting illnesses and their families. PPC aims to alleviate physical, psychological, and social distress in children with life-threatening/life-limiting illnesses and their families and improve their quality of life. PPC is an essential service that should be implemented in all nations, as it is a human right. Moreover, a core value of PPC services is to alleviate children's suffering, irrespective of cure availability. Hence, the global consensus on palliative services must be universal and include developing countries with limited resources. While PPC services are growing internationally, the GCC countries have yet to implement these valuable services in the region. This work aims to define the local base information important to facilitating the PPC program. We explored and identified the information vital for establishing a successful program, which was then categorized and mapped into subgroups. In doing so, we outline a roadmap to facilitate the smooth introduction of PPC in GCC countries to benefit the lives of children with life-limiting illnesses.

**Keywords:** Complex life threatening condition, Gulf Cooperation Council, life-limiting illnesses, pediatric palliative care

Received: 14 December 2022; revised manuscript accepted: 30 August 2023.

## Background

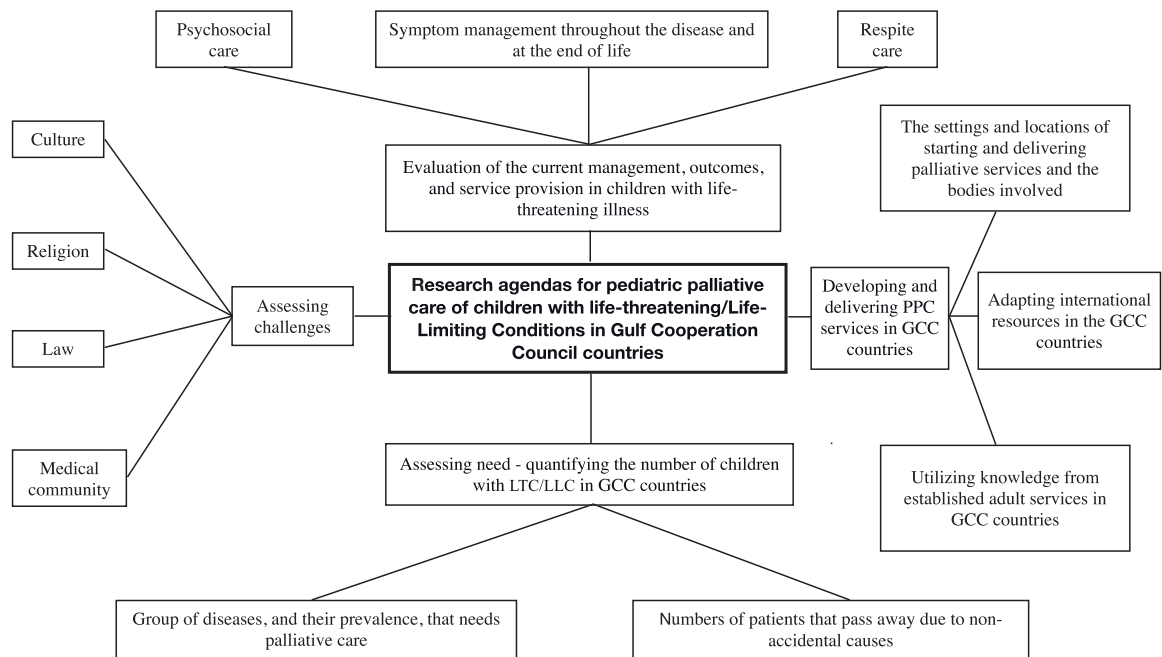
Pediatric palliative care (PPC) provides services and care to all children with Life-Threatening/Life-Limiting Conditions (LTC/LLC) from diagnosis and throughout the course of the disease. There is an ongoing discussion about the ideal term to describe the health conditions relevant to PPC, including life-limiting conditions<sup>1</sup> and life-threatening conditions.<sup>2</sup> These terms refer to health conditions acquired before birth or during childhood, that put the child at risk of dying before adulthood, and should therefore be assessed for PPC services.<sup>1,2</sup>

PPC is not solely about end-of-life care; the field focuses on improving the quality of life for both

the child and family by relieving physical, social, emotional, and spiritual suffering.<sup>3</sup> PPC is delivered by a multidisciplinary team including, but not limited to, physicians, nurses, counselors, and social workers, who coordinate their expertise to address the physical, psychosocial, and spiritual needs of the child and family in multiple settings.<sup>4</sup>

The World Health Organization (WHO) values the importance of PPC and its integration into public health care, considering it as an essential part of the universal health continuum.<sup>3,4</sup> The many benefits of implementing palliative care for patients, their families, and medical institutions are now well established. For example,

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**Figure 1.** Scheme for justifying the creation of PPC services in GCC countries.

PPC improves the quality of life of children living with serious illnesses and their families by managing distressing physical symptoms, providing emotional support, helping with medical decision-making, and other services provided by PPC.<sup>4-9</sup> Families who received PPC have reported an improved satisfaction with health care.<sup>10</sup>

People living in the Gulf Cooperation Council (GCC) countries (Bahrain, Kuwait, Oman, Qatar, Saudi Arabia, and the United Arab Emirates) generally share similar cultures, values, lifestyles, populations, education, and ancestries. Currently, however, PPC in the Middle East is far from meeting WHO standards, especially in the GCC countries.<sup>3,11</sup> There are many obstacles to developing PPC in the GCC countries, including a lack of professional knowledge and inadequate support from policymakers.<sup>3,11</sup> Furthermore, PPC is an emerging subspecialty, so it suffers from many misconceptions from other professionals such as only being ‘appropriate for children with cancer’, denial, and ‘palliphobia’; together these attitudes further challenge the adoption of this valuable service in these countries.<sup>4,12</sup> Such obstacles hinder the development of programs to properly care for children with LTC/LLCs.

Although replicating international PPC programs in GCC countries might benefit children with LTC/LLCs, simply transplanting these programs into the Middle East context would not be a successful approach. PPC aims to meet personal goals that align with society’s values.<sup>13</sup> Moreover, it is a new specialty that has yet to adapt to all the attitudes, spiritual values, and current legislation in specific regional contexts.<sup>3</sup> Hence, local research is required to understand the context and provide an evidence base to inform the establishment of palliative care programs for children in GCC countries. We have therefore devised a focused agenda to develop region-specific PPCs in GCC countries (Figure 1).

**Priorities**

The four main priorities for program development are outlined below and in Table 1.

*Priority 1: Assessing need – quantifying the number of children with LTC/LLCs in GCC countries*

It is first necessary to define the patient population likely to benefit from PPC. We define two main groups of patients with LTC/LLCs who might benefit from PPC<sup>14</sup>: Those with diseases

**Table 1.** Priorities for implementing PPC in GCC countries with examples of key research questions.

Priority 1: Assessing need – quantifying the number of children with LTC/LLCs in GCC countries	Priority 2: Evaluation of the current management, outcomes, and service provision in children with life-threatening illness	Priority 3: Developing and delivering PPC services in GCC countries	Priority 4: Assessing challenges
<p>How many children pass away annually due to non-accidental causes in GCC countries, and where (home, hospital, hospice, ICU)?</p> <p>What are the preferences of children with LTC/LLCs and their families regarding:</p> <ul style="list-style-type: none"> <li>• Place of care</li> <li>• Involvement in medical decision-making</li> <li>• Sharing medical information</li> </ul> <p>What is the prevalence of diseases eligible for PPC in GCC?</p> <p>For example:</p> <ul style="list-style-type: none"> <li>• Extreme prematurity</li> <li>• Malignancy</li> <li>• Congenital immune deficiency</li> <li>• Genetic or metabolic syndromes</li> <li>• Inoperable congenital diseases</li> <li>• Neurodegenerative diseases</li> </ul>	<p>What is the current psychosocial support for children with LTC/LLCs and their families in GCC countries?</p> <p>For example</p> <ul style="list-style-type: none"> <li>• Governmental assistance</li> <li>• Grief care</li> <li>• Nonprofit organizations</li> </ul> <p>What are the children's with LTC/LLCs and their families' views on care provided and level of satisfaction?</p> <p>What is the current symptom management for patients with LTC/LLCs in GCC countries?</p> <p>For example,</p> <ul style="list-style-type: none"> <li>• Medical staff attitudes toward opioids</li> <li>• Prevalence of pain in patients with LTC/LLCs</li> <li>• Medical staff goals of care for patients with LTC/LLCs</li> <li>• Symptom management of imminent death</li> </ul> <p>What are the benefits of having respite services in GCC countries and what services are currently available?</p>	<p>In GCC countries, what PPC services are delivered in the following settings?</p> <ul style="list-style-type: none"> <li>• Hospital wards</li> <li>• Outpatient clinics</li> <li>• Community</li> </ul> <p>Which international PPC programs could be adapted to GCC countries?</p> <p>Which international tools/resources could be adapted to GCC countries?</p> <p>What expertise is needed to form PPC service in GCC countries?</p> <p>What facilities are required to deliver PPC services in the Middle East?</p> <p>What role could nonprofit organizations take to advance PPC in GCC countries?</p> <p>What is the role of the private sector for providing PPC in GCC countries?</p>	<p>What is the public's and medical community's beliefs on:</p> <ul style="list-style-type: none"> <li>• Good quality of life</li> <li>• Survival <i>versus</i> quality of life</li> <li>• PPC</li> <li>• Which and when should patients be referred?</li> </ul> <p>What are the medical community/public/religious/legal views on:</p> <ul style="list-style-type: none"> <li>• Stopping disease-directed management</li> <li>• Allowing natural death</li> <li>• Palliative sedation</li> <li>• One-way extubation</li> <li>• Holding artificial feeds</li> </ul>
GCC, Gulf Cooperation Council; LTC/LLCs, life-threatening/life-limiting conditions; PPC, pediatric palliative care			

that have improbability of cure, and those with diseases where a cure is possible but can be unsuccessful. This is described in a somewhat similar way *via* the 'four categories' model widely cited in the United Kingdom and elsewhere.<sup>1</sup>

Recent medical advances have improved survival rates for children with otherwise deadly diseases. As a result, more children with LTC/LLCs are living longer.<sup>7,15,16</sup> Therefore, updated data on the numbers of such patients is a research priority. Such population-based research would develop an evidence base to support and inform local PPC planning.

There are a variety of approaches to establish population estimates in the GCC countries. Simply extrapolating the number of patients receiving PPC in nations with advanced palliative care services to the regional setting is unlikely to be accurate because

only a small proportion of eligible patients may be receiving it.<sup>5,6</sup> Furthermore, different populations suffer from a different spectrum of disease; for example, in Africa, communicable diseases are significantly more likely to kill children than in other parts of the world, whereas in the United States congenital diseases have a higher rate.<sup>3</sup>

Another way of quantifying patients with LTC/LLCs is to determine the number of children who died due to non-accidental causes, thereby establishing a baseline who would at least benefit from comprehensive end-of-life care plus bereavement services.<sup>3</sup> This approach, however, provides a very limited view of the population eligible for, and likely to benefit from a PPC program. For example, a multicenter study by Feudtner *et al.* showed that 66.7% of children referred to PPC programs are alive 1 year later; even for children with a malignancy rate of 50%.<sup>17</sup> Therefore,

based on the studied population in North America, children with LTC/LLC likely form an 'at risk' pool that is much larger than would be estimated from mortality data alone. In addition, mortality data cannot account for the fact that children can move in and out of palliative care as their condition improves, such as extremely premature neonates who stabilize, or teens who live into adulthood as medical advances prolonging living with childhood diseases.<sup>6,7,16</sup>

There are approaches that determine the prevalence of patients with specific diseases carrying a high probability of death during childhood and qualify them for PPC.<sup>1,15</sup> These diseases are not limited to high-risk curable conditions (e.g. childhood malignancies) but also to conditions requiring intensive long-term treatment that aims to maintain quality of life (e.g. epidermolysis bullosa), progressive conditions in which treatment is exclusively palliative (e.g. trisomy 18), and nonprogressive diseases associated with severe complications (e.g. cerebral palsy with recurrent aspirations).

Hence, population-based studies are required in GCC countries to identify the at-risk population living with LTC/LLC who, along with their families, would be users of PPC programs. These population studies require a secure data-linkage approach. Anonymized data are linked across relevant data sets such as diagnostic information, vital statistics, health care utilization, and so on, and is a valuable tool to derive prevalence rates, including estimates of children dying from non-accidental injury and the prevalence of diseases likely to benefit from PPC.

#### *Priority 2: Evaluation of the current management, outcomes, and service provision for children with LTC/LLCs*

It is important to understand how patients with LTC/LLCs are currently managed, what existing services are available, and the level of satisfaction with these services by the patients and their families in GCC countries.<sup>18</sup> That allows us to estimate the resources required, including the cost of care for LTC/LLC patients, and impact of PPC. We suggest that research on current management should be conducted in three areas: psychosocial care, symptom management, and respite care.

1. *Psychosocial care:* LTC/LLCs incur a considerable burden on patients and their

families, as they disrupt daily lives, cause emotional and psychological strain, and introduce financial stress.<sup>3</sup> LTC/LLCs cause grief to families from the time of diagnosis, throughout the course of illness, and after the child's death.<sup>19</sup> These burdens impact the community and available support resources. Therefore, assessing what support is available, its nature, and its outcomes is necessary to estimate what role exists for palliative care in improving or replacing current practice.

2. *Symptom management for patients throughout the course of their illness and at the end of life:* Symptom management is the core clinical practice in PPC, and providers are experts in evaluating and alleviating symptoms in patients with LTC/LLCs. Before implementing PPC, it is necessary to evaluate current symptom management, especially attitudes to opioids that are an important class of drugs used to manage symptoms in palliative care. Opioids can often be viewed unfavorably due to misconceptions, such as the 'double effect' of hastening death.<sup>7</sup> The effectiveness of current practices on symptoms, patient satisfaction, family opinions, cost-effectiveness, and involved experts is required so that this important aspect of palliation is optimally delivered in PPC.
3. *Respite care* is an interval service provided by medical professionals for children with LTC/LLCs at home or as inpatients in a hospital or hospice to provide rest or relief to caregivers.<sup>20,21</sup> Depending on resources and staffing there are options to provide additional care in the form of expert symptom management, counseling support, emotional and symptom support *via* art, music, and play therapy, and recreational therapy. Respite care has been shown to benefit both children and their families, and it is now established as an essential component of care.<sup>20-22</sup> Therefore, any absence in respite care provision is worth investigating, as well as its impact in medical institutions.

#### *Priority 3: Fundamental planning to develop and deliver PPC services*

If PPC is implemented in GCC countries, three issues need to be addressed:

1. *The settings of palliative services and the programs involved.* Palliative care can be delivered in different settings including inpatient, outpatient, and home care.<sup>3-7,23,24</sup> The decision on where to deliver the care depends on families' preferences and available resources. Hence, research into the role of palliative care services in different settings could reveal existing need and potential benefits as well as highlight which other entities could be useful for delivering palliative care, such as nonprofit organizations or the private sector.
2. *Adapting international resources.* GCC countries do not need to reinvent PPC but can instead adapt existing programs, policies, tools, and references, evaluating what is transferable and usable as a starting point.
3. *Utilizing knowledge from established adult services.* Palliative services for adults have historically predated pediatric services in health systems. Hence, researching and evaluating available adult palliative services and how they were established could provide useful roadmaps for the implementation of children's services. It must be acknowledged, however, that adult services have historically focused on cancer and end-of-life care; neither of these are core characteristics of PPC that encounters a wide range of diseases and cares for children over prolonged time periods.

#### Priority 4: Assessing challenges in GCC countries

Establishing PPC will always face challenges, not least because it is a relatively new subspecialty. Hence, it is necessary to assess and recognize these challenges before establishing a program in a new environment.

The first challenge are the cultures and shared social beliefs in GCC countries. The core principles of PPC were created in Western nations, and therefore must be adjusted to fit GCC cultural values<sup>3,9,10</sup>; for example, the meaning of 'quality of life' needs to be relevant to people in GCC countries. Second, spiritual values must also be considered. Islam is the main religion in GCC countries, and it is a source of cultural and spiritual values. Furthermore, it represents the law in Saudi Arabia and influences most civil laws in the

other five countries including divorce, custody, and inheritance. Hence, considering Islamic views of palliative care is essential to support it. Third, the laws and legislations that direct medical practice are already established, and it will be essential to consider some palliative practices within the prism of the law. Additionally, the medical community's attitudes must be factored into PCC provision, and understanding these views is essential to effecting any change, such as replacing disease-targeting (but ineffective) treatments with symptom management that prioritizes comfort over perusing aggressive disease management treatments.

Finally, it is vital to assess public and medical understanding of PPC in GCC countries. Friedrichsdorf *et al.* summarized seven almost universal myths associated with PPC: the belief that PPC is usually for children with cancer, causes children to die earlier, starts when curative treatments stop, asks parents 'to give up hope', should only be in hospital, that opioids quicken death, and that it places a financial burden on healthcare systems.<sup>8</sup> These myths should be evaluated and challenged in GCC countries, and others need to be identified in advance, coupled with seeking solutions such as education and training.<sup>10</sup>

#### Conclusion

PPC is an emerging subspecialty for children living with LTC/LLCs that aims to deliver patient- and family-centered care, enhance the quality of life throughout the illness trajectory, and ease the symptoms, discomfort, and stress for both patient and family. As the health systems of the GCC countries modernize, incorporating PPC principles and practice will become more necessary to be provided alongside disease-directed care. Research in this field in GCC countries along the lines described in this article would provide practitioners and planners with valuable information needed to tailor the approach to the needs of local population, and in turn expand access to PPC. Research of the kind we describe would also inform the PPC field internationally by highlighting the unique characteristics of the GCC countries. By presenting this coherent research agenda, we aim to provide a roadmap to provide children in the Middle East and their families with a valuable, evidence-based service.



## Declarations

### *Ethics approval and consent to participate*

Not applicable

### *Consent for publication*

Not applicable

### *Author contributions*

**Qutaibah Alotaibi:** Conceptualization; Data curation; Formal analysis; Writing – original draft; Writing – review & editing.

**Harold Siden:** Conceptualization; Methodology; Supervision; Visualization; Writing – review & editing.

### *Acknowledgements*

None.

### *Funding*

The authors received no financial support for the research, authorship, and/or publication of this article.

### *Competing interests*

The authors declare that there is no conflict of interest.

### *Availability of data and material*

Data sharing is not applicable to this article as no datasets were generated or analyzed during the current study.

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