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## Review Article

# Home-based Pediatric Palliative Care: A Narrative Review

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### Abstract

**Aims:** Home-based pediatric palliative care (HBPPC) seemingly would be a promising approach to support families who have and take care for children with life-threatening disease (LTD) and life-limiting disease (LLD) in a holistic manner. PPC is not only provided in the hospital, but also delivered in the outpatient care; community settings, including hospice and patients' homes. The aim of this study is to delineate findings from previous studies about home-based pediatric palliative care (HBPPC) for gaining information about the benefits of implementing HBPPC.

**Methods:** Several search strategies, mainly using electronic databases, were employed to gain a solid body of literature constructing this article. The inclusion criteria of the studies were English text, full text, and children as the specific investigated population which were published between 2014 until 2022. We used the Scale for the Assessment of Narrative Review Articles (SANRA) for appraising and establishing a robust body of literature regarding the topic and finally there were 9 studies included in this literature review.

**Results:** From reviewing the available literature, it is found that home-based PPC may be an ideal approach to care for children with LTD and LLD and their families. By employing home-based PPC, both patient and caregiver may gain several benefits to manage physical, psychosocial, and emotional issues, which enhance the quality of life (QoL) for both the patients and their parents.

**Conclusions:** The implementation of HBPPC may improve the QoL of children with LTD and LLD, as well as their families.

### Keywords:

Children, Home-based care, Palliative, Pediatric

## INTRODUCTION

Having and taking care of children with life-threatening disease (LTD) and life-limiting disease (LLD) could be outdaring as the caregivers would be facing multiple physical, psychological, and financial-related circumstances (1-5). Moreover,

changes and challenges within the family may give negative impacts on the family's role while adapting to the trajectory of the disease (6). In addition, care must be more burdensome while the child is getting nearer to end-of-life decision-making (7). Therefore, palliative care, as an approach to support parents dealing with distressing

circumstances, has been modeled to ease suffering for both child patients and their families (1, 8, 9). Palliative care is world widely acknowledged as a holistic approach to assisting and promoting children and their families who are in a long-suffering because of the trajectory of diseases by improving the quality of life of patients and their families (1, 4, 10, 11).

Palliative care is recommended to be delivered not only in the hospital but also in out-patient care, such as community settings, including patients' homes. The World Health Organization (WHO) emphasizes that palliative care for children commence since the diagnosis is declared and should be accessible for children and their family in both hospital and patients' homes (12). Similarly, National Hospice and Palliative Care Organization (NHPCO) (10) also promotes a palliative care model delineating that palliative care for children should involve various settings, including children's homes. Regarding the growth of pediatric palliative care (PPC), Indonesia has specifically been developing the provision of the PPC. Nowadays, several hospitals in the capital city (Jakarta) have palliative care for children. Such care is not only found in the hospital but also in the community setting, such as home-based care.

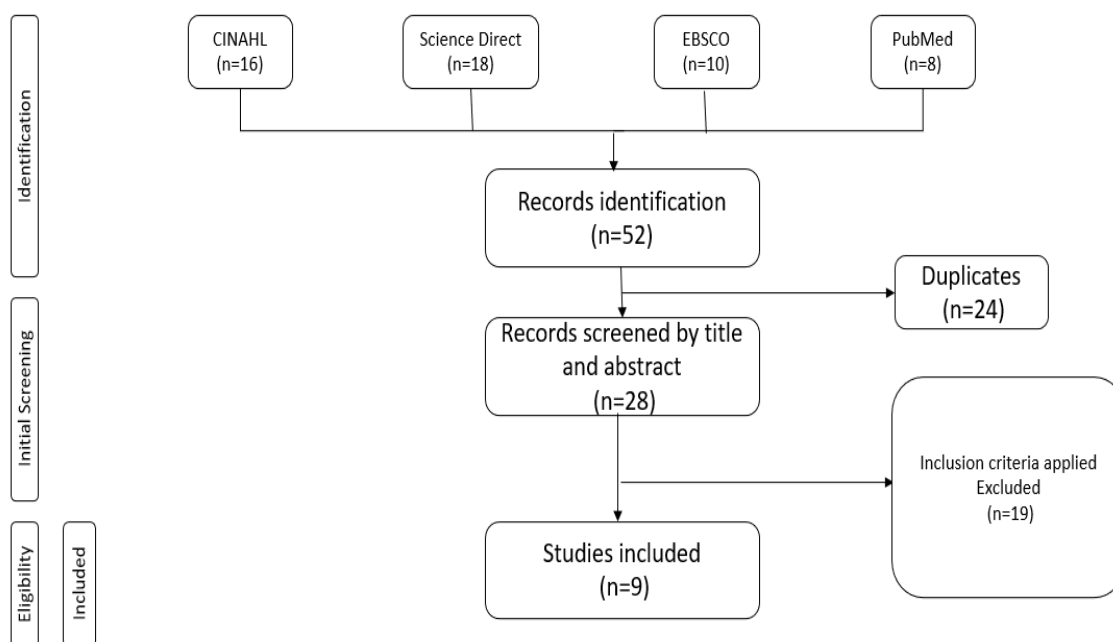
Being at home together with families is considered as the most comfortable condition and safest place for the children. However, despite its benefits, the evolvement of home-based pediatric palliative care (HBPPC) has been occurring in several big cities only. There have been several studies conducted regarding PPC, but little were the studies investigating the HBPPC. Therefore, this article describes findings from previous studies about HBPPC and provides information about the benefits of implementing HBPPC.

## METHODS

This study used narrative review method. A robust body of literature within this study employed several search strategies. The search strategies used electronic databases, such as Science Direct, EBSCO, PubMed, and Cumulative Index to Nursing and Allied Health Literature (CINAHL). Following single or combined terms were used to acquire salient papers: "children palliative" or "palliative care" or "pediatric palliative care" or "community-based" or "home-based". Combining two or three terms using Boolean operator "AND" was also done to obtain more specific and related literature.

There is no certain criteria for inclusion and exclusion to be pre-defined in narrative review method (13). However, for gaining the most recent and decent literatures, inclusion criteria were applied in this study. The inclusion criteria of the studies were English text, full text, and children as the specific investigated population published between 2014 and 2022. A total of 52 studies were found, with several duplicated research resulting in 28 studies. From the title and abstract, 19 studies excluded because of the irrelevance to pre-determined inclusion criteria. Finally, nine studies included in this literature review (Figure 1).

Different from the systematic review that uses Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement as its guidelines, there are no specific guidelines for narrative reviews (14). Although there is no acknowledged reporting guidelines, there is an appraisal instrument named the Scale for the Assessment of Narrative Review Articles (SANRA) which was developed to assess the quality of narrative review (15). Therefore, to maintain the goodness of this narrative review, we used SANRA to appraise the searched literatures.



**Figure 1. Search Strategy**

## RESULTS

There were nine studies included in this narrative review, published between 2015 and 2021. The results of the study are shown through the table below (see Table 1).

**Table 1. Summary of reviewed studies**

No.	Title & Author(s) (Publication year)	Published year	Design	Major Findings
1.	Parental experiences and coping strategies when caring for a child receiving paediatric palliative care: A qualitative study.  Authors: Verberne, L. M., Kars, M. C., Schouten-van Meeteren, A. Y., van den Bergh, E. M., Bosman, D. K., Colenbrander, D. A., ... & van Delden, J. J. (2019).	2019	Interpretive qualitative study with inductive thematic analysis	<ul style="list-style-type: none"> <li>Six main experiences were identified: confrontation with loss and related grief; preservation of meaningful parent-child relationship; tensions regarding end-of-life decisions; ambiguity towards uncertainty; daily anxiety of child loss; engagement with professionals.</li> <li>Four main coping strategies: taking control; seeking support; suppressing emotions; and adapting-accepting.</li> </ul>

No.	Title & Author(s) (Publication year)	Published year	Design	Major Findings
2.	Family experiences with palliative care for children at home: a systematic literature review.  Authors:  Winger, A., Kvarme, L. G., Løyland, B., Kristiansen, C., Helseth, S., & Ravn, I. H. (2020).	2020	Systematic review	<ul style="list-style-type: none"> <li>• Most families preferred to stay at home since it might be easier for them to maintain normality within family life.</li> <li>• Furthermore, caring for child with long-term disease at home may be less stressful for the sick child and strengthening the bonding within family.</li> <li>• Families found a range of issues regarding the coordination of care, including a lack of support and highly competent staffs with appropriate experience.</li> </ul>
3.	Pediatric palliative care in oncology.  Authors:  Snaman, J., McCarthy, S., Wiener, L., & Wolfe, J. (2020).	2020	Literature review	Four focuses on advancements in the specific domains of PPO care: assessment and management of physical symptoms and distress; family-centered communication; spiritual considerations of the patient, parents, and siblings; and psychosocial concerns.
4.	Personalized and yet standardized: An informed approach to the integration of bereavement care in pediatric oncology settings.  Authors:  Wiener, L., Rosenberg, A., Lichtenthal, W., Tager, J., & Weaver, M. (2018).	2018	Quantitative research	<ul style="list-style-type: none"> <li>• A significant association was found between facilities with a dedicated PPC program and longer duration of bereavement care (<math>p = 0.042</math>).</li> <li>• Program size was not associated with the duration of bereavement care (<math>p = 0.525</math>).</li> </ul>
5.	Home-based Palliative Intervention to Improve Quality of Life in Children with Cancer: A Randomized Controlled Trial.  Authors:  Andriastuti, M., Halim, P. G., Tunjungsari, E., & Widodo, D. P. (2019).	2019	Randomized controlled trial study	<ul style="list-style-type: none"> <li>• Significant difference in QoL was found between two groups (<math>p &lt; 0.001</math>).</li> <li>• The most improved aspect in QoL are pain and nausea (<math>p &lt; 0.001</math>), followed by procedural anxiety (<math>p = 0.002</math>), treatment anxiety (<math>p = 0.002</math>), and worry (<math>p = 0.014</math>). Palliative intervention was found to be able to reduce sleep disturbances (<math>p = 0.003</math>) and anorexia (<math>p &lt; 0.001</math>) significantly.</li> </ul>



No.	Title & Author(s) (Publication year)	Published year	Design	Major Findings
6.	What do parents value regarding pediatric palliative and hospice care in the home setting?  Authors:  Boyden, J. Y., Ersek, M., Deatrck, J. A., Widger, K., LaRagione, G., Lord, B., & Feudtner, C. (2021).	2021	Cross-sectional assessment/ survey	<ul style="list-style-type: none"> <li>The most prioritized domains were physical care, followed by symptom management, psychological/emotional aspects of care for the child, and care coordination (N=47 parents).</li> <li>The least prioritized domains were spiritual and religious aspects of care and cultural aspects of care.</li> <li>Parents who had other children showed a higher priority rating for psychological/emotional aspects of care compared to those who did not have other children (p= 0.02).</li> <li>Bereaved parents rated the caregiver support at the end-of-life domain significantly higher than parents who were currently caring for their child (p= 0.04).</li> </ul>
7.	Improved quality of life at end of life related to home-based palliative care in children with cancer.  Authors:  Friedrichsdorf, S. J., Postier, A., Dreyfus, J., Osenga, K., Sencer, S., & Wolfe, J. (2015).	2015	Retrospective survey cohort study	<ul style="list-style-type: none"> <li>Greater perceived suffering from pain in the oncology group (70%) compared with PPC/oncology group.</li> <li>End-of-life planning: parents in PPC/Oncology group (n=28, 97%) said they preferred that their child die at home instead of at the hospital compared with 21 (72%) in Oncology group (p=0.04).</li> <li>Significant greater proportion of parents perceiving the improvement of child's QoL (n=21, 70%; versus n=13, 45%; p=0.03)</li> </ul>
8.	Paediatric palliative care at home: a single centre's experience.  Authors:  Chong, L. A., & Khalid, F. (2016).	2016	Retrospective case notes review	<ul style="list-style-type: none"> <li>Of those who died during the study period and preferred a home death, 78.9% (n = 30) died at home (p &lt; 0.001).</li> <li>The median duration of end-of-life care for patients with cancer was almost eight weeks (range 1–832 days) and 22 weeks (range 6–1,812 days) for patients with noncancer diagnoses.</li> <li>The majority (93.3%, n = 70) of families had at least one bereavement follow-up.</li> </ul>
9.	Lived experiences of parents caring for a child with a life-limiting condition in Australia: a qualitative study.  Authors:  Collins, A., Hennessy-Anderson, N., Hosking, S., Hynson, J., Remedios, C., & Thomas, K. (2016).	2016	Qualitative study	Four key themes represented the prevalent experiences of parents: trapped inside the house, the protector, living with the shadow, and travelling a different pathway.

## DISCUSSION

### a. Palliative care

World Health Organization (WHO) defined palliative care as an approach to improve the QoL of any-aged-patients and their families in dealing with any issues which raised by LTD-LLD. It relieves and prevents suffering through the early identification, correct assessment, and treatment of pain and other psychosocial, physical, or even spiritual problems (9). Palliative care aims to enhance the QoL of both patients and their families who are facing the challenging issues evoked by the trajectory of the chronic and LTD in a holistic manner that cares for physical, psychological, social, or spiritual aspects (1, 4, 9, 16). The earlier a patient receives palliative care for his/her chronic or a terminal condition, the more effective it could be for the patient and his/her family (17, 18). Palliative care could reduce the use of health services as well as the hospital admission rate (1, 19, 20). Therefore, palliative care is seemingly the most proper approach of care for taking care patients with LTD-LLD diseases. Sufficient national programs, resources, policies, and training are essential to enhance the accessibility to palliative care.

### b. Pediatric Palliative care (PPC)

Children are unique individuals. They are not little adults. Therefore, they should not be treated as adults. PPC is unique compared to the palliative care given to the adult patient as it requires consideration of multi aspects which vary within a wide range of ages. Prominent differences between palliative care for adults and children may include the different development stages within child-age range, communication needs and approach, dependency on adults, family-focused, health status (several cases are genetic or congenital conditions which are rare and not found

in adults), formulation and dosage of essential medicines, level of difficulty of clinical-decision making, and child-friendly clinical environment (11). Therefore, the goal of PPC is to lighten affliction and improve the QoL of children with LTD-LLD diseases (21-23) and advance assistance for their parents and other family members (23, 24). There are at least three characteristics of PPC.

Firstly, PPC has been aimed to aid children with LTD-LLD and their families to preserve with the physical, psychological, spiritual, and social burdens of disease, as well as its treatments. The goal of care of PPC is similar to adult palliative care, but the focus of care is not only centralized on helping the condition and child's needs, but also on the family to whom the child depends on (23, 25, 26). Children are part of the family; therefore, the scope of the holistic care concept in PPC should be expanded to other family members.

Secondly, PPC aims to improve the QoL for child patients and their parents (22, 23, 27). One of the main goals of PPC is elevating better QoL outcomes at end-of-life. Children who suffer from long-term diseases are supposed to long to experience several meaningful and fun events that add meaning to their lives. Furthermore, they are more likely to stay and even die at home, together with their family (22). Parents whose children are sick also feel distressful about their children's condition, ambiguities, and other family members' needs (25, 28). Therefore, it might be paramount in PPC to also improve parents' quality of life as they are the primary caregiver for their children.

Thirdly, PPC may also help in improving the psychosocial status during the family bereavement process (23, 29). During the deliverance of palliative care, the parents were partaken and trained to improve their ability to control the child's symptoms. Furthermore, the care

focuses on minimalizing the children's pain and preparing their parents for the end-of-life phase by 'being there' with their children at critical times.

Through above explanations, we could see that there are several differences while implementing palliative care for children and adults. The differences may not in terms of aims or benefits but more about the approach while the palliative care is delivered.

### c. Home-based Pediatric Palliative Care (HBPPC)

Children with LLD or LTD, such as cancer, may need PPC, not only in a hospital settings but also at home (1). Care for children with LLD or LTD at home might be also provided by the parents, as the caregiver. As the consequence, the caregiving role of the parents becomes more complex and extensive (30). Caregiving for children with palliative conditions includes not only routine childcare, but also various demanding technical, emotional, and nursing tasks (1). Therefore, there were several previous studies reviewed to extend and sharpen the authors' point of view about HBPPC (Table 1), which finally clustered into two main points below.

- Required Support for HBPPC

In the most recent study, Boyden, et al. conducted a cross-sectional survey which explored how parent consider the most and least prioritized domains of PPC at home setting (this project was entitled as PPHC@Home) (26). The data was collected by using 15 discrete choice experiment (DCE) sets. Moreover, the domain weightiness scores were analyzed by using multinomial logistic regression with Bayesian analysis. The confidence interval (CI) was 95%. The raw logit scores were then converted to score ranged 0–100 across all domains. All comparisons were also analyzed using two-sample

independent t-tests with p-values < 0.1. There were forty-seven parents participated in this study. The result indicated that the most prioritized domains were the management of physical problems, symptom management, coping with psychological/ emotional issues while taking care for the child, and care coordination. Whereas, the least prioritized domains were cultural aspects of care and spiritual-religious aspects of care. Furthermore, this study found that parents with other children rated the psychological/ emotional aspects significantly higher than parents who did not have other children ( $P = 0.02$ ) (26). This result may be indicating that parents strongly need psychological/ emotional support while caring for children with the palliative condition, especially those who also have other children. From this study, it can be seen that both children and caregiver require holistic support to deal with the complexity of palliative condition.

It is also believed that bereavement support must be included in delivering HBPPC (21, 29). In a study which was conducted by Chong & Khalid (21), it was shown that most families who got the HBPPC had at least one bereavement follow-up (93.3%,  $n = 70$ ). Bereavement support might be one of the most unique features of HBPPC (23). The provided HBPPC must also cover the support for bereaved parents.

A literature review of PPC in oncology reveals that there are four focuses on enhancement for PPC. Family, especially parents who care for a child with LLD or LTD, might expect to receive holistic care for these areas. The focuses included physical symptoms and distress assessment and management; psychosocial care; spiritual care of the patient, parents, and siblings; and family-centered



communication (23).

Furthermore, there are common experienced faced by parents who take care of child with LLD or LTD. A qualitative study in Australia (31) explored the lived experiences of parents (N=14) who are providing care for a child with LLD. Firstly, the results showed that the parents experienced the feeling of being trapped inside the house. This indicates that they isolated themselves from the social community because of their role as the primary caregiver for their children. Therefore, this impacted their health and well-being (31). This may imply that the parents need continuous support from 'someone' to stay healthy holistically, thus they could take care of their children. Secondly, the study found that by becoming the primary caregiver for their children, the parents are conceptualized as being the protector whose role includes having sufficient knowledge of their children's unique and specific care needs (31). To be able to do this role, parents may need training or shared knowledge about caring for their children from health care professionals (HCPs), as well as continuous monitoring from HCPs (1). Lastly, this study gained information about the parents' feelings about living with the shadow indicating that the parents faced daily uncertainty and grief for the life. They live with the probability of their beloved one's death, and it was mostly unspeakable and suffocating (31). Therefore, the HBPPC will be well delivered if it is implemented in a holistic manner for both children and family. It may include social support from support group and/or counsellor, sufficient training for parents to deal with child's physical problems, and emotional-spiritual support in preparing to end-of-life stage.

Similar to ideas above, Verberne, et al. conducted research to explore parent's experiences and coping strategies when caring for a child receiving PPC (28). This qualitative study identified that parents whose child suffered from LLD or LTD experienced things such as confrontment with loss and possible experienced grief, stronger parent-child relationship, daily anxiety of child loss, tensions regarding end-of-life decisions, ambiguity toward uncertainties, and engagement with professionals. To cope with these tough-but-should-be-adjusted conditions, parents conveyed four main coping strategies which are seeking support, suppressing emotions, taking control, as well as adapting and accepting (28). This study identified that parents experienced positive impacts if the primary HCPs have had previous experience in caring child with LLD and expertise in PPC (28). Parents asserted several disappointing experiences including feelings of abandoned especially while there was no treatment available to heal the children, and the children were being sent home without any proper process of care plan and a lack of coordination and continuity of care after the diagnosis incurable disease (28). These findings imply that parents' burden becomes greater when the care for their children with palliative conditions should be delivered at home.

Hence many studies imply that there have been many needs to be considered and helped when taking care for children with chronic diseases. Both children and families must be facing many challenges in many aspects during the care. Therefore, they may need assistance and holistic long-termed care to live with this kind of condition.

- Benefits of HBPPC

The explanation above showed the needs of HBPPC in taking care children with LLD or LTD. The HBPPC is likely beneficial both for the parents and children. During the palliative trajectory of their child, parents' resiliency and ability to might strongly need to be improved to deal with children's condition after being sent home (1). For instance, HCPs should encourage parents, from the commencement of the disease process, to value and tighten up a meaningful bonding with their child. Additionally, HCPs should be obligated to help parents in learning many new skills that are needed to care for their children, as well as strengthen their coping strategies (1). Furthermore, it was noted that because of their children condition, the family's social support system might become smaller, whereas social support has been considered as one of the most effective and common approaches to help parents cope with their stress and maintain physical and psychological well-being. Therefore, HCPs should encourage parents to look for support group and help them to have contact with social. This study suggests that directing new skills for parents in taking care of their children and receiving social support are paramount in taking care of children with LLD or LTD at home. These needed things, therefore, could be attained by simultaneously implementing HBPPC. The existence of and assistance from competent HCPs would somehow make the parents feeling secured to take care of their children at home and less stressed because the HCPs would listen to their struggle and support them (1).

Moreover, Winger, et al. conducted a systematic literature review involving

23 studies that emphasizing the family members' experiences when receiving HBPPC (children aged 0 – 18-year-old) (32). The review represented the data from the families of almost 300 children with LLD or LTD who received HBPPC. Families experienced various challenges regarding the coordination of care, including a lack of assistance from competent and experienced staff. Families receiving PPC expected organized and individualized support from skillful PPC team (1, 32). Furthermore, the studies indicated that respite care is important for the parents to be able to carry out the demanding home-care situation and support for siblings. In addition, the family might strongly need financial support to meet the entire family members' needs. A parental decision to care for their terminally ill child at home may entangle multiple considerations, such as their children's wishes; the sufficiency of psychological, medical, cultural, and social support; as well as the accessibility to physician, respite care, and financial resources.

Furthermore, another study investigating the benefits of HBPPC found that there is a greater number of parents witnessed their children having more fun ( $n = 21, 70\%$  compared to  $n = 13, 45\%$ ;  $p = 0.03$ ) and experiencing events that precious to his/her life ( $n = 24, 89\%$  compared to  $n = 19, 63\%$ ;  $p = 0.02$ ) after receiving HBPPC (22). This implicitly showed that the children's QoL increased while receiving PPC in a home-based setting. This research, however, used a retrospective approach which may correlate with recall bias as the nature of retrospective study. In addition, the sample size, and characteristics of respondents (excluding non-English-speaking parents) may make the

results becoming less generalizable.

In a randomized control trial, Andriastuti, et al. conducted a study to determine the benefits of integrated HBPPC to the QoL and symptom intensity of children with malignancies in Indonesia (27). The given intervention was a 3-month-home visit for children (2 up to 18-year-old) with cancer diagnosis who were consulted to palliative team. This study used two independent populations with CI of 95% and power of 80%, resulting the calculation of sample size of 30 for each group (1:1 ratio). The sampling method was using consecutive sampling, in which the patients were randomly divided into two groups namely intervention group (I) and control group (C). The randomization used blocked randomization (IICC) method. The data was collected by assessing the patients with the Pediatric Quality of Life Inventory (Peds-QLTM) questionnaire cancer module 3.0 (report by proxy or self-report) in the first and twelfth week of the intervention. In addition, symptom intensity (pain, anorexia, sleep disturbance) was assessed by using Edmonton Symptoms Assessment Scale (ESAS). Finally, data from 50 participants were considered complete and valid to be analyzed with the Mann-Whitney formula. The analysis showed that QoL in the intervention group has tendency to improve as the disease progress compared to those in the control group (mean score in control group was 62.39 while intervention group was 81.63,  $p < 0.001$ ). Furthermore, this study found that the most improved aspect in QoL is regarding pain and nausea problems ( $p < 0.001$ ), followed by treatment anxiety ( $p = 0.002$ ), procedural anxiety ( $p = 0.002$ ), and worry ( $p = 0.014$ ). Furthermore, the intervention was

also considered effective in reducing sleep disturbances ( $p = 0.003$ ) and anorexia ( $p < 0.001$ ) (27). Therefore, it could be implied that HBPPC might improve several aspects of the QoL and provide better symptom management for children suffer from cancer. It is likely that HBPPC would be more effective in improving QoL when it is provided earlier (33).

From several studies we could see that there are many advantages of implementing HBPPC. The advantages might be taken by both the children and families. The benefits of PPC are not only related to physical issues but also psychological and emotional management.

## IMPLICATION

Parents and hospital-based healthcare professionals might need to consider the implementation of HBPPC for children who need palliative care. The findings acknowledged the multiple benefits of implementing PPC at home, for both children and families. Further studies in the expansion and integration of HBPPC with hospital-based PPC is paramount.

## LIMITATION

Despite the meaningful contributions of this review, certain limitations do exist. First, it might be challenging to classify some articles as they settle with several issues or multiple factors simultaneously. This might increase the possibility of redundancy. Another limitation is almost all (8 from 9 sources) the studies included in this narrative review were done in developed countries that may have different policies from developing countries.

## CONCLUSION

Home-based PPC may be an ideal approach to care children with LTD and LLD and their families. By employing HBPPC, both patient and caregiver may gain several benefits to manage physical, psychosocial, and

emotional issues, which improve the QoL for both the patients and their parents. The implementation of HBPPC may improve the QoL of children with LTD and LLD, as well as their families. This study may give explanation about the advantages of implementing home-based PPC. The findings from previous studies might be used to promote the implementation of home-based palliative care for children with LTD and LLD.

### CONFLICT OF INTEREST

There is no conflict of interest declare for this paper.

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