Lam *et al. BMC Nursing* (2025) 24:1432
https://doi.org/10.1186/s12912-025-04084-8

BMC Nursing

RESEARCH **Open Access**

Associations among parental self-efficacy, symptom burden in children with medical complexity, and their use of health services

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Abstract

Background Children with medical complexity not only have physical but also psychological symptoms. The pattern of their health service use based on symptom burden and how symptom burden affects the parental self-efficacy in symptom management is not well identified. It is crucial to understand the relationships among them for developing effective strategies in enhancing parental knowledge and skills in responding to symptom management for children with complex health conditions.

Methods This study conducted a secondary analysis of data from a randomised controlled trial. Convenience sampling was adopted to recruit 102 parents of children from four special schools and three non-government organisations in Hong Kong between March 2023 and May 2024. Regression bootstrapping methods were used to analyse the mediating effects of parental self-efficacy between parent-reported children's symptom burden and their health service use.

Results The mediation analysis showed that parent-reported symptom burden had a significant relationship with health service use ($B = 2.30$, $p = 0.0003$; 95% Confidence interval [CI]: 1.1, 3.5) and parental self-efficacy ($B = -14.7$, $p = 0.0025$; 95% CI: −24.7, -5.3). However, the mediating role of parental self-efficacy between the parent-reported symptom burden and health service use was not statistically significant ($B = 0.17$; 95% CI: −0.18, 0.62). Moreover, the parent-reported children's symptom burden had a significant correlation with the type of CMC ($r = 0.36$, $p < 0.001$) and the education level ($r = 0.22$, $p = 0.025$). Additionally, parental self-efficacy was found to be positively correlated with their financial status ($r = 0.21$, $p = 0.03$).

Conclusion The severity of child symptom burden was found to have a significant direct effect on parental self-efficacy and child health service utilisation, thereby contributing valuable insights to the existing literature in this field. Understanding how these factors interact can provide valuable insights to improve the supporting system and intervention development for these parents.

Keywords Paediatric palliative care, Children with medical complexity, Symptom burden, Parental self-efficacy, Health service use

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Background

Children with medical complexity (CMC) represent a distinct segment of the paediatric population who face multiple health challenges that require close monitoring and extensive use of healthcare services [1]. The most widely accepted definition includes four key types that describe these children, as outlined by Cohen et al. [2]. They are substantial family-identified service care needs, having one or more severe chronic clinical condition(s), functional limitations needing assistance from technology such as for feeding, breathing, or ambulation, and significant use of healthcare resources that may include frequent hospitalization or specialty care. Globally, the number of CMC is increasing primarily due to advancements in health care and rising survival rates. They now constitute approximately 0.4–0.7% of the paediatric population [3]. In the United States, approximately 3 million of the 76 million children have medical complexities, and this number is growing at a rate of around 5% per year, surpassing the overall child population growth rate [4]. In Japan, the prevalence of CMC was 1.88 per 1,000 among those under 20 years of age in 2018, and it increased 1.9 times compared to 2007 [5]. In Hong Kong, about 1,200 children with medical complexity require ongoing nursing services and support each year [6]. Although CMC represent less than 1% of the global paediatric population, the rising number of diagnoses and their considerable use of healthcare resources [3] have made this group a key focus within child healthcare systems [7]. Due to the complex nature of their conditions, these children often need continuous care provided by both families and healthcare professionals.

Parents, as the primary caregivers, play a crucial role in decision-making, planning, and coordinating care to meet their children's evolving needs [4]. Parents face significant daily challenges due to the unpredictable changes of their children's complex health conditions and the possibility of a shortened life expectancy [8]. Caring for a CMC places considerable stress on primary caregivers, particularly parents. They often experience intense burdens when managing multiple simultaneous symptoms [8, 9]. In addition to providing complex daily care, parents must escort their children to various medical appointments within an already packed schedule [9]. To reduce their child's symptom burden, parents must learn to manage the symptoms and address the complex healthcare needs [10], which requires both parental confidence and competence to navigate challenging circumstances.

Parental self-efficacy refers to a parent's belief in his or her ability to successfully manage the challenges of raising a child [11]. It is a crucial element that boosts parental confidence in responding to their CMC's needs [10]. Parental self-efficacy can positively influence children's health outcomes [12, 13] and affect their level of health service utilisation, as fluctuations in health conditions may result in new symptoms that can either be managed at home or require a hospital visit [14, 15]. Given the intricate medical care these children require, parents must possess essential knowledge and skills for effective symptom management at home. A lack of parental self-efficacy in managing their child's symptoms may lead to distress for both parent and child [16], and negatively affect their quality of life [17]. Parental decisions, such as whether to seek hospital care or continue managing their child's symptoms at home, are often influenced by these factors. Symptom burden refers to the frequency, severity and distress level of symptoms experienced by the CMC [18]. These symptoms may be physical, psychological or emotional in nature and can cause a variety of adverse health reactions [19]. Studies suggest that the symptom burden of a child with chronic diseases affects their patterns of health service utilisation, including frequency of hospital visits and duration of hospital admissions [20, 21]. Among CMC, the pattern of their health service use based on symptom burden and how symptom burden affects the parental self-efficacy in symptom management is not well identified.

It is crucial to understand the relationships among symptom burden, parental self-efficacy, and health service utilisation for developing effective strategies that enhance the quality of life for both child and their parents, as well as improve child health outcomes. A deeper understanding of how these factors interact, particularly in CMC, can inform the nursing profession in designing tailored interventions that strengthen parental knowledge and skills in symptom management and decision-making capabilities. Therefore, this study aimed at examining the associations between symptom burden in CMC and their health service use, and to explore how parental self-efficacy mediates these relationships.

Methods

Study design

This study conducted a secondary analysis of baseline data obtained from a randomised controlled trial.

Participants and sample size

Convenience sampling was used to recruit 102 Chinese parents. The eligibility criteria for parents were as follows: (1) parent of a child with medical complexity aged 2–18, (2) able to communicate in Chinese and read Chinese, and (3) living with his/her CMC at home. The exclusion criterion for parents was reported as having apparent mental health disorder in which they are unable to provide consent and impaired decision-making ability related to their mental health status. The inclusion criteria for the children were (1) between 2 and 18 years of age, (2) diagnosed as a CMC by a paediatrician. The children who meet any one of the following four conditions would be diagnosed as having CMC by a paediatrician. First, the condition is potentially treatable but may fail to respond, such as cancer or irreversible organ failure. Second, the condition requires a prolonged period of intensive treatment to maintain daily living, such as spinal muscular atrophy and Duchenne muscular dystrophy. Third, the condition is progressive and incurable, a metabolic disorder, i.e., type I diabetes or chromosomal abnormalities. Fourth, the condition is irreversible and non-progressive but leads to degeneration, severe disability or even premature death, such as severe cerebral palsy, or brain or spinal cord injuries with severe disabilities [22]. The exclusion criteria of CMC had been (1) admitted to a hospital in the previous seven days, and (2) receiving end-of-life service. By using the methods of delta and bootstrap calculation, the estimated sample size ranged from 90 to 100 subjects to achieve the complete simple mediation effect [23]. Accordingly, 102 participants were enrolled in this study, which was deemed adequate.

Data collection procedure

Study information sheets were distributed to invite Chinese parents of CMC to participate in this study, via the person-in-charge of seven special schools for children with physical disabilities and six non-governmental organisations. Ultimately, 102 eligible parents were referred to the research team by social workers from four Hong Kong special schools and three non-governmental organisations between March 2023 and May 2024. The research team subsequently approached the parents to obtain written consent, with an explanation of the study's purpose provided either at their homes, at the special schools, or at another preferred location. Before administering the set of self-administered questionnaires, the project assistant explained to the parents how to complete them.

Measures

Demographic data were collected to provide a context for the children and parents. The parental demographic data included age, marital status, education level, financial status, religion, people living in the same household, and insurance coverage. The children's demographic data included their health history, physical condition, medication, and medical appointments.

Caregiving Self-efficacy (Chinese version)

The scale consists of 18 items to measure the Chinese caregivers' self-efficacy in three domains: (1) care of the care recipient; (2) managing information and self-care; and (3) managing emotional interaction with the care recipient, reflecting the ability to interact actively with patients in dealing with emotional situations [24]. It rates the level of caregiver confidence from 1 to 9, with higher scores indicating a higher level of caregiving self-efficacy. The test-retest reliability was satisfactory, with a Pearson correlation coefficient of 0.78–0.83. The Cronbach's alpha coefficients of the three sub-scales are in the range 0.84–0.9.

Modified memorial symptom assessment scale (Modified MSAS Chinese version)

A modified 40-item MSAS (Chinese version) was used to measure the symptom burden (occurrence, frequency, severity, and physical and psychological distress symptoms) experienced by CMC in the previous seven days. There is no assessment scale for symptoms reported by children with medical complexity. A review of the literature was conducted, and an additional 10 physical symptoms were identified and added to the original 30-item MSAS [18]. The inclusion of these symptoms was based on other studies done in this field. The modified MSAS has been validated by a panel of academic experts, nine paediatric nurses with knowledge in caring for CMC and their families. Each panel member received a questionnaire that included all 10 items and was asked to rate whether each item appeared to be relevant to the intended constructs under study. They reviewed the 10 physical symptom items using a 4-point Likert scale, where 1 = not relevant, 2 = somewhat relevant, 3 = quite relevant, and 4 = highly relevant. The Content Validity Index (CVI) was computed at both the item level (I-CVI) and the scale level S-CVI) to indicate the agreement among the nine experts. For each item, I-CVI was calculated based on the number of experts giving a rating of either 3 or 4 divided by the total number of experts. For the scale level, S-CVI was calculated using the average method, representing the mean I-CVI across the 10 items. The level of the CVI was calculated to be 0.9. The test-retest reliability was satisfactory, with a Pearson correlation coefficient of 0.75. Cronbach's alpha coefficient was 0.8. Dichotomous questions are used to measure the occurrence of symptoms. The items for measuring the frequency and severity of symptoms are rated on a 4-point Likert scale from one (almost never) to four (always). The items for measuring distress are rated on a 5-point Likert scale from one (not at all) to five (very). If a symptom is experienced, the score for that symptom is determined as a composite of the average scores on the severity, frequency, and distress scales, or on the severity and distress scales only. An overall MSAS score was calculated based on the responses from the 40 items, and a higher score indicates a higher level of symptom burden in the children [25].

Children's health service utilisation

This was a record used for parents' use to summarise a child's non-scheduled visits to private or public outpatient clinics and private or public emergency rooms, and the child's unplanned admission history in the three months. The admission history includes (1) frequency of private and public hospital admissions, and (2) number of hospitalised days of each admission.

Ethical considerations

This research study was approved by the Institutional Review Board of the Hong Kong Polytechnic University (HSEARS20220721005), the three participating non-government offices, and four special schools. All parents provided their informed written consents to participate in this study and provided their demographic data before starting the interviews. Information sheets with a verbal explanation of the study were given upon subject recruitment. Parents were assured of confidentiality and anonymity, told of their right to withdraw from the study at any time, and informed that their refusal to join would not affect their child's care. The names of the parents, children, non-government organisations, and special schools were replaced with codes and kept anonymous in all publications.

Statistical analysis

Analyses were performed using SPSS (version 29). Descriptive statistics were reported by percentage or mean (SD), as appropriate, to summarise the sample characteristics and study variables, and Spearman correlations were computed to examine and describe the relationships among the study variables. The PROCESS macro version 4.2 with the regression bootstrapping method (Hayes, 2022) was used to test the proposed hypotheses. Specifically, mediation analysis was performed by examining the mediating effect of the parents' self-efficacy (M) on the relationships of the parent-reported children's symptom burden (X) with their health service use (Y1). Demographic variables that were significantly associated with the study variables in the bivariate analyses were also included in the mediation analyses to control their effects. In the analysis, the PROCESS (model 4) macro-generated 5000 bootstrap samples with a 95% confidence interval (CI). A P-value of less than 0.05 was considered statistically significant.

Results

A total of 102 Chinese children with different types of CMC and their parents were included in this study. Among the children, the majority type of CMC was irreversible, complicated, and resulted in severe disability, i.e., cerebral palsy ($n = 40$, 39.2%). Sixty-one (59.8%) were male, and the average age, height, and weight were 10.7 years, 130.9 cm and 31.4 kg, respectively. Regarding mobility, chairbound was the largest category ($n = 53$, 52%), followed by walking without aid ($n = 19$, 18.6%). More than 30% use either BiPAP ($n = 24$, 23.5%) or a ventilator ($n = 9$, 8.8%). Among those using mechanical ventilation, about a quarter of them use it only when sleeping ($n = 22$, 21.6%). The majority were not tube-fed ($n = 67$, 65.6%), and the most common type of tube feeding was percutaneous endoscopic gastrostomy ($n = 33$, 32.4%). The average age of onset of diagnosis was 1.4 years. Most of the children attended the speciality outpatient clinic for medical follow-up and received medication ($n = 78$, 76.5%). Oral medication was the most used ($n = 70$, 68.6%). The two largest sources of medical fees for CMC were government subsidies ($n = 102$, 100%) and self-supported ($n = 66$, 64.7%). The mean frequency of hospital admission was low, and the average length of hospital stay was approximately 3.6 days in the past three months. The number of children's non-scheduled outpatient visits to public and private clinics was 25 and 14, respectively, while the number of children's accidents and emergency visits at the public hospital was 19. More than 70% of children with CMC had been absent from school ($n = 77$, 75.5%).

Among the parents, most primary caregivers were mothers of children with CMC ($n = 93$, 91.2%), and their average age was 43.4 years. More than two-thirds of them were housewives, and approximately one-third of them had a full-time or part-time job and had an educational level of junior/senior secondary/postsecondary level ($n = 40$, 39.2%). Less than 10% of primary caregivers were fathers of CMC ($n = 8$, 7.8%), and their average age was 46.4 years. Most fathers had a full-time job ($n = 84$, 82.4%), and an educational level of undergraduate ($n = 37$, 36.2%). The majority of the primary caregivers were married ($n = 84$, 82.3%). All the CMC lived with mothers ($n = 102$, 100%), followed by fathers ($n = 88$, 86.2%) and siblings ($n = 62$, 60.7%) respectively. More than half of the families reported that they had just enough financial status ($n = 56$, 55%), and nearly 60% had no religion ($n = 62$, 60.8%). The primary caregivers reported that they had taken an average of 9.4 years to take care of their children.

The descriptive statistics of the parent-reported children's symptom burden, parental self-efficacy, as well as all relevant information on children's health service use were summarised as follows. Seventeen CMC did not present with any symptoms (16.6%). The mean level of the parent-reported children's symptom burden was low (mean = 0.41, SD = 0.4) and the perceived self-efficacy in the parents was high (mean = 111.5, SD = 19). The mean number of children's health service visits was 1.7, and the SD was 2.4. Table 1 shows the correlation analysis result of parent-reported children's symptom burden, parent-reported self-efficacy, and the summative measure of children's health service use. The scores of the parent-reported children's symptom burden was correlated significantly and negatively with parental self-efficacy scores (r=-0.248, $p = 0.01$); the scores of the parent-reported children's symptom burden was correlated significantly and positively with total health service use ($r = 0.329$, $p < 0.001$), and parental self-efficacy scores were correlated significantly and negatively with total health service use (r=-0.257, $p = 0.008$).

Table 1 Correlation matrix of MSAS, CGI and children's health service use ($n = 102$)

Spearman correlation (*p*-value)	**MSAS score**	**CGI score**	**Total health service use**
MSAS score	-	-	-
CGI score	-0.248 (0.010)	-	-
Total health service use including frequency of hospital admission, non-scheduled visits to the outpatient clinic & AED	0.329 (< 0.001)	-0.257 (0.008)	-

MSAS: The modified Memorial Symptom Assessment Scale (MSAS) (Chinese version)

CGI: Chinese version of the Caregiver Inventory to measure self-efficacy of parents

Table 2 Correlation matrix of selected demographics against MSAS, CGI and children's health service use ($n = 102$)

Spearman correlation (*p*-value)	**MSAS score**	**CGI score**	**Total health service use**
Number of years in taking care of CMC	-0.08 (0.44)	-0.12 (0.21)	-0.12 (0.24)
CMC Type	***0.36 (< 0.001)***	-0.16 (0.11)	0.10 (0.32)
Marital status	-0.13 (0.2)	0.03 (0.76)	0.01 (0.91)
Religion	0.12 (0.23)	0.11 (0.28)	0.03 (0.73)
Living with siblings	-0.12 (0.22)	-0.08 (0.41)	0.11 (0.27)
Family financial status	-0.05 (0.61)	***0.21 (0.03)***	-0.16 (0.10)
Education level of the father	0.09 (0.35)	0.12 (0.23)	-0.04 (0.67)
Education level of the mother	***0.22 (0.025)***	0.04 (0.68)	0.09 (0.35)

MSAS: The modified Memorial Symptom Assessment Scale (MSAS) (Chinese version)

CGI: Chinese version of the Caregiver Inventory to measure self-efficacy of parents

Table 2 shows the correlation analysis result of selected demographics with parent-reported children's symptom burden, parental self-efficacy, and the summative measure of children's health service use. The result showed that the type of CMC ($r = 0.36$, $p < 0.001$) and the education level ($r = 0.22$, $p = 0.025$) were correlated positively and significantly with parent-reported children's symptom burden, as well as the family financial status correlated positively and significantly with parental self-efficacy ($r = 0.21$, $p = 0.03$). Using the PROCESS macro version 4.2 (Hayes, 2022) with model 4, a simple mediation model was tested to examine the direct and indirect effects of the parent-reported children's symptom burden on children's health service through parental self-efficacy, by controlling for three covariates (type of CMC, financial status, and education level of mother) (Fig. 1). The bootstrapping results showed that the parent-reported children's symptom burden had significant direct effects on parental self-efficacy (B = − 14.7, $p = 0.0025$; 95% CI, − 24.7 to − 5.3) and children's health service (B = 2.30, $p = 0.0003$; 95% CI, 1.1 to 3.5), but the mediating effect of parental self-efficacy was not statistically significant (B = 0.17; 95% CI, − 0.18 to 0.62).

Discussion

In this study, the level of symptom burden had a significant relationship with health service use and parental self-efficacy. However, the relationship between

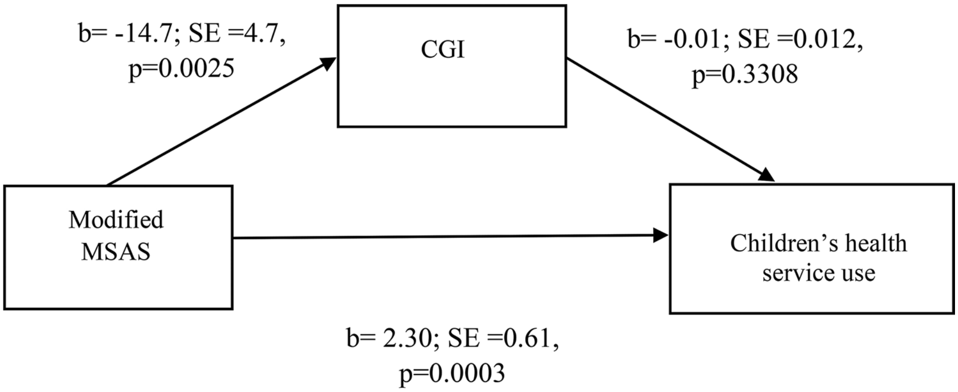

Fig. 1 Mediating effect of parents' self-efficacy on the relationship of parent-reported children's symptom burden with children's health service use (controlling for covariates: CMC type, financial status, and education level of mother). The indirect effect (IE = 0.2298) is not statistically significant: 95% CI= -0.16, 0.69

parent-reported children's symptom burden and health service use is unclear, particularly in the presence of parental self-efficacy. Understanding how these factors interact can provide valuable insights to improve the supporting system and health intervention development for parents of CMC.

Proactively enhancing parental knowledge and skills in symptom management

The current study has shown that parent-reported children's symptom burden had a negative relationship with parental self-efficacy. Parents demonstrated lower self-efficacy when their child had a higher symptom burden score. This could be due to parents' increased stress and anxiety due to their child's health condition change and the severity of the symptoms [8, 26]. This finding is in line with an Australian study in which parents of CMC demonstrated lower self-efficacy [27] when their children's health conditions changed. Parents of CMC are considered the main caregivers to manage their children's needs at home. As such, they seek emotional and practical support that boosts their confidence and competence to provide home care [9, 27]. This suggests that boosting parents' knowledge and skills in symptom management should be a primary focus in paediatric home nursing education and practice, as effective symptom management is fundamental to paediatric palliative health services [28]. Therefore, tailored intervention should be developed to enhance parental competencies based on the nature of their child's symptom burden.

Furthermore, community paediatric nurses should regularly review the health profiles of CMC to provide proactive nursing advice, rather than only conducting assessments and health education during scheduled medical follow-ups. Additionally, discussions about advanced nursing care should occur early in the follow-up process to help parents understand and prepare psychologically for the progressive health deterioration of their children. This allows time for the families to obtain necessary equipment and seek health support to deliver home care to their children.

In this study, parental self-efficacy did not mediate the relationship between parent-reported children's symptom burden and health service utilisation. This may be because parents experience significant stress and anxiety due to the increased symptom burden in their children, which can overshadow parental self-efficacy [29]. This stress might lead them to seek healthcare services regardless of their confidence in managing symptoms at home. When symptoms are severe or acute, parents may prioritise immediate medical attention over their perceived ability to manage nursing care at home [30], diminishing the role of self-efficacy in their decision-making, as the symptom burden has a negative relationship with self-efficacy in this study. Thus, it is essential to facilitate smoother transitions between home care and hospital services, ensuring that parents understand when to seek help from health professionals and how to manage their child's symptoms at home. Overall, improving parental competencies in symptom management and ensuring accessibility to appropriate medical health services should be warranted to ensure optimal health outcomes for these children living at home.

Protocol for triage and care coordination for CMC living in communities

The CMC symptom burden was found to significantly influence their health service utilisation. Parents usually viewed their child as more vulnerable due to their underlying health conditions. They considered the observed children's symptoms to be high-risk, and sought emergency care when they felt unable to manage the symptoms at home [15]. This finding is consistent with the study conducted by Nelson et al., in which parents want to seek health advice for their children if they feel that the health condition of their children is worsening due to increased pain or a new onset of symptoms [15]. Similarly, a study conducted in Australia revealed that high health service attendance was observed among children who had frequent episodes of a disease (>15 episodes per year), and multiple comorbidities [31]. Contrary to this, parents may also choose to keep their children at home to prevent hospitalisations, believing they can provide sufficient care [32]. They are willing to learn and undertake complex medical tasks, feeling a strong commitment to caring for their children, even when professional nursing support is accessible. However, health service utilisation is still an essential part of care for CMC, particularly for those symptoms that are considered severe and need hospital admission for medical treatment. Therefore, the health care system, nurses, and parents should assess the children's symptom burden to determine the appropriate level of nursing or medical care based on the nature and severity of the child's illness. The paediatric home nursing services for CMC may require greater prioritisation and redesign [7]. Key areas to explore include developing effective triage strategies for paediatric hospital admission, improving care coordination, and enabling families to make informed decisions about when to seek help from health professionals.

Limitations and recommendations

The convenience sampling adopted in this study may limit the generalizability of the study findings. Most participating parents were mothers (91.2%). Caution must be taken when generalising results to all parents, because fathers' perceptions of self-efficacy might vary. Considering the differences in cultural backgrounds, the perception of self-efficacy in taking care of CMC of parents from eastern countries may be different from that of parents from western countries. Chinese parents tend to use an authoritarian approach when taking care of their children [33]. They tend to use controlling and restrictive approaches in child rearing. As the health condition of CMC may change suddenly, it makes parents feel frustrated and have limited control over the things happening to their child. These kinds of experiences can cause parents to lack confidence and self-efficacy when providing caregiving activities. Future studies with larger samples should examine the replication of the study's findings to confirm the results across different regions, genders, and cultural backgrounds.

Conclusion

This study found the relationship between CMC's symptom burden, parental self-efficacy, and health service utilisation, thereby contributing valuable insights to the existing literature in this field. Lower parental self-efficacy is associated with higher symptom burden, suggesting that the challenges of managing complex medical conditions can undermine parents' confidence in their caregiving abilities. Furthermore, this study found a correlation between symptom burden and increased health service utilisation, indicating that greater symptom severity often leads to a higher demand for healthcare service use. This implies that while less severe symptoms can be managed at home with support from healthcare professionals, more serious and newly emerging symptoms may require immediate support from health professionals. Priority should be given to proactively enhancing parental competence in symptom management and developing triage protocols to guide nurses and healthcare professionals in advising parents of CMC on whether to visit the accident and emergency department or attend an outpatient clinic.

Implications for nursing practice and health policy

The severity of symptom burden directly affects parental self-efficacy and child health service utilisation. Supporting parents in managing their children's health needs by enhancing their self-efficacy through proactive strategies such as structured telephone calls is vital in mitigating the challenges associated with symptom burden. This approach can ultimately improve the quality of life for both CMC and their parents. Currently, there is a severe shortage of nursing and medical taskforces locally and globally. Besides, the pandemic outbreak of communicable diseases such as Covid-19 may also hinder paediatric home visitation. This underscores the importance of reviewing the delivery mode of existing paediatric home nursing services and evaluating the role of health technology applications within them.

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12912-025-04084-8.

Supplementary Material 1

Supplementary Material 2

Acknowledgements
We would like to thank all the parents and children who took part in this research study.

Author contributions

Study design: WL, VN, CF. Data collection: WL, VN. Data analysis: WL, VN, RC, RTG. Study supervision: WL, VN. Manuscript writing: WL, VN, RC, RTG. Critical revisions for important intellectual content: WL, CF.

Funding
The work presented in this paper was fully supported by the Research Grants Council of the Hong Kong Special Administrative Region, China, in 2023 (Project No. PolyU15103622).

Data availability

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

Declarations

Ethics approval and consent to participate

Ethical approvals were obtained from the Institutional Review Board of Hong Kong Polytechnic University (Reference number HSEARS20220913002) and the special schools before data collection started. This study adhered to the Declaration of Helsinki. Prior to the implementation of the program, written consents were obtained from the participants, and they were provided with a detailed explanation of the study objectives, procedure, and ethical issues. The parents were told that participation in the research study was voluntary, and they could withdraw at any time. The names of parents and the special schools were kept anonymous in any publications and reports.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

Received: 25 April 2025 / Accepted: 3 November 2025

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