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Parental Stress as the Mediator Between Symptom Burden and the Quality of Life of Chinese Children With Cancer

KEY WORDS

Cancer
 Child
 Parental stress
 Pediatric quality of life
 Symptom burden

Background: Because of their cancer and treatment adverse effects, most pediatric oncology patients will experience 1 or more symptoms at one time that can seriously affect their quality of life. Because these children are attached to parents, their symptom burden directly influences the parental stress level and parental interpretations of their children's quality of life. **Objective:** The aim of this study was to examine the association between child-reported symptom burden and the pediatric quality of life reported by children with cancer and their parents, and whether parental perceived stress mediates these relationships. **Methods:** In a cross-sectional design, convenience sampling was used to recruit 80 parent-child dyads. Advanced statistical methods were adopted to analyze the mediating effects of parental stress between children's symptom burden and their quality of life. **Results:** The results revealed that parental stress was the mediator in the relationship between child-reported symptom burden and children's quality of life reported by parents. The results also showed that parental stress was not a mediator in the relationship between child-reported symptom burden and their quality of life. This underscored the differences in interpretations of quality of life reported by children and their parents. **Conclusion:** Children's symptom burden is an important factor in predicting parental stress level and the quality of life reported by the children. Children's

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voice should be incorporated whenever possible. **Implications for Practice:** The knowledge gained from this study will facilitate intervention development to enhance parents' abilities in stress management and symptom management for their children with the support of the nursing profession.

A diagnosis of cancer causes a crisis not only for the child but also for the entire family.¹ Every year, approximately 34 000 new cases of pediatric cancer occur in mainland China and 180 occur in Hong Kong.^{2,3} Typical cancer treatment phases can be classified into acute chemotherapy, maintenance therapy, and posttreatment survivorship.⁴ Most of these children experience high levels of physical and/or psychological symptom burdens in the acute phase, particularly when receiving chemotherapy and/or radiotherapy. After completion of the intense phase of acute chemotherapy and long hospitalization, children will enter the phase of maintenance chemotherapy and be discharged from hospital to home if their health condition reaches an optimal level. Cancer and treatment adverse effects can continue to cause physical and psychological suffering to children, most of whom will experience 1 or more symptoms at a time that can seriously affect their physical and psychosocial well-being.^{5,6}

Parents, as the main caregivers, have to take on the role of care provider to comfort the unwell children at home. For example, they manage the child's symptoms, provide related nursing care, attend medical follow-up appointments, and so forth. Children are attached to their parents. Parent-child interaction operates according to the concept of reciprocal determinism, which is dynamic and involves a parent and a child mutually influencing each other.⁷ The severity of the symptom burden directly lowers the child's quality of life and concurrently increases the level of parental stress.^{8,9} The greater the symptom burden experienced by the children, the greater the caregiving demands placed on the parents. Cancer causes more stress, anxiety, and fear to parents than other chronic diseases.^{8,10-13} This distress does not diminish over time.^{14,15}

Stress might increase the likelihood of reporting bias.¹⁶ Evidence shows that parental stress level might influence the parents' interpretation of their children's health outcome. For example, when a child was thought to be anxious, parents more frequently experienced higher psychological distress and perceived the quality of life of the child to be lower.¹⁷ In addition, parents with emotional disturbances often reported a higher symptom burden for their children.¹⁸ Importantly, parents' interpretation of their children's symptom burden and quality of life directly affected the healthcare they provided to their unwell children.

Research studies have found that parental stress has a mediating effect between a child's quality of life and the barriers to health services, or a child's quality of life and the family's lifestyle.^{19,20} However, its mediating effect between the child-reported symptom burden and the child's quality of life has not been examined. Hence, it is worth including parents' views when examining the associations among child-reported symptom burden, parental stress, and children's quality of life. The aim of this study was thus to test the association between the child-reported symptom burden and the pediatric quality of life reported by the children and their parents, and to determine whether parental perceived

stress mediates these relationships. Understanding these associations would help in identifying children and parents who are at a greater risk of poor health outcomes and the potential pathway by which this outcome occurs. This information will further facilitate the development of effective and sustainable interventions to enhance children's quality of life and reduce parents' stress level.

■ Methods

Study Design

This was a cross-sectional exploratory study. A questionnaire with close-ended questions was used in this study to gather the data.

Sample

Convenience sampling was used to recruit 80 parent-child dyads in this study. All children and parents were Chinese and living at home. The inclusion criteria for the children were as follows: (1) being aged between 10 and 18 years, (2) being given a diagnosis of any type of pediatric cancer, and (3) ability to communicate in and read Chinese. The inclusion criteria for the parents were as follows: (1) being a parent of a child with cancer and (2) ability to communicate in and read Chinese.

The exclusion criteria were as follows: (1) child having been admitted to a hospital in the previous 7 days, (2) child having been newly given a diagnosis of cancer within the previous 12 months, (3) child being in survivorship having completed cancer treatment, (4) child and parent receiving end-of-life service, and (5) parent or child reported as having a mental health disorder.

Procedures

The eligible children and one of their parents were identified and referred by the pediatric teams of 2 participating hospitals in Shenzhen, China, and 1 participating hospital from Hong Kong, China, during their outpatient consultations within the period from December 2019 to January 2021. Self-administered questionnaires were used to collect data from children and their parents. Children and parents were interviewed individually at the same time in different corners of a single interview room provided by the outpatient clinics. The research assistant would explain the purpose of the questionnaire and how to complete it to the children and parents before data collection.

Measures

Demographic data were collected to provide a context for the children and parents. This information included (1) parents' age, marital status, education level, financial status, and insurance

coverage for the child and (2) the children's age, diagnosis, disease status, frequency of admissions in the past year, and total number of hospitalized days of all admissions in the past year.

MEMORIAL SYMPTOM ASSESSMENT SCALE 10-18 (CHINESE VERSION)

The Memorial Symptom Assessment Scale (MSAS) 10-18 is a 30-item MSAS (Chinese version) used to measure the occurrence, frequency, intensity, and distress of symptoms reported by Chinese children with cancer aged 10 to 18 years in the previous 7 days.^{21,22} The scale consists of 3 subscales: a physical subscale, a psychological subscale, and a global distress index. The overall reliability has been found to be satisfactory, with a Pearson correlation coefficient of 0.95. Dichotomous questions are used to measure the occurrence of symptoms. The items for measuring the frequency and intensity of symptoms are rated on a 4-point Likert scale from 1 (almost never) to 4 (always). The items for measuring distress are rated on a 5-point Likert scale from 1 (not at all) to 5 (very). An overall MSAS score was calculated based on the responses from the 30 items, with a possible range 0 to 4 of each item and a higher score indicating a higher level of symptom burden in the children. The Cronbach's α value of this scale in the current samples was 0.869.

PEDIATRIC QUALITY-OF-LIFE INVENTORY (CHINESE VERSION)

The Pediatric Quality-of-Life Inventory was developed to capture the multidimensional construct of health-related quality of life among pediatric patients. It is a self-reported instrument, including physical, psychosocial, and school functioning dimensions, reported by the child and his/her parent. Individual items are rated by the child and the parent on a 5-point Likert scale from 0 (never) to 4 (almost always). The internal consistency was an α coefficient of .89. The test-retest reliability coefficient was 0.79.²³

PERCEIVED STRESS SCALE-10 (CHINESE VERSION)

The 10-item version of the Perceived Stress Scale (PSS-10) was used to measure the degree to which situations in one's life are appraised as stressful.²⁴ Each item is rated by parents on a 5-point Likert scale, ranging from 1 (not at all) to 5 (extremely). The overall score of PPS-10 was calculated by summing up the 10 items, with a possible range 0 to 40 and a higher score indicating greater parental stress. The Cronbach's α value of the PPS-10 was 0.603 in the current samples.

Ethical Consideration

Ethical approvals were obtained from the Human Research and Ethics Committee of the university and the 3 participating hospital outpatient clinics before data collection commenced. Written consents were obtained from parents and their children, and they were provided with a detailed explanation of the study purpose, procedure, and ethical issues before the interviews started. The parents and children were informed that participation in the research was voluntary and that they could withdraw at any time. The names of the parents, children, and outpatient clinics were substituted by codes and kept anonymous in any publication.

Statistical Analysis

Analyses were performed using SPSS (version 26). Descriptive statistics were reported by percentage or mean (SD), as appropriate to summarize 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 3.4 with the regression bootstrapping method (Hayes, 2018) was used to test the proposed hypotheses. Specifically, 2 sets of mediation analyses were performed by examining the mediating effect of the parents' perceived stress (M) on the relationships of the children's symptom burden (X) with their self-reported quality of life (Y_1) and parent-reported quality of life (Y_2), respectively. 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 macro-generated 5000 bootstrap samples with a 95% confidence interval (CI). A P value of less than .05 was considered statistically significant.

Results

A total of 80 Chinese children with cancer and their parents were included in this study. Among the children, 44 (55.0%) were male and the average age was 12.3 years. They were given a diagnosis of cancer at 9.6 years old on average, and most of them (85.0%) were in the initial treatment phase. Most had followed their doctor's instructions to continue the treatments for cancer. Most of the respondents reported that the medical cost due to the cancer-related treatment was paid by themselves or social insurance. The mean number of admissions to the hospital in the past year for the children was 3.0, with a mean length of stay of 15.2 days. Furthermore, 57.5% of the children had deferred their studies because of the disease (Table 1). Among the parents, most were mothers of children with cancer, and their average age was 40.5 years. Approximately half of them had a full-time or part-time job, and most of them had education to secondary/postsecondary/tertiary level, did not have any religion, and were married. In addition, 68.8% of them reported good or very good perceived economic status. They reported that they had taken, on average, 92.1 days away from work to take care of their children (Table 2).

Table 3 summarizes the descriptive statistics of the children's symptom burden, self-reported quality of life, and parent-reported quality of life, as well as the parents' perceived stress level. The mean levels of symptom burden in the children and the perceived stress in the parents were low. The children's mean level of self-reported quality of life was high, whereas their quality of life as reported by their parents was moderate. The scores of the children's symptom burden correlated significantly and negatively with the scores for the children's self-reported and parent-reported quality of life, and positively with parents' perceived stress. The parents' perceived stress scores were associated significantly and positively with the children's symptom burden scores and negatively with the children's self-reported and parent-reported quality of life. Bivariate analyses found that 4 demographic variables—relationship

Table 1 • Sociodemographics of Children

| N = 80 | |
|---|-------------|
| Gender | |
| Male | 44 (55.0%) |
| Female | 36 (45.0%) |
| Average age, y | 12.3 ± 2.1 |
| Average age of receiving diagnosis of the illness, y | 9.6 ± 2.5 |
| Treatment stage | |
| Initial treatment | 68 (85.0%) |
| Treatment for relapsed case | 12 (15.0%) |
| Diagnosis of case receiving initial treatment | |
| Hemopoietic malignancies | 41 (60.3%) |
| Tumor | 27 (39.7%) |
| Diagnosis of relapsed case | |
| Tumor | 12 (100%) |
| Stopped treatment and did not follow doctor's prescription | |
| No | 78 (97.5%) |
| Yes | 2 (2.5%) |
| Medical expense supported by self-finance | |
| Yes | 47 (58.8%) |
| No | 33 (41.3%) |
| Medical expense supported by donation | |
| Yes | 5 (6.3%) |
| No | 75 (93.8%) |
| Medical expense supported by insurance | |
| Yes | 7 (8.8%) |
| No | 73 (91.3%) |
| Medical expense supported by Rural Cooperative Medical Care | |
| Yes | 14 (17.5%) |
| No | 66 (82.5%) |
| Medical expense supported by social insurance | |
| Yes | 52 (65.0%) |
| No | 28 (35.0%) |
| Medical expense subsidized by the government | |
| Yes | 5 (6.3%) |
| No | 75 (93.8%) |
| Average no. times of admissions in the past year | 3.0 ± 6.9 |
| Average no. days of hospitalization in the past year | 15.2 ± 37.8 |
| Deferred study because of the disease in the past year | |
| Yes | 46 (57.5%) |
| No | 34 (42.5%) |

with the child, parent's employment status, child's gender, and number of days of hospitalization—were significantly associated with the child's symptom burden or the parent's perceived stress; deferment of study in the past year was significantly associated with children's self-reported and parent-reported quality of life; and family financial status was significantly associated with child-reported quality of life. Hence, they were added to the mediation analyses to control for their effects.

Using the PROCESS macro (Hayes, 2018), 2 sets of mediation models were tested. The first examined the direct and indirect effects of the children's symptom burden on their quality of life through parental stress, controlling for 6 covariates (relationship with the child, parent's employment status, family financial status, child's gender, number of days of hospitalization, and deferment of the study) (Figure 1). The bootstrapping results showed that the children's symptom burden had significant direct effects on parents' perceived stress ($B = 5.321$; 95% CI, 1.757–8.885)

and children's quality of life ($B = -28.307$; 95% CI, -42.981 to -13.633), but the mediating effect of parents' perceived stress was not statistically significant ($B = -0.287$; 95% CI, -7.302 to 5.028).

Figure 2 shows the results of the mediation analysis of parents' perceived stress on the relationship between symptom burden and parent-reported children's quality of life, controlling for 5 covariates (relationship with the child, parent's employment status, family financial status, child's gender, number of days of hospitalization, and deferment of the study). The direct effect of the symptom burden on parents' perceived stress was significant ($B = 5.335$; 95% CI, 1.793–8.877), and the direct effects of symptom burden ($B = -11.269$; 95% CI, -26.089 to 3.551) and parents' perceived stress ($B = -0.856$; 95% CI, -1.822 to 0.110) on the children's quality of life were not significant. The indirect effect of symptom burden on parent-reported children's quality of life via parents' perceived stress was significant ($B = -4.566$; 95% CI, -13.127 to -0.001).

Discussion

To our knowledge, this is the first study to fill the knowledge gap by providing an understanding of the associations among child-reported symptom burden, parental stress level, and children's quality of life. The mediating effect of parental stress between

Table 2 • Sociodemographics of Parents

| N = 80 | |
|---|--------------|
| Sex | |
| Male | 17 (21.3%) |
| Female | 63 (78.8%) |
| Age, y | 40.5 ± 4.7 |
| Employment status | |
| Full-time | 29 (36.3%) |
| Part-time | 16 (20.0%) |
| Unemployed | 35 (43.8%) |
| Educational level | |
| Primary school | 4 (5.0%) |
| Secondary school | 47 (58.8%) |
| Postsecondary/tertiary | 27 (33.8%) |
| Postgraduate | 2 (2.5%) |
| Religion | |
| No | 55 (68.8%) |
| Worshipping ancestors | 10 (12.5%) |
| Christianity | 5 (6.3%) |
| Buddhism | 10 (12.5%) |
| Marital status | |
| Married | 70 (87.5%) |
| Others ^a | 10 (12.5%) |
| Family financial status | |
| Poor | |
| Good | 25 (31.3%) |
| Very good | 48 (60.0%) |
| | 7 (8.8%) |
| Average no. days left from work because of taking care of the child | 92.1 ± 142.5 |

^aIncluding single, divorced, and widowed.

**Table 3 • Descriptive Statistics of MSAS, PSS-10, Parent-Reported PedsQL, and Child-Reported PedsQL**

| | Mean ± SD | MSAS | | PSS-10 | | Parent-Reported PedsQL | | Child-Reported PedsQL | |
|------------------------|-------------|--------|-------|--------|------|------------------------|-------|-----------------------|-------|
| | | r_s | P | r_s | P | r_s | P | r_s | P |
| MSAS | 0.28 ± 0.28 | — | — | 0.376 | .001 | -0.293 | .008 | -0.474 | <.001 |
| PSS-10 | 17.8 ± 4.2 | 0.376 | .001 | — | — | -0.320 | .004 | -0.241 | .031 |
| Parent-reported PedsQL | 69.8 ± 17.9 | -0.293 | .008 | -0.320 | .004 | — | — | 0.681 | <.001 |
| Child-reported PedsQL | 75.9 ± 18.3 | -0.474 | <.001 | -0.241 | .031 | 0.681 | <.001 | — | — |

Abbreviations: MSAS, Memorial Symptom Assessment Scale; PedsQL, Pediatric Quality-of-Life Inventory; PSS-10, 10-item Perceived Stress Scale.

child-reported symptom burden and parent-reported children's quality of life in a Chinese population has also been identified. This knowledge may shed light on the development of future interventions for pediatric cancer care in relation to parental stress management and children's involvement in decision making.

Priority Service Need to Enhance Parents' Abilities in Stress Management and Symptom Management for Their Children

Parents of a child with cancer are predisposed to psychological distress. The diagnosis, along with caring for children with cancer, evokes various emotional reactions (ie, stress, depressed mood) in these parents. The results of this study indicate that children's symptom burden is significantly associated with parents' perceived stress level ($P = .001$). Parents, as caregivers, might become hidden patients if they are under persistent stress and are unattended by health professionals. Under such circumstances, parents' health condition and caregiving role might be more likely to be impaired; thus, the quality of the care they provide to their children with cancer might also be adversely affected.²⁵

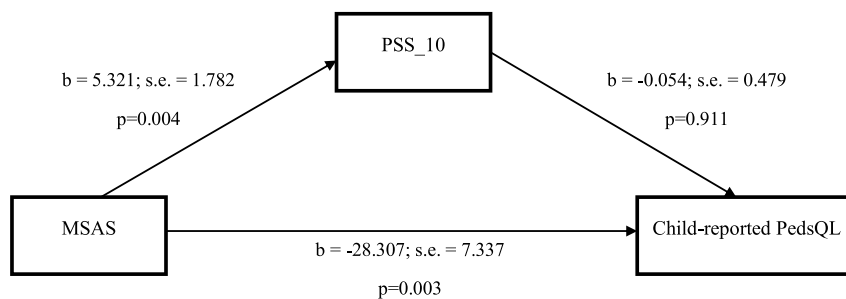
Yi-Frazier et al²⁶ reported that parents who managed their own stress well might be more successful in caring for their children's medical needs. As such, health service to enhance parents' abilities in stress management is of paramount importance in cancer care and needs to be addressed by health professionals immediately. Although psychological support for parents of children with cancer has been identified as one of the most important aspects of cancer care,²⁷ existing local pediatric cancer services are often primarily focused on the children. The parents' health might be left

unattended. Thus, it is crucial to provide regular screening for these parents to ensure their optimal health outcomes. Intervention development specifically for enhancing parental abilities to maintain mental health in the face of stress should also be implemented. The potential benefits of controlling stress levels and seeking social supports should be promoted to parents in a proactive way, because these would help them to cope with their caregiving role and improve their quality of life.^{25,28}

The findings of this study indicated that symptom burden was prevalent in Chinese children with cancer and directly influenced their parents' stress level ($P = .004$). Children may experience more than 1 symptom at one time, and these symptom burdens directly affect their quality of life ($P = .003$). Children are attached to their parents, and they will interact on a daily basis. When they feel unwell, they need their parents' support in symptom management. This is challenging for parents, because they may have less experience in handling various symptoms within a short period by themselves at home. Thus, local health authorities should consider parental training in symptom management with nurses' support as one of the cornerstones in pediatric cancer care.²⁹ The development of such an intervention will alleviate the symptom burden of children having cancer with the goal of improving their quality of life, as well as extending its potential benefits to promoting the emotional well-being (ie, stress reduction) of their parents.

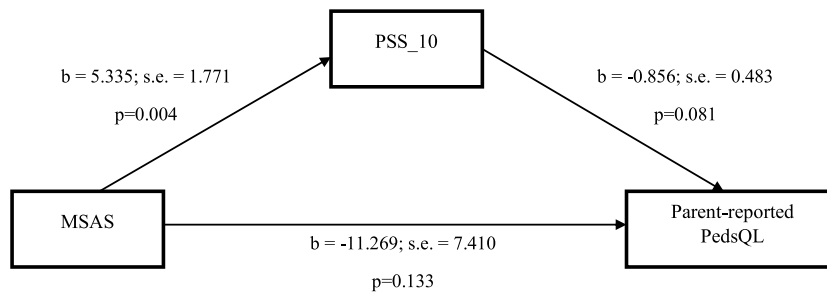
Advocacy of Children's Involvement in Medical Decision Making

An interesting finding of this study was that parental stress was a mediator that impacted the relationship between children's symptom burden and their quality of life as reported by their parents.



The indirect effect (IE = -0.287) is not statistically significant: 95%CI = -7.302 – 5.028.

Figure 1 ■ Mediating effect of parents' stress on the relationship of children's symptom burden with children's quality of life. (Covariates included relationship with child, parent's employment status, family financial status, child's gender, number of days of hospitalization, and deferment of study.)



The indirect effect (IE= -4.566) is statistically significant: 95%CI = -13.127 – -0.001.

Figure 2 ■ Mediating effect of parents' stress on the relationship of children's symptom burden with parent-report children's quality of life. (Covariates included relationship with child, parent's employment status, child's gender, number of days of hospitalization, and deferment of study.)

However, it was not a mediator between children's symptom burden and their self-reported quality of life. This might be due to the discrepancies observed in this study between the scores for children's self-reported and parent-reported quality of life. The mean scores of child-reported pediatric quality of life (mean, 75.9) were higher than those of parent-reported pediatric quality of life (mean, 69.8).

The findings were congruent with the evidence from previous research studies—that parents' and children's interpretations of children's health condition might vary.³⁰ Pediatric patients' self-report was regarded as the criterion standard for identifying the presence of a symptom.^{31,32} Historical reliance on the reporting of health condition (ie, the child's symptom burden) by parents was problematic because many symptoms are subjective (eg, pain, fatigue, and worry).^{17,30} Furthermore, evidence has demonstrated that surrogate assessments tend to be inaccurate and parent proxies are prone to reporting bias, particularly among parents who are in psychological distress.³³ Health professionals should be aware of the differences of proxy ratings between parents and children regarding children's health conditions, particularly when doing health assessments and planning health interventions. As recommended, children's ideas on their symptom experiences and health conditions should be well considered and validated in medical decision making so as to fit the children's actual needs, enhance their compliance with cancer care, and minimize their psychological distress during cancer care.^{33,34} Hence, children should be included in parent–health professionals' communications to a certain extent, regarding their medical condition and treatment plan.

Future research studies should be conducted to understand (1) the proxy rating of health conditions (ie, symptom burden) and health outcomes (quality of life) reported by children with cancer and their parents and (2) the interpretation on children's quality of life from the unwell children as well as their parents. The knowledge and evidence may facilitate explanation of these disagreements and assist health professionals in setting priorities for developing home interventions for symptom management for pediatric oncology patients and their parents.

Limitations and Recommendations

The relatively small sample size and convenience sampling adopted in this study may limit the generalizability of the study

findings. Considering the variances in cultural backgrounds, there is a difference in stress adjustment between Chinese parents and Western parents.³⁵ Chinese people's life situations are predetermined externally and cannot be changed; therefore, they have to endure it with courage. In Western culture, people may take an active role in removing the stressor rather than accepting it as a part of life.³⁶ Thus, the perceived stress level might be different in Chinese and Western parents, and the findings may not be fully generalized to other cultures. Furthermore, because most participating parents were mothers (78.8%), caution must be taken when generalizing results to all parents, because fathers' perceptions of stress and their interpretation of their children's quality of life might vary. Another limitation is the marginal internal consistency of PSS-10 of 0.603 in the current study, which might reflect measurement errors in this tool among parents of children with cancer. Although the PSS has been shown to have good psychometric properties in the general Chinese population,³⁷ further psychometrical testing of the tool in parents of cancer children is warranted. Future studies should examine the replication of the study to confirm the study results across different regions, genders, and cultural backgrounds, with larger samples.

Conclusion

The findings of this study contribute to the literature findings that symptom burden is a common health problem among Chinese children with cancer. The symptom burden is highly associated with parental stress, which can adversely affect children's quality of life. This evidence is important in paving the path for the development of future interventions. Parents' resilience in stress management and the enhancement of their abilities in symptom management for their children should be a priority for health authorities to address. Differences in the interpretation of pediatric quality of life were observed between parents and children. Children's voices should be taken into consideration when planning and implementing cancer care for children.

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