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RESEARCH ARTICLE

Agreement Between Child Self-Report With Parent Proxy Report on the Quality of Life of Children With Medical Complexity: A Cross-Sectional Study

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ABSTRACT

Objective: This is the first study to investigate the agreement between children's self-reports and parents' proxy reports on the quality of life (QoL) of children with medical complexity in the Chinese context. We further examined if there were differences in the concordance between children's self-reports and parents' proxy reports.

Methods: A cross-sectional study of 113 parent–child dyads was conducted on parents and their children aged 10–18 years with a diagnosis of medical complexity. The intra-class correlation coefficients between the scores of children and parents were excellent in total PedsQL and physical functioning, good in school functioning, and fair in social functioning and emotional functioning.

Results: Children rated themselves better than their parents for emotional, social, school, and physical functioning. Discordance between the emotional and social components was observed from parent-reported and child-reported. There are some discrepancies in interpretation on pediatric QoL between children with medical complexity and their parents.

Conclusion: The study suggested both parents and children's voices should be taken into account during health assessments and health-decision making to ensure tailor-made and appropriate nursing care is provided to the CMC.

1 | Background

Children with medical complexity (CMC) are an increasing population requiring clinical and research initiatives (Cohen and Patel 2014). These children are defined as those with chronic medical conditions coupled with a congenital or acquired multisystem disease, a severe neurologic condition, or cancer with marked functional impairment which may result in premature death (Pediatric Complex Care Association 2016; Liu et al. 2013; Huijer et al. 2013). Because of the disease itself and side effects brought from the medical treatment, the majority of these children will experience physical symptoms along with psychological distress (Ullrich et al. 2018; Liu et al. 2013) which can seriously lower their QoL in terms of physical, psychosocial, and school function (Cohen et al. 2011; Huijer et al. 2013). According to the international epidemiological data, the prevalence of children with medical complexity was less than 1% of all children in a given population (Amarri et al. 2021; Cohen et al. 2012;

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Summary

- Children with medical complexity (CMC) are defined as those with chronic medical conditions coupled with a congenital or acquired multisystem disease, a severe neurologic condition, or cancer with marked functional impairment that may result in premature death.
- The chronic medical complexity not only affects the QoL of these children in different spheres of life but also their parent's mental health.
- There is an urgent need to shed light on the level of agreement on the quality of life between Hong Kong Chinese CMC and their parents. Additionally, there is a need to identify and suggest how nurses can help address the discrepancies during assessment and daily pediatric nursing care.

Yamada et al. 2020). In Hong Kong, it was estimated that around 1500 CMC require constant access to nursing services and support every year (MingPoa News 2018; Child Assessment Service, Hong Kong Department of Health 2017).

The chronic medical complexity not only affects the QoL of these children in different spheres of life but also their parent's mental health. Parents, as the main caregivers, are often confined to home due to caregiving activities (Chung et al. 2018). Difficulties are experienced in obtaining community resources, and help gaining and clarifying information about their child's condition (Barke et al. 2016; Band-Winterstein and Avieli 2017). Under such conditions, parents may feel challenged and stressed caring for their children's health condition and maintaining family daily activities (Di Pede et al. 2018). When children are sick, the unstable health condition can increase parents' psychological distress that affects their interpretation of their children's QoL, causing reporting bias of parent proxies (Eche et al. 2019; Lam et al. 2022). A review of the literature reveals that, so far, no study has examined the agreement between children's self-reports and parent-proxy reports on the QoL of CMC in the Hong Kong Chinese context. Due to Hong Kong's sociocultural emphasis on academic performance, social conformity, and avoidance of being deviant and a restrictive approach to child rearing (Pryde and Tsoi 1999; Lam et al. 2016), the perceived QoL in Chinese children and their parents in Hong Kong may be different from the West. The purpose of this study was to shed light on the level of agreement on the QoL between Hong Kong Chinese CMC and their parents, as well as to identify and suggest how nurses can help to address the discrepancies during assessment and daily pediatric nursing care.

2 | Study Aims

The aim of this study was to investigate the agreement between children's self-reports and parents' reports of QoL in CMC. We then further examined if there were differences in the concordance between children's self-reports and parents' reports of children's QoL by associated factors in these children.

3 | Materials and Methods

3.1 | Study Design

A cross-sectional exploratory study was employed in this study using a questionnaire with closed-ended questions to gather the data.

3.2 | Study Sampling

A convenience sampling strategy was adopted to recruit 113 parents and their CMC in this study. The prior sample size calculation assumed a correlation of $r \geq 0.3$, alpha = 0.05, and beta = 0.1. With these parameters, a sample of 113 patients was shown to be statistically sufficient. All participants were Chinese and living at home with regular medical follow-up. The inclusion criteria for the children were (1) between 10 and 18 years of age, (2) described as a CMC confirmed by the pediatrician team, and (3) able to communicate in Chinese and read Chinese. The inclusion criteria for the eligible parents were (1) a parent of a CMC, and (2) able to communicate in Chinese and read Chinese. The exclusion criteria were (1) child having been newly diagnosed as a child with medical complexity within the last 12 months; (2) child and parents receiving bereavement services; and (3) parent or the child reported as having a mental health disorder.

3.3 | Procedures

The eligible children and one of their parents were identified and referred by the pediatrician team at the two participating hospitals in Shenzhen, China, and one participating hospital in Hong Kong during their out-patient consultations within the period from December 2019 to January 2021. Self-administered questionnaires were adopted 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 out-patient clinic. The research assistant would explain to the children and parents the purpose of the questionnaire and how to complete it before data collection commenced.

3.4 | 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, religion and (2) the children's age, diagnosis, age of diagnosis, treatment stage, and deferment of study in the past year.

3.5 | Pediatric Quality-Of-Life Inventory (PedsQL) (Chinese Version)

PedsQL is a self-reported instrument, including physical, emotional, social, and school functioning dimensions, reported by the child and his/her parent. It is used to capture the multidimensional construct of health-related QoL among pediatric patients. Individual items are scored by parents and their children on a five-point Likert scale from 0 (never) to 4 (almost always).

The overall score of the PedsQL ranged from 0 to 100, with a higher score indicating better child QoL. The internal consistency was an alpha coefficient of 0.89. The test–retest reliability coefficient was 0.79 (Varni et al. 2002). The PedsQL was rated by both the children and their parents in the current sample, with Cronbach's alpha values of 0.931 for children and 0.934 for parents, respectively.

3.6 | Statistical Analysis

Analyzes were performed by SPSS (version 26.0). Descriptive statistics were calculated for CMC and parent characteristics, with categorical variables presented as observed frequencies and proportions and continuous variables in means and standard deviations (SDs). Agreement between parent proxy-reports and children self-report PedsQL was assessed at both individual and group levels (Upton et al. 2008). Agreement at the group level was evaluated using paired-sample *t*-tests, and agreement at the individual level was evaluated by the two-way random model (absolute agreement, average measures) intra-class correlation coefficients (ICC). The strength of ICC was interpreted as poor agreement if $ICC < 0.4$; fair agreement if $0.4 < ICC < 0.59$; good agreement if $0.6 < ICC < 0.74$; excellent agreement if $ICC \geq 0.75$ (Cicchetti 1994). A series of mixed factorial ANOVA further assessed the mean differences in PedsQL overall scores, subscale scores, and domain scores between children self-reports and parent reports with the control of associated factors at the group level (Murrar and Brauer 2018). The variable called *type of measure* was created to indicate the source of the reported PedsQL scores (i.e., children self-reports vs. parent-proxy reports) and examined as a within-subject factor, and between-subject factors included the associated factors of children's age, gender, age at diagnosis, treatment stage, and deferment of school and parent's age and stress. A significant result on the within-subjects factor indicates that there is a significant effect of children self-reports and parent-proxy reports on PedsQL after controlling the effects of the associated factors, and a significant interaction term between type of measure and the associated factor indicates the effect of the associated factor on level of agreement is different according to the level of the associated factor.

4 | Results

A total of 113 CMC and their parents were included in this analysis. Among the children, 56 (49.6%) were male and the average age was 12.3 years They were diagnosed with the disease at the age of 8.2 years; a majority were diagnosed with diseases that may be treated potentially but can fail to respond (70.8%), and most of them (78.8%) were in the initial treatment stage. Most of them (94.7%) had followed the doctor's instructions to continue the treatments for the disease, while half of the children (51.3%) had deterred study because of the disease in the past year (Table 1).

TABLE 1 | Sociodemographic information of children.

Variable	*N* = 113
Sex	
Male	56 (49.6)
Female	57 (50.4)
Average age in year	12.3 ± 2.0
Average age of the diagnosis	8.2 ± 3.9
Type of medical conditions	
May be treated potentially but can fail to respond i.e., cancer, irreversible organ failure	80 (70.8)
Needs to have intensive treatment for maintenance of daily living i.e., Duchenne muscular dystrophy	19 (16.8)
Progressive and cannot be cured i.e., metabolic disorder, chromosomal abnormality	8 (7.1)
Irreversible and non-progressive complicated with severe disability or even premature death i.e., cerebral palsy, brain or spinal cord injury	6 (5.3)
Treatment stage	
Initial treatment	89 (78.8)
Treatment for relapsed case	24 (21.2)
Stopped treatment and did not follow doctor's prescription before	
No	107 (94.7)
Yes	6 (5.3)
Deferred study due to the disease in the past year	
Yes	58 (51.3)
No	55 (48.7)

Among these parents, most (78.8%) were the mothers of CMC and the average age of them was 41.3 years. About half of them (47.8%) were unemployed or retired, and the majority (91.2%) had education at secondary/post-secondary/tertiary level, were married (85.0%) and did not have any religion (69.9%). It was reported by 34.5% as having poor perceived economic status and low mean level of stress (Table 2).

4.1 | Agreement in Children's Self-Reports and Parent-Proxy Reports in PedsQL

Health related quality of life (HRQOL) refers to the quality of life relative to one's health or disease status. Table 3 summarizes the descriptive statistics of children's self-reports and parent-proxy reports of HRQOL for the total and the domain scores as measured by PedsQL and the agreement between children's and parents reports of these scores. The children reported high mean levels in HRQOL for the total, emotional functioning, and social functioning scores and moderate levels in school functioning scores and physical functioning of PedsQL. On the other hand, the parents reported high levels in the emotional functioning and social functioning scores and moderate levels in the other PedsQL scores.

At the individual level, ICCs ranged from 0.49 to 0.83, indicating fair to excellent agreement. The results of the agreement in the ICC were excellent between the child self-reports and parent proxy reports of HRQOL for physical functioning and total score. Good agreement was found in school functioning while fair agreement was found in emotional functioning and social functioning. At the group level, paired-sample *t*-tests results revealed that children reported higher scores than their parents on the total and four domain PedsQL scores. Significant differences were found on all except one, including the total PedsQL scores ($d=6.7$; $p<0.001$), emotional functioning domain ($d=10.4$; $p<0.001$), social functioning domain ($d=9.1$; $p<0.001$), physical functioning domain ($d=6.0$; $p=0.003$), while the difference in school functioning was non-significant ($d=1.6$; $p=0.5$).

TABLE 2 | Sociodemographic information of parents.

Variables	$N=113$
Sex	
Male	24 (21.2)
Female	89 (78.8)
Average age in years	41.3 ± 5.6
Employment status	
Fulltime	39 (34.5)
Part time	20 (17.7)
Unemployed/Retired	54 (47.8)
Educational level	
Primary school	10 (8.8)
Secondary school	64 (56.6)
Post-secondary/Tertiary	36 (31.9)
Postgraduate	3 (2.7)
Marital status	
Married	96 (85.0)
Others	17 (15.0)
Religion	
Yes	34 (30.1)
No	79 (69.9)
Family financial status	
Poor	39 (34.5)
Good	66 (58.4)
Very good	8 (7.1)
Stress	18.5 ± 4.8

4.2 | Mean-Level Differences Between Children Self-Reports and Parent-Proxy Reports in PedsQL Scores With the Control of Associated Factors

Table 4 shows the results of mixed factorial ANOVA comparing the mean differences between children's self-reports versus parent-proxy reports in total PedsQL scores with the control of the effects from the associated factors: child's age, sex, deferment of school, treatment stage and age of diagnosis and parent's age and stress level. The main effect of the type of measure was not significant, but significant main effects were found in four associated factors, including child's deferment of school ($p=0.002$) and age of diagnosis ($p=0.033$) and parent's age ($p=0.028$) and stress level ($p<0.001$). No interaction effect was statistically significant.

Results of the comparison of the four domain scores in PedsQL were shown in Table 5. Type of measure had a significant main effect on school functioning ($p=0.038$) and a non-significant effect on physical, emotional, and social functioning, suggesting children's self-reports and parent-proxy reports were close in the latter three PedsQL domains after controlling for the effect of the between-subject factors. Significant main effects were also found in deferment of school on physical functioning ($p=0.030$) and school functioning ($p<0.001$), in child's age of diagnosis of the disease on physical functioning ($p=0.007$) and social functioning ($p=0.018$), in parent's age on social functioning ($p=0.048$) and school functioning ($p=0.025$), and in parent's stress on all the four domains. Notably, the interaction effects of measure type with child's age at disease diagnosis on social functioning and with parent's age on school functioning were

TABLE 3 | Mean, standard deviations, and intraclass correlation coefficient of children's self-reports and parent-proxy reports PedsQL ($N=113$).

PedsQL	Child	Parent	Mean difference (95% CI)	ICC (95% CI)
Total score	72.5 ± 19.9	65.9 ± 19.7	6.7 (3.6–9.7)**	0.77 (0.63–0.85)
Domain score				
Emotional functioning	81.8 ± 19.5	71.4 ± 21.0	10.4 (6.1–14.6)**	0.49 (0.24–0.66)
Social functioning	81.7 ± 21.0	72.6 ± 22.7	9.1 (4.8–12.4)**	0.59 (0.38–0.72)
School functioning	62.0 ± 28.5	60.4 ± 25.1	1.6 (−3.1–6.4)	0.71 (0.58–0.80)
Physical functioning	67.6 ± 28.2	61.6 ± 27.7	6.0 (2.1–9.9)*	0.83 (0.74–0.88)

*$p<0.005$.
**$p<0.001$.

TABLE 4 | Comparisons between children self-reports and parent-proxy reports on total PedsQL scores ($N = 113$).

Variables	*F*-statistic (1105)	*p*
Main effect		
Measure	3.888	0.051
Deferment of school	10.235	0.002
Child's age	0.508	0.478
Child's gender	0.943	0.334
Child's treatment stage	0.254	0.615
Child's age of diagnosis	4.676	0.033
Parent's age	4.955	0.028
Parent's stress	15.205	< 0.001
Interaction effect		
Measure × Deferment of school	0.358	0.551
Measure × Child's age	0.012	0.914
Measure × Child's gender	1.647	0.202
Measure × Child's treatment stage	0.717	0.399
Measure × Child's age of diagnosis	3.304	0.072
Measure × Parent's age	3.182	0.077
Measure × Parent's stress	0.543	0.463

Note: Measure (children self-reports vs. parent-proxy reports).

significant. A larger discrepancy between children's self-reports and parent-proxy reports of social functioning was observed at a younger age of diagnosis, with a pattern of children tending to report higher levels in social function (Figure 1). For school functioning, larger discrepancies were observed in older parents, although for younger parents the estimated mean values of school functioning were closer (Figure 2).

5 | Discussion

To our best knowledge, this is the first research study to fill the knowledge gap by providing an understanding of the agreement between children's self-report and parent proxy-report on the QoL of children with chronic medical conditions. It can be seen that there is a substantial difference between mothers' and fathers' participation in this research (78.8 vs. 21.2). Since the responsibilities of caregiving and hands-on care are usually provided by mothers, this may lead to differences in HRQoL perception between fathers and mothers. Fair agreement of ICC between child and parent in emotion and social functioning was observed. Children reported higher scores (mean = 72.5) than their parents (mean = 65.9) on the total and four domains (school, emotion, social, physical) of PedsQL scores (Table 3). Significant differences were found in the total PedsQL scores and the other three domains (emotion, social, physical). A larger discrepancy for social functioning was observed at a younger age of diagnosis, with a pattern of children tending to report higher levels in social function (Figure 1). For school functioning, a larger discrepancy was observed in older parents, although the estimated mean values of school functioning were close for younger parents (Figure 2). These knowledge and evidence may shed light on the development of future interventions for child and family health care in relation to children's involvement in health assessment and health decision-making.

5.1 | Including Child's Voice in Health Assessment and Health Decision Making

The findings of this study reported that there are significant differences between parent proxy reports and child self-rating on the total PedsQL scores, emotional functioning, social functioning, and physical functioning. Similar to the findings from the study conducted in Germany, children reported higher HRQOL than their parents (Witt et al. 2019). However, contrary to the findings from Witt's study that there was no significant difference in school functioning reported by local Chinese parents and their children. Children's self-report and parent proxy report of QoL are not substitutable (Varni et al. 2007; Eiser and Varni 2013; Sprangers and Aaronson 1992). Parents of sick children should be trained to examine not only physical health, but also emotional and social factors that impact their child's quality of life. Proxy ratings of parent might not reflect the subjective experience of the child, particularly in the aspects of psychological and social aspects because health related quality of life (HRQOL) is an individual's subjective perception of the impact of health status, including disease and treatment (Harmer et al. 2019). Furthermore, surrogate assessment tends to be inaccurate, and parent proxies are prone to reporting bias, particularly among parents who are suffering from psychological distress (Lam et al. 2022). It is important for nurses and other health professionals to gain reliable and valid sources of information when performing health assessments and setting up the treatment plan. Therefore, it is crucial to adopt an individualized approach, providing the child with an opportunity to report his or her own subjective experiences or feelings about health and well-being (Cremeens et al. 2006; Rajmil et al. 2013). The voice of children should be actively involved in parent-health professional communication to provide children with a more tailored and individualized treatment plan; meanwhile, this also helps to enhance children's active compliance with the treatment and nursing care (Shoshani and Kanat-Maymon 2018).

5.2 | Enhancing Parenting Competence in Addressing the Actual Needs of Chinese Children With Medical Complexity

The results of this study echoed other studies that parents tended to underestimate their children's social functioning (Jardine et al. 2014). It might be due to parental judgments based on different reasoning processes, i.e., attending different medical appointments causes missing out staying with schoolmates, etc., and their anticipation of a more negative effect on the disability than the child actually experienced (Lim et al. 2014). Parents

TABLE 5 | Comparisons between children's self-reports and parent-proxy reports on PedsQL domain scores ($N = 113$).

Variables	**Physical functioning**		**Emotional functioning**		**Social functioning**		**School functioning**	
Main effect	***F* (1105)**	***p***	***F* (1105)**	***p***	***F* (1105)**	***p***	***F* (1105)**	***p***
Measure	1.357	0.247	0.361	0.549	3.086	0.082	4.406	0.038
Deferment of school	4.817	0.030	2.968	0.088	3.273	0.073	20.969	< 0.001
Child's age	0.223	0.638	1.311	0.255	0.227	0.635	1.510	0.222
Child's gender	0.036	0.849	1.008	0.318	1.241	0.268	2.114	0.149
Child's treatment stage	0.574	0.450	0.156	0.693	0.003	0.953	0.021	0.884
Child's age of diagnosis	7.578	0.007	0.513	0.475	5.814	0.018	0.003	0.959
Parent's age	3.260	0.074	0.795	0.375	3.994	0.048	5.157	0.025
Parent's stress	7.843	0.006	22.473	< 0.001	7.150	0.009	9.108	0.003
Interaction effect								
Measure × Deferment of school	0.235	0.629	0.686	0.409	0.000	0.997	3.529	0.063
Measure × Child's age	1.203	0.275	1.277	0.261	0.207	0.650	0.095	0.759
Measure × Child's gender	1.662	0.200	0.695	0.406	0.046	0.831	1.228	0.270
Measure × Child's treatment stage	0.021	0.884	0.573	0.451	0.623	0.432	0.784	0.378
Measure × Child's age of diagnosis	2.967	0.088	0.010	0.921	4.457	0.037	1.070	0.303
Measure × Parent's age	3.917	0.050	0.004	0.949	0.056	0.814	6.077	0.015
Measure × Parent's stress	0.530	0.468	3.028	0.085	0.337	0.563	0.021	0.885

Note: Measure (children self-reports vs. parent-proxy reports).

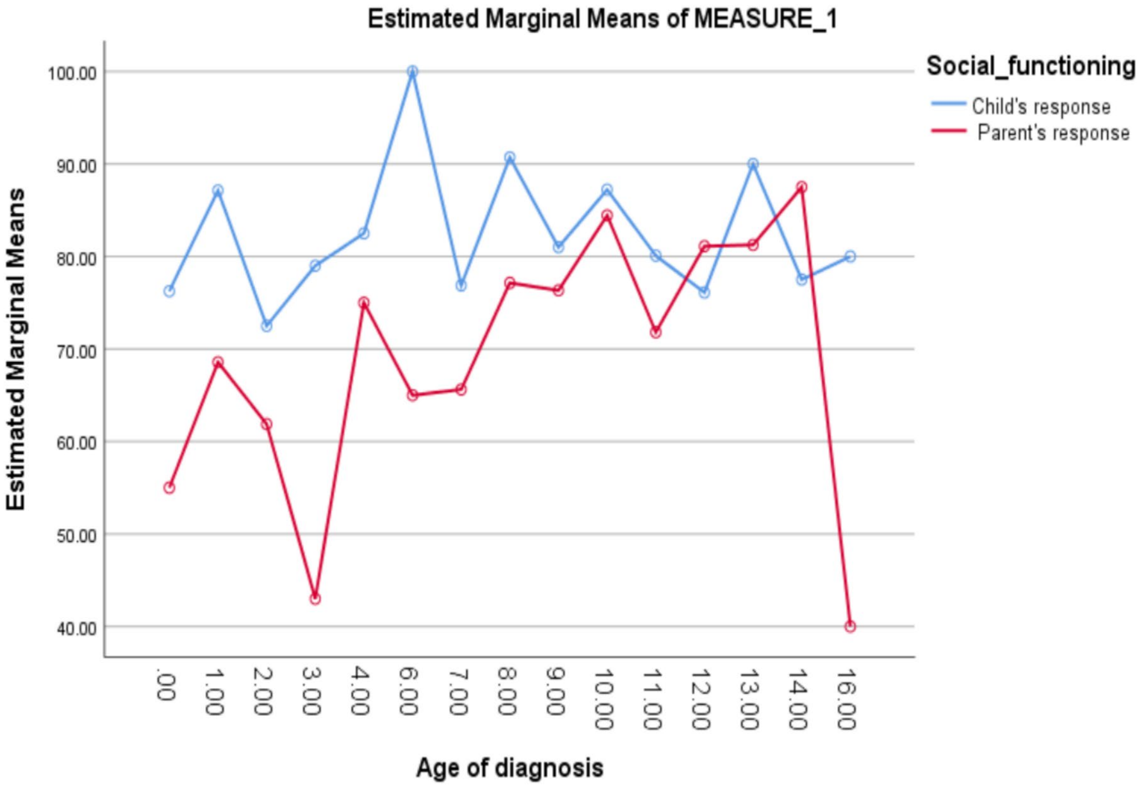

FIGURE 1 | Estimated mean values of social functioning in PedsQL by type of measure and child's age of diagnosis of the disease.

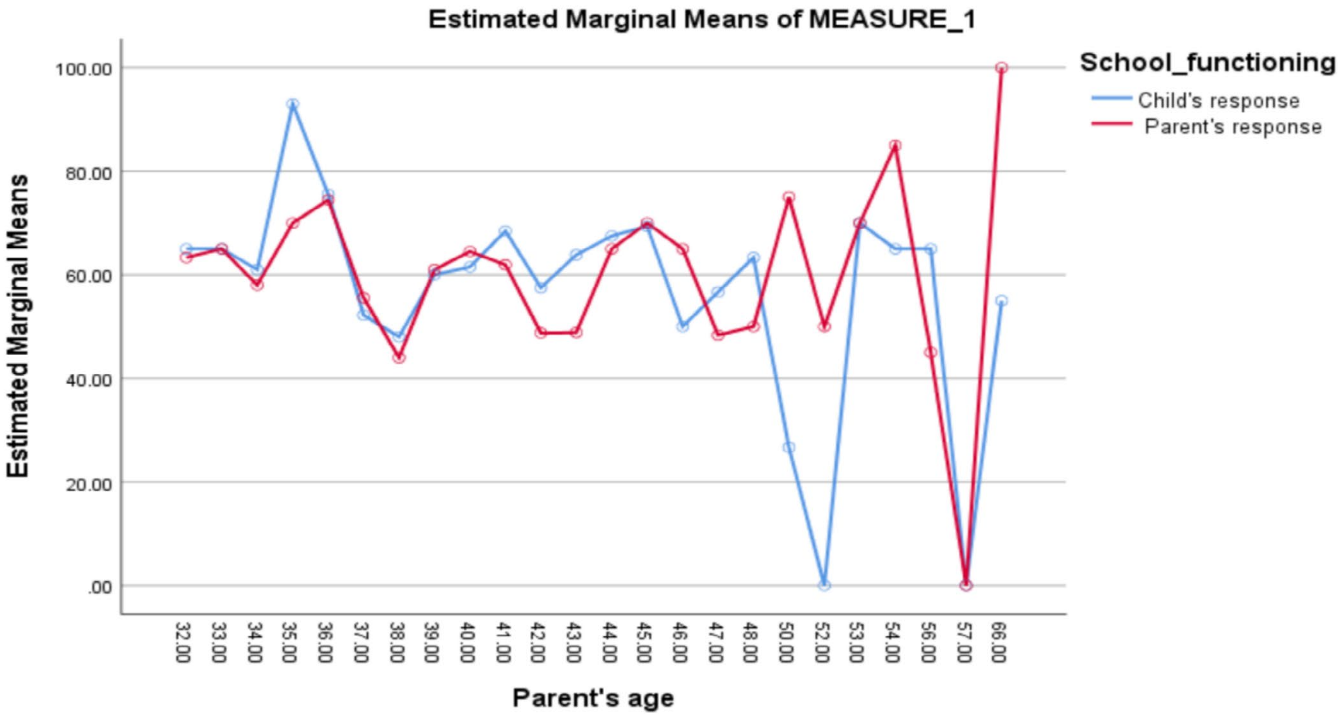

FIGURE 2 | Estimated mean values of school functioning in PedsQL by type of measure and parent's age.

may increase the level of stress because of medical management issues, which might skew their interpretation of their child's QoL (Tomlinson et al. 2020). Parents may have a more protective attitude or focuses on their child's health limitations. Children, on the other hand, may emphasize their strengths or have a different emotional understanding of their situations. Thus, future studies should delve deeper into the reasons behind this discordance (Kuyken et al. 1994). Children self-reported scores on their social functioning were higher than the parents' proxy score. It may imply that children were more socialized than the parents realized. As in Hong Kong, it is common for children to have an iPhone for use. Parents might not be aware of their children using the internet or different media, i.e., WhatsApp, Facebook, etc., to connect with their friends, schoolmates, and outside world.

The proxy score of older parents (aged 48 or above) on school functioning differed greatly from the self-rating of their child. The proxy score of younger parents does not exhibit a large discrepancy from the score of their children. Hong Kong Chinese parents place a considerable emphasis on academic performance, and they regard academic achievements as one of the priorities in childcare (Li et al. 2010). Parents may have a higher expectation of children studying in higher form because these children will have their public examinations approaching the end of their primary or secondary schooling. When academic performance is the major indicator for parents to assess the school functioning of their children, the parent may be doubtful of their children's abilities in adapting to schooling and academic challenges because of their physical health condition and absence from school.

Inconsistent agreements between children and parents have been reported in the HRQOL of children with chronic health conditions (Rajmil et al. 2013; Upton et al. 2008; Varni et al. 2006; Lam et al. 2022). However, parental proxy-reports remain the most frequent source of additional information on children's wellbeing and functioning in local communities. Parental interpretation of their children's QoL will influence their decision-making on providing physical and psychological care to their children and choices of health care services (Campo et al. 2002; Janicke et al. 2001). Thus, training in parenting competence, i.e., assessment of signs of depressive symptoms, and communication using age-appropriate words with the sick children should be the priority of local health authorities as a cornerstone for medical complexity health service. The program might help to enhance parent–child relationships with each other. Our findings highlight the need for additional study on parent–child agreement over time, spanning multiple developmental and therapeutic periods.

6 | Limitations and Recommendations

The participants of this study aged from 10 to 18 years old. Their interpretations of QoL might be different from the children aged below 10 years old. The result of this study might not apply to these children of younger age. The convenience sampling adopted in this study may limit the generalizability of the study findings. Considering the differences in cultural backgrounds, there is a difference in stress adjustment between Chinese parents and western parents (Zhao and Wang 2006). 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, as fathers' perceptions and interpretation of their children's QoL might vary. Cultural disparities exist between Chinese and Western families regarding quality of life and stress adjustment. QoL refers to an individual's subjective judgment of his life based on his cultural background and value system. Cultural differences regarding perception of stress, resilience, and coping are well recognized (Kar et al. 2014). Caution and careful consideration should be taken when using assessment tools across different population groups to ensure accuracy and cultural relevance. Future studies should examine the replication of the study to confirm the study results across different regions, genders, and cultural backgrounds. To effectively treat chronic illness in young patients, it is crucial to promote cross-communication among all concerned parties and understand the various perceptions of sickness. Given the cross-sectional research design, it is not possible to establish causality among the variables. It would be important to conduct additional longitudinal studies to test the direction of these effects over time.

7 | Conclusions

This is the first study to investigate the quality of life (QoL) of children with complex medical illnesses in a Chinese setting, comparing the children's self-reports to the parents' proxy assessments. This cross-sectional study reports that there was a discordance between the emotional and social components observed from parent-reported and child-reported QoL. QoL is a subjective measurement. CMC's voice related treatment plan and nursing care should be taken into account in health decision making. Therefore, the actual needs of the CMC will be addressed accordingly. Given the crucial role parents play in the care and treatment of CMC, it is imperative to address patients' mental health as well as how they view their own and their child's lives.

Relevance for Clinical Practice

The study shed light on the level of agreement on the QoL between Chinese children with medical complexity and their parents. The foundation works of this study are so important to pave the way forward for better child–parent–nurse communication as well as pediatric clinical practices.

Patient or Public Contribution

The eligible children and one of their parents were identified and referred by the pediatrician team. Self-administered questionnaires were adopted 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 out-patient clinic.

Clinical Resources

- Maruzza Foundation: Children's Palliative Care https://www.fondazionemaruzza.org/en/.
- Pediatric Palliative and Hospice Care https://www.nhpco.org/pediatrics/.
- Pediatric Hospice Palliative Care Guiding Principles and Norms of Practice By Canadian Hospice Palliative Care Association https://www.chpca.ca/wp-content/uploads/2019/12/Pediatric_Norms_of_Practice_March_31_2006_English.pdf.
- The Hong Kong Society of Children's Palliative Care https://hkscpc.org/.

Author Contributions

Winsome Lam: conceptualization, methodology, software, data curation, investigation, funding acquisition, project administration, resources, writing – original draft, writing – review and editing, validation, supervision, formal analysis. **Fei Wan Ngai:** software, data curation, formal analysis, writing – original draft, writing – review and editing, investigation. **Kitty Y. Y. Chan:** software, data curation, formal analysis, writing – original draft, writing – review and editing. **Doris Y. P. Leung:** writing – original draft, writing – review and editing, formal analysis. **Stephen C. W. Chan:** writing – original draft, writing – review and editing, formal analysis. **Cathrine Fowler:** writing – original draft, writing – review and editing, project administration, supervision, validation, visualization. **Zehua Zhao:** writing – original draft, writing – review and editing, formal analysis, software, data curation.

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Ethics Statement

This study received ethical approvals from the university IRB (approval number: HSEARS20190120001-01) on 21-03-2019, and the three participating hospital out-patient clinics (approval numbers: KW/FR-19-069 (137-10); [2019]069; 2019010) on 09-10-2019, 25-02-2019, and 30-04-2019, respectively, before data collection commenced. The names of the parents, children, and out-patient clinics were substituted by codes and kept anonymous in any publication.

Consent

Written consents were obtained from parents and their children, and a detailed explanation of the study purpose, procedure, and ethical issues was provided 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 out-patient clinics were substituted by codes and kept anonymous in any publication.

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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