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ORIGINAL ARTICLE

Participation of children with long-term health conditions compared to that of healthy peers: A cross-sectional comparative study

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ABSTRACT

Background: Knowledge is limited on attendance and involvement of perceived participation of children with long-term health conditions.

Aims: To evaluate the perceived participation of children with long-term health conditions and to compare their participation with that of healthy peers.

Material and methods: A cross-sectional comparative study was designed using self-reported data from 65 children with long-term health conditions and from 65 healthy peers, utilising the simplified Chinese version of Picture My Participation (PMP-C; Simplified).

Results: The frequency scores of children with long-term health conditions were significantly lower than those of healthy peers in terms of attendance for the total domain and for 13 activity items. The involvement scores of children with long-term health conditions were significantly lower than those of healthy children in 3 items. There was a strong correlation between rank orders of the most important activities for the two groups ($r = 0.83$).

Conclusions: Children with long-term health conditions participated less in activities compared to healthy children. Further studies are required to investigate factors of the participation of children.

Significance: The PMP-C (Simplified) offered an opportunity for children to express their own perspectives of participation based on their individual experience of the activity.

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Child; China; picture my participation; rehabilitation; self-report

Introduction

The global prevalence of children with long-term health conditions has increased dramatically over the past 30 years [1]. China, as a rapidly developing country, has the largest population of children with long-term health conditions in the world, with an estimated prevalence of 14% [2]. Long-term health conditions refer to health problems lasting over three months, impacting children's regular activities and requiring hospitalisations, home health care and/or extensive medical care, which has played a crucial role in medical care and health planning [3]. Long-term health conditions cannot be resolved spontaneously, and are rarely completely cured, which negatively impacts on children's medical care, health and well-being [4]. Emerging research appears to indicate that this impact is not diagnosis specific [5], although more evidence is required. Maintaining the health of these children is crucial for preserving their quality of life (QoL). Thus, developing new, long-term, patient-oriented models of medical care for children that also affect participation in everyday life is an urgent need to guide paediatric health care services for the future.

Participation in home, school and community activities is known to play a vital role in promoting children's development, health and well-being. According to the World Health Organization's (WHO) International Classification of Functioning, Disability, and Health (ICF), participation is broadly considered as a child's involvement in a life situation [6,7]. A recently published systematic review regarding the Family of Participation-related Constructs (FPRC) suggests that participation comprises two essential constructs: attendance and involvement [8]. Attendance is regarded as 'being there' in activities and can be measured as the frequency of attending an

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activity. Involvement is considered as the experience of participation while attending the activity and can be assessed by measuring the level of perceived involvement [8]. Both dimensions are important aspects of participation and more needs will be done to understand children's experiences while attending daily activities [9].

The United Nations Convention on the Rights of the Child (CRC) suggested that it is in the child's best interest to express their own perspective of participation because it is the child who experiences the activities [10]. Measuring participation by self-rating may provide a picture of the child's actual daily life and offer the child an opportunity to express his/her own perspective of participation based on the individual experience of the activity. Recent studies have focussed on studying the value and importance of listening to a child's own voice in matters relating to them, rather than relying on adults who act as proxy participants on behalf of the child [11,12].

A child's participation is influenced by age, gender, residential location and income [13]. Especially for children with long-term health conditions, who are usually discouraged and restrained from participating in sports or other activities because they have lower fitness levels, more negative side effects of their medication and less free time than their healthy peers. As a result of this lower physical fitness, their participation may be restricted at home, at school and in the community [14,15]. Studies highlight that children with long-term conditions also participate less in recreational and competitive sports when compared to their healthy peers [16]. Apart from challenges related to physical conditions, medical contraindications and lack of access to safe and adequate physical activity programs may also become limiting factors to participation for children with long-term health conditions [17,18]. Furthermore, the opposition received from significant others, particularly immediate family members, as well as the child's school and community, can also form a pertinent barrier to the child's participation [19]. Caregivers' concerns regarding potential bullying or risk of infection are likely problems and will prevent children from opportunities to participate in everyday or in school activities [20]. Thus, participation has become a primary goal of rehabilitation for children with long-term health conditions.

Previously, a limited body of work has evaluated the diversity and intensity of participation in children with long-term health conditions and how individual and environmental factors are related to participation [21]. To our knowledge, no previous research has investigated the participation dimensions of attendance and involvement in children with long-term health conditions. Furthermore, previous studies have primarily focussed on parent's judgement related to their child, implying that the child's voice is rarely heard. Only some studies concerning children with disabilities have shown that children's own voices can be elicited regarding their participation in activities of daily living [11,22].

The purpose of the current study was to evaluate the level of perceived participation of children with long-term health conditions and to compare their participation in home, school, and community activities with that of healthy peers by means of the simplified Chinese version of the Picture My Participation (PMP-C [Simplified]) instrument. Three specific research questions were set:

1. What is the level of perceived participation (attendance and involvement) of children with long-term health conditions?
2. What are the three activities that the largest proportion of children perceived as the most important in which to participate?
3. What are the differences and similarities in perceived participation (attendance and involvement) and the three activities selected as the most important when children with long-term health conditions and healthy peers are compared?

Materials and methods

A cross-sectional comparative study was designed using self-reported data from children with long-term health conditions and from healthy peers, utilising the simplified Chinese version of an existing survey measure, Picture My Participation (PMP-C; Simplified).

Participants

This study was approved by the Research Ethical Committee of Tianjin Medical University. It included two groups: children with long-term health conditions and healthy peers. For children with long-term health conditions, they were included if they were between 5 and 18 years of age, had a long-term health condition, and had receptive and expressive Chinese language skills on par with healthy peers. The exclusion criteria were as follows: (i) children with a physical or psychological disability; (ii) children with an intellectual disability; (iii) children with a sensory disability; and (iiii) children with an acute disease or injury. Eligible participants were approached with the help of a

patient schedule. Researchers were interviewed with doctors and nurses to get the feedback of the eligible children's health conditions and to ensure that the children had a stable health status in the rehabilitation period, allowing them to participate in the study. According to the inclusion criteria, the patient schedule and the feedback, researchers selected potential participants *via* convenience sampling at paediatric inpatient wards from two specialized hospitals in Tianjin, China between November 2018 and August 2019. Then researchers went into wards at afternoon to explain the study to potential participants and their primary caregivers *via* a face-to face interview. Researchers asked potential participants whether they would like to participate in the research (i.e. provide assent). Then an information letter introducing the study was given to the caregivers of the potential participants, asking them whether their children could participate in the research (i.e. provide consent).

For the healthy group, three schools run by the government were selected using convenience sampling method from rural and urban areas of Hebei Province, China, between May 2018 and January 2019, and at one pre-school and two schools in Tianjin, China, between October and December 2019. Healthy children were recruited if they were between 5 and 18 years of age, attended a pre-school or mainstream public school, and had receptive and expressive Chinese language skills expected for their age. Healthy children were excluded if they experienced a significant event (e.g. surgery), were diagnosed with an acute or a long-term health condition (e.g. cancer), had a disability diagnosis, or repeated a year of school. Using the inclusion criteria and the class list provided by the teacher, researchers selected potential participants *via* convenience sampling from each class at these selected schools to make the distribution of healthy children similar to the children in the long-term health condition group according to age and gender. Then researchers went into the classrooms during the rest time when classes were finished, and asked the potential participants whether they would like to participate in the research (i.e. provide assent). Next, these children's primary caregivers came to the school for a face-to face interview conducted with researchers. An information letter introducing the study was given to the caregivers of the potential participants, asking them whether their children could participate in the research (i.e. provide consent) as well as to confirm information about their child's medical history.

For both groups, prior to data collection, oral assent was obtained from children, after which written informed consent was obtained from primary caregivers.

Attrition

Of the 131 children, 23 children were excluded because they were younger than 5, 8 children were excluded due to limited Chinese language skills, and 20 children were excluded because they couldn't be interviewed with researchers due to their serious health conditions, leaving 80 children met the inclusion criteria. Of the remaining 80 children, 12 children chose to not participate while a further 3 children's primary caregivers did not give consent for their children to participate. This resulted in 65 children with long-term health conditions, which included different diagnoses (e.g. leukaemia and congenital heart disease). The attrition rate may reflect lack of time in families to be involved or no direct benefit to families for participation in this study. All 65 healthy children who met the inclusion criteria were identified as potential participants and provided assent, and their primary caregivers also consented for them to participate in the study. At the time of data collection, all 130 children were present and provided full data, giving a response rate of 89.7% ($n = 130$).

Instruments

Ten questions questionnaire (TQQ)

The Ten Questions Questionnaire (TQQ), which was developed to screen for neurological disability in children, was used [23]. Primary caregivers were asked to answer the TQQ to ensure that their children had no existing neurological disabilities and were thus eligible to be involved in the study. The TQQ consists of 10 items in a yes/no format, including five questions related to cognitive development, two related to motor development and one question each addressing vision, hearing and seizures. Zero points indicate no problem at all, and ten points show problems in relation to disability. The TQQ is the most widely used screening tool for childhood disability and has been validated in numerous studies [24].

PMP-C (simplified)

PMP-C (simplified) is a new self-reported instrument designed to assess attendance and involvement as two components of participation in children aged 5–21 years, especially in low-and-middle-income countries (LMICs), and it consists of three sections

[25]. The first section includes demographic questions; e.g. gender, age, and type of community. The second section contains 20 activity items about the attendance and involvement of perceived participation in daily life, covering home, school and community activities. For each activity item, the participant is asked to identify how frequently he or she participates in that specific activity on a 4-point rating scale (ranging from 1= never to 4= always), as well as how involved he or she is while participating on a 3-point rating scale (ranging from 1= not involved to 3= very involved). In the third section, participants are asked to select the three activities they regard as the most important for their own participation.

PMP has been demonstrated to be a useful tool for children with and without intellectual disabilities, in Sweden and South Africa [25,26]. Transcultural adaption, content validity and reliability of the simplified Chinese version of PMP-C (Simplified) has been established [27]. Specifically, the internal consistency was good ($\alpha = 0.80$), as was the test-retest reliability across a period of 2 weeks (ICC = 0.89) [27]. In an ongoing project, the PMP-C (Simplified) has also been used in children with other health conditions, such as Autism Spectrum Disorder. Therefore, the PMP-C (Simplified) is considered a suitable measure for participation for children in China.

Picture symbols (namely, Picture Communication Symbols [PCS]) were utilized partly in this study as part of the PMP-C instrument. The Talking Mats framework was used by the researcher to facilitate responding [28]. The Talking Mats framework included using an A3 hard fibre mat with visual images along the top, representing the response category, and is described in more detail in the data collection section.

Data collection and procedures

The researcher sought to achieve a diverse sample by child age and gender. After the TQQ screening, recruited participants were asked to participate in face-to-face, structured interviews with researchers to respond to the PMP-C (Simplified) using the Talking Mats framework. Children with long-term health conditions were interviewed at paediatric inpatient wards, while healthy children participated in the interview in the classrooms. Three steps were used to conduct the interview. First, the participant was asked demographic questions. Second, the researcher showed participants the Talking Mats framework and PMP-C (Simplified) concerning the frequency of the 20 activity items. Three trial items (i.e. eating ice cream, watching TV, and playing with real snakes at home) were introduced to ensure that the participant understood how to rate the frequency of the activities. The participant was asked, 'How often do you participate in this daily activity?' while being shown the corresponding picture symbol of the specific activity. The child had to sort each of the 20 activities on the frequency mat. Next, the researcher explained the mat as it related to the 'involvement' component of participation. For example, the child was asked, 'When you attend meal preparation with or for the family, how involved are you?' while being shown a corresponding visual image of the specific activity. The child had to rate their involvement by placing the picture symbol under the correct visual scale that indicated the response that most accurately represented their involvement in the activity. The attendance and involvement responses were recorded by the researcher on a separate score sheet until all 20 items were completed. Third, the researcher asked the participant to select three activities from the list of all 20 activities that they thought were the most important for themselves. The child was asked 'Of all of the activities we have discussed, what are the three activities which are the most important to you?' while being shown the corresponding picture symbols of the specific activities. The child had to select three picture symbols and place them on the mat to represent their prioritisation of the activities. Children were encouraged to share their own stories and thoughts about their perceived participation throughout the conversations with researchers. It took each participant approximately 20–30 min to complete this measurement using the PMP-C (Simplified) instrument. Data were collected in the same manner for children with long-term health conditions and healthy children. Three researchers with rich experience in working with children and trained in talking with children using the PMP-C (Simplified) conducted the interviews. The training protocol contained an interview schedule and a training video, and role-playing was used throughout.

Statistical analysis

The statistics analysis was performed using IBM SPSS Statistics 21.0 (Armonk, NY, USA). Demographic characteristics were calculated using descriptive statistics of mean, standard deviation (SD) or frequency. Chi-squared tests were performed for the comparative analysis in terms of gender and type of community between children with long-term health conditions and healthy peers. As the ages had a skewed distribution, the nonparametric Mann-Whitney test was

conducted to examine the difference between the two groups. TQQ scores were also calculated using mean and SD.

Frequency scores of the dimensions of participation (attendance and involvement) were calculated across the activities selected by children, item by item, and total scores of attendance and involvement were calculated. As many scores were not normally distributed, range, mean and SD were used for summarising the rating scores. For each group, we also calculated the proportion of children who chose each activity item as one of the three most important in which to participate.

Both groups were compared at item level by calculating differences in the participation frequency scores (attendance and involvement) for each activity using Mann-Whitney tests. This method was also used to determine the mean differences in total scores of attendance and involvement, respectively. Spearman's rank order correlation was used to test the relationship between the two groups on frequencies of the items chosen as most important. Cronbach's alpha was calculated to examine the internal consistency of the PMP-C (Simplified) items for the total scale in children with long-term health conditions.

Results

Participants and descriptive data

In total, the study included 65 children with long-term health conditions (24 boys and 41 girls) and equal numbers of healthy children ($n = 65$, 25 boys and 40 girls). The children with long-term health conditions included 32 children with congenital heart disease and 33 children with leukaemia. The participants ranged in age from 5–18 years. The mean age of children with long-term health conditions was 11.3 years (SD = 3.1), and it was 10.7 years for healthy children (SD = 2.7). The TQQ showed no problems related to disability for either group (children with long-term health conditions and healthy children). Demographic characteristics of the two groups, i.e. gender, age, type of community and results of the TQQ, are presented in Table 1. A comparative analysis indicated no significant differences between the two groups in terms of age ($Z = -1.15$, $p = 0.14$), gender ($\chi^2 = 0.03$, $p = 0.86$), or type of community ($\chi^2 = 0.32$, $p = 0.86$). As expected, the TQQ showed no problems related to disability for either group.

Internal consistency of the PMP-C (simplified) items for the total scale

All 65 children with long-term health conditions were able to complete the PMP-C (Simplified). Cronbach's alpha, computed to examine the internal consistency of the PMP-C (Simplified) items in children with long-term health conditions, was 0.75.

Comparison of the attendance component of participation

All 130 children were able to respond to the attendance scale of PMP-C (Simplified). Table 2 displays the results of the comparison of frequency of attendance scores between the two groups. The frequency of attendance scores of children with long-term health conditions were significantly lower than those of their healthy peers for the total score for attendance and for 13 activity items: item 4 (gathering supplies), item 5 (meal preparation), item 6 (cleaning at home), item 7 (caring for family), item 8 (caring for animals/pets), item 10 (celebrations), item 11 (playing with others), item 14 (spiritual activities), item 15 (shopping), item 16 (social activities), item 17 (health centre), item 18 (school), and item 19 (trips and visits).

Comparison of the involvement component of participation

Full data on the involvement component of the PMP-C (Simplified) were available for all 130 children. Table 3 presents the results for the comparison of involvement scores between the two groups. The involvement scores of children with long-term health conditions were significantly lower than those of

Table 1. Descriptive data regarding gender, age, type of community, and TQQ results for both groups.

	Group 1 Long-term health conditions ($n = 65$) *n* (%)	Group 2 Healthy ($n = 65$) *n* (%)
Gender		
Girls	41 (63.1)	40 (41.5)
Boys	24 (36.9)	25 (38.5)
Age (years; months) (Mean ± SD)	11.3 ± 3.1	10.7 ± 2.7
Type of community		
Urban	27 (41.5)	26 (40.0)
Rural	38 (58.5)	39 (60.0)
TQQ (Mean ± SD)	0 (0)	0 (0)

Table 2. Comparison of the PMP-C attendance of participation for both groups.

	Group 1			Group 2			
	Long-term health conditions ($n = 65$)			Healthy ($n = 65$)			
Activity item in PMP-C (Simplified)	Min-Max	Mean	SD	Min-Max	Mean	SD	*p*-value
1. Personal care	2.00–4.00	3.63	0.72	2.00–4.00	3.75	0.50	.606
2. Family mealtime	2.00–4.00	3.74	0.59	2.00–4.00	3.74	0.51	.635
3. My own health	1.00–4.00	2.98	0.80	1.00–4.00	3.20	0.85	.099
4. Gathering supplies	1.00–4.00	2.29	0.82	1.00–4.00	2.88	0.86	.000*
5. Meal preparation	1.00–4.00	1.92	0.84	1.00–4.00	2.60	0.97	.000*
6. Cleaning at home	1.00–4.00	2.71	0.82	1.00–4.00	3.28	0.82	.000*
7. Caring for family	1.00–4.00	2.62	0.95	1.00–4.00	3.22	0.82	.000*
8. Caring for animals/pets	1.00–4.00	1.88	1.04	1.00–4.00	2.68	1.21	.000*
9. Family time	1.00–4.00	3.23	0.86	2.00–4.00	3.43	0.68	.244
10. Celebrations	1.00–4.00	2.58	0.92	1.00–4.00	2.97	0.94	.015*
11. Playing with others	1.00–4.00	3.03	0.87	1.00–4.00	3.42	0.77	.008*
12. Organized leisure	1.00–4.00	2.69	0.98	1.00–4.00	2.71	1.06	.862
13. Quiet leisure	1.00–4.00	3.06	0.81	1.00–4.00	3.22	0.88	.198
14. Spiritual activities	1.00–4.00	1.29	0.61	1.00–4.00	1.63	0.84	.010*
15. Shopping	1.00–4.00	2.63	0.88	1.00–4.00	3.18	0.85	.000*
16. Social activities	1.00–4.00	1.95	0.94	1.00–4.00	2.42	1.06	.013*
17. Health centre	1.00–4.00	2.46	0.71	1.00–4.00	2.25	0.79	.033*
18. School	2.00–4.00	3.78	0.45	3.00–4.00	3.94	0.24	.019*
19. Trips and visits	1.00–4.00	1.60	0.79	1.00–4.00	2.12	0.94	.001*
20. Employment	1.00–3.00	1.29	0.55	1.00–4.00	1.43	0.81	.616
Total attendance	1.80–3.30	2.58	0.33	2.00–3.75	2.89	0.41	.000*

*$p < 0.05$.

Table 3. Comparison of the PMP-C involvement of participation for both groups.

	Group 1			Group 2			
	Long-term health conditions ($n = 65$)			Healthy ($n = 65$)			
Activity item in PMP-C (Simplified)	Min-Max	Mean	SD	Min-Max	Mean	SD	*p*-value
1. Personal care	1.00–3.00	2.65	0.57	1.00–3.00	2.83	0.38	0.052
2. Family mealtime	1.00–3.00	2.74	0.57	1.00–3.00	2.74	0.48	0.643
3. My own health	1.00–3.00	2.32	0.79	1.00–3.00	2.43	0.71	0.504
4. Gathering supplies	1.00–3.00	2.09	0.79	1.00–3.00	2.29	0.74	0.142
5. Meal preparation	1.00–3.00	1.86	0.81	1.00–3.00	2.23	0.82	0.011*
6. Cleaning at home	1.00–3.00	2.23	0.81	1.00–3.00	2.52	0.64	0.039*
7. Caring for family	1.00–3.00	2.23	0.77	1.00–3.00	2.35	0.72	0.368
8. Caring for animals/pets	1.00–3.00	1.66	0.87	1.00–3.00	2.03	0.87	0.014*
9. Family time	1.00–3.00	2.63	0.57	1.00–3.00	2.51	0.69	0.358
10. Celebrations	1.00–3.00	2.43	0.75	1.00–3.00	2.34	0.82	0.569
11. Playing with others	1.00–3.00	2.52	0.71	1.00–3.00	2.55	0.66	0.899
12. Organized leisure	1.00–3.00	2.34	0.80	1.00–3.00	2.08	0.89	0.094
13. Quiet leisure	1.00–3.00	2.52	0.69	1.00–3.00	2.48	0.64	0.518
14. Spiritual activities	1.00–3.00	1.23	0.58	1.00–3.00	1.29	0.58	0.325
15. Shopping	1.00–3.00	2.29	0.74	1.00–3.00	2.47	0.71	0.127
16. Social activities	1.00–3.00	1.92	0.87	1.00–3.00	2.02	0.87	0.546
17. Health centre	1.00–3.00	1.78	0.80	1.00–3.00	2.05	0.76	0.053
18. School	1.00–3.00	2.75	0.56	1.00–3.00	2.75	0.53	0.868
19. Trips and visits	1.00–3.00	1.51	0.79	1.00–3.00	1.74	0.83	0.078
20. Employment	1.00–3.00	1.32	0.71	1.00–3.00	1.28	0.60	0.978
Total involvement	1.55–2.75	2.15	0.26	1.45–2.90	2.24	0.37	0.189

* $p < 0.05$.

healthy children in item 5 (meal preparation), item 6 (cleaning at home) and item 8 (caring for animals/pets). The overall score for involvement was not significantly different between two groups.

Comparison of the proportion of children who selected each activity item as one of the three most important activities

All 130 children were able to select the three most important activities from the 20 total activities based on the PMP-C (Simplified) items. Results for frequencies, item by item, of how often the 20 activity items of PMP-C (Simplified) selected as important to attend and to be involved in are provided in Table 4. All 20 items were selected as important by children with long-term health conditions, while healthy children identified only 18 items as important, with no children selecting item 14 (spiritual activities) or item 20 (employment). Item 1 (personal care) and item 18 (school) were common activities among the top selections for both groups.

The analysis from the Spearman's rank order correlation shows that there was a strong correlation

Table 4. Proportion of children who selected each activity item as one of the three most important activities.

Activity item in PMP-C (Simplified)	Group 1 Long-term health conditions ($n = 65$) (%)	Group 2 Healthy ($n = 65$) (%)	All ($n = 130$) (%)
1. School	12.8	14.9	14.1
2. Personal care	11.3	16.4	13.8
3. My own health	10.3	7.2	8.7
4. Family mealtime	6.7	9.2	7.9
5. Cleaning at home	5.6	9.7	7.7
6. Caring for family	5.1	7.7	6.4
7. Family time	7.2	5.1	6.2
8. Playing with others	7.2	3.6	5.4
9. Organized leisure	4.1	6.7	5.4
10. Quiet leisure	5.1	3.6	4.4
11. Caring for animals/pets	3.6	3.6	3.6
12. Trips and visits	4.6	2.1	3.3
13. Gathering supplies	2.1	3.6	2.8
14. Shopping	4.6	1.0	2.8
15. Meal preparation	2.6	1.5	2.1
16. Celebrations	2.6	1.0	1.8
17. Social activities	1.5	1.5	1.5
18. Health centre	0.5	1.5	1.0
19. Employment	2.1	0	1.0
20. Spiritual activities	0.5	0	0.3
Total	100.0	100.0	100.0

between the rank orders of the most important activities for the two groups ($r = 0.83$), which implies that the children selected similar activities as important to attend and to be involved in.

Discussion

This paper is to compare the self-ratings of two groups of children on a measure of participation. On the PMP-C (Simplified) scales, the frequency scores of children with long-term health conditions were significantly lower than those of healthy peers on attendance for the total domain and for 13 activity items in home, school and community. The involvement scores of children with long-term health conditions were significantly lower than those of healthy children in 3 items, when both groups indicated no significant differences in terms of age, gender and type of community. This result supports previous findings that participation in daily activities among children with long-term health conditions is impeded in comparison to what is expected at their age [13]. Restrictions for children with long-term health conditions may limit them to performing these activities in specific environment, e.g. home, school and community. The low level of participation among children with long-term health conditions may result from their specific type of disease, disease severity, physical ability, motivation, self-efficacy, parental beliefs, liability concerns, and lack of access to appropriately safe and enjoyable physical activity programs [4,29–32].

The results revealed that children with long-term health conditions in general perceived themselves as doing home activities less often than their healthy peers. In fact, children with long-term health conditions usually spend less time in the home environment because of being admitted to the hospital for medical treatment or examination [21,33]. Moreover, this result could also be explained by the amount of family support provided for each activity at home. Parents' or caregivers' perceptions of home environmental support mediate the participation in home-based activities [34]. This overprotectiveness might be attributed to parent's or caregiver's guilt concerning their child's long-term health challenges, as they might feel responsible for them. Thus, parents or caregivers perform more activities for their children, such as household chores. Furthermore, due to the child's treatment contributing to the family's financial burden, their parents may tend to work outside the home for long time periods. This could have an impact on home activities, such as caring for family. The results also imply that children with long-term health conditions participated less in more strenuous or complex activities (for example, household chores such as cleaning at home and meal preparation). These more complex activities are skills that parents or caregivers can work on with children to promote successful participation in all daily activities and to lay the groundwork for their future, which could be influenced by the severity of the child's medical conditions and family expectations. The differences could be affected by the severity of the child's medical conditions and family expectations [13].

Going to school is a main activity of children. Participation in school is confirmed to be linked to

the children's health and well-being [35]. Our study also found that children with long-term health conditions participate less frequently in activities at school. This finding is in accordance with existing research that children with long-term health conditions and/or disabilities participate less in the school context [36]. Due to their medical conditions, children with long-term health conditions may receive continuous attention from teachers. Adult protection in the school context limits children's participation with peers [37]. Moreover, frequent admissions and prolonged hospital stays could be factors related to reducing a child's level of attendance in school activities [38]. Upon returning to school, many children with long-term health conditions may be excluded from participating in sports activities or physical education at school [39]. Moreover, many days missed at school can result in barriers in maintaining peer relationships and low participation in extracurricular activities, which can contribute to social isolation, low self-confidence and -esteem, as well as depression [30].

Community participation refers to the participation in activities in the neighbourhood and typically includes some activities such as shopping, celebrations and social activities. These activities require physical strength or mobility for participation–aspects that children with long-term health conditions may struggle with. Furthermore, it could also be explained by parental fear of their child becoming overfatigued, injured or ill (e.g. infection) when playing with others, having celebrations, shopping or going on trips or visits [40–42]. This is in concurrence with the work of Chadwick, who found that children with asthma mostly experience problems with social activities or outdoor play, including horseback riding, camping and walking [43].

Involvement of children with long-term health conditions was restricted compared to their healthy peers in activities of meal preparation, cleaning at home and caring for animals/pets. Children with long-term health conditions might be less involved in such home activities because parents or other caregivers can help, or do the activities for them, in contrast to their healthy peers, who are more independent and able to participate in these activities on their own. Indeed, one previous study mentioned that activities of children with long-term health conditions are mostly performed at home and are dependent on adults [44]. However, the most important finding is that children with long-term health conditions rated their overall involvement at about the same level as healthy children in most activities. The result indicated that if having the opportunity to attend an activity, children with long-term health conditions perceived the activities just as engaging as healthy children. This is also supported by the results for the selection of the most important activities.

An interesting finding from this study is that overall, both groups selected similar activities as being the three most important activities. This finding is based on a summarized proportion of selections and indicates that both groups had similar expectations of activities for their lives. The selections made by children may be the activities they typically like to do, are willing to do, or do frequently [11]. To gain a more comprehensive understanding of the three most important activities, future research could investigate the individual responses, item by item, to determine whether children perceived participation as important based on the frequency of attendance or involvement or whether they are interested in participation in a broader range of activities. This can be helpful for parents or caregivers to provide guidance for improving children's participation and/or skills of living.

The outcomes concerning involvement may have important implications for intervention programs that focus on the individual and environmental factors that may enhance participation in the activities perceived as being of great importance. A previous study underscored the importance of exercise and physical activity on children's health, which is regarded as a prevention measure to reduce disease risk and benefit treatment [45]. There is evidence that more family participation, especially the engagement of mothers in physical activities, has positive effects on increasing children's participation [46].

Further studies are required to investigate what factors can enhance or limit the participation of children with long-term health conditions. This information will help parents, caregivers, service providers, and policymakers understand the personal and environmental factors regarding participation for children with long-term health conditions and how these factors enhance or limit participation. Future studies should also investigate parent-child differences in participation to explore interventions that are responsive to the demands and priorities of both the parent and the child.

A strength of our study is that participants of two groups indicated no significant differences in terms of age, gender and type of community having the potential to influence participation, and we used outcome measures known to be valid and reliable for children.

This study is based on self-reports by children, and not on proxy ratings by adults. This study also evaluated two dimensions of participation (attendance and involvement) not previously explored and calculated the proportion of the three activities that the children perceived as being the most important in which to participate. Moreover, a comparison of these three aspects was made between children with long-term health conditions and their healthy peers.

Limitations

This study has some limitations. The primary limitation is the small sample size. Future studies in this area will benefit from a larger sample size. Second, cross-sectional data of participation in children with long-term health conditions and healthy peers was collected in this study. A longitudinal analysis of participation is needed to evaluate changes of participation over time. Third, the variability of diagnosis within the long-term health conditions is small. Further investigations might be needed to complement the diversity of diagnosis. Another limitation is that the study did not examine personal factors and environmental factors on participation. Future directions for research will consider these factors that contribute to develop an effective intervention to enhance participation.

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