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Coping with paediatric illness: Child's play? Exploring the effectiveness of a play- and sports-based cognitive behavioural programme for children with chronic health conditions

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Abstract

Little is known about how play affects the development of children with a chronic condition. Studying play poses major methodological challenges in measuring differences in play behaviour, which results in a relative scarcity of research on this subject. This pilot study seeks to provide novel directions for research in this area. The effectiveness of a play- and sports-based cognitive behavioural programme for children (8–12 years) with a chronic condition was studied. The children and parents completed a battery of measurement tools before and after the programme. Moreover, the application of automated computer analyses of behaviour was piloted. Behaviour (Child Behavior Checklist) seemed to be positively affected by the programme. An increase in psychological well-being was observed (KIDSCREEN). Perceived competence (Self-Perception Profile for Children) and actual motor competence (Canadian Agility and Movement Skill Assessment) did not show any positive trends. These results of 13 participants suggest that children might learn to better cope with their illness by stimulating play behaviour. For the analysis of the effectiveness of programmes like this, we therefore propose to focus on measuring behaviour and quality of life. In addition, pilot measurements showed that automated analysis of play can provide important insights into the participation of children.

Keywords

Child, chronic illness, cognitive behavioural therapy, coping, development, group intervention, health, physical activity, play

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Introduction

Children with a chronic medical condition are more vulnerable to physical, emotional, social and cognitive problems later in life (Maurice-Stam et al., 2019; Patenaude & Kupst, 2005; Pinquart & Shen, 2011; Pinquart & Teubert, 2012). Paediatric patients also report a lower quality of life when they are young adults (Stam et al., 2006). It is likely that this range of problems is not only the direct consequence of the disease itself but is also caused by stressful events and environmental changes that are the result of the chronic condition (Mickley et al., 2013).

Play is essential for children in growing up and developing into competent adults (Ginsburg, 2007; Lillard, 2017). Chronically ill children have fewer opportunities for healthy play and play development, which has recently been proposed to be both a result and a contributing cause of the problems in different aspects of personal development (Nijhof et al., 2018). It is believed that play is important in the development of social and emotional capacities, resilience, creativity and problem-solving skills of children (Erikson, 1977; Ginsburg, 2007; Habermas & Bluck, 2000; Nijhof et al., 2018; Piaget, 1962). Not being able to participate in playful activities may negatively impact the development of these skills. Therefore, play interventions could be offered to chronically ill children to promote adaptation. How to do this exactly remains unclear due to a lack of suitable theory and practical research on play, and the effects of play, in children with a chronic condition. This is partly caused by the major methodical challenges in measuring inter-individual differences in play behaviour. This pilot study seeks to provide novel directions for research in this area.

In recent years, there have been a number of programmes around play and sports to specifically target children aged 8 to 12 years with a chronic medical condition, who encounter bodily, emotional, cognitive or social difficulties because of their illness. Such programmes have been shown to be effective in improving the empowerment and psychosocial functioning of the participants (Maurice-Stam et al., 2009; Moola et al., 2014; Odar et al., 2013; Scholten et al., 2013). However, not much is known about the effective elements of these programmes. The Wilhelmina Children's Hospital of the University Medical Center Utrecht (The Netherlands) has offered the preventive cognitive behavioural group programme 'Dit ben ik' ['Here I am'] since 2009. Based on play and sports, the programme targets the integration of bodily self-awareness, emotional self-experience, cognitive development and social interaction. In standard qualitative assessments, the programme has always been evaluated very positively by children who participated and their parents. Yet, it remains unclear how the programme contributes to such a positive experience because the connection between various aspects of well-being hinder a straightforward assessment of the effective elements. The diverse backgrounds of the children in terms of health conditions and physical, cognitive, social and affective competencies add to the challenge. It is thought that the considerable presence of playful activities in the programme resulted in the positive qualitative evaluation. However, to learn more about the relation between play and development, objective measurements should be used to give more information about the relation between the play- and sports-based programme and the different outcomes regarding well-being and development.

This pilot study not only uses a combination of self- and parent-reported questionnaires and a motoric test but also targets the automated measurement of play itself. To enable future larger-scale interdisciplinary research projects on the analysis of play and sports behaviour in relation to the physical, emotional, cognitive and social development of chronically ill children, the aim of this study is to help to assess vulnerabilities among paediatric patients and support the future research and tailoring of play- and sports-based approaches to prevent a detrimental developmental outcome in children with medical conditions. It was hypothesized that there will be no clear statistically significant results because of the small amount of participants. However, because the programme aims to improve these various aspects of well-being, the expectation is that trends will

Table 1. Characteristics of the participating children.

Gender	Age (years)	Medical condition
Female	8	Hyper-IgD syndrome
Female	8	Hirschsprung's disease
Male	8	Endocrinologic syndrome (unknown)
Male	9	VACTERL association
Male	9	MAT1a deficiency
Male	9	VACTERL association
Male	9	Kidney transplant after obstructive uropathy
Male	9	Hereditary haemorrhagic telangiectasia and partial paralysis
Male	10	Transposition of the great arteries and a pacemaker
Female	10	Celiac disease and growth hormone deficiency
Female	10	Nephronophthisis and kidney transplant
Male	11	Tetralogy of Fallot
Male	11	Esophageal atresia

be found in the instruments measuring patients' behaviour, self-perceived competence, quality of life and physical competence. This study is expected to give insights into the possible effectiveness and effective elements of the programme itself and contribute to the research design of other future play- and sports-based interventions. It is also expected to give more insight into the usability and potentials of automated measurements.

Methods

Participants

A total of 15 children (in two groups) participated in the programme. One participant was excluded from the study because the pre- and post-programme measurements were both incomplete. Another participant dropped out of the programme after two sessions. She was therefore excluded from the study as well.

The mean age of the participants at the start of the programme (t_0) was 9.67 years ($SD = 1.15$, range = 8–12 years). The characteristics of the participants can be seen in Table 1. All children were patients in the Wilhelmina Children's Hospital and were advised to participate in the programme by someone from their treatment team. They were all outpatients at the time of the study.

Ethics

The study protocol was reviewed and approved by the Medical Ethical Committee of the University Medical Center Utrecht (Application No. 18-257/C). The parents agreed to participate and signed informed consent forms.

Intervention

'Dit ben ik' consists of eight weekly 90-minute sessions. It is a cognitive behavioural group programme based mainly on sports and play activities. Activities focus on improvement of self-esteem, collaboration, emotional self-experience, bodily awareness and social skills. More information about the programme appears in Supplemental Appendix 1.

Measurements

To tackle the complexity of the intervention and to give more insights into the feasibility of the different research methods, we used a battery of measurements, including self- and parent-reported questionnaires for self-perception, behaviour and quality of life, assessment of motor competence and automated measurements of play behaviour.

Questionnaires

Behaviour. The presence of problematic behaviour of the children was assessed using the validated Dutch translation of the Child Behavior Checklist (CBCL) (Ivanova et al., 2007). The CBCL is completed by the parents (or caregivers) of children aged between 6 and 18 years. It quantifies emotional and behavioural problems of the child in a standardized way. The CBCL provides a general problem score as well as scores on eight different subscales: social withdrawal, somatic complaints, anxiety/depression, social problems, thought problems, attention problems, delinquent behaviour and aggressive behaviour. There are also two combined scales: 'internalizing problems' consists of the scales social withdrawal, somatic complaints and anxiety/depression and 'externalizing problems' consists of the scales delinquent behaviour and aggressive behaviour. The CBCL also provides scores of the children on several DSM-oriented scales (*Diagnostic and Statistical Manual of Mental Disorders*, fourth edition (DSM-IV)) as follows: affective problems, anxiety problems, somatic problems, attention-deficit hyperactivity disorder (ADHD) problems, oppositional defiant problems and conduct problems. Scores above the 97th percentile are considered to be clinical (Achenbach & Edelbrock, 1991).

Quality of life. Health-related quality of life was assessed using the Dutch version of the KIDSCREEN questionnaire. This questionnaire consists of a self-report version, filled in by the child, and a proxy version, filled in by a parent. It is suitable for youth aged 8 to 18 years (Ravens-Sieberer et al., 2014). In this study, the 27-item version was used with five dimensions, such as physical well-being, psychological well-being, parent relations and autonomy, social support and peers and school environment. The shorter but psychometrically strong 27-item version is derived from the KIDSCREEN-52 which has a good validity (Ravens-Sieberer et al., 2008; Robitail et al., 2007). A higher score corresponds with a higher quality of life.

Self-perception. The children's self-perception was measured with the validated Dutch version of the Self-Perception Profile for Children (SPPC) (Harter, 1984, 2012; Veerman et al., 1996). The SPPC is a validated questionnaire to measure self-esteem and self-competence in children aged 8 to 14 years (Muris et al., 2003). It measures self-esteem in six different domains: scholastic competence, social acceptance, athletic competence, physical appearance, behavioural conduct and global self-worth (Harter, 1984).

Motor competence

To assess motor competence, the children performed the Canadian Agility and Movement Skill Assessment (CAMSA) (Longmuir et al., 2017). The CAMSA measures combined rather than isolated movement skills. Children are instructed to complete a circuit of movement exercises as fast as possible with as good as possible performance of the skills, such as throwing a ball at a wall target. The final score consists of a combination of the time and the quality of the assessed movement or action (Longmuir et al., 2015, 2017). The children were filmed while performing the test.

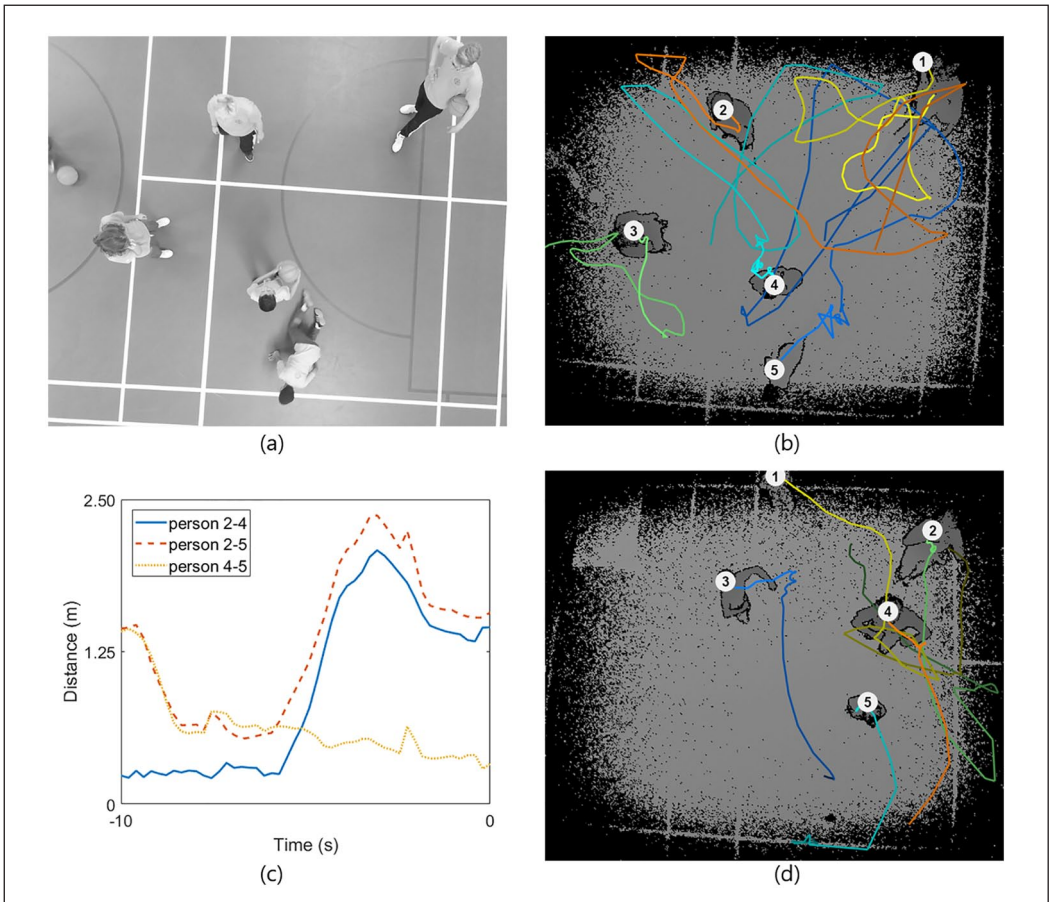

Figure 1. Example 1: (a) example frame from overhead camera, (b) tracks of five people over 20-second interval, (c) proximity of Persons 2, 4 and 5. Example 2: (d) tracks of five people over 20-second interval.

Measurement of time and quality was carried out by two researchers (N.B.D.J. and E.H.J.H.) together using these video recordings.

Automated measures of play behaviour

All sessions were recorded with a camera that was suspended at a height of approximately 4.5 m and was pointing downwards. This allowed for the observation of people in a play area of approximately 3 m × 4 m (see Figure 1(a)). The camera recordings were processed similarly to Moreno and Poppe (2016).

This automated tracking of participants in the playground can reveal both qualitative and quantitative insights. At the level of the individual, we can measure how much distance a person has covered and how fast. At the group level, patterns of interactions can be analysed. Such analyses may reveal differences between people but can also be used to identify changes in behaviour over time within an individual. Systematic analyses of interaction patterns appear in Moreno and Poppe (2016) and Moreno et al. (2019). For the purpose of this article, some visualizations and quantitative examples are presented.

Table 2. Number of clinical scores at T_0 and T_1 on the CBCL.

Case	Broadband scales		Syndrome scales		DSM scales	
	T_0	T_1	T_0	T_1	T_0	T_1
1	2	0[a]	1	0[a]	0	0
2	1	0[a]	1	0[a]	1	0[a]
3	3	2[a]	5	3[a]	5	3[a]
4	0	0	0	0	0	0
5	0	0	0	0	1	0[a]
6	0	0	0	0	0	0
7	2	3[b]	1	1	1	1
8	3	2[a]	4	1[a]	4	1[a]
9	0	0	0	0	0	0
10	0	0	0	0	0	0
11	3	2[a]	5	0[a]	2	1[a]
12	3	3	5	6[b]	4	4
13	2	2	3	4[b]	1	1

CBCL: Child Behavior Checklist; DSM: *Diagnostic and Statistical Manual of Mental Disorders*.
[a]Fewer clinical scores at T_1 compared to T_0.
[b]More clinical scores at T_1 compared to T_0.

Statistics

SPSS (IBM SPSS Statistics 25) was used for the statistical analyses. The data were tested on normality by the Kolmogorov–Smirnov test. Because many variables were not normally distributed, Wilcoxon signed-rank tests were used to compare scores at T_0 and T_1.

Results

A total of 15 children participated in the programme. However, 13 children completed the whole programme (adherence 86%). No adverse events were reported.

Questionnaires

All 13 children and their parents completed the questionnaires at T_0 and T_1 (adherence 100%).

CBCL. Table 2 shows the number of clinical scores at the start and at the end of the programme in different scales. At the start of the programme (T_0), 9 of the 13 children (69%) showed one or more clinical scores. In six of these children (67%), the number of problems had decreased after the programme.

Table 3 shows the mean *T*-scores on the CBCL scales at T_0 and T_1 and the results of the Wilcoxon signed-rank test. For every scale, the score at T_1 was lower than the score at T_0. However, most of the differences were not statistically significant.

KIDSCREEN, self-report and proxy. Tables 4 and 5 show the *T*-values and outcomes of the Wilcoxon signed-rank test of the self- and parent-reported questionnaires, respectively. Also, the 50th percentiles of the Dutch norm data are shown in the tables. In the self-reported as well as in the parent-reported

Table 3. CBCL *T*-scores at T_0 and T_1 and the results of the Wilcoxon signed-rank test.

	T-scores				Wilcoxon signed-rank test	
	T_0		T_1		*Z*	Asymp. sig. (2-tailed)
	M	*SD*	*M*	*SD*		
Syndrome scales						
T Score Anxious/depressed	65.08	11.18	63.15	11.14	−1.051	.293
T Score Withdrawn/depressed	65.00	10.19	61.00	8.89	−2.228	.026*
T Score Somatic complaints	62.31	7.36	61.31	8.33	−0.357	.721
T Score Social problems	60.92	12.51	59.23	13.39	−1.481	.139
T Score Thought problems	63.62	10.17	60.08	8.50	−1.561	.119
T Score Attention problems	63.85	11.89	62.77	14.74	−0.589	.556
T Score Rule-breaking behaviour	56.08	6.63	55.15	5.55	−1.133	.257
T Score Aggressive behaviour	60.38	8.50	58.62	8.16	−1.068	.285
Broadband scales						
T Score Internalizing problems	66.46	9.60	63.69	10.74	−1.424	.154
T Score Externalizing problems	57.92	10.14	54.38	12.31	−1.682	.092
T Score Total problems	62.85	10.49	59.38	11.70	−2.068	.039*
DSM scales						
T Score Depressive problems	65.85	9.52	62.69	9.91	−2.144	.032*
T Score Anxiety problems	64.77	11.92	63.77	12.56	−0.267	.789
T score Somatic problems	59.77	9.86	58.38	8.19	−0.664	.507
T Score Attention-deficit hyperactivity	59.77	9.24	59.15	9.31	−0.256	.798
T Score Oppositional defiant problems	59.69	6.90	57.85	6.63	−1.078	.281
T Score Conduct problems	57.23	8.54	55.08	7.14	−1.479	.139
T Score Sluggish cognitive tempo	63.08	7.85	61.00	9.69	−1.126	.260
T Score Obsessive-compulsive	65.15	10.81	62.69	9.80	−0.934	.350
T Score Stress problems	67.85	10.53	65.00	11.90	−1.051	.293

CBCL: Child Behavior Checklist; *SD*: standard deviation; DSM: *Diagnostic and Statistical Manual of Mental Disorders*.
*Significantly different at $p < .05$.

results, no statistically significant differences were found between T_0 and T_1. The scores reported by the children were higher than the parent-reported scores.

SPPC. Table 6 shows the mean scale percentile scores on the SPPC at T_0 and T_1 and contains the results of the Wilcoxon signed-rank test. No statistically significant differences were found in percentile scores at T_0 and T_1.

CAMSA

In total, 10 children completed the CAMSA before (T_0) and after the programme (T_1). Three participants did not do both tests and could therefore not be scored. The outcomes are shown in Table 7. From low to high, children can score beginning, progressing, achieving and excelling. All children scored beginning or progressing at T_0 as well as at T_1.

Table 4. KIDSCREEN *T*-scores self-reported questionnaires, norm data and the results of the Wilcoxon signed-rank test.

Scales	*T*-values					Wilcoxon signed-rank test	
	T_0		T_1		Norm data	*Z*	Asymp. Sig. (2-tailed)
	M	*SD*	*M*	*SD*	50th percentile		
Physical well-being	48.17	8.51	51.97	10.78	55.73	−1.201	.230
Psychological well-being	50.60	8.16	56.65	13.17	53.47	−1.363	.173
Autonomy and parents	53.39	7.18	51.50	9.03	53.27	−.059	.953
Peers and social support	53.75	10.42	52.86	8.23	53.23	−.312	.755
School environment	56.28	10.97	53.35	12.42	57.96	−1.245	.213

SD: standard deviation.

Table 5. KIDSCREEN *T*-scores parent-reported questionnaires, norm data and the results of the Wilcoxon signed-rank test.

Scales	*T*-values					Wilcoxon signed-rank test	
	T_0		T_1		Norm data	*Z*	Asymp. Sig. (2-tailed)
	M	*SD*	*M*	*SD*	50th percentile		
Physical well-being	40.29	8.03	40.32	6.91	56.50	−.133	.894
Psychological well-being	40.54	7.30	45.46	6.93	52.38	−1.259	.208
Autonomy and parents	49.09	3.85	51.59	4.48	43.18	−1.543	.123
Peers and social support	49.97	9.18	48.97	8.35	52.90	−.968	.333
School environment	51.16	9.62	52.45	12.89	55.59	−.612	.540

SD: standard deviation.

Table 6. SPPC percentile scores at T_0 and T_1 and the results of the Wilcoxon signed-rank test.

Scales	Percentile scores				Wilcoxon signed-rank test	
	T_0		T_1		*Z*	Asymp. Sig. (2-tailed)
	M	*SD*	*M*	*SD*		
Scholastic competence	54.08	30.40	50.46	36.71	−.904	.366
Social acceptance	64.08	24.88	67.54	29.70	−.847	.397
Athletic competence	51.92	26.50	63.85	32.96	−1.202	.229
Physical appearance	52.00	33.43	44.08	25.93	−1.112	.266
Behavioural conduct	57.92	33.06	52.54	32.57	−.267	.790
Global self-worth	54.77	36.50	59.15	35.83	−.756	.450

SPPC: Self-Perception Profile for Children; *SD*: standard deviation.

Table 7. CAMSA scores and outcomes. Outcomes can be beginning, progressing, achieving and excelling.

Case	Age (years)	Gender	T_0		T_1	
			Score	Outcome	Score	Outcome
1	10	Boy	18	Progressing	17	Progressing
2	11	Boy	21	Progressing	21	Progressing
3	10	Girl	16	Beginning	16	Beginning
4	9	Boy	17	Progressing	16	Beginning
5	8	Girl	16	Progressing	15	Progressing
6	9	Boy	15	Beginning	13	Beginning
7	8	Boy	12	Beginning	16	Progressing
8	9	Boy	15	Beginning	14	Beginning
9	8	Girl	14	Beginning	14	Beginning
10	10	Girl	12	Beginning	15	Beginning
M			15.6		15.7	

CAMSA: Canadian Agility and Movement Skill Assessment.

Automated measures of play behaviour

The additional value of objective measurements of the player's positions was evaluated. Two 20-second intervals were manually selected and the tracked people were visualized. Example 1 (Figure 1(b) and final frame Figure 1 (a)) is taken from an exercise in which participants chase each other to steal a basketball. While Persons 2, 4 and 5 fully engage in the play, Person 1 is taking less initiative and Person 3 is a bystander. Such observations can be quickly made from visualizations. The players' movements can also be quantitatively analysed. For instance, Persons 3 and 5 covered 3.7 and 17.0 m in the 20-second interval, respectively. From Figure 1(c), it can be seen that initially Persons 2 and 4 are very close, but then Person 5 starts chasing Person 4. Such analyses reveal who is interacting with whom, how often and for how long. When interpreted in the context of the activity, this might be indicative of the social relations between people. In Example 2 (Figure 1(d)), Persons 1 and 2 have engaged in rough and tumble during a dancing exercise. Person 4 intervenes and Persons 3 and 5 continue the exercise. From the quantitative analyses, such disruptive events can be detected.

Discussion

We have conducted a pilot study of a sports- and play-based cognitive behavioural programme ('Dit ben ik') for chronically ill children to understand in what way the programme helps the children and to learn more about the needed future research designs of such programmes.

Because this pilot study was implemented in an existing programme, the research was bound by some restrictions, such as the small group size. This resulted in lower statistical power. We therefore highlight trends. Many children missed one or more lessons, which is common for children with a chronic medical condition. Different questionnaires and tests were administered to measure the effects of the programme in physical, emotional, cognitive and social functioning, as well as self-reported quality of life.

Many participating children had one or more behavioural problems, and in the majority of these children, the number of problems had decreased after the programme, as measured with the CBCL. The differences for the scales regarding depression were statistically significant. There

is a limitation with the use of the CBCL. The CBCL asks about behaviour in the past 6 months. The programme lasted only 2 months, so there is overlap in time when comparing the questionnaires at T_0 and T_1. The high number of behavioural problems is in line with previous research, which also showed behavioural problems and higher scores on the CBCL in children with chronic conditions compared to healthy peers (Carotenuto et al., 2013; Ferro & Boyle, 2015; Meijer et al., 2000).

The lack of clear differences between chronically ill children and the norm values on perceived competence, measured using the SPPC questionnaire, matches with previous studies (Ferro & Tang, 2017; Meijer et al., 2000). Some studies, however, find the SPPC scores to be lower in children with a chronic illness (Ferro & Boyle, 2013, 2015). These somewhat counter-intuitive findings raise the question if the SPPC is a suitable, robust questionnaire for this particular group of children.

We found a positive trend on the quality of life scores on the scales of the programme's focus: physical and psychological well-being. For psychological well-being, a similar positive trend was observed in the parent reports. Previous research showed that children with a chronic condition report a lower health-related quality of life compared to their healthy peers (Bai et al., 2017; Varni et al., 2007). In the current study, children reported their physical and psychological well-being to be slightly lower than the national norm data before the start of the programme. Psychological well-being after the programme was even higher than the norm data. On the other scales, there was not much room for improvement, as the scores were quite close to the national norm data. The participating children seem to have few problems with their quality of life. Most of the children had a congenital condition and therefore do not know life without the condition. That may be one explanation for the quite high scores on quality of life. Another explanation could be that the children are very well shielded from difficulties by their parents and other people in their environment. Furthermore, parents rated the quality of life of their children lower than the children themselves, in particular, for the physical and psychological well-being scales (The KIDSCREEN Group Europe, 2016; Ravens-Sieberer et al., 2008). This was also found in other studies (Levi & Drotar, 1999; Marisa et al., 2016; Verhey et al., 2009). In contrast, healthy children rate their quality of life similar or slightly lower than their parents (Berman et al., 2016; Jozefiak et al., 2008; Levi & Drotar, 1999). According to Eiser and Varni (2013), the differences between reports by children with a chronic condition and their parents are caused by judgements based on different information. Even though parents rated their children's quality of life to be lower than the norm data, they did not see much improvement after the programme.

All children scored relatively low on CAMSA (beginning or progressing). While they had a chronic physical disease, most children did not have a physical disability that directly impaired their motoric abilities. Further research is needed to assess if the lack of motor skills is a general problem in children with a chronic illness. Furthermore, the scores did not change much after the programme. This was probably a result of physical activity being mostly an instrumental resource in the programme rather than something that was focused on as an outcome. Specific movement skills were not practised and the additional physical activity of 90 minutes once a week was not enough to improve motoric competencies. It should also be noted that the test was performed in the group, which resulted in a somewhat different ambiance between the measurements that could have influenced the performance of the test.

Finally, this pilot study shows that automated analysis of play behaviour can reveal the patterns of positive and adverse interactions as well as provide insights into the participation of the children. Current analyses were limited by the partial view of the play area. In addition, a strong sense of context is required for the interpretation of the observable behaviour. For example, running might indicate the strong participation in chasing game, but can also be the result of disengagement

during an exercise on breathing. Indicators for various aspects of behaviour are needed and should be tailored to the exercises.

Conclusion

We found that the programme seems to have effect on behaviour and psychological well-being. Perceived competence and actual motor competence did not show any positive trends despite the programme's focus on sports and play.

These results suggest that children learn to better cope with their illness through the programme. For the analysis of the effectiveness of programmes, such as 'Dit ben ik', we propose to focus on behaviour and quality of life. Sports and play appear to be instrumental for the promotion of psychological well-being. The further understanding of how physical and social play results in higher levels of psychological well-being might benefit from a more systematic, automated analysis of play behaviour, as children themselves tend to overestimate their abilities and caregivers tend to underestimate them. Having a more objective baseline against which to evaluate subjective assessments would be very valuable for the much needed further research in this field of study.

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Supplemental material

Supplemental material for this article is available online.

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