# Global Health

# How children and their parents value using the Canadian Occupational Performance Measure (COPM) with children themselves

Gijs J.Q. Verkerk\*, Lisanne van der Molen-Meulmeester and Mattijs W. Alsem Amsterdam UMC, University of Amsterdam, Rehabilitation, Amsterdam Movement Sciences, Amsterdam, The Netherlands

#### Abstract.

**PURPOSE:** Although the Canadian Occupational Performance Measure (COPM) is used with children, it is unclear how they and their parents experience this. This study aims to investigate the opinions of children and their parents about the COPM when it is used with children.

**METHODS:** Semi-structured interviews were performed with 23 children varying in age between 8 and 18 years. The transcripts of the interviews were analysed using MAXQDA software to discover overarching themes. Parents' responses to an eight-item multiple-choice questionnaire were analysed using SPSS software.

**RESULTS:** Five themes extracted from the interviews with the children show: My way of doing the COPM; The COPM shows my own problems and wishes for change; The COPM is important for identifying the support I need; The influence of my parents and my therapist; and The COPM is suitable for me. The children experienced the COPM as a valuable tool for determining and measuring the impact of an intervention. The parents experienced the COPM as suitable for their child and judged that the child's scores were useful for showing the outcome of an intervention.

CONCLUSION: Both the children and their parents valued the COPM as an outcome measure for intervention.

Keywords: Validity, COPM, children, patient reported outcome measurement, PROM for children, feasibility

# 1. Introduction

Paediatric rehabilitation services aim to help children identify their abilities, so they can fulfil their potential. In recent decades there has been a move to more client-and family-centred services (FCS) with a focus on the needs of children and their families. A main component of FCS is collaborative goal-setting to address the needs of children and their family [1,2] which tend to

be expressed by the parents. Little by little as children grow, they learn to express their own needs becoming less dependent on parents and gradually developing autonomy and independence in society. As they develop, they become increasingly aware of their own capacities, wishes and preferences and are more involved in setting their own goals for appropriate forms of intervention. The self-determination theory (SDT) argues that interventions are much more effective when they support children's inner motivation and resources for change by acknowledging feelings of autonomy, relatedness and competence [3]. Children want to feel choice, connection and competence as they develop and learn new skills [1,4]. Administering the Canadian Occupational Performance Measure (COPM) helps children deter-

<sup>\*</sup>Corresponding author: Gijs J.Q. Verkerk, Department of Rehabilitation, A-01-414, Amsterdam University Medical Centers, location AMC, Meibergdreef 9, 1105 AZ Amsterdam, The Netherlands. Tel.: +31 20 5663345; Fax: +31 20 5669154; E-mail: G.J.Verkerk@amsterdamumc.nl.

mine their own ideas about the support they themselves think they need [5,6].

The Canadian Occupational Performance Measure (COPM) is an individualised measure designed to detect changes in a client's self-reported occupational performance over time and can be used among children with a minimum mental age of 8 years [5]. The COPM consists of 5 steps and involves a semi-structured interview performed by a therapist. During this interview, children prioritise a maximum of five important activities they would like to address as part of an agreed intervention. The children identify the activities they want to do, need to do, or are expected to do; however, they are not able to do or are not satisfied with the way they presently do them. For each of these activities they rate their performance and satisfaction on a 10-point scale which ranges from a score of 1 representing 'not able to do it'/'not satisfied at all' to a score of 10 indicating 'able to do it extremely well'/'extremely satisfied'. These priorities can be used to determine the goals for intervention [6]. After an appropriate period of intervention, the final step of the COPM is reassessment which takes place by asking the children to rate their performance and satisfaction for the five prioritised activities again. The change in the occupational performance reported is calculated by subtracting the ratings given at the start of the intervention from the ratings determined at reassessment.

The use of the COPM with children helps to increase self-awareness of their own needs and competencies. Further, it stimulates their autonomy by inquiring about wishes for their own life. In addition, working from requests for help made by the children tends to increase their motivation to engage with a specific intervention to support them [1,7]. Goals for intervention set by children themselves sometimes differ from those set for them by their parents [8]. In most published health studies, the COPM is completed by a child's parents [9–12] or by the child with their parents [13,14]. More recently, studies have also used the COPM with children themselves [15,16]; however, it is not known whether administering the COPM with children corresponds with their needs. Validity and feasibility studies involving the use of the COPM with children are missing and specific instructions for using it are not available [5,17] although desired [COPM newsletter July 2018 accessible via [17]. In order to clarify how the COPM could be used with children, a research project was designed with the aim of developing a manual containing specific instructions for its use. The project consisted of (1) collecting the perspectives of children and their parents on the COPM, (2) collecting the opinions and working methods of several paediatric occupational therapists, and finally (3) aiming at consensus regarding specific instructions for using the COPM with children. This paper describes the opinions of the children and their parents about administering the COPM with the children themselves. The COPM is a patient-reported outcome measure for children; therefore, the value of it should be confirmed by them.

The primary aim of this study was to clarify whether the administration of the COPM with children fit with the needs of them and their parents. More specifically, it explored whether the COPM matched the capabilities of children with a minimum mental age of 8 years and whether it is an appropriate tool for collecting the wishes of children themselves concerning their occupational performance. With respect to parents, the study aimed to clarify how they valued their child's own wishes in relation to their own desires for their child and how they judged the appropriateness of the COPM as an outcome measurement. The secondary aim of this study was to investigate whether the three psychological needs of the SDT (autonomy, relatedness and competence) could be detected in using the COPM.

#### 2. Method

# 2.1. Design

A qualitative research design was used to collect the perspectives of the children [18]. In order to identify their experiences and needs regarding the COPM, semistructured face-to-face interviews were performed at the practice site by the researcher (GV or LM) who used a topic list to guide the interviews. The list contained the five steps of the COPM and examples of questions which could be asked. The content of these questions reflected the clinical expertise of the researchers; see Appendix. A general inductive approach [19] was taken to analyse the content of the interviews. The parents of the participating children completed a questionnaire which sought to elicit their own views of the COPM as an outcome measure for their child's intervention and for collecting socio-demographic characteristics. The questionnaire contained eight statements for which the parents had to choose from the following answers: fully agree, somewhat agree, no opinion, slightly disagree, completely disagree. The questionnaire was created for this study and not tested for reliability and validity. For the statements of the questionnaire, see Table 3.

#### 2.2. Participants

Children with a mental age of at least 8 years referred by a physician to an occupational therapist were included in the study. Mental age was determined by their occupational therapist using medical records, educational level and information from the parents. The sampling approach was purposely designed to include participants of both sexes, varying in age, diagnosis, treatment setting and ethnic background. In particular children attending primary school, younger than 12 years of age, were included to investigate the applicability. No other inclusion or exclusion criteria were implied.

#### 2.3. Procedure

The study was approved by the Medical Ethics Committee of the Amsterdam University Medical Centres in Amsterdam in the Netherlands. Participants were recruited by their occupational therapists. Occupational therapists who were accustomed to administering the COPM were asked to participate in the study via newsletters and the Dutch journal for occupational therapy. Because we aimed to gather a wide spectrum of opinions of the target group, the sample of this study strived for a variety in workplaces of the occupational therapists including rehabilitation centers, hospitals and private practices. The occupational therapists who were willing to participate received information letters and informed consent forms which they sent to potential participants i.e. parents of the children to whom the COPM would be administered within a few weeks, as part of an intervention. The information letter explained the aim and content of the COPM and the study procedures. In the Netherlands, children 12 years and older also have to give their signed consent so relevant children were also given an information letter and consent form to complete.

The evening before the COPM was administered, the researcher phoned the parents. During this phone call the researcher explained the COPM and the research procedures, answered all questions of the parents and asked them to deliver the signed informed consent the next day.

The following day, the occupational therapist administered the COPM with the child sometimes in the presence of the parents. Directly after administering the COPM, the researcher collected the completed informed consent forms of the parent and the child, and then interviewed the child. These interviews were au-

diotaped. While the interview was taking place, the parents completed a questionnaire.

On the same day, the researcher summarised the interview and sent it to the children via their parents' email address, asking the parents to check the summary with their child. After receiving an email reply from the parents, a cinema voucher was sent to the participating child as a gift.

# 2.4. Data collection and analysis

The two researchers involved in this study both work in a University Hospital and have used the COPM over several years with children. GV, a paediatric occupational therapist with 15 years' experience and LM, a paediatric occupational therapist/ortho-pedagogue (remedial educationalist) with 7 years' experience both of whom worked with seven of the participants (five GV and two LM).

The audiotaped interviews were transcribed verbatim and coded by numbering. These transcripts were read and coded independently by both researchers (GV and LM) using MAXQDA software. During coding, the researchers independently grouped codes into categories. After coding ten transcripts, the researchers agreed about codes and categories (Codes 1). Codes 1 were used to recode the next 13 transcripts. This resulted in several additional codes but no new categories. Agreement on a revised set of codes, Codes 2, was obtained by reviewing and discussing the new codes and integrating them into the categories within Codes 1. Finally, both researchers independently reviewed the possible relationships between the categories in order to discover the overarching themes and they reached consensus [19,20].

In generating the overarching themes, the researchers used their professional backgrounds and specifically, the underlying theories of the COPM [21]. For the secondary aim of the study, the content of the overarching themes was examined to detect the three psychological needs of the SDT (autonomy, relatedness and competence) [1,3,22].

Questionnaires completed by the parents were anonymised and analysed using Statistical Package for the Social Sciences (SPSS). Standards for reporting qualitative research were used [23].

### 3. Results

A total of 23 children were interviewed directly after the completion of the COPM. Parents of 14 children attended its administration. Fifteen children's parents attended the semi-structured interview about the COPM. The parent who attended was not directly involved in the child's response. Among the 23 children, the COPM was administered as part of standard care with 18 who were starting their intervention and with five at the end of the intervention. These five children completed the reassessment of the COPM, with the same occupational therapist who administered it at the start of the intervention, and talked about the difference in their scores for performance and satisfaction. The replies of the parents with respect to the summaries of the interviews showed that no changes were made to the summary of the interview by any child or parent.

All parents completed the questionnaire. Diagnoses and socio-demographic characteristics of the children, their parents and occupational therapists are shown in Table 1. All children followed age-appropriate education, had not failed any grades. Two were in a school for special education i.e. primary and high school.

# 3.1. Thematic analysis

The codes of the interview transcripts were grouped into 12 categories which resulted in five overarching themes; see Table 2. The themes were: (1) my way of doing the COPM, (2) the COPM shows my own problems and wishes for change, (3) the COPM is important for identifying the support I need, (4) the influence of my parents and therapist, and (5) the COPM is suitable for me. Each theme will be described in the following paragraphs and illustrated with text extracts which include quotations from the children's transcripts. In addition, the identified psychological needs of the SDT (autonomy, relatedness and competence) are reported.

## 3.1.1. My way of doing the COPM

In general, the therapists and/or parents did not explicitly prepare the child for the administration of the COPM. However, all children were able to complete it. This theme shows how the children spoke about their problems in occupational performance, rated these in importance and then prioritised their problems, and rated these in terms of performance and satisfaction. In this theme the need for autonomy and competence of the SDT were identified.

Children were asked to describe what activities they usually do during a typical day:

"She asked how the day had started and what I found difficult" (boy 10 y.).

Table 1 Sociodemographic characteristics of the participants (n = 23) their parents (n = 28) and their therapists (n = 13)

parents ( $n = 28$ ) and their therapists ( $n = 13$ )				
Child factors				
Age $< 12$ years, $n = 13$ , mean (range)*	9.6 (7-11)			
Age $\geq 12$ years, $n = 10$ , mean (range)	15.1 (12–17)			
Male, $n$ (%)	15 (65)			
Child diagnosis				
Chronic pain	5			
Cerebral Palsy (CP)	5			
Limb girdle dystrophy	2			
Developmental Coordination Disorder (DCD)	2			
Spinal Muscular Atrophy (SMA)	1			
Chorea	1			
Pyramidal syndrome	1			
Neurological disorder after chemo in Leukaemia	1			
Combination of CP, PDD-NOS and DCD	1			
Sensory processing disorder	1			
ADHD	1			
Highly intelligent	1			
No diagnosis	1			
Child's intervention setting	0 (20)			
Rehabilitation Centre n (%)	9 (39)			
University Hospital n (%)	8 (35)			
Private Practice n (%)	6 (26)			
Parental factors	7 (25)			
Male, $n$ (%) <sup>a</sup>	7 (25)			
Age of Mothers, mean (range) <sup>b</sup>	44 (36–52)			
Age of Fathers, mean (range) <sup>b</sup>	47 (42–57)			
Both parents born in the Netherlands $n$ (%)	16 (57)			
Education level low <sup>c</sup> n (%)	9 (32)			
Education level middle n (%)	12 (43)			
Education level high $n$ (%)	7 (25)			
Occupational therapists Work place				
University Hospital	2			
Private practice	4			
Rehabilitation Centre	7			
Graduation	,			
≥ 20 years ago	3			
Between 20 and $\geqslant$ 15 years	6			
Between 15 and $\geqslant 15$ years	2			
Between 10 and $\geqslant$ 5 years	1			
< 5 years	1			
Using the COPM with children	1			
≥ 15 years	4			
Between 15 and $\geq$ 10 years	2			
Between 10 and $\geqslant$ 5 years	6			
< 5 years	1			
< 5 jours				

<sup>&</sup>lt;sup>a</sup>Questionnaires were completed by: both parents (n=5), by mothers (n=16) and by fathers (n=2). <sup>b</sup>Age of the parent(s) who completed the questionnaire. <sup>c</sup>Education level of the parent(s) who completed the questionnaire Low: primary school/entry level for lower professional education/lowest level of professional education. Middle: finished high school/professional education levels 2, 3, 4. High:  $\geqslant$  Bachelor level. \*In the Netherlands, children finish primary education when they are about 12 years.

Other children talked spontaneously about their issues. Children considered themselves competent enough to rate the importance of the activity, their performance of the activity and their satisfaction with that performance:

Table 2

Overview of 5 overarching themes including 12 categories

#### My way of doing the COPM

How I prepare myself

How I speak about my problems

How I prioritise my most important wishes

How I score importance, performance and satisfaction

The COPM shows my own problems and wishes for change

How I describe the COPM

The COPM is important for me

#### The COPM is important for identifying the support I need

It is an important outcome measure of my intervention

What should be done with my COPM outcomes

## The influence of my parents and my therapist

The influence of my parents

The interaction with my therapist

The COPM is suitable for me

How I feel about the COPM

Children who benefit from the COPM

The codes detected from the interviews with the children were grouped into 12 categories. Additionally, these categories were grouped into 5 overarching themes.

"Those numbers, yes ... I really liked it.

So why is that nice?

Why, because you can choose for yourself how you experience it yourself" (boy 9 y.).

This text extract shows some fulfillment of the need for autonomy.

However, children said they needed time to think about their rating:

"It [the rating] is difficult because you do not pay attention to what you do in your daily life.

OK.

But it is useful to answer with numbers" (girl 17 y.).

"Well you had to rate yourself. How did you do that?

Yes ... uh ... yes ... it was ... I did not have ... I did not think it was weird or so ... No, because in the end you are here for yourself.

Yes, but could you do it?

Yes, I could, it is easy and difficult ... complicated.

Yes.

Some things are more difficult than others.

Yes.

Because for some things ... yes ... you need some self-reflection ... yes ... It is not that you just put 5, 7, 8, 6, you have to use self-reflection" (boy 11 y.).

These two text fragments reveal that the children felt competent enough to rate themselves which is in accordance with SDT's need for competence.

Children expressed their ideas about how the difference in scores represented a change. Some said that the scores should improve by at least two points, while others aimed to get sufficient marks.

# 3.1.2. The COPM shows my own problems and wishes for change

The researcher asked the children what they talked about during the COPM and for whom it might be useful. The answers show that children really expressed their own wishes in the COPM interview. The need for autonomy, an aspect of SDT, is evident in what the children said:

"What I wanted to improve" (girl 13 y.).

"Eh...just talk about what is bothering me...What I really want to tell...I think it's OK because it is what I want to change, other people do not want that necessarily, but they want to help me with my own things" (boy 12 y.).

The following text extract shows how a child dealt with the issues of his parents:

"Maybe there are also things that mum and dad think are important for you?

Yes.

Or the teacher at school?

Yes.

How should we deal with that?

You have to ask mum and dad.

OK we should ask mum and dad themselves the same thing?

Yes" (boy 10 y.).

# 3.1.3. The COPM is important for identifying the support I need

This theme includes statements which show that children appreciate their own issues being brought to the attention of professionals who help solve these issues. The following quote is an example of how their wish expressed in the COPM will be addressed:

"...I hope something is done ... yes of course ... yes, I mean it's all wasted effort if nothing is done ... yes" (boy 15 y.).

Children stated that being able to say what the issues are helps them find ways to solve them for themselves. The COPM also helps make issues clearer and specific.

"Well, because it was very clear to really look at what the problem was and to what extent it was a problem ... and really in daily life ... And that we could therefore deal with it very precisely, so you do not just generally address issues but very specifically ... so you can really tackle the problem uh ... uh ... I found that very useful" (girl 16y.).

In this theme the need for autonomy, an aspect of SDT, is detected. Examples are the following two quotes:

"I think I have also made a schedule for football and just tried all things because of this COPM. Uh ... it [completing the COPM] is important because I started to see that I really, really wanted to do these things again" (boy 13 y.).

"This way they can give information to a doctor and the doctors can see what they can do on the basis of the COPM form. It [the COPM] is also important for me because I also know what I can do and cannot do well" (girl 17 y.).

Five children were interviewed after the reassessment. Results confirm that the wishes of the children, which were collected using the COPM, were integrated into the goals relating to the various interventions. The discussions with the children show that they were very pleased to see how they were improving, based on their own efforts and the help they got from the professional:

"I think it's nice that I can see that these numbers have improved a lot and that we have worked on them too" (boy 13 y.).

"Uh... Uh... well, really clear progress... really from pretty low numbers to high numbers and that is also very good to see, because I myself had the feeling that I had improved, but if you see it in numbers, oh yes... it has actually improved a lot" (girl 16 y.).

"At least I'm glad that everything, almost everything is improved so, without surgery, it would not have been better . . . I think that I should need more help than I have now. I really have less help now compared to what I had before the operation" (boy 15 y.).

# 3.1.4. The influence of my parents and therapist

The interviews with the children revealed that parents perform different roles during the administration of the COPM. In addition, the degree of help children needed from their parents varied. Therefore, the therapist should encourage parents to help support their chil-

dren determine their own wishes. Also, children needed the therapist to adapt their communication style to the child's particular style. This theme clearly shows the psychological need for relatedness as an aspect of SDT. The following text extracts show examples:

"Your mother was there as well. How did you feel about that, because you are 12 years old?

*Uh...my mother is of course allowed to know what I'm saying ... yes ... and can also help a little if I accidentally tell something wrong*" (boy 12 y.).

"What is actually the best thing for you with dad and mum or without?

Well I do not know, so some things are pretty private, uh...so I would say without" (girl 9 y.).

"So, let the child decide whether the parents attend the COPM and what kind of role they take" (girl 17 v.).

The children also commented on their interaction with the therapist:

"How she talked.

OK, because how was that?

It was just normal. Just normal uh . . . uh.

So, what did she not do, for example?

*Uh...do not treat me like a little child*" (girl 13 y.).

"How can we make such a conversation better for children?

Well uh ... Just use simple language.

Use simple language. OK.

Yes...yes...because some children do not understand eh...the way you are speaking now" (girl 9 y.).

"How could your therapist have done it [completing the COPM] better for you?

*Uh...actually not...she is very nice and makes it comfortable for me*" (boy 9 y.).

# 3.1.5. The COPM is suitable for me

The 5th theme focuses on how the children experienced the COPM. Children said they liked the COPM and the three psychological needs for autonomy, relatedness and competence were also visible in this theme. This quote shows that the boy felt competent enough to complete the COPM when he was asked: How did you like doing the COPM?

	_			•					
	Fully agree (5)	Somewhat agree (4)	No opinion (3)	Slightly disagree (2)	Completely disagree (1)	Missing (0)	Median	(P25; p75)	Range
Statement 1	21	1	1	0	0	0	5	(5; 5)	3–5
Statement 2	19	2	1	1	0	0	5	(5; 5)	2-5
Statement 3	22	1	0	0	0	0	5	(5; 5)	4-5
Statement 4	17	5	0	1	0	0	5	(4; 5)	2-5
Statement 5	15	5	2	0	1	0	5	(4; 5)	1-5
Statement 6	1	5	1	9	7	0	2	(1; 4)	1-5
Statement 7	16	5	0	0	1	1	5	(4; 5)	1-5
Statement 8	16	3	2	0	1	1	5	(4; 5)	2-5

Table 3 Result of Questionnaires (n=23): completed by mothers (n=16) fathers (n=2) and both parents (n=5)

Statements: 1. It is important to assess which activities my child wants to perform better. 2. The COPM conversation with my child is a good way to assess what my child would like to do better. 3. It is important that in the intervention the activities that my child wants to be able to do better are taught and practiced. 4. It is important that in the intervention both the activities that my child wants to perform better and the activities that I as a parent want to see that my child does better, will be learned and practiced. 5. It is more important that the activities that my child wants to perform better are addressed in the intervention than the activities that I as a parent want my child to perform better will be addressed in the intervention than what my child wants to do better. 7. The COPM is used to evaluate the intervention. Prior to the intervention, your child gives the activities he wants to improve a score, on a scale of 1 to 10. He gives all activities a score for: 1. Performance, how well does your child thinks that he is carrying out the activity? 2. Satisfaction, how satisfied is your child with it? I think my child can give these scores well. 8. At the end of the intervention, your child will be asked to score again the activities he wanted to improve (for the performance and satisfaction). The difference with the scores your child gave at the start of the intervention indicates the effect of the intervention. I find it important to express the effect of the intervention in a number that is based my child's scores.

The table shows the answers of the parents for each statement using the 5 point scale. Each statement is written in full and the score result is summarised by showing the median, the p25;p75 (the interquartile range: the numerical difference between the  $25^{\rm th}$  and  $75^{\rm th}$  centile) and the range.

"Was easy" (boy 10 y.).

The following quote shows that the COPM encourages autonomy:

"The reason it [the COPM] is nice is because you can judge yourself and you don't do that often" (boy 11 y.).

The following quotes show that during the administration of the COPM, the children could relate to the therapist and were able to complete the COPM. The step-by-step procedure and the adaptation to individual needs were also valued:

"It [the COPM] is pretty good because first they ask what you can do and what you can't do. Then you have to give these a score. I think it's very good how they do it and yes, I'm satisfied with it" (girl 17 y.).

"So, why does this really suit you?

*Uh...yes, because the way the COPM is done is very quiet and it's uh...well planned in advance"* (boy 15 y.).

Two children were less positive, especially about the first step of the COPM:

"I had to tell it [problems] ... to every doctor ... so every time I had to say it again" (boy 13 y.).

"Why it's not fun to talk about my problems? Just because I've been through so much...or so" (girl 8 y.).

Children's thoughts differed about the applicability of the COPM for other children in need of intervention. They said that they find the COPM useful for children when they are at least 6 to 8 years. The issue of unsuitability was also spoken about:

"Some children cannot talk at all and then they are nervous inside and then they cannot control their speech device" (girl 9 y.).

# 3.2. Suggestions to make the COPM more attractive for children

In general, the children who participated in this study were satisfied with the COPM and proposed three suggestions: (1) make it more attractive by using colors, (2) make rating easier and (3) give a reward. These quotes and text extracts illustrate the suggestions:

"Maybe they can colour it in ... or instead of giving numbers, something with colour ... Yes, say red is bad and green is just 10" (girl 16 y.).

"I think that children would like it better if they got a reward at the end or so, kids like that a lot. And what kind of reward should that be?

 $Uh \dots a$  sticker and  $\dots uh \dots just$  something children like" (boy 9 y.).

## 3.3. The parents' answers to the questionnaire

The questionnaire was completed for all 23 children by 16 mothers, 2 fathers and 5 times by both parents. The results of their answers to eight statements are shown in Table 3. The answers to the first three statements demonstrate that almost all parents agreed that it is important to use the COPM to identify activities that their child wanted to improve and to address them in an appropriate intervention. However, one parent answered 'slightly disagree' regarding using the COPM.

The answers to the fourth statement show that 22 of the parents want both their wishes and their child's to be addressed in the intervention. When parents have to choose what the focus of the intervention should be, their child's wishes or their wishes (statements five and six), 20 chose the wishes of their child. Only one parent answered 'completely disagree' to statement five. This is supported by answers to the sixth statement which show that six parents prioritised their wishes to be addressed in the intervention while 16 parents prioritised their child's wishes.

Answers to the seventh statement reveal that for the 23 children in the study, 21 parents judged that their child was able to rate his/her own performance and satisfaction regarding the activities which the child wanted to improve. Finally, 19 parents answered that these ratings are valuable for determining the impact of the intervention.

# 4. Discussion

The results show that children as well as their parents consider the COPM to be a valuable instrument for collecting the child's wishes regarding daily activities in which the child would like to improve performance and/or satisfaction. Nearly all children said that they wanted their wishes to be addressed in an appropriate intervention. Results also show that the wishes of the five children who were interviewed after re-assessment were integrated in the goals for intervention. Both children and parents consider that the difference in scores, calculated before and after the intervention, are an important outcome.

#### 4.1. Theoretical remarks

According to Self-Determination Theory (SDT) there are three basic psychological needs which are important for supporting a child's motivation for goal setting in rehabilitation: autonomy, relatedness and competence [1,3,4]. These three needs within the SDT are evident in the results. The need for autonomy is visible in all themes. The need for relatedness is evident in themes: 'The influence of my parents and therapist' and 'The COPM is suitable for me'. The need for competence is mainly evident in: 'My way of doing the COPM', and 'The COPM is suitable for me'. These findings confirm that the COPM is helpful in motivating a child to set personal goals.

Several studies show that goals for intervention set by children differ from the goals set for them by their parents [8,24,25]. This qualitative study corroborates this finding because children said that they prioritised different activities from those which their parents identified for them.

## 4.2. Other tools for goal setting with children

This study corroborated the value of the COPM as an important tool for the first step concerning children's ability to set their own goals. The wishes collected by means of the COPM can be used in the process of collaborative goal setting between clinicians, children of 8 years and older, and their parents [26]. There are several other instruments for collaborative goal setting with children which are used in paediatric rehabilitation and which utilise a family-centred service approach. These include: The Perceived Efficacy and Goal Setting System (PEGS) designed for children between the ages of 5 and 9 years [27], the Child Occupational Self-Assessment (COSA) designed for ages 8-13 years [28], and the Paediatric and Preschool Activity Card Sort (PACS) [29] designed for ages 3–14 years. The PEGS and PACS use pictures to help children think about what they would like to change, and the COSA is a questionnaire. The pictures and questions direct the children's thinking, whereas the COPM is a semistructured interview about aspects of their own life. Therefore, the COPM helps children think about the activities they would like to improve instead of choosing activities from a set of possible difficulties. The COPM is a patient-reported outcome measure. Unfortunately, the PEGS, COSA and PACS are not outcome measures.

# 4.3. Suggestions for making the COPM even more suitable for children

In general, the children said that the COPM is pleasant and appropriate for them to use, and might be used with children of 8 years or even younger. Interestingly, in their accounts the children gave implicit and explicit suggestions to make it more applicable to their peers and younger children. It is important to remember that not all children want to talk about their problems. Although the COPM is designed to identify problem areas in occupational performance [5] it does encourage children to identify and talk about their own wishes in relation to their occupational performance. The word 'problem' comes from a problem-oriented approach to health care instead of a strength-based approach [30] which focuses on competencies and solutions. It helps to develop and draw on a child's capacity for dealing with the challenges of living with a chronic disease [31]. Therefore, caution is recommended when using the word 'problem' during the COPM interview. The focus during the interview should be on the child's own wishes for change.

Other suggestions to make it more suitable are to give children enough time to formulate their wishes and for rating their performance/satisfaction. In addition, the participating children also expressed their need for the communication style of the therapist to be adapted to their communication needs. Furthermore, this study shows that during the COPM interview, the role of parents obviously varies and is dependent on the individual needs of their child. Finally, there are children who have trouble rating performance and satisfaction using the rating cards. These children might benefit from symbols being added to the rating cards so that the meaning of the numbers is more visible.

#### 4.4. Methodology

The children in this study were invited to participate, via their parents by an occupational therapist experienced in the use of the COPM. Occupational therapists included children with a minimum mental age of 8 years. The occupational therapists used their clinical reasoning and therapeutic skills to assess whether the COPM was appropriate for the child. This requires clear clinical reasoning which takes into account available medical information about the child and the therapist's own expertise in using the COPM. It can be argued that using a standardised measurement to establish the child's mental developmental age would have resulted

in a different sample of participants. In addition, the results of this study are not representative of all occupational therapists who use the COPM with children because novice therapists were not included in the study. Furthermore, the therapists selected the participating children which might have led to the exclusion of children/parents who themselves were sceptical about using the COPM.

Seven children were already familiar with their interviewer. It is assumed that this increased the depth of the study results because the children felt at ease and dared to share their personal experiences.

The themes derived from the interviews with the children resemble the topic list used during the interviews. It could be argued that a more open approach to interviewing might result in different themes. However, specific questions do need to be asked in order to encourage the child to start talking about the COPM. Moreover, it is not very likely that children of 8 years old would spontaneously talk extensively and in an abstract way to an unfamiliar researcher during the interview.

Our study includes data from 23 interviews. Most qualitative studies include fewer participants because saturation of data is mostly achieved with 12 participants [32]. However, 23 were included because of the need to gather opinions from a broad group of children selected on the basis of age, diagnosis, treatment setting, and ethnic background.

To corroborate the trustworthiness of the data, the principle of member checking was used, i.e., all children and their parents checked the summary of the interview. All participants agreed with the text in the summary and did not make any changes. In addition, the principle of peer checking was applied during coding of the transcriptions, organising the codes into categories and determining the overarching themes.

The results of the study concern a sample with a wide variety of treatment settings, diagnosis, age, ethnic background of the child, and educational level of parents. Therefore, it is assumed that the results of this study are transferable to children referred to paediatric occupational therapists. Nevertheless, the study has been performed in the Netherlands with 23 Dutch children and might not sufficiently represent children from a different cultural background or health care system.

#### 5. Conclusion

This paper describes the opinions of the children and their parents about the COPM when it is administered with the children themselves. Children experienced the COPM as a suitable and valuable tool for helping them express their wishes about the activities which they wanted to improve and for showing improvement. Overall, the parents considered the issues that their child identified to be very important for the goals of the intervention. They judged their children's performance and satisfaction ratings to be important for the outcome of the intervention. As administering the COPM with children complies with the psychological needs described in the Self-Determination Theory, it potentially helps with intrinsically motivating them for their treatment. This qualitative study confirms that the COPM is a patient-reported outcome measure which can be used with children who have a mental developmental age of 8 years or above.

## Acknowledgments

We would like to thank the children, their parents and their occupational therapists for their involvement. Special thanks to J. Beelen PhD, for help with the design and performance of this study.

#### **Conflict of interest**

The authors have no conflict of interest to report.

# **Funding**

Funding for this study came from four sources: HandicapNL, Johanna Child Fund (Johanna Kinderfonds), Foundation Child Fund Adriaanfoundation (Stichting Kinderfonds Adriaanstichting), Amsterdam University Medical Centres. These funding bodies did not in any way influence the data collection, data analysis or the drafting of this manuscript.

# References

- Poulsen A, Ziviani J, Cuskelly M. Goal setting and motivation in therapy, enabling children and parents. London UK: Jessica King Publishers, 2015.
- [2] Rodger S, Keen D. Child and Family-centred Service Provision. In: Roger S, Kennedy-Behr A, editors. Occupation-Centred Practice with Children, a practical guide for occupational therapists. 2nd ed. West Sussex, UK: Wiley Blackwell, 2017.

- [3] Ryan RM, Deci EL. Self-Determination Theory. Basic Psychological Needs in Motivation, Development and Wellness. New York: The Guilford Press, 2018.
- [4] Deci EL, Ryan RM. Self-determination theory in health care and its relations to motivational interviewing: a few comments. Int J Behav Nutr Phys Act. 2012 Mar 2; 9: 24.
- [5] Law M, Baptiste S, Carswell A, McColl MA, Polatajko H, Pollock N. Canadian Occupational Performance Measure 5th ed. Ottawa, Ontario, Canada: CAOT Publications ACE, 2014.
- [6] Law M, Pollock N. Canadian Occupational Performance Measure. In: Poulsen A, Ziviani J, Cuskelly M, editors. Goal setting and motivation in therapy, enabling children and parents. London, UK: Jessica King Publishers, 2015.
- [7] Vroland-Nordstrand K, Eliasson A-C, Krumlinde-Sundholm L, Johansson U. Parents' experiences of conducting a goaldirected intervention based on children's self-identified goals, a qualitative study. Scand J Occup Ther. 2018 Jul; 25(4): 243-251.
- [8] Vroland-Nordstrand K, Krumlinde-Sundholm L. The Perceived Efficacy and Goal Setting System (PEGS), part II: evaluation of test-retest reliability and differences between child and parental reports in the Swedish version. Scand J Occup Ther. 2012 Nov; 19(6): 506-14.
- [9] An M, Palisano RJ, Yi C-H, Chiarello LA, Dunst CJ, Gracely EJ. Effects of a Collaborative Intervention Process on Parent Empowerment and Child Performance: A Randomized Controlled Trial. Phys Occup Ther Pediatr. 2019; 39(1): 1-15.
- [10] Ferre CL, Brandão M, Surana B, Dew AP, Moreau NG, Gordon AM. Caregiver-directed home-based intensive bimanual training in young children with unilateral spastic cerebral palsy: a randomized trial. Dev Med Child Neurol. 2017 May; 59(5): 497-504.
- [11] Ghorbani N, Rassafiani M, Izadi-Najafabadi S, Yazdani F, Akbarfahimi N, Havaei N, et al. Effectiveness of cognitive orientation to (daily) occupational performance (CO-OP) on children with cerebral palsy: A mixed design. Res Dev Disabil. 2017 Dec; 71: 24-34.
- [12] Morgan C, Novak I, Dale RC, Guzzetta A, Badawi N. Single blind randomised controlled trial of GAME (Goals – Activity – Motor Enrichment) in infants at high risk of cerebral palsy. Res Dev Disabil. 2016 Aug; 55: 256-67.
- [13] Gharebaghy S, Rassafiani M, Cameron D. Effect of cognitive intervention on children with ADHD. Phys Occup Ther Pediatr. 2015 Feb; 35(1): 13-23.
- [14] Miller L, Ziviani J, Ware RS, Boyd RN. Mastery motivation: a way of understanding therapy outcomes for children with unilateral cerebral palsy. Disabil Rehabil. 2015; 37(16): 1439-45.
- [15] Arman N, Tarakci E, Tarakci D, Kasapcopur O. Effects of Video Games-Based Task-Oriented Activity Training (Xbox 360 KinectTM) on Activity Performance and Participation in Patients with Juvenile Idiopathic Arthritis: A Randomized Clinical Trial. Am J Phys Med Rehabil. 2018.
- [16] McPherson AC, McAdam L, Keenan S, Schwellnus H, Biddiss E, DeFinney A, et al. A feasibility study using solution-focused coaching for health promotion in children and young people with Duchenne muscular dystrophy. Dev Neurorehabil. 2018 Feb; 21(2): 121-130.
- [17] The Canadian Occupational Performance Measure (COPM) [Internet]. Available from: http://www.thecopm.ca/.
- [18] Green J, Thorogood N. Qualitative methods for health research. 3rd ed. London, UK: Sage Publications Ltd., 2014.
- [19] Thomas DR. A general inductive approach for analyzing qual-

- itative evaluation data. American Journal of Evaluation. 2006; 27: 237-46.
- [20] Saldana J. The coding manual for qualitative researchers. London, UK: Sage Publications Ltd., 2009.
- [21] Townsend AE, Polatajko HJ. Enabling Occupation II: Advancing an Occupational Therapy vision for health, well-being & justice through occupation. Ottawa, Ontario, Canada: CAOT Publications ACE, 2007.
- [22] Rodger S, Kennedy-Behr A. Occupation-Centred Practice with Children, a practical guide for occupational therapists. 2nd ed. West Sussex, UK: Wiley Blackwell, 2017.
- [23] O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. Acad Med. 2014 Sep; 89(9): 1245-51.
- [24] Costa UM, Brauchle G, Kennedy-Behr A. Collaborative goal setting with and for children as part of therapeutic intervention. Disabil Rehabil. 2017 Aug; 39(16): 1589-1600.
- [25] Livingston MH, Stewart D, Rosenbaum PL, Russell DJ. Exploring issues of participation among adolescents with cerebral palsy: what's important to them? Phys Occup Ther Pediatr. 2011 Aug; 31(3): 275-87.
- [26] Brewer K, Pollock N, Wright FV. Addressing the challenges of collaborative goal setting with children and their families. Phys Occup Ther Pediatr. 2014 May; 34(2): 138-52.
- [27] Pollock N, Missiuna C. The perceived efficacy and goal setting system. 2nd ed. Hamilton, Canada: Can Child, 2015.
- [28] Keller J, Kafkes A, Basu S. A user's guide to Child Occupational Self-Assessment (COSA); version 21. Model of human occupation. Chicago, USA: Clearing House. Department of occupational therapy, College of applied health sciences, University of Illinois, Chicago, USA, 2006.
- [29] Mandich AD, Polatajko HJ, Miller LT, C. B. Paediatric Activity Card Sort. Ottawa, Ontario, Canada: CAOT Publications ACE, 2004
- [30] Swartz MK. A Strength-Based Approach to Care. J Pediatr Health Care. Jan-Feb 2017; 31(1): 1.
- [31] Chung RJ, Burke PJ, Goodman E. Firm foundations: strength-based approaches to adolescent chronic disease. Curr Opin Pediatr. 2010 Aug; 22(4): 389-97.
- [32] Guest G, Bunce A, Johnson L. How many interviews are enough? An experiment with data saturation and variability. Field Methods. 2006; 18: 59-82.

# Appendix – Topic list for the semi-structured interviews with the children regarding COPM assessment

COPM Step 1: Identify the child's problems; wishes for change.

- What was it like to talk with the therapist?
- Did the therapist explain things well? Was it clear what you were going to do?
- Did you talk about which daily activity was important for you and that you wanted to do better?
- How did you feel about talking with the therapist about the things which matter to you and that you wanted to do better?
- Did you forget to talk about anything?

- Were you able to talk about what is important for you and which you want to do better?

COMP Step 2: Rating the importance of each problem; wish for change.

- Could you rate the importance?

COPM: Step 3 and 4: Rate performance and satisfaction.

- How did you rate things? Did you use the rating cards?
- Did you give high or low numbers?
- Do you think that next week you will still want to improve the same things?
- Do you think that you will give roughly the same numbers next week?
- What do you hope will happen now that you have talked about things you like to improve?
- What else do you want to say about the conversation with the therapist?
- What was difficult?
- What was boring?
- What was fun?
- What could be done better?
- Were your parents there? If so were you happy with this?

Additional questions for children who performed the re-assessment.

General questions:

- How did the conversation go?
- How do you feel about it?
- Did you remember what you told the therapist at the first interview?
- What has changed/improved?

COPM step 5: Reassessment.

- How do you experience doing the rating?
- Did you remember the rating you gave the first time you did this?
- Do you think that giving a new rating is a good way to know whether the treatment has helped you?
- If you come to occupational therapy again, would you like to do the COPM again?

Topic list with examples of questions. These were used as a reminder during interviewing the children about their experiences with the COPM. The topic reassessment was only addressed when children had completed an intervention and had performed step 5 of the COPM.