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# Insight into Performance of Daily Activities in Real Life of A Child with Limited Physical, Cognitive and Communication Abilities: A Case Report

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## Introduction

In pediatric health care there is increasing attention for a child-centered approach, also referred to as personalized care (Coyne, Hallstrom, & Soderback, 2016). In this care it is essential to assess personal relevant functioning, hence, to explore which activities are important for a child and to assess the quality of performance of these meaningful activities (Coster & Khetani, 2008; Rodger & Kennedy-Behr, 2017). Therefore, we need to ask children what they do or want to do and then assess the performance in their own context. However, how can we *ask* children with multiple disabilities how they feel on the meaningfulness of activities?

Effective communication about wants and needs is important for personalized care, particularly for “communication vulnerable people” (Stans, Dalemans, de Witte, & Beurskens, 2013). Several assessment tools to explore meaningful activities in children are available, such as the Children’s Assessment of Participation and Enjoyment (CAPE) Imms, 2008; King, G. A., Law, M., King, S., Hurley, P., Hanna, S., Kertoy, M., et al, 2000), the Preferences for Activities of Children (PAC) (Imms, 2008; King, G. A., Law, M., King, S., Hurley, P., Hanna, S., Kertoy, M., et al, 2000) and the Pediatric Activity Card Sort (PACS) (Mandich, Polatajko, Miller, & Baum, 2004). Although these measures may be applicable to children with some restrictions in communication and/or cognition, children with more severe limitations will not be able to provide reliable answers on these measures. An alternative method is Talking Mats® (TM) (Murphy & Cameron, 2006), a pictorial framework that has been used as a tool for people with communication difficulties (Germain, 2004). It has been used also as an effective communication resource for people with intellectual difficulties and can support conversations between professionals and communication vulnerable people and help people with intellectual disabilities to express their views by increasing both the quantity and quality of information communicated (Murphy &

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Cameron, 2008; Stans, Dalemans, de Witte, & Beurskens, 2019). Therefore, TM might be a suitable method to explore meaningful activities in children with limited communication and cognitive abilities.

To address meaningful activities as part of the treatment, measuring the quality of performance of activities is required. Brink et al. (2021) suggested the Perceive, Recall, Plan and Perform (PRPP) System of task analysis (Chapparo & Ranka, 1996) as the most suitable assessment for quality of performance in children with multiple disabilities. In this observational instrument, the performance level is not compared to others' (Anastasi, 1988) but shows an overall personalized performance mastery score as well as how well information processing strategies are applied during occupational performance. The PRPP-Assessment can be used in direct observation or through the use of video material (Chapparo & Ranka, 1997). Use of video material could have advantages because it can provide better insight into actual daily functioning compared to observation during a hospital visit. Furthermore, as a result of COVID-19 a lot of care is now given at a distance. However, the feasibility of the use of PRPP-Assessment by parent-provided videos is unknown.

In conclusion, to provide personalized care and plan interventions that focus on meaningful activities we need insight into the performance of meaningful activities in the daily living environment. Therefore, this case report describes whether the combined use of TM and the PRPP-Assessment of home videos in a child with limited communication and cognitive abilities is feasible.

## Case Description

Jerome is a 14-year-old boy who attends classes for special education. Jerome lives with his parents and his 16-year-old sister in a rural area of the Netherlands. The boy experiences physical, cognitive and communication difficulties due to a mitochondrial disorder with a mutation in his nuclear DNA. He has ataxia, uses a manual-driven wheelchair and his speech is difficult to understand for unfamiliar persons. His level of cognitive development is in the lower extreme range ( $IQ < 70$ ) and his attention capacity is comparable to a 3-year-old child. His parents state that Jerome is a very happy boy who likes to have fun. He is interested in other people and in various activities. Jerome likes playing with his sister and going to school. Jerome is referred to an occupational therapist (OT) for assessment and, if possible, advice on improving his everyday functioning. The OT chooses to use parent-provided videos as Jerome lives too far away from the hospital to observe him in his own environment and also the presence of the OT during his everyday activities would probably influence performance due to his limited concentration abilities.

## Materials and Methods

TM was used to collect the child's perspective on everyday activities. Subsequently, parents videotaped three meaningful activities (selected from the child's perspective) that were scored by the OT using the PRPP-Assessment. To evaluate if the combined use of the two methods is feasible, semi-structured interviews were conducted with the parents and the OT. These interviews were analyzed through, first, open coding the transcriptions

and, second, pattern coding the open codes into categories and themes, which resulted in a narrative description of the categories and themes (Miles, Huberman, & Saldana, 2013).

### **Talking Mats®**

TM (Murphy & Cameron, 2006) was used by the OT researcher (M.L.) who was trained in its use and is also a pediatric OT. TM originally utilizes one “set” of cards that one can sort to a top scale of meaning that is suitable to the questions, for example, “like,” “don’t know” and “dislike.” Examples of sets of activities are mobility, self-care or domestic life. There are 34 different sets. For this study, the focus was not on one set as the aim was for insight into meaningful activities across different TM sets. Therefore a set of cards that represent activities of daily life was compiled from several existing sets. This set was further reduced by the parents according to the known activities for the boy, resulting in a set of 64 activities that were used in the conversation with Jerome according to the TM procedure (Murphy & Cameron, 2006):

- (1) The OT researcher introduced the topic (activities of daily living) and then the topic scale (*like, dislike, in the middle*);
- (2) The OT researcher turned the mat in front of Jerome to create ownership;
- (3) Jerome was physically in control of the options and placements;
- (4) The OT researcher asked open questions (*What do you feel about . . . ? Where would you put this on the mat?*) and handed over the cards;
- (5) The OT researcher remained neutral in facial expression and tone of voice;
- (6) The OT researcher summarized at the end of the mat.

To give an overview, the meaningful activities were organized into the occupational performance areas of personal maintenance, productivity and leisure (Reed & Sanderson, 1999). Categorization into these areas was conducted based on the individual meaning of each meaningful activity as expressed by Jerome during the conversation.

#### **The PRPP-Assessment**

As the PRPP-Assessment is observation based, gives an overall performance mastery score and uses self-chosen activities, it serves the aim of this case report to gain insight into the performance of meaningful daily activities in real life. The PRPP-Assessment uses a two-stage analysis process, both of which are relevant for treatment planning. In Stage 1, errors in everyday task performance are identified and an overall performance mastery score is generated. In Stage 2, a cognitive task analysis is used to analyze the information processing strategies required for the performance of the task. The information processing strategies are divided into four quadrants (perceive, recall, plan and perform) and 35 descriptors that are rated on a three-point scale (Chapparo & Ranka, 1996). The psychometric properties of the PRPP-Assessment have been studied in several target groups, such as children with learning difficulties, children with autism and intellectual difficulties, and typically developing pre-school and school-aged children (Lowe, 2010; Mills, Chapparo, & Hinitt, 2016; Nott, Hons, Chapparo, & Nott, 2006; Stewart, 2010). The findings show adequate outcomes on content validity, construct validity, inter-rater reliability, intra-rater reliability and responsiveness.

The OT, who was trained in the PRPP-Assessment, scored the videos according to PRPP standardized scoring principles (Chapparo, 2017). Parents received a report on the outcome of the PRPP-Assessment. The OT already knew Jerome from a previous consultation (1 year ago) and had watched the videotape of the TM conversation.

### ***Semi-structured Interviews***

To evaluate if the two methods are feasible from the perspective of the parents and the OT, two semi-structured interviews (45 minutes) were conducted. Topics in the parent's interview were: value of TM compared to usual communication; comprehensibility and feasibility of "assignment of making video material"; the similarity of videotaped performance to Jerome's general performance in daily life (ecological validity); and comprehensibility and value of the report of the PRPP-Assessment. Topics in the OT's interview were: value of TM in relation to determining meaningful activities; the usability and suitability of videos for scoring with the PRPP-Assessment; the ecological validity; the scoring process of the PRPP-Assessment and the value of the PRPP-Assessment.

## **Findings**

### ***Talking Mats® to Gain Insight into Meaningful Activities***

#### ***Researcher's Report of Process and Outcome of the Conversation Using TM***

During the conversation utilizing TM, Jerome was very enthusiastic. He did not use many words but expressed himself through facial and body expressions. He communicated for 60 minutes and kept his focus and attention. Twice he was distracted by the red light of the voice recorder but got back to the content of the interview independently. The conversation took place at the kitchen table in Jerome's home. His mother was present and added some information and occasionally asked Jerome a question.

With the use of TM, Jerome expressed that he liked a lot of the activities he performed (see Table 1). He gave some activities more emphasis than others. For example, gardening is

**Table 1.** Activities the boy liked to perform, organized according to the three occupational performance areas of Reed and Sanderson (1999).

Personal maintenance	Productivity	Leisure
Drinking	Feeding the cat	Cuddling the cat
Going to the toilet	Cleaning up toys	Gardening
Sleeping	Helping with doing the groceries	Mowing the lawn
Getting dressed	Counting at school	Cycling on tricycle
Closing Velcro of shoes	Calculating at school	Go-karting
Brushing teeth	Keeping an agenda	Making jokes
Washing	Swimming at school	Singing
Showering	Coloring at school	Listening to music
Taking medicine	Painting/crafting at school	Calling to dad
Making a snack		Watching television
Spreading the bread		Playing a game on the tablet
Clearing the table		Bowling
Going to the hairdresser		Horse riding
		Going somewhere with wheelchair
		Eating pancakes with grandparents
		Playing on the school playground

an activity that gives him much fun and he would also like to work in the garden sector in the future. He also emphasized that he liked to help his parents in and around the house because he preferred things to be proper and neat.

### **Parent Perspective on the Use of TM to Gain Insight into Meaningful Activities**

Jerome's mother expressed the experience that her son was able to express a lot due to the use of TM:

*Mother: Sometimes Jerome can't find the right words. But in the end, he expressed a lot of activities he liked. Jerome was also able to express in which activities he was not as good as he wanted to be. When it is visual, by the use of pictograms, Jerome is much more capable of telling what he likes.*

She also stated that performing the interview at their home was probably another reason why Jerome was able to express as much as he did. The mother stated that what Jerome expressed was reliable; he really likes a lot of activities and Jerome expressed the true reasons why some activities are meaningful for him. Also, TM enabled Jerome to give his personal perspective, instead of the mother telling the perspective of the child. Therefore, she suggested that TM could be used in the hospital for finding out which activities are important to a child.

### **Professional Perspective on the Use of TM to Gain Insight into Meaningful Activities**

The OT, not present during the conversation, watched the videotape of the conversation with TM. She expressed her surprise by the level of engagement of the boy. For a child who is known to her for his limitations in concentration and communication, he was able to attend for an hour and kept his focus on the cards and the conversation:

*OT: It was nice to see how the three of you interact. TM was a nice method to use with Jerome. Especially together with his mother. She gives her son a lot of space to express his own story. I feel that this is because of the cards. They give structure to the conversation and therefore, the mother can trust the outcomes. She lets Jerome tell his own story, but also reflects on it or elaborates on the moments that it is needed.*

The OT mentioned similarities between TM and the photo-interview (Dutch version of the PACS; Mandich et al., 2004) and stated that this was a nice variation on it. The photo-interview uses pictures of real-life situations, which can be helpful with some children but also can give wrong associations. She thought, however, that TM gave more structure to the conversation. A disadvantage of using TM in this way is that it was time-consuming due to the large case report set of 64 activity cards. The therapist mentioned that to use it in practice, she would need to make a selection of the cards, which could lead to bias. However, this is also the case for the photo-interview.

### **The PRPP-Assessment Conducted by Parent-provided Videos**

Based on the conversation with Jerome, the researcher selected three activities (clearing the table, gardening and coloring at school) based on the aim to gain insight into meaningful everyday functioning. Consequently, the selected activities were fun and meaningful for Jerome because they had a link to his everyday life (at school and at home), his character (keeping things neat and helping parents) and his future plans (working in the gardening sector).

The parents were asked to film the three activities. They received written instructions that they could use a phone, tablet or camera to film Jerome in full position (his whole body and his interaction with objects should be visible) and to start filming at the time the activity started and stop when the whole activity was ended. If Jerome wanted a break, they could keep filming. The length of the video should be based on the length of the activity. When Jerome normally received help with this activity, this should also be done during filming.

As well as the written instructions, verbal instructions by means of a telephone call were given on request of the mother. Her questions were very practical. For example, a gardening activity could take about 4 hours. She wanted to know when she had enough footage. It was suggested that she tried to film a whole activity or task that lasted for a maximum of 15 minutes. She was also wondering how Jerome would react when he noticed that she was videotaping him. Therefore, her personal suggestion was to film using a mobile phone because it would be the least conspicuous. The last question addressed the position of the camera: in front of the boy, from the back, zooming in on something, etc. It was suggested that this could differ per activity as it depended on what she wanted to show to us and what was important for the task. As long as the child's actions were clearly on the videotape, it was fine. Both parents videotaped the activities.

Four themes emerged from the interviews with parents and the OT: value of the PRPP-assessment, considerations in choosing activities, challenges of video material and challenges in scoring the PRPP-Assessment.

### ***Value of the PRPP-Assessment***

The OT and the parents expressed that the video material really gave a look at the child in his own environment and that observing the activities in the hospital would not give the same amount of information.

In general, the report gave a good overview of the occupational performance of Jerome for the parents. They expressed that it was nice to read the analysis of the occupational performance so clearly. They found the four quadrants recognizable due to the described behavior. The report made them think about how they gave instructions to their son. They did mention that the report would become even more useful when there was a clear conclusion with advice on how to enhance the performance of meaningful activities.

Although the OT experienced difficulties in scoring the overall performance, she expressed that she felt that the PRPP-Assessment conducted by parent-provided videos had an added value for her daily practice as it gave a clear insight into the occupational performance of Jerome.

The OT stated that if the focus were to be more on limitations in physical functioning, other instruments would be more suitable than the PRPP-Assessment. When there are limitations in cognitive functioning the PRPP-Assessment gives practical information on daily functioning.

### ***Considerations in Choosing Activities***

The parents reflected that the activities were not only fun for Jerome but were also meaningful for him. The OT mentioned that the three activities gave various insights into the different areas of everyday life. The parents mentioned that gardening was quite a challenge



as it was winter at that time, but they were content that this was one of the chosen activities due to the meaningfulness of the activity for Jerome:

*Father: The weather did not cooperate with us. We planned to go gardening and then it started snowing. Usually, Jerome performs the activity crawling over the ground, but with this weather, that was not such a good idea. But as he was so motivated for this activity we performed it anyways, although we performed it slightly different than we usually do.*

According to the OT, the choice of activities influenced the scoring of the PRPP-Assessment. Scoring became more difficult as the activity was too easy and had few tasks/skills. The OT expressed that there are certain conditions to making an activity fit for scoring:

*OT: The more tasks/skills needed for the activity, the more you can see. Especially for stage 1, where you need to specify the different tasks, the more variation, the more you see. (...) Also, the number of choices that need to be made by the child facilitates scoring (...) In the PRPP-Assessment you need activities that are challenging enough for children. In this case, the activities were physically challenging, but not cognitively challenging, which made scoring the cognitive strategies difficult. (...) You should be able to score any activity or task, as long as you see all four quadrants. But, in particular, the plan quadrant would be nice to see. That a problem occurs and the child needs to solve this problem by himself.*

The parents also expressed that they were not aware of the suitability of the activity when making the video footage. After reading the PRPP-Assessment report they commented that it had not been clear to them that the focus was on perceive, recall, plan and perform. They expressed that it would have been helpful to know this focus; they would have given their son an assignment while clearing the table, so it would have been easier to observe his ability to follow the assignment. On the other hand, they stated that if this were the case it would not be an everyday life situation.

The ecological validity of the video material was also discussed. Despite the fact that the parents had to adapt the gardening activity, they felt that it was still representative. The three activities together give a good insight into everyday functioning, although the presence of a camera was influencing the situation. The mother stated that Jerome reacted to her with aberrant behavior when she was videotaping but there was less reaction when his sister or teacher were videotaping.

The OT and the parents expressed that Jerome was aware that he was being videotaped. However, both parties felt that this did not influence the actual performance or scoring and that the videotaped activities gave insight into the actual quality of occupational performance.

### **Challenges of Video Material**

The OT stated that it is important that the video material reflects what is important for the activity:

*OT: When someone is playing soccer and it is important for the child that the ball goes into the goal, then that needs to be videotaped. If it is important that he makes a good move, then the ball should not be the focus of the film, but the movement is. Therefore, you should record what is important for the child or parent.*

In addition, the OT expressed that the duration of the video material was not important. However, what was important is that the whole task is videotaped, including the assignment or appointments/rules of the activity.



There were some technical difficulties in using the video material in practice. The OT expressed that playing the video material on the computers in the hospital was difficult and the process was time-consuming. The parents chose to use WhatsApp to send the videos but experienced difficulty as the phone did not have enough storage capacity. They were aware that WhatsApp is not a “safe” medium for transferring files but they felt this was the easiest way for them.

### **Challenges in Scoring the PRPP-Assessment**

It became clear in the PRPP scores and the interview with the OT that difficulties in scoring the PRPP-Assessment occurred due to the lack of information on the criteria for the activities:

*OT: I was not able to score the performance mastery as I did not know what was needed for the task, I did not know the expectations of the activity. For example; I did not know which items he had to transport from the table to the countertop. And also; if putting it on the countertop was sufficient, or that he had to place it into the dishwasher. He also puts objects on each other, which does not seem a good strategy, but then again there was not much more space on the countertop, so what is expected in this situation? Therefore I was not able to state the quality of performance of these activities. It led to difficulties in scoring stage 1 and in stage 2 as I did not know when a cognitive strategy was applied sufficiently for the demands of the task.*

The OT mentioned that if the parents had a specific question they would like to be answered it would be good to know and then you could refer to it in your report. Also, knowing if the activity is familiar to the child will help to score the recall and plan quadrant because then you know what is expected.

### **Summarizing the Lessons Learned**

TM led to the expression of (a lot of) meaningful activities and gave the child a voice. A facilitator was that the conversation took place in the home environment. Even with the number of cards being reduced by the parents, the conversation was still time-consuming. This should be further explored when implementing TM in daily practice.

The selected activities were rightly chosen to gain insight into meaningful activities and were chosen for their level of fun and relevance to his everyday life, character and future plans. Activities represented several occupational performance areas that gave various insights. In choosing activities it is sensible to be aware of the “fit conditions”: for instance, if the current weather is suitable for performing the activity. Furthermore, activities should contain enough of a cognitive challenge for the child to make it fit for scoring with the PRPP-Assessment. For example, if a child is able to dress himself, then this activity does not contain enough challenge. However, if he struggles with tying the laces of his shoes because he does not know how to start, then the observation should focus on dressing himself and putting his shoes on.

When instructing parents to make videos it should be considered which type of device influences performance the least. In this case the parents used a phone to videotape. Although Jerome was aware of being filmed, he performed and continued his activity as he was used to, according to his parents, and therefore the videotaped activity was representative for the regular performance of the activity.

It was shown that the use of videos enhanced insight in real everyday life (in contrast to observation of activities in the hospital). To make video material suitable for scoring with the PRPP-Assessment the whole task should be filmed from the beginning until the end, including the assignment or appointments/rules of the activity. To use parent-provided videos, parents should be able to save the videos on a device with enough storage capacity. Furthermore, they should be able to have an easy and safe way of transferring the video to the OT. Moreover, the OT should be able to watch the video material on a suitable device.

In our case study the OT was not able to give specific advice to enhance meaningful performance because she did not have enough information on the familiarity of the activity for the child or on the guiding questions and concerns from the perspective of the parents. Thus, the procedure for obtaining this information from parents should be improved for future practice.

## Discussion

This case study explores whether the combined use of TM and the PRPP-Assessment of parent-provided videos is feasible to gain insight into which everyday activities are meaningful for children with multiple disabilities and to analyze their level of functioning in these meaningful activities in the daily environment. Findings show that the combination of both instruments gave insight into the child's everyday functioning in the meaningful activities expressed by the child, despite his communication problems. This made goal-setting on performing these meaningful activities in their daily living environment based on both TM and PRPP-Assessment possible. Lessons learned focused on the conditions to facilitate the use of TM in everyday practice, the considerations when selecting the activities to observe, the considerations of taping, storing and transferring video material of children's everyday activities by parents and the challenges of scoring the video material.

The use of TM in this case study was experienced positively by the child, the parents and the OT. TM gave more structure to the conversation and helped Jerome to elaborate on the activities. This is congruent with the review of Stans et al. (2019): it facilitates communication, which involves facilitating expression (opinions, thoughts, feelings), interaction and thinking and understanding. However, they state that one study (Hallberg, Mellgren, Hartelius, & Ferm, 2013) found that TM was experienced as time-consuming. This was confirmed by the OT for daily practice in our study, who proposed limiting the selection of activity cards; however, this could lead to bias. Although TM can be time-consuming, no better option is available yet for children with limited communication and cognitive abilities to determine meaningful activities from the child's perspective. Therefore, it is suggested that an overview of all the TM activity cards be sent to parents so that they can select the activities that are known by the child.

In this case report, the PRPP-Assessment was considered to be ecologically valid by the parents and the OT and both experienced added value for insight into the quality of performance of everyday activities. However, challenges were discovered when conducting the PRPP-Assessment by parent-provided videos. Although some of these challenges are part of the PRPP guidelines, they could be emphasized or specified more in the instructions for parents when using video material. The first administration step of the PRPP-Assessment is that tasks should be essential to role performance and difficult for the client (i.e., present qualitative difficulties in performance from the

perspective of the client and/or others) (Chapparo & Ranka, 1996, 2008). This was recognized in this case, although the OT emphasized that the challenge should be in the cognitive part of the task in particular because the PRPP assesses applied cognition. Secondly, the whole task, including completion of the criterion, needs to be videotaped as the PRPP is a criterion-referenced instrument (Chapparo & Ranka, 1996). Thirdly, a solution needs to be sought to get parents' information about the familiarity, expectations and criterion of the activity, preferably without direct consultation because this was the reason for choosing the application of the PRPP through videotaping. Fourthly, a safe and easily accessible way of transferring video material is needed. Lastly, the goal of the PRPP-Assessment should be clear to parents and the OT; parents stated that if the goal of the PRPP-Assessment had been clearer, they would have been able to make the video material more useful. All these challenges can largely be overcome by carefully instructing the parents, preferably by combining written instructions with a short verbal contact. The application of the PRPP-Assessment using parent-provided videos will now be extra relevant because COVID-19 requires more care at a distance.

Drawing conclusions based on only one case is unusual. Some nuance to stating the added value of TM to gain insight into the child perspective is needed because not only the competence of the child is important but also the competence of the parent and the OT (Dedding, 2009). When implementing the lessons learned, several other considerations should be taken into account. In this case, the mother was very capable and supported Jerome to give his own perspective. The researcher had experience as a pediatric OT, was experienced in interviewing children and was trained in the use of TM. In addition, Jerome might have felt more comfortable in his home environment than in a practice setting. There were no negative influences, such as the time pressure that is usually present in daily practice. Finally, for the application of PRPP by parent-provided video material, we need to be cautious in the conclusions as the parents received more guidance than would be expected as part of general care.

## Conclusion

The combination of TM and the PRPP-Assessment by parent-provided videos was feasible and led to insight into meaningful everyday functioning. TM showed potential as a method for investigating meaningful activities in children with communication and cognitive difficulties and exposing the child's perspective. Also, the PRPP-Assessment by parent-provided videos can contribute to personalized care because it showed potential in measuring ecologically valid and personally relevant activities, specifically for children with cognitive difficulties. Several lessons were learned regarding the set of TM cards: considerations in choosing the activities for observation, the challenges of making and transferring video material and the challenges in scoring the PRPP-Assessment. These findings can be used for future studies to test the adaptations needed for the combined use of TM and the PRPP-Assessment by parent-provided videos for determining which meaningful activities on which level of functioning can be used for goal-setting on performing these meaningful activities in their daily living environment. Many of the challenges can be overcome by making changes in the

process (i.e., instructing parents and using parent's knowledge). More in-depth studies with the implementation of the lessons learned, in larger groups of children with multiple disabilities, are required to show the feasibility of this combination of methods in daily practice.

## Data Availability

The data (Dutch transcripts) that support the findings of this study are available from the corresponding author, ML, upon reasonable request. The data are not publicly available due to their containing information that could compromise the privacy of research participants.

## Ethical Approval

The ethical board of the regional research committee provided their consent in undertaking this research. The research was conducted in accordance with the ethical principles of the 1964 Declaration of Helsinki and its later amendments (General Assembly of the World Medical Association, 2014).

## Consent to Participate

Written informed consent was obtained from the parents and from the OT. The child was asked to participate in order to recognize his volition/agency (Stafford, Laybourn, Hill, & Walker, 2003).

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