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# Ingredients and change processes in occupational therapy for children: a grounded theory study

**Background:** Evidence about the effectiveness of occupational therapy interventions for participation outcomes in children with coordination difficulties is limited. The first step for advancing the evidence-base is to develop theory about the interventions, i.e. their ingredients and change processes.

# Aim:

To explore occupational therapy interventions for children with coordination difficulties and their parents, especially to develop theory about the key ingredients of therapy and about the processes through which change in participation might happen.

**Material and Methods**: Grounded theory methodology, as described by Kathy Charmaz, was used to develop the theory. Within this, families (parents and children) were invited to participate in semi-structured interviews during which their experiences of occupational therapy and processes of change were explored. Data collection and analysis were completed concurrently using constant comparison methods.

**Results**: Children's and parent's accounts described five key ingredients of occupational therapy interventions: i) performing activities and tasks; ii) achieving; iii) carer support; iv) helping and supporting the child; and v) labelling. Key ingredients related to participation through changing children's mastery experience, capability beliefs and sense of control; and parents' knowledge and skills, positive emotions, sense of empowerment, and capability beliefs.

**Conclusion and significance:** The results identify potential intervention ingredients and change pathways within occupational therapy to increase participation. It is unclear how

explicitly and often therapists currently consider and make use of these ingredients and pathways; the wider evidence suggests this may not be as explicitly and frequently as desirable.

Key words (3-10): coordination difficulties, interventions, participation

#### Introduction

Children with difficulties in co-ordinating their movements ('coordination difficulties'), often experience limitations in daily activities (1), restricted participation in life situations (2), and dysfunction within family routines (3). Occupational therapy is one of the core healthcare interventions for children with coordination difficulties, but evidence about the effectiveness of interventions is limited (4, 5).

A key part of advancing multifaceted interventions such as occupational therapy is to develop theory about its specific components ('intervention ingredients' or 'techniques') and change pathways ('mechanisms of change') and how these may be related to outcomes (6). Developing such theory facilitates: new understanding about what it is about interventions that might work; how the interventions might work; how the interventions can be improved; and what aspects of the interventions should be implemented, how and in which circumstances (7).

Most published, peer-reviewed occupational therapy intervention descriptions lack explicit description of theory(8). Where theories are present, these are often broad conceptual frameworks (e.g. Person-Environment-Occupation (9) rather than specific causal theories and hypotheses. Some interventions (e.g. Cognitive Orientation to Occupational

Performance (10)) provide a list of specific intervention techniques, but publications rarely explicitly specify how these techniques are hypothesised to relate to specific occupational outcomes (8). The lack of specificity over the interventions and their hypothesised causal mechanisms makes the interventions difficult to evaluate robustly and hinders cumulative learning across studies (6, 8, 11). Furthermore, evidence suggests that while occupational therapy interventions are recommended to utilise a broad range of pathways to change (e.g. Person-Environment-Occupation), in practice therapists (12) or researchers (8) rarely use them in this way. Interventions tend to focus on children's biomedical impairments and basic movement skills, and rarely consider environmental factors or the child's psychological factors (e.g. confidence, motivation) (8, 12).

The existing evidence relies primarily on therapist and researcher descriptions, and quantitative analyses of these. A further qualitative exploration of parents' and children's lived experiences of occupational therapy interventions and perceived pathways to change is needed to complement these data. For this reason, the present study explored parents' and children's views of:

- (i) The key ingredients of occupational therapy interventions for children with coordination difficulties
- (ii) The processes through which these ingredients might relate to the children's participation outcomes

## Material and Methods

The Kathy Charmaz's (13) grounded theory methodology was used to enable parents and children to give accounts of their views and experience of occupational therapy interventions and to begin developing theory about the processes for change from these data.

A specialist paediatric National Health Service (NHS) Local Research Ethics Committee (LREC) approved the study (Ref:12/NW/0093), as did the participating university and the local NHS Trust research department.

# Sampling and recruitment

Participants were recruited through a single NHS Trust between January and August 2012. Purposive sampling was used to identify children who; (1) were aged 7-11 years, (2) had been referred to services due to symptoms related to coordination difficulties, and (3) had received occupational therapy interventions. Children were excluded if intervention was currently on-going. Following initial interviews with two sets of children and parents, additional theoretical sampling methods were applied. Theoretical sampling restricted inclusion criteria in order to seek and collect specific data to develop emerging categories indepth e.g. specifying the inclusion of children who had attended groups. It was estimated that participation by eight families (i.e. 8 parents and 8 children) would enable the collection of in-depth data to meet the aims of the study whilst remaining feasible within the resources. Local occupational therapists sent pre-prepared information sheets, designed for both children and parents, to potential participants. Families contacted the authors directly to express interest to participate.

#### Data Collection

Semi-structured, in-depth interviews with open-ended questions were used to collect data on children's views and experiences of occupational therapy. Picture cards, drawings and common therapy materials such as gym balls, scooter boards and pencil grips were used as prompts when interviewing children. Parents were interviewed with verbal prompts from the interviewer. Children and parents decided whether to be interviewed at home or at their local therapy centre, and children chose whether to be interviewed independently or with their parent present.

Prior to interviews, informed consent was gained from parents for participation in the study and assent gained from children. The interviews were undertaken by the first author, and were audio recorded. Field notes were written immediately following the interviews by the interviewer, including contextual information such as interview setting, time of day, people present and participant behaviours. Interviews were transcribed and field notes typed by the first author, and both were anonymised at this stage.

Data collection and analysis (below) were completed concurrently so that interpretations from analysis could be further explored through the views and experiences of subsequent participants. The theoretical sampling strategy, interview guide and topic guide were amended as the analysis advanced in order to increasingly focus the data collection on important analytical constructs related to intervention ingredients, intervention processes and causal mechanisms.

#### <u>Analysis</u>

In vivo coding methods were used in the initial phase of analysis (13). Interview transcripts were read line by line, and each line coded in terms of 'who was doing what' from the participant's perspective. Participants' own terms and language for describing their experiences were used as codes so that codes were symbols of participant's speech and

meaning (13). Codes were then grouped together into conceptual categories so that each category included codes that symbolised a similar concept. For example, a conceptual category for the children was "playing games" with relevant codes including "scoring", "competing", "winning" and "playing by rules". Categories were diagrammatically mapped to represent relationships between codes and categories as they emerged within the data. Relationships may be temporal, sequential or co-occurring within and across the transcripts e.g. transcripts containing "playing games" may also contain "achieving", and one may be temporally and/or sequentially positioned in relation to the other. The mapping, and the identification of the relationships, led to the development of theory about the relationships between therapy ingredients and processes to change. The constant comparative method of analysis, that of moving back and forth between collected data and analysis (13), was applied so that codes, categories, mapping and theory development could be specified and tested by applying and modifying analysis across the data set.

Field notes were read alongside transcripts to reflect on the context of the data and to see if this challenged or supported analysis findings. Analytical comments and memo-writing (13) were also used to create a trail of the thinking processes running through analysis.

#### Results

Seven children (age 7-11 years) and six parents, from six families, responded and all participated (Table 1). Four of the families had received occupational therapy only while two families had received occupational therapy and physiotherapy.

Across the children and parents, five conceptual categories of ingredients perceived to affect children's participation were identified. Three of these described therapy ingredients in terms of the contents of therapy: "performing activities and tasks", "achieving" and "carer support". A further two described the ingredients as factors outside therapy: "helping and supporting the child", and "labelling". The following sections present the key contents of the findings in the following order: 1) Ingredients within therapy: performing activities and tasks, achieving and carer support; 2) Ingredients outside therapy: parents' moderating the child and labelling; and 3) Change processes: the relationships between the ingredients and participation outcomes.

# Ingredients within therapy: performing activities and tasks, achieving, and carer support

Performing activities and tasks, and achieving, were described as key ingredients of interventions by the children whilst carer support emerged as a key ingredient from the parent's perspective. **"Performing activities and tasks"** was described by the children as doing specific actions or sets of actions, in the context of therapy, especially within playful exploration or repetitive practice. Playful exploration included playing games, playing by rules, competing, winning, losing and scoring points.

"... there's a game always on it, like rallying games and racing games...you pedal on the bike and look at the screen and it will show you what to do..." – child 3, age 9
Repetitive practice was particularly commonly described in relation to specific skill-based activities such as writing their name, making sandwiches, or being in the football goal.

"...I remember drawing on the board, I practiced my name ... " - child 2, age 11

*"Achieving"* was described as successfully performing an activity (e.g. writing their name) or reaching an end point within a playful activity, a game or a competition (e.g. scoring most points to win a game, punching a boxing bag to hit the floor, and staying on a climbing wall for the longest time).

"...*I won, I won because* you had to stay on [the climbing wall] for quite a long time, maybe 20 seconds...*I won each round*" – child 4, age 9

In contrast to the children's views, parents' descriptions focused on the ingredient **"Carer support".** Carer support was described as parents receiving verbal reassurance about the actions they were already taking to help their child, receiving advice about how to help the children at home and/or school, discussing their child's needs with a therapist at times of crisis, and socialising with other parents. The carer support took place during the face-to-face session or by phone with therapist, as well as by other parents attending therapy sessions.

"...she [therapist] said 'you're doing all the right things', just, you know, 'keep doing it'. I don't think she told me anything different, just reinforcing what I was doing but it was really valuable" – parent 2

"...I've rung them [therapist] and been really upset... tearful and frustrated. If I've rung they've always squeezed me in..." – parent 3

"... I've been under a lot of pressure...so to speak to other parents, it helps..." – parent 4

# Ingredients outside therapy: Helping and supporting the child and labelling

"Helping and supporting the child" was discussed by all parents and encompassed parent descriptions of the routine actions they took to enable and as well as to restrict their child in everyday life situations. The actions by parents included adapting tasks, deciding what activities the children do and do not do, and judging when and how to do activities.

"...I've stopped the swimming lessons because he [child] couldn't grasp the butterfly stroke..." – parent 4

"...I have to kind of judge [his] mood, when I think he'll do [the school work] and you know, when you start if he's going to achieve it and you know if you just push him a bit too far he will start crying....." parent 1

"Labelling" was also discussed by all parents and consisted of descriptions of parents assigning various labels to the children as a way to define and explain the problems they perceived their child had. Parents described that they sought out, received, and further refined labels through interactions with therapists, medical and school staff, and other parents.

"...they [therapist] said 'yeah, he's got dyspraxia'...it was just a side line comment...I suppose it is just something I've picked up on." - parent 4

"...his [child's] teacher came out and said 'I think you should take him to the doctors because I think it's more than hypermobility'...he should now be seeing educational psychology too and being tested for dyslexia..." – parent 3

"...to speak to other parents who say 'oh yes, that's exactly how mine is', it helps you define what is the dyspraxia?" - parent 5

Change processes: the relationships between the ingredients and participation outcomes.

In the data, the descriptions of the therapy ingredients were highly contextual and situated with much broader descriptions of proposed causal links and relationships. Descriptions of the ingredients alone does not, therefore, provide a true representation of the data. While it is not possible to represent here all the different complex links and relationships that were identified, some of the most prominent ones are presented as a way of illustrating the full data.

Using performing activities and tasks within therapy sessions as a starting point for unpacking the children's descriptions of relationships, performing activities were closely and directly linked to the ingredient 'achieving'. This was because performing activities was described as providing many opportunities for children to achieve.

"...I wanted to be in [football] goal so in the therapy sessions we did penalty shootout and I practiced in goal, everyone against me and only one person scored...I did it!" child 3

Children described working hard and increasing their efforts as activities and tasks were repeatedly practiced, and persevering when performing activities and tasks in therapy in order to achieve the end point of the task. By increasing efforts and persevering, children mastered the skills needed for the task.

"There was a boxing bag...you have to punch it so it goes back to the floor... It took quite a while, you know, lots of go's to knock it down... you had to work really hard but I did it; I won!" – child 4

The combination of performing activities and achieving was reported as resulting in children developing confidence in doing further activities, both within and outside of the sessions

Children described how believing that they could achieve further helped them perform activities and achieve the end points, and how this ultimately enabled participation across a range of situations.

"...I got boosted confidence so I'm getting better at catching a ball from them, they would throw a ball to me and I'd try and catch it ...I have confidence of doing all this stuff so it's helped me. I'm happy to try and I never give up! I'm better at riding a bike now...we [family] was in Yorkshire...I was OK on this bike ride...it [therapy sessions] just makes me think that I'm quite healthy, I think 'I can do it' so I won't have that much problem pedalling" – Child 4

In unpacking parents' descriptions, parents described how receiving carer support provided the parents with new knowledge and skills, and reassured them, which in turn enhanced their ability to moderate their child's actions and activities.

"...she [therapist] showed me how to help [child]. I know now that I'm doing the right thing to help him ...he managed to cut a burger for the first time the other night so I feel confident that we can go out to a restaurant now and he'll do OK!" – parent 6

While labelling was also described in some instances as increasing knowledge, its main effects were primarily described as emotional and empowering. Parents described how finding the words to describe and discuss their child's difficulties provided a sense of relief and control, and gave them the tools to make sense of the difficulties.

"...it was kind of a relief actually finding out what it [dyspraxia] is, so that was quite helpful...we can now talk to [child] about what his problems are, he knows he's just

got to work harder at things *and we've talked to him about the advantages of having dyspraxia as well because you can pick up on those too..."* – parent 3

An overall sense from the data and the analysis was that parents' sense of control and capability represented the core process of change described by the parents. The descriptions about the sense of control and capability were repeatedly and substantially entwined with descriptions of labelling, carer support, moderating the child's actions, and the child's ultimate participation in life situations. The following longer quotation reflects the overall data, and illustrates how these themes linked into relationships within the narratives.

"...you feel like you're the only person in the world that's got this problem...you think 'is it because I'm a poor parent? Is it because I don't parent them correctly? Has everybody else got this parenting masterclass that I've not followed and my children have this problem because of me?'...If I know what something is then I can go and research it and work out how I can cope...Now I know! [later in the interview] If you get together with other people whose children have these things you can help each other, you feel as a parent that you're not on your own, there's another person in exactly the same boat as you and they're doing something about it so I can too! I now run a beaver's colony, the reason I run a beaver colony is because [child] wanted to join [the beavers], I thought 'I'll just make my own beaver colony'. The reason he [child] didn't get thrown out of beavers for bad behaviour was because I was the beaver leader and I'm not going to throw my own child out! – parent 5

### Discussion

The study applied Grounded Theory methodology to explore children's and parent's accounts of their experiences of occupational therapy. The study identified five potential intervention ingredients: performing activities and tasks, achieving, carer support, parent's supporting and helping the child, and labelling. A number of potential change pathways through which interventions could relate to participation outcomes were illustrated. For example, the child performing activities and achieving were described to result in increased mastery and capability beliefs which in turns was described to translate to improved participation. Similarly, for example, providing carer support and enabling parents to label their child's difficulties was described to increase parent knowledge, positive emotions and capability beliefs, which in turn enabled parents to support and help their child, resulting in improved participation for the child.

The ingredients and change pathways that were identified map onto evidence about intervention techniques and change pathways shown to relate to what people do ('human behaviour') more generally. For example, beliefs about capabilities have been shown to influence what people do and how they engage in life situations (14), with applicability to rehabilitation (15). The results from this study therefore support the proposals that considering participation as a therapeutic outcome may benefit from considering participation as human behaviour (15-17), and that therapists should explicitly consider human behavioural factors when designing therapy interventions (12). The results further expand the existing literature by identifying and illustrating specific ways in which behaviour change techniques and change processes may be present in children's therapy. For example, the findings show that therapists to name and describe their child's difficulties may enable parents to make sense and gain a sense of control over the situation.

In terms of limitations, the study sampled a small number of participants from one healthcare organisation. Nevertheless, the data allowed some possible ingredients and change pathways to be identified, and it illustrates the value of qualitative explorations in the development of theory about occupational therapy intervention. While the present study did not set out to establish all therapy ingredients or scope out the frequency of different ingredients—and no such conclusions can be made on these—the results do have theoretical validity (13) in the sense that the ingredients and change processes identified are plausibly some of the important aspects of therapy, and set the basis for further hypothesis testing.

Motor and physical factors were not found as a feature in the present study which is in contrast to other studies in this clinical area (4, 5). It may be that the prominence of behavioural factors described, and subsequent theoretical sampling techniques employed, allowed in-depth exploration of a limited number of intervention themes (e.g. behavioural) and excluded other features and processes (e.g. motor and/or physical processes). However, it is also possible that parents and children do not find motor and physical factors as important as therapists do (12).

The study has contributed to further development of occupational therapy intervention theory and research by identifying potentially helpful intervention techniques and change pathways. The next steps are to expand the range of possible techniques and change pathways, and to advance the identified techniques and processes for formal evaluations of effectiveness.

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| Family | Interviews   | Interview context  |
|--------|--|--|
| 1      | <ol> <li>Mother</li> <li>Child, Male, age 7, no diagnosis</li> </ol>   | At home, interviewed separately.                           |
| 2      | 3. Mother and child aged 11 years, diagnosis<br>Autistic Spectrum Disorder (ASD)   | At therapy centre, together                                |
| 3      | <ol> <li>4. Mother</li> <li>5. Child, male aged 9 years, no diagnosis</li> </ol>   | At home separately   |
| 4      | <ul> <li>6. Mother</li> <li>7. Child, male, aged 9 years, diagnosis</li> <li>Developmental Coordination Disorder<br/>(DCD)</li> </ul>              | At home, together for child's interview,<br>Mum separately |
| 5      | <ul> <li>8. Mother</li> <li>9. Child, female aged 11 years, diagnosis DCD</li> <li>10. Child, Male aged 8 years, diagnosis DCD and ASD.</li> </ul> | At home, children with Mum present, Mum separately.        |
| 6      | <ol> <li>Mother</li> <li>Child, male aged 7 years, no diagnosis</li> </ol>   | At home, child with Mum present, Mum separately.           |

Table 1: Characteristics of participants and interview context