STUDY PROTOCOL

Children and young people's experiences of living with developmental coordination disorder/dyspraxia: study protocol for a qualitative evidence synthesis [version 1; peer review: awaiting peer review]

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Abstract

Children with developmental coordination disorder (DCD) face significant challenges to deal with everyday activities due to underlying motor proficiency difficulties. These challenges affect children and young people’s participation; that is, involvement in daily life situations. In the past, limited consideration was given to personal experience of events, relationships and everyday life in children and young people with DCD; as a result, understanding what it is like to live with DCD is not well conceptualised in the literature. There is a pressing need to synthesise the findings of discrete qualitative studies to advance the conceptual understanding of living with DCD, to inform health service delivery and the development and implementation of complex interventions. This study aims to systematically review and synthesise qualitative literature regarding children and young people’s experiences and views of everyday life and living with DCD. The method of qualitative evidence synthesis that will be followed in this review is a meta-ethnography. The eMERGe and PRISMA reporting guidelines will be used in the development, design and reporting of this review. Nine databases will be searched; Academic Search Complete, AMED, CINAHL, MEDLINE, PsychArticles, PsychInfo, EMBASE, SPORTDiscus, and Web of Science. Two independent reviewers will use the Joanna Briggs Institute Checklist to appraise all included papers. The findings of this meta-ethnography will endeavour to inform future research, policy and practice. In particular, the results will help to inform the design of future complex interventions to meet the needs of children and young people with DCD. Dissemination will involve the publication of the results in a peer-reviewed journal. Increasingly researchers and policymakers are calling for services to be informed by the perspective and voice of children with DCD; therefore, a policy brief will be published so that the findings are widely available.

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**Keywords**
Developmental Coordination Disorder, children, young people, meta-ethnography

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Introduction

Children with developmental coordination disorder (DCD) struggle to master numerous everyday activities, that involve motor coordination (APA, 2013), such as dressing, self-care, feeding, and writing skills, as well as sports, and leisure activities (Summers et al., 2008; Van der Linde et al., 2015). The core features of this diagnostic condition are; A) learning and execution of coordinated motor skills is below expected level for age given the opportunity for skill learning; B) motor skill difficulties significantly interfere with activities of daily living and impact academic/school, leisure and play; C) onset is in the early developmental period; and D) motor skill difficulties are not better explained by intellectual delay, visual impairment or other neurological conditions that affect movement (APA, 2013). Prevalence rates of DCD are considered to be between 5 and 6% of the population (Blank et al., 2019). Amongst physicians, teachers and parents, knowledge and awareness of DCD as a health condition is limited (Wilson et al., 2013).

The consequences of DCD are wide-ranging and enduring. DCD negatively impacts children’s participation in a range of life situations and the long-term sequelae of DCD are well documented, including diminished social, academic, work, vocational and leisure outcomes (O’Dea & Connell, 2016; Kirby et al., 2011). Adverse, secondary health outcomes in DCD include poor cardiovascular health and obesity (Cairney et al., 2010), psychiatric conditions (Pratt & Hill, 2011), and mental health difficulties (Harrowell et al., 2017). Secondary health outcomes persist across the lifespan with adults with DCD describing higher levels of depression and anxiety (Hill & Brown, 2013).

Recent systematic reviews and meta-analyses show that task-oriented interventions are effective at improving activity and body functions level outcomes (Miyahara et al., 2017; Smits-Engelsman et al., 2018). Current evidence regarding which interventions are effective at improving participation outcomes for these children and young people is not as clear (Novak & Honan, 2019; O’Dea et al., 2019). The construct of participation is defined as involvement in life situations (WHO, 2007). Participation in everyday life is an important indicator of overall health and well-being, and a key outcome for parents of children with DCD and health professionals (Novak & Honan, 2019). Current trends in paediatric health service delivery and health policy are towards family-centred care. A central component of this approach being a parent–child-therapist collaboration in designing intervention that improves the families’ priorities for everyday life (Hanna & Rodgers, 2002). Clinical guidelines advocate that health service interventions should target child- and family-led goals that improve everyday activities, and involvement in life situations across the school, home, and community environments (Forsyth et al., 2008). There is a pressing need to advance the evidence-base about effective interventions that can improve outcomes for children and adolescents with DCD, such as participation in life situations (Novak & Honan, 2019).

Research indicates that children are capable of identifying and setting goals and that the goals they set are attainable to the same degree as parent identified goals (Vroland-Nordstrand et al., 2016). Therefore, determining children and young people’s goals require that their perspectives, views and experiences are elicited, recognised, listened to, and respected (Söderbäck et al., 2011). According to the United Nations Convention on the Rights of the Child (1989), children have participation rights; that is, they are entitled to express opinions, and to have a say in matters that affect their lives (Children’s Rights Alliance, 2010). This policy shift is reflected in the launch of “Beyond Limits” a forum to promote the voices of young people with disabilities and stimulate conversations on their involvement and active social participation in all life areas by the Irish Ombudsman for Children (Ombudsman for Children’s Office, 2019). Recent pan-European research aiming to achieve consensus on health and well-being clinical indicators for children and young people highlighted that future research needs to include children and young people’s perspectives (McQuinn et al., 2019). The “new social studies of childhood” places children as knowledgeable, capable and proficient research participants (Christensen & Prout, 2005). Indeed, children want to be included in decisions that may impact their health; and children value potential contributions to research (Lynch & Lynch, 2013). Children can make valuable contributions to research and their health care; thus, ongoing efforts must be made to include the child and young person’s perspective (Söderbäck et al., 2011).

To date, a small but growing body of research has been conducted with children and young people with DCD to explore and represent their experiences (Payne et al., 2013; Zwicker et al., 2018). This contrasts with the historic focus on exploring parental perceptions of the profile of DCD symptomology, their experiences of raising a child with DCD, and accessing services and support for their child with DCD (Maciver et al., 2011; Missiuna et al., 2006; Missiuna et al., 2007; Morgan & Long, 2012; Novak et al., 2012). Studies that have compared parental experiences of DCD with their children’s experiences and views reveal a dichotomy of priorities and results (Morgan & Long, 2012; Jasmin et al., 2018; Timler et al., 2018). Research comparing parental assessment and young people’s self-assessment of motor competence highlights that parents recognise fewer motor difficulties than the young person (Timler et al., 2018). With regard to effective interventions and participation in home and community environments, parents prioritise training and coaching on DCD to help facilitate their child’s learning and autonomy with activities of daily living; whereas, as children with DCD, prioritise aspects such as play (Jasmin et al., 2018; Morgan & Long, 2012). These findings are in line with previous studies of children with disabilities, concluding that children have different opinions about their social lives compared to their parents (Teachman & Gibson, 2012).

The body of qualitative research examining children’s experiences of living with DCD (Payne et al., 2013) and related topics, such as identity and self-management (Lingam et al., 2011), priorities and preferences for treatment (Dunford et al., 2005), participation (Jasmin et al., 2018) and quality of life (Zwicker et al., 2018), is expanding. In the past, limited
consideration has been given to children and young people with DCD personal experience of events, relationships and everyday life; as a result, understanding what it is like to live with DCD is not well conceptualised in the literature. There is a pressing need to synthesise the findings of discrete qualitative studies to advance the conceptual understanding of living with DCD to inform health service delivery and the development and implementation of complex interventions. It is timely that a systematic review using a meta-ethnographic approach would synthesise the qualitative body of knowledge and develop new conceptual understanding of the lived experiences, views and preferences of children and young people with DCD. This review is well timed to identify future qualitative research priorities in understanding the experiences of children with DCD as qualitative studies.

Objective

The principal objective of this study is to systematically review and synthesise qualitative literature regarding children and young people’s experiences and views of everyday life and living with DCD.

Methods

A meta-ethnographic approach has been chosen as the method of qualitative evidence synthesis for this review. The meta-ethnographic synthesis approach of Noblit & Hare (1988) will be employed. It involves a seven-stage process; it moves beyond the collation of qualitative evidence and towards the generation of new understandings. In health services research, meta-ethnographic synthesis has become a popular methodology for qualitative evidence synthesis. However, robust reporting is essential to the process of synthesis, and for new interpretations to be generated (France et al., 2019), therefore the eMERGe reporting guideline, aimed at increasing the transparency and completeness of conducting and reporting a meta-ethnography guided the development and preparation of this protocol (France et al., 2019). The predominant reasons for choosing a meta-ethnographic approach in this review was that it would enable the researchers to develop a conceptual understanding of children’s subjective experiences of everyday life and living with DCD. This systematic review is registered with the International Prospective Register of Systematic Reviews (PROSPERO): registration number CRD42019129178.

Search strategy

As suggested by Toye et al. (2014), there is no methodological agreement concerning the need to search for, all possible articles to complete a “good” qualitative synthesis. However, for this review, we chose to complete a comprehensive systematic search strategy for nine databases, Academic Search Complete, AMED, CINAHL, MEDLINE, PsychArticles, PsychInfo, EMBASE, SPORTDiscus, and Web of Science. The rationale being that we wanted to capture all possible qualitative studies that have examined children and young people’s perspectives of living with DCD. We did not envisage a large volume of papers that is 40 or more articles. However, it was deemed necessary to capture a wide range of studies, in order to obtain enough data representing children’s experiences, and allow robust conceptual categories to be developed (Toye et al., 2014).

To complement, the clarity and reporting of the search strategy and procedures, we used the Preferred Reporting Items for Systemic Reviews and Meta-Analysis Protocols (PRISMA-P) checklist (Moher et al., 2015). A thorough search string was formulated based upon the comprehensive review of DCD literature by Smits-Engelsman et al. (2018), and a review paper focused on searching for qualitative research (Booth, 2016). The keywords used were “Developmental Coordination Disorder/DCD” and “qualitative research” alongside thesaurus and Medical Subject Headings terms (MeSH). The search strategy used in MEDLINE is presented as an example (Table 1).

Study selection

The SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, and Research type) search strategy tool helped to structure the criteria developed to screen studies, firstly by title and abstract and, subsequently, by full-text review (Cooke et al., 2012). Table 2 outlines each aspect of SPIDER and inclusion/exclusion criteria. Included studies will describe a sample of children aged five to eighteen years with a diagnosis of DCD or probable DCD according to the Diagnostic and

Table 1. MEDLINE search strategy.

| S1 | Motor Skills Disorder* OR developmental coordination disorder OR clumsiness OR clumsy OR in-coordination OR dys-coordination OR minimal brain dysfunction OR minor neurological dysfunction OR motor delay disorder OR perceptual-motor impairment OR motor coordination difficulties OR motor learning difficulties OR mild motor problems OR non-verbal learning disability OR non-verbal learning disorder OR non-verbal learning dysfunction OR motor coordination problems OR sensorimotor difficulties OR sensory integrative dysfunction OR physical awkwardness OR physically awkward OR psychomotor disorders OR motor control and perception OR developmental dyspraxia OR perceptual motor dysfunction OR minimal cerebral dysfunction |
| S2 | qualitative OR experience* OR perception* OR perspective* OR case study* OR interview* OR focus group* OR mixed methods OR participant observation OR transcript* OR ethnograph* OR phenomenon* OR grounded theor* OR grounded-theor* OR purposive sample OR lived experience* OR narrative* OR life experience* OR life stor* OR action research OR observational method OR thematic analysis OR narrative analysis OR field stud* OR field-notes OR videorecording |
| S3 | child OR children OR adolescent OR teen OR teenager OR youth OR young person OR young adult |
| S4 | S1 AND S2 AND S3 |
Statistical Manual of Mental Disorders 5th Edition (DSM-V) criteria (APA, 2013). Where children are described as having probable DCD, the authors must outline how each criterion of the DSM-V was fulfilled:

1. Motor impairment scores are recorded as less than the 15th percentile on a standardised motor test.
2. Describe how the participants’ everyday activities are affected because of the motor skills difficulties.
3. Explain the participants cognitively ability and confirm that it is within the normal intellectual ranges.
4. Indicate that no underlying medical condition is reported by parents, guardians, teachers or health professionals.

Participants with DCD and a co-occurring specific learning difficulty or neurodevelopmental diagnosis such as ADHD will be included as co-occurrence is very common (Blank et al., 2019).

Participants must meet the Diagnostic and Statistical Manual of Mental Disorders 5th Edition (DSM-V) criteria for DCD. Where children and young people are described as having probable DCD, the authors must outline how each criterion of the DSM-V was fulfilled:

- Motor impairment scores below the 15th percentile on a standardised motor test;
- Describe how the participants’ activities of daily living are affected as a result of the motor skills difficulties;
- Explain the participants cognitively ability and confirm that it is within the normal intellectual ranges;
- Indicate that no underlying medical condition is reported by parents, guardians, teachers or health professionals.

Studies examining parental and child experiences will be included, but it must be possible to extract data on the child and young person views and experiences of living with DCD.

Table 2. Inclusion and exclusion criteria.

<table>
<thead>
<tr>
<th>Phenomenon of interest</th>
<th>Inclusion Criteria</th>
<th>Exclusion criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sample</td>
<td>Children aged five to eighteen years with a diagnosis of DCD or probable DCD.</td>
<td>Children younger than five years will be excluded as a diagnosis of DCD is not confirmed below five years of age (Blank et al., 2019).</td>
</tr>
<tr>
<td></td>
<td>Participants with DCD and a co-occurring specific learning difficulty or neurodevelopmental diagnosis such as ADHD will be included as co-occurrence is very common (Blank et al., 2019).</td>
<td>Studies that include a sample of children and young people with a different diagnosis will be excluded if it is not possible to extract the views and experiences of children and young people with DCD within such studies.</td>
</tr>
<tr>
<td></td>
<td>Participants must meet the Diagnostic and Statistical Manual of Mental Disorders 5th Edition (DSM-V) criteria for DCD.</td>
<td>Studies examining the opinions and experiences of parents of children with DCD will be excluded.</td>
</tr>
<tr>
<td>Phenomenon of interest</td>
<td>Children and young people who describe their views, opinions and experiences of living with DCD.</td>
<td></td>
</tr>
<tr>
<td>Design</td>
<td>Qualitative or mixed-methods studies reporting primary qualitative data (e.g., data collected through qualitative methods such as interviews, focus groups, or participant observation etc.)</td>
<td>Where the qualitative data from the child cannot be identified, such as summaries or aggregated data of parent and child experiences, these papers will be excluded.</td>
</tr>
<tr>
<td>Evaluation</td>
<td>Qualitative analysis of experiences, feelings, views, opinions, and experiences of living with DCD. All settings such as school, home, community, etc. will be included.</td>
<td>Studies where a method of qualitative analysis is not described.</td>
</tr>
<tr>
<td>Research type</td>
<td>Peer-reviewed journal articles and thesis. Full text available in English Published between No date limit- 2019</td>
<td>Systematic reviews, protocols, theoretical work, editorials, opinion pieces and dissertations.</td>
</tr>
</tbody>
</table>
of time and the financial burden associated with translation, searches will be limited to English publications only. No date limit will be applied to the search to capture all possible citations.

Studies will be excluded, if (a) they include a sample of children with a range of neurodevelopmental diagnoses and the qualitative data for the children with DCD cannot be extracted, or (b) the data presented is aggregated (for example, a mix of parent and child data that cannot be easily identifiable). Finally, systematic reviews, study protocols, and theses will be excluded.

Once, the search strategy has been completed in each of the identified databases, the citations retrieved will be uploaded to Endnote software and the duplicate citations removed. These citations will be exported to Rayyan software, to facilitate the screening of the papers by title and abstract (Ouzzani et al., 2016). Study titles and abstracts will be screened by ÁOD, according to the study selection criteria to identify the papers for full-text screening. If there is any ambiguity about an article title or abstract, it will be added for full-text review. Two independent reviewers (ÁOD and KR) will use the selection criteria to conduct a full-text review for all included papers. Where any discrepancies arise at the full-text review stage, these differences will be resolved through discussion. If it is challenging to resolve differences of opinion, a third reviewer (SC) will help to facilitate a final decision. The PRISMA-P flowchart will be populated to present the results generated at each stage of the process (Moher et al., 2015).

Quality appraisal of the included studies

This meta-ethnography aims to add to the conceptual understanding of living with DCD from the child and young person’s perspective so that it can inform practice, research and policy; therefore, the studies included in this qualitative evidence synthesis must be ‘good enough’ (Toye et al., 2013). Toye et al. (2013) present a conceptual model of quality, which centres on conceptual clarity and interpretive rigour; and the researchers advocate the need for such a model to be used when completing meta-ethnography. The two principal features are defined as 1) “Conceptual clarity (how has the author articulated a concept that facilitates theoretical insight)”, and 2) “Interpretive rigour (What is the context of interpretation? How inductive are the findings? Has the interpretation been challenged?)” (Toye et al., 2013). In line with this conceptual model of quality, we have selected the Joanna Briggs Institute (JBI) Checklist for Qualitative Research (Lockwood et al., 2015) to appraise all included papers. The JBI checklist is the most sensitive tool when examining methodological validity, given its focus on congruity (Hannes et al., 2010).

All included papers will be critically appraised by two independent reviewers (ÁOD and KR) using the JBI Checklist (Lockwood et al., 2015). The JBI tool will be used to inform judgements about the methodological quality of the articles; decisions will be categorised as ‘include’ or ‘exclude’ and comments on the decisions will be recorded. The outcomes of the critical appraisal process will be compared; any variances in decisions will be discussed in order to reach consensus on the appraisal. If the involvement of a third reviewer is necessary, SC will contribute to the final decision-making process. In light of the quality appraisal results, the synthesis and interpretation of the included studies will be discussed.

Data extraction and synthesis

The analytical and synthesis process in meta-ethnography commences by reading the studies, described as phase three by (France et al., 2019; Noblit & Hare, 1988). Reading and re-reading the studies in depth is a fundamental aspect to data extraction and continues to be an iterative process during data extraction and synthesis (Toye et al., 2014). The views, perceptions, or concepts presented in the results and discussion of primary studies are considered the raw data of meta-ethnography (Toye et al., 2014). These concepts and ideas are labelled as second-order constructs and are derived from the researcher’s analysis and interpretation of the research participants words used to describe their experiences of the phenomenon such as living with DCD, also known as first-order constructs or key concepts (Toye et al., 2014).

Previous authors have emphasised the importance of deciding what data to extract, and process of completion (Toye et al., 2014; Wong et al., 2018). In this review, two independent reviewers will use a Microsoft Excel sheet to collate information on the characteristics of each study, such as citation, study setting/country, sample size, participant characteristics, aims of the study, data collection and methods, and summary of findings. ÁOD will also upload a PDF of each paper to QSR International’s NVivo 12 software. The first- and second-order constructs will be extracted and interpreted; the researchers (AOD and KR) will generate codes that describe and explain the key concepts within each study. NVivo software will provide an organised database through which interpretation can be completed. The researchers ÁOD and KR will code second-order findings as they present within each paper. These interpretations and synthesis of the second-order contrast become the third-order constructs (Noblit & Hare, 1988). No second-order constructs that are considered unrelated to the phenomena or experience of living with DCD will be included for synthesis (Toye et al., 2014).

Phase four of meta-ethnography involves determining how studies are related (France et al., 2019). Following coding of second-order constructs, ÁOD and KR will meet regularly to discuss and compare their concepts and determine how the studies relate to each other, and the review question (France et al., 2019). These meetings will aim to challenge the interpretation of concepts and compare them across each study. This method of identifying the similarities and differences, across the included studies will be a prerequisite step that informs the “translation” process described as phase five by (Noblit & Hare, 1988).

Phase five; the next stage will involve translating studies into each other (Noblit & Hare, 1988). France et al. (2019) suggest that translation can be performed in different ways. In
this review, the authors will follow a method described by (Toye et al., 2014). Toye & colleagues (2014) suggest that constructs should be constantly compared until similarities and differences between concepts can be organised into conceptual categories to represent the third-order constructs. Given that the sample of children and young people included in this study is 5 to 18 years, the primary studies may report a variety of experiences depending upon the age of the included sample. It will be essential to preserve the context and meaning of the identified concepts during the translation concerning any subgroups such as age, as recommended by (Campbell et al., 2003). For this reason, the method of constant comparison across studies was deemed more appropriate rather than translating studies in chronological order (Toye et al., 2014).

Once, preliminary conceptual categories are created, ÁOD will present the findings to the broader research team, including SC (third author) and Mandy Stanley (MS) an invited expert in the area of meta-ethnography. Through discussions, these third-order constructs will be further developed and refined.

The final stages, phase six and seven, will involve the research team synthesising the conceptual categories into a line of argument, which provides greater conceptual understanding to the phenomena of interest as a whole; that is children and young people with DCD perspectives and experiences of everyday life and living with DCD. The conceptual categories and line of argument synthesis will be presented narratively; tables and figures will be created to support the narrative account. The findings of this meta-ethnography, endeavour to inform future research, policy and practice. Therefore, dissemination will involve the publication of the results in a peer-reviewed journal. An infographic designed policy brief will be published, to capitalise on knowledge translation and target a broader audience of policymakers, service providers, and clinicians. The policy brief will be distributed to advocacy groups who work on behalf of children and young people with DCD. Knowledge translation is challenging; in the context of childhood disability it is imperative that findings are easily accessible and usable (Novak & Honan, 2019). Given the nation and international focus upon promoting the voice of the child, the findings of this study must be presented in an easily accessible format for all possible stakeholders (Ombudsman for Children’s Office, 2019).

Discussion

Limitations and strengths

To the best our knowledge, we believe this is the first systematic review to integrate and synthesise the findings of qualitative studies on the views and experiences of children and young people living with DCD. The findings of this review will be relevant for researchers, practitioners, and policymakers working with children and young people with DCD. Given that there is a paucity of evidence regarding effective interventions to improve participation outcomes for children with DCD (Novak & Honan, 2019; O’Dea et al., 2019), the results of this review will add to the empirical evidence when designing a complex intervention for children with DCD to improve participation in everyday life. Thus, adding to research knowledge and reducing research waste by synthesising and conceptualising available evidence that can be used in the development of a complex intervention (Bleijenberg et al., 2018).

Addressing rigour is an essential aspect for the qualitative researcher. It is necessary to recognise that ÁOD is a PhD scholar and an Occupational Therapist who has worked clinically with children and young people with DCD. The other members of the research team have extensive research experience in a range of methodologies. It is envisaged that the meetings to discuss the analysis and interpretation of results will challenge any possible pre-existing assumptions that may influence results.

Data availability

Underlying data

No data are associated with this article.

Reporting guidelines


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