**Through the lens of Developmental Coordination Disorder (DCD): experiences of a late diagnosis**

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**Abstract**

A late diagnosis of a lifelong neurodevelopmental condition has been shown to be an important life event with implications for well-being and life outcomes. Developmental Coordination Disorder (DCD/Dyspraxia) is a common, yet little known neurodevelopmental disorder but, as our knowledge expands, it is clear that many individuals with DCD are not being diagnosed until late adulthood (i.e., after 30 yrs). However, there is a paucity of research investigating the experiences of individuals with DCD who only received their diagnoses in later adulthood. Adults and older adults with DCD have expressed a need for more research that will help to understand their positions and subsequently, lead to the development of appropriate support. Therefore, the aim of the study is to answer the following research questions: What is the emotional reaction surrounding the moment of receiving a late DCD diagnosis and the aftermath? How does self-concept change alongside the emotional consequences of a late DCD diagnosis and what impact does this have on one’s perception of the past, present, and future? The study will consist of semi-structured interviews with up to 15 individuals who received a diagnosis of DCD aged 30 years or later. Interviews will be analysed using thematic analysis.

1. **Introduction**

Developmental Coordination Disorder (DCD/Dyspraxia) is an idiopathic movement disorder that affects the development of fine and gross motor coordination. The motor difficulties are observed from childhood, significantly affect everyday activities (American Psychiatric Association, 2013) and persist into adulthood (Kirby, et al 2011). DCD manifests with difficulties in handwriting, the ability to ride a bicycle and participation in sports (American Psychiatric Association, 2013). However, the impact of DCD extends beyond motor functioning and may also negatively affect academic achievement, social interaction, and executive functioning (Harrowell et al., 2017, Purcell et al., 2015). DCD affects approximately 5% of the population (American Psychiatric Association, 2013), but despite the high prevalence and impact on individuals with the condition, DCD is not well understood or recognised in educational, occupational, and medical settings, especially when concerning adults (Missiuna et al., 2006; Novak et al., 2012). Consequently, for many adults with DCD in the UK, the pathway to diagnosis varies significantly between individuals and subsequent service provision remains elusive (Williams et al., 2015). Previous research has found that adults with DCD struggle to gain and maintain employment; experience decreased feelings of competence and self-esteem and have an increased risk of mental health problems (Gagnon-Roy et al., 2016; Missiuna et al., 2008; Tal-Saban et al., 2012).

 Similar difficulties have been found in adults with other neurodevelopmental disorders, such as autism spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD). For example, adults with ADHD found that there were often barriers to employment and not enough support within the organisational structure (Adamou et al, 2013). In addition, it was found that adults with ASD are more likely to experience challenges with cognitive skills and mental health problems (Howlin & Magiati, 2017). Considering the similarities across the experiences of adults with neurodevelopmental disorders (ADHD, ASD and DCD), and the fact that these conditions commonly co-occur, we have decided to inform the current study’s methodology and our expectations on the body of research that already exists for ASD and ADHD.

One particularly important aspect of the experience of a neurodevelopmental condition is receiving the diagnosis. In a recent survey of Australian professionals, it was found that DCD is one of the least known neurodevelopmental conditions (Hunt et al., 2021). Additionally, given the lack of appropriate motor assessments for adults older than 21 years (Mayes et al 2021), and the multi-dimensional issues experienced by individuals with DCD (Kirby et al., 2011; Poulsen, 2007), defining DCD in adulthood is not straight forward (Williams, et al., 2015). Pathways to diagnosis are frequently lengthy, stressful and costly (Cleaton et al., 2020; Pless et al., 2001; Rodger & Mandich, 2005) and it is therefore unsurprising that DCD is generally underdiagnosed (Miyahara, Yamaguchi and Green, 2008; Tamplain and Miller, 2021).

Most of the studies investigating experiences of the diagnostic pathway for individuals with DCD have focussed on the parental perspective, and findings show that they experience relief when a diagnosis is finally received for their child (Ahern, 2000, Soriano, et al., 2015). However, to our knowledge, the only research investigating the impact of receiving a DCD diagnosis on the individuals themselves has been an exploratory study conducted by Williams et al., (2015). Using a sample of 4 females aged from 31-50 years, findings showed that participants experienced varying reactions to their diagnosis, from relief at having responses to unanswered questions and acceptance of their behaviours, to feeling overwhelmed at receiving answers to so many questions all at once. Furthermore, the paper highlights the attitudes of family members prior to a diagnosis as the children were considered deviant or careless, the authors posit this is because families knew very little about the condition.

The main aim of this study is to expand on the findings from Williams et al (2015), to understand the experiences of adults who received a late DCD diagnosis (beyond 30 years old) and evaluate the emotional consequences and impact on self-concept for individuals with DCD. The study will contribute to our understanding of the circumstances of those individuals who were not able to receive a diagnosis and appropriate support for DCD early on in their life. Therefore, the findings from this work will be particularly informative for professionals working with adults who have suspected DCD.

There has been a number of studies investigating the impact of receiving a late diagnosis in both ASD and ADHD. The moment of receiving the diagnosis has been described as a “milestone event” associated with a strong emotional reaction (Johnson and Joshi, 2016). The emotions arise in the context of life experiences as individuals construct a new identity, begin to reflect on their past and formulate new expectations for the future (Tan, 2018). Our approach to investigate the experiences of adults who received a late diagnosis of DCD is therefore based on two theoretical accounts. The Murphy and LeVert’s (1995) staged process of emotional adjustment and the biographical illumination theory by Tan (2018). We adopt the concept of a ‘lens’ as an analogy for the late diagnosis following Tan’s (2018) observation that a diagnosis gives “a new lens to construct a valued self-concept and explicate the root of behaviours”. Both theories will guide our interpretation of emotional consequences following a late diagnosis in the context of changes in perceptions of one’s past, present, and future.

The emotional reaction experienced as a result of the diagnosis is long lived and may follow different stages with often conflicting feelings. Murphy and LeVert (1995) suggested a staged process of emotional adjustment following adult ADHD diagnosis which involves chronologically: a) relief and optimism, b) denial, c) anger and resentment, d) grief, e) mobilisation and f) accommodation. This model was confirmed in the study by Young et al. (2018) who found that it accurately reflects the experiences of adults who received a late ADHD diagnosis. Across other studies on late ADHD and ASD diagnoses, participants widely reported experiencing the feelings of relief, elation, and satisfaction from finally obtaining an explanation and validation for their difficulties (Hansson Halleröd et al., 2015; Johnson and Joshi, 2016; Young et al., 2008). Though as individuals start to reflect on their past, they often felt anger, regret and sadness linked to their belief that their lives could have been better had they known about their condition earlier on (Bargiela et al., 2016; Hansson Halleröd et al., 2015; Jones and Hesse, 2018; Young et al., 2008). The feeling of regret was especially strong at older ages as a response to a lengthy period of time during which individuals blamed themselves for the personal challenges they experienced (Johnson and Joshi, 2016). These findings indicate that individuals who received a later neurodevelopmental diagnosis are likely to experience a mixture of emotions. Whilst obtaining the diagnosis itself has been found to lead to generally positive emotions, more negative feelings emerge once individuals begin to reinterpret events from their past knowing they had this condition all along (Hansson Halleröd et al., 2015; Jones and Hesse, 2018; Tan, 2018l Young et al., 2008). Based on these findings showing important emotional and psychological implications of late neurodevelopmental diagnoses, our first research question is:

*RQ1: What is the emotional reaction surrounding the moment of receiving a late DCD diagnosis and the aftermath.*

We have chosen to include Qualitative Hypotheses (QH) in addition to our research questions. Carefully specified hypotheses are an essential element of registered reports (RR; Chambers & Tzavella, 2021), which help researchers to keep track of their expectations and mitigate questionable research practices such as hypothesising after the results are known (HARKing). However, within the RR context, hypotheses are normally discussed as testable hypotheses. Qualitative RRs are still quite rare (Karhulahti, 2022) and the concept of QH emerged only recently. QHs serve to disclose biases and preconceptions surrounding the research question. In this way authors can disclose their expectations based on their experiences and the knowledge of the research topic before any data is collected. This approach was demonstrated in a recent qualitative Stage 1 RR also concerning clinical populations (Karhulahti, Siutila, Vahlo, & Koskimaa, 2021).

Therefore, for our first QH, we considered the different stages of emotional processing identified by Murphy and LeVert (1995) as well as the changing and often conflicting feelings experienced by individuals with late diagnoses of ADHD and ASD. DCD is a neurodevelopmental disorder like ADHD and ASD with certain overlapping characteristics and therefore we expect similar outcomes in the current study. Our first qualitative hypothesis is:

*QH1: Participants who received a late DCD diagnosis will have different feelings towards this experience depending on how much time has passed since receiving the diagnosis. Participants are likely to describe a range of mixed emotions which may change over time.*

 It is important to consider the experienced emotions in the context of changes in self-concept[[1]](#footnote-1)\*.Tan (2018) developed the biographical illumination theory based on her work with adults who received a late ASD diagnosis. Biographical illumination theory illustrates how new knowledge about self is applied across time to give an explanation of the past. This leads to individual re-interpretation of own identity where the neurodevelopmental condition becomes part of the intrinsic self. It has implications for the present as individuals feel that they are not just a single case with such difficulties, and they can become part of groups and communities of individuals who are like them. It also impacts their expectations of the future as they learn that their difficulties are not curable and their goals for the future shift from “getting better” to “adaptation”. Based on this framework, our second research question is:

*RQ2: “How does self-concept change alongside the emotional consequences of a late DCD diagnosis and what impact does this have on one’s perception of the past, present, and future?”*

Research with individuals with ADHD and ASD shows that a late neurodevelopmental diagnosis has widespread positive and negative implications. In terms of self-concept, a late diagnosis helped individuals to construct a new understanding of their previous difficulties in social and educational contexts. For instance, individuals with an adulthood ADHD diagnosis expressed that due to their childhood difficulties they were called “stupid” or “lazy”, which led them to believe that this was true. They had negative self-concept and believed they had bad personal qualities. Following the diagnosis, they attributed their childhood difficulties to the condition and perceived themselves as children who were misunderstood (Young et al., 2008). Similarly, in terms of self-concept in the present and the future, participants reported an improvement in self-concept, self-worth and confidence as a result of the diagnosis which shifted the attribution of their problems from internal (you are responsible for your difficulties) to external (the difficulties are due to your condition; Hansson Halleröd et al, 2015; Young et al., 2008). One report suggested that this shift was specifically evident in individuals over the age of 30 years old who could reflect upon many different situations from their past (Johnson & Joshi, 2016). At the same time, some participants reported seeing the diagnosis as a flaw and confirmation that there is “something wrong with them” (Jones and Hesse, 2018). These findings suggest that self-concept changes can be seen as both positive and negative which could be linked to the experience of mixed emotions post late diagnosis.

 Importantly, the consequences of the shift in self-concept were observed to impact individuals in their daily lives, especially in social and occupational contexts. Individuals felt that the diagnosis opened doors to many supportive and understanding communities of individuals who had the same conditions (Hansson Halleröd et al., 2015; Tan, 2018) but they were also afraid to reveal the diagnoses to other people, fearing exclusion and stigmatisation (Hansson Halleröd et al., 2015). A similar dilemma was reflected in terms of the impact on the workplace. Individuals with ASD knew that revealing their diagnosis in their workplace could lead to improved access to support but at the same time, they were apprehensive and selective with regards to who should know about this for the fear of stigma (Johnson and Joshi, 2016). We again expect that individuals with DCD will share similar accounts as those presented in research on ADHD and ASD, but the examples of their experiences will include descriptions of difficulties that are core to DCD. Therefore, our second qualitative hypothesis is:

*QH2: “Participants will report changes in self-concept when considering their past, present, and future. We expect that the impact of the diagnosis and changes in self-concept will be described in educational, social, and occupational contexts.*

To investigate the above, the current study will involve semi-structured interviews with individuals who received a DCD diagnosis at the age of 30 or above. An interpretive approach will be used through thematic analysis as this will allow us to identify patterns across individual experiences which will help us to understand varied and complex accounts of participants’ experiences at the moment of receiving the late DCD diagnosis as well their perceptions of life before and after. We aim for the study to accurately represent the voices of our participants. We have therefore engaged with the community of adults diagnosed with DCD in adulthood to consult research aims and the interview schedule. We also plan to present our conclusions for review to individuals with DCD ahead of the publication of the study. Lastly, following the wishes of the community, we aim for the study to be educational for the occupational and medical professionals (GP’s, Occupational Therapists & workplace psychologists) who might work with adults with suspected DCD, or who might in the future give DCD diagnoses to adults. We will therefore anonymise the interview transcripts and make them openly available on the project’s OSF page (<https://osf.io/2ueha/>). As the OSF is a tool to promote open science, it offers an excellent opportunity for the general public, practitioners and researchers to view on-going research from conception to completion.

1. **Method**
	1. **Ethics information**

No funding has been received to conduct this study. The study received favourable ethical opinion from the University of Surrey ethics committee. Consent will be obtained by providing participants with an information sheet and a corresponding consent form using Qualtrics (Qualtrics, 2021). Participants will be clearly informed that their transcribed and anonymised interviews will be made publicly available. They will also be encouraged to ask questions to the research team to clarify any uncertainties on that matter before agreeing to sign the consent form. To ensure confidentiality, participants will be assigned a unique participant ID by the researchers, and all collected data will be linked to that ID.

Anonymised data consisting of responses to questionnaires and transcribed interviews will be deposited in an open repository following the University of Surrey’s Open Research Policy. Participant records will be amended to remove all identifiable information following guidance provided by the UK Data Service (UK Data Service, 2021). Anonymisation of the interview transcripts will adhere to the following three steps:

1. Ahead of the interview, participants will be asked to not mention names of people, places, organisations, employers, clinics etc. in their answers to the questions.
2. All identifiable information as listed above will be replaced with square brackets and a description, for example, [alma mater] will be used to replace the name of the university where a participant studied in case this is mentioned in the interview.
3. An anonymisation aiding tool provided by the UK data service (UK Data Service, 2021) will be used to check anonymised transcript to ensure that identifiable information was not missed ahead of making materials publicly available.
	1. **Participants**

Participants will be recruited from around the University of Surrey campus using advertisement posters placed at approved sites. A study advert will also be published on the University of Surrey research recruitment system (SONA) as well social media groups for adults with DCD. In addition, information about the study will be sent to the Dyspraxia Foundation for review and, if approved, will be advertised on their website, in their newsletter and through their social media. All advertisement procedures will commence at the same time.

The study will consist of 10-15 adults who received a diagnosis of DCD at the age of 30 years old or later. During recruitment and data analysis, we will systematically reflect on the adequacy of the sample size considering study aims (see the “Justification for Sample Size” section below).

Participants’ age at diagnosis is in-line with previous studies investigating the impact of a late neurodevelopmental diagnosis. Johnson and Joshi (2016) argue that adults experience different emotions and perceptions around the diagnosis from the age of 30 due to the wealth of life experiences prior to the diagnosis and ruminations about situations which could have been different had they known about their condition earlier on. Therefore, this age is appropriate for study of mixed emotions experienced over time following a late adult DCD diagnosis as well as diagnosis-related self-concept changes in the context of the past, present and future.

**Inclusion and exclusion criteria.** All participants will need access to the internet in order to sign-up to take part in the study, complete online forms and participate in interviews which will be held via Microsoft Teams. To ensure that we meet the UK guidelines for assessment of adults with DCD (Barnett et al., 2015) and the DSM-5 criteria for research into DCD (American Psychiatric Association, 2013), participants will be screened using the Adult Developmental Coordination Disorder Checklist (ADC; Kirby, Edwards, Sugden & Rosenblum, 2010). The ADC is a suitable tool for this purpose as it has been rigorously tested on individuals aged 17-42 years (Niklasson, et al., 2018). A total score of over 65 (and over 17 in section A reflecting the severity of DCD-related difficulties in childhood) will be required to participate in the study. Those with co-occurring conditions (neurodevelopmental disorders such as ASD, ADHD), will not be included in the study to reduce the potential influence of additional diagnoses. These additional diagnoses will be screened for in the demographic questionnaire. Participants will not be invited to participate in the interview if they answer “yes” to question number 11 (Do you have any other neurodevelopmental diagnoses?).

**Justification for sample size**. We approached the sample size estimation following the information power principle proposed by Malterud, Siersma and Guassora (2016) which focuses on the following five elements: 1) research aims; 2) sample specificity; 3) theoretical background; 4) quality of dialogue; and 5) analysis strategy. With regards to the first two elements, the aims of our study are rather broad, and the target sample is likely to be heterogeneous which would indicate the need for a larger sample size. However, we are planning to use thematic analysis as the analysis method (element 5). Braun and Clarke (2021) emphasise that it is a challenging task to decide on the sample size for studies using thematic analysis and saturation may not be suitable. Specifically, they highlight that in thematic analysis, meaning is generated through the interpretation of interviews, not excavated from them. In addition, we have a strong theoretical background based on previous work with individuals with neurodevelopmental disorders which specifically addresses emotional and self-concept-related consequences of late diagnoses (Murphy & LeVert, 1995; Tan, 2018) and an interview schedule that was adapted from a previous study to help facilitate good communication quality (elements 3 and 4). We therefore believe that a large sample size should not be necessary to address our research questions and we will apply a reflective process across data collection to ensure that our small to moderate sample will be adequate for our study aims

The minimum sample size we will consider for the study is ten participants. We acknowledge that the outcomes of the study could differ depending on the recruited sample size because the interpretation of data could differ as a result of exposure to more examples of discussed experiences. Therefore, after the first ten interviews, the team will reflect on the gathered data, the range of experiences conveyed by the participants and the extent to which it is possible to answer our two research questions. Depending on the outcome of these deliberations, we will decide to either continue or finish data collection. If data collection continues, we will interview five additional participants. The reflections from the meeting will be recorded and shared as part of the study materials. The maximum number of participants we would recruit is 15. This maximum sample size can be interpreted as moderate and is thus consistent with our sample size predictions based on the information power principle. It is also consistent with previous literature using similar methodology with populations with other neurodevelopmental disorders, for example, ADHD and ASD (Smith & Jones, 2019, Young et al, 2008).

It is unlikely that an adequate sample size would not be reached because DCD is a prevalent condition and there is no specific time limit for the completion of the current study.

**Materials**

**Demographic Questionnaire.** Participants will be asked to provide information about themselves including age, gender, ethnicity, occupation, and questions about their general health. Information collected from the demographic questionnaire will be used for completing a demographic analysis. This will be followed by questions regarding their DCD-related difficulties and experiences. The demographic questionnaire can be found in the study repository (<https://osf.io/ep53y/>).

**Adult Developmental Coordination Disorder (Dyspraxia) Checklist (ADC; Kirby et al., 2010).** The ADC has been designed to help identify DCD in adulthood, and, whilst the ADC is not a diagnostic tool, it is frequently used to indicate if there are areas of difficulty associated with DCD. The ADC takes approximately 10 minutes to administer and can be completed by adults over 16 years old. It is divided into two sections. Section 1 has ten questions investigating difficulties from childhood. Section 2 has 30 questions designed to investigate difficulties that might currently affect everyday life. Participants rate their difficulty on a 4-point Likert scale (0-3) with the following descriptions: ‘never’, ‘sometimes’, ‘frequently’, ‘always’. Higher scores indicate more difficulties. Section 1 and 2 are summed separately. A score of 17 or more in section 1 confirms that participants meet the criteria for having DCD-related childhood difficulties. This score is then added to that of section 2 to provide an overall total. If the total score ranges between 56 and 65, the participant is regarded as ‘at risk’ of having DCD, if the total score is greater than 65, they are regarded as having ‘probable’ DCD.

**Interview Schedule.** Interviews will be conducted via Microsoft Teams with one member of the research team (GA) and will last approximately one to two hours. Interviews will be audio recorded and transcribed verbatim through Microsoft Teams, with checks for anomalies conducted by the research team. All interviews will be semi-structured based on a prepared schedule. The interview schedule was adapted from that used by Young et al. (2008) in their study on ADHD. Questions that were not relevant for DCD participants or for the aims of the current study were removed whilst some additional, more relevant questions were added. A consultation with a member of the DCD community was held to ensure questions were appropriate for the aims of the study. The full interview schedule can be accessed at <https://osf.io/y3rzv/>.

* 1. **Procedure**

Individuals who express an interest in taking part in this study will be sent an email containing the information sheet. Participants will be asked to confirm that they are over 18 years and will also be invited to ask the research team any questions ahead of signing up for the study. Participants will be informed, that they will need to complete a screening check before it can be confirmed whether they can participate in the whole study. Participants who confirm that they want to continue with the study will be provided with a Qualtrics link to a form including the participant information sheet, consent form, demographic questionnaire, and the ADC questionnaire. These documents will be completed and returned electronically. The demographic questionnaire and the ADC answers will be assessed for meeting inclusion criteria. Provided, that all criteria are met, participants will be invited for the interview and asked to provide their availability. The interviews will be delivered via Microsoft Teams (MS Teams). To ensure consistency, we plan for all interviews to be conducted by one researcher: GA. Participants who do not meet the inclusion criteria will be informed that their questionnaire answers will not be used for the purpose of the current study.

During the interviews, the researcher will clearly explain the objectives for the meeting and reiterate that participants are welcome to leave at any time. Participants will also be reminded that the discussion is being audio recorded. The researcher will make it clear that their role as moderator is to guide the discussion but to encourage participants to speak freely and share their experiences. The conversation will be allowed to flow naturally but will be guided by the researcher to ensure that data collected from the meeting is focused on the line of enquiry.

Depending on participants’ individual wishes, they will be informed about all outputs from the study, and they will be provided with the link to the project’s open repository.

* 1. **Data Analyses**

**Analysis plan.** We will analyse the transcripts from the interviews using codebook thematic analysis (Braun and Clarke, 2022), here interpreted as utilizing fixed premade coding instructions with independent coders. This approach was chosen as it will allow researchers to use a more structured approach whilst allowing a reflexive space to hold the subjectivity of qualitative research (Braun and Clarke, 2022). As such, the analysis will be completed by two coders (GA and MT). We will follow a realist epistemology, as we are attempting to find the real truth, independent of the observer (Bhaskar, 1975), and this position is most optimal for addressing both our research questions. Research Question 1 because, we hope to capture what emotions arise for individuals receiving a diagnosis later in life, as there is currently little understanding of these experiences. Research Question 2, as we are interested in understanding how individuals make sense of their experiences and their self-concept through the ‘lens’ of DCD. Although our epistemology is realist, we have included reflexive practices such as the qualitative hypotheses and our reflexivity statements as we are aware of our expectations and preconceptions. However, in the analysis of data we will be identifying themes within the data itself from participants rather than constructing themes that are driven by the researcher’s subjectivity. In order to support this approach and reduce researcher bias, the two coders will be given the same instructions to assist with generating codes and identifying themes, (https://osf.io/d5cbn).

Both research questions will use the same analysis plan as the questions are closely related. Research questions 1 is related to the emotional impact of a late diagnosis and question 2 concerns the contextual information for the emergence of these feelings based on changes in self-concept. We will be using the Braun and Clarke (2006) six step model as follows:

1. *Familiarising with the data*-Researcher GA will be completing the interviews and both researchers responsible for coding will be transcribing data, which will allow them to become familiar with the data before coding. Both coders will read and re-read the transcribed interviews, marking relevant areas and noting down initial ideas to ensure they are actively immersed with the collected data.
2. *Generating initial codes*-Once Researcher GA and MT are familiar with the data, they will begin independently noting down initial codes or ideas that are of interest to them. We will be using inductive and semantic codes, which means codes will be data-driven and taken from the surface information provided in interviews. This will be appropriate in answering the research questions, as we are concerned with understanding the explicit experiences of those who experienced a late DCD diagnosis. This approach is in line with our epistemological position and will allow us to identify common patterns reflecting the impact of a late DCD diagnosis. The coders will be instructed to identify codes in accordance with the research questions through general focus on interview contents concerned with emotional functioning (RQ1) and self-concept (RQ2) in order to capture common patterns. Coders will record these in their own codebooks to monitor the developing analysis and to guide data coding. (Braun and Clarke, 2022). We expect that initial codes will reflect our hypotheses. For instance, we expect that the codes will capture mixed emotions following a late DCD diagnosis (RQ1), but the specific emotions, their context and impact will emerge from the data. Therefore, we expect novel insights specific to DCD. Codes will be identified by going through the transcripts systematically and highlighting emerging patterns.
3. *Search for themes*-Once data have been coded, researcher GA and MT will independently begin searching for themes by collating codes that may share a common idea or ‘theme’. At this stage, interview data will be analysed to discover what possible themes link the coded data in terms of shared experience of individuals who have received a late diagnosis. Mind maps will be used and shared in the final version of the report.
4. *Reviewing themes*-At this stage, both coders will work together to find which of the candidate themes capture the experiences of those who participated in the study. Themes may be combined, or broken down, depending on how the data drives the analysis. This stage, therefore, reflects the moment of result synthesis between the two coders and the process of obtaining the final results. Any disagreements at this stage will be resolved by consensus and in-depth discussion with the whole research team. It will be important to re-read the data to ensure the themes fit well with the narrative of the data. The reflective nature of our approach will be useful in this phase to be aware of when to stop refining themes.
5. *Defining and naming themes*-Themes will be identified by ordering the codes, and the researchers’ understanding of what is interesting about the codes, and why.
6. *Produce report*- Once themes have been identified, the report will be completed using anonymised extracts from the data which will answer our research questions by highlighting patterns within individuals experience of receiving a late diagnosis of DCD.

This approach will help meet the aims of the study in developing our understanding of the common themes associated with emotions and self-concept of individuals who received a late diagnosis of DCD as seen in previous research with other neurodevelopmental disorders (Smith & Jones, 2019; Johnson & Joshi, 2016). To investigate the participants’ experiences through their own words, a semantic-realist approach to the data is justified. In addition, by interpreting participants’ accounts of individual experiences, we will provide meaningful information that can be applied in practice by professionals working with individuals with DCD.

It is unlikely that we will deter form the above plan, however qualitative research has the benefit of having some flexibility, if required. In the unlikely circumstance that we must deviate from the plan, all changes will be transparently documented in the analysis log and clearly justified in the Stage 2 report. In addition, the analysis log will include all emerging codes, sub-themes, and themes. This will help to track the process of interpretation and generating meaning from the interviews. This comprehensive approach will ensure a genuine representation and interpretation of information provided by the participants in the current study.

**Quality Checks.** We aim to maintain a high level of rigor in the current study and thus we followed advice for ensuring validity and reliability as outlined by Morse (2015). Validity of the current study has been facilitated through our theoretical basis built on previous studies with similar aims. In addition, our interview schedule was adapted from a previous similar study including adults with ADHD. Lastly, interview questions were adapted following a consultation with a member of the target group for the current study.

Reliability is a complex term in qualitative research, however being mindful of context, researcher’s own subjectivity and having a clear action and thought process can facilitate this (Syed and Nelson, 2015). We therefore addressed researcher bias by providing reflexivity statements for each researcher to acknowledge potential biases that could influence data collection and analysis. These can be accessed at the project’s repository (https://osf.io/y7a6q/). A second, general reflexivity statement will be completed in retrospect, following the completion of analysis to ensure the reliability of the study and allow the researchers responsible for analysing data an opportunity to reflect on their own biases and subjectivity as part of the coding process. We have also carefully planned an inductive analysis approach, which means that the analysis will be driven by the data rather than preconceptions of the research team about the study or existing theory. The use of qualitative hypotheses allows us to declare our pre-existing expectations regarding the possible outcomes of the study early on. We aim to reflect this in the data analysis log, which will be openly shared as part of the study materials.

We also have a well-established connection with the communities of individuals with DCD which falls under the “prolonged engagement” approach proposed by Morse (2015) to facilitate the procurement of rich data. The Motor Development and Impact Lab (MoDI) headed by researcher JG maintains contact with participants who took part in studies in the past as well as charity organisations focused on DCD to provide opportunities for discussions around research. We will seek feedback from this community, which is an approach described as member checking by Morse (2015). Member checking has been criticised as it is often not possible to incorporate participant feedback into the results after data analysis in the case that they might not agree. To address this issue, we will invite 3-5 members of the DCD community who did not take part in the study and ask for their perceptions on the results after analysis is finalised. We will ask whether they feel that the results reflect experiences that are typical of individuals with DCD, whether we have used appropriate language and whether the results are likely to be helpful for the community. The feedback form that will be used for this purpose can be accessed at (https://osf.io/m5qjz/). We might change the language used to express the results if needed following the feedback, but we will not change the results. Instead, we will use participant feedback to reflect on possible limitations of the study especially drawing on situations where our results may not be best applied – known as negative case analysis. With this approach, we will better understand the reliability and the scope of generalisability of the results. Participants who agree to give us feedback on the results will receive the study information sheet and will be asked to sign a consent form before any feedback is sought. Lastly, we have also completed the COREQ checklist (Tong, Sainsbury, & Craig, 2007) which provides items to guide researchers through the process reporting qualitative research methodology (https://osf.io/g8cxd/).

* 1. **Data availability**

Anonymised transcripts and demographic data will be deposited on the Open Science Framework under a CC-By licence with the project’s DOI. The data will be stored and preserved on the OSF indefinitely (<https://osf.io/mswn4/>). Theme codes will be available in analysis logs, which will be shared within the project’s repository and hold information regarding coding of data and the themes they were linked to. A participant recruitment log will also be made available, which will include decisions regarding the sample size.

1. **Results**
2. **Discussion**
3. **References**

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1. \* Throughout the manuscript, we adopt Baumeister’s (1999) definition of self-concept as follows: *"The individual's belief about himself or herself, including the person's attributes and who and what the self is".* [↑](#footnote-ref-1)