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Developmental coordination disorder: the impact on the family

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Abstract

Purpose Developmental coordination disorder (DCD) is a neurodevelopmental disorder with an estimated prevalence of 2–6% in school-aged children. Children with DCD score lower in multiple quality of life (QOL) domains. However, the effect of a child's DCD on their parents' and family's QOL has not previously been assessed in a UK population. We aimed to assess parental and family QOL within UK families containing at least one child aged 6–18 years who was diagnosed with DCD.

Methods A mixed-methods study was designed, using an online questionnaire that incorporated the Family QOL Scale and the 12-Item Short Form Health Survey.

Results The emotional and disability support domains of family QOL were markedly negatively affected by DCD, with lack of support by medical and educational professionals cited as a major source of stress. Parental mental health was also negatively affected. In many cases, the child's DCD impacted on parental work life, family social life and siblings' well-being.

Conclusions Having a child with DCD has a considerable impact on families. This needs to be recognised by healthcare and other professionals; otherwise, services and support may not be appropriately targeted and the negative sequelae of DCD may ripple beyond the individual with costly social and economic consequences.

Keywords Developmental coordination disorder · Family · Parent · Sibling · Quality of life · Work life

Introduction

Developmental Coordination Disorder (DCD) is a neurodevelopmental disorder with an estimated prevalence of between 2 and 6% in school-aged children ([1, 2], respectively). Its core characteristics, as defined by the Diagnostic and Statistical Manual of Mental Disorders—5th edition (DSM-5) [2] and the International Classification of Diseases—10th edition (ICD-10) [3–5], are a deficit in coordinated motor skills that significantly or persistently interfere with activities of daily living and/or academic or vocational activities and are not caused by or better explained by intellectual disability, visual impairment or a neurological condition affecting movement such as Cerebral Palsy or Muscular Dystrophy. However, DCD has a number of other, less commonly recognised features associated with it, including poor academic performance, poor physical fitness, poor social skills, low self-esteem, anxiety and depression, higher-than-average risk of suicide and, in some children, additional sensory processing challenges [6]. Additionally, DCD frequently co-occurs with other neurodevelopmental disorders such as Attention-Deficit/Hyperactivity Disorder (ADHD) and Autism Spectrum Disorder (ASD) [7].

Quality of life (QOL) is an important metric to guide healthcare decisions [8]. QOL is defined in the constitution of the World Health Organisation as "individuals' perception of their position in life, in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns" which incorporates "physical health, psychological state, level of independence, social relationships, personal beliefs and their relationships to salient features of the environment" [9]. Increasingly, recognition is being given to how medical and psychiatric conditions affect the QOL not only of individuals but also their families [10].

Several studies have considered QOL in individuals with DCD. These found that children with DCD have significant challenges to their QOL [11], score lower in multiple

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QOL domains [12, 13] and boys with DCD have lower self-concept [14]. Likewise, adults with DCD have lower QOL across all domains [15] as well as lower self-reported mood, health, well-being, and employment status [16]. The QOL of children with DCD is correlated with the severity of gross motor and balance deficits [17]. The presence of a co-occurring DCD diagnosis may also further reduce QOL in children who have other neurodevelopmental disorders [18].

Only one study has assessed the effect of DCD on parental and/or family QOL. Wuang et al. assessed the QOL of Taiwanese parents of children with DCD using the 12-Item Short Form Health Survey (SF-12) [19, 20]. Parents of children with DCD scored significantly lower on both the physical and mental components of the SF-12 compared with parents of typically developing children. It is unclear if these findings can be extrapolated to other countries, given that parental well-being is known to vary between countries [21]. Additionally, this study only considered parents, not families as a whole. However, studies of other neurodevelopmental disorders, such as ASD and ADHD, have found a marked impact on family, parental and sibling well-being [22–24]. Therefore, we assessed parental and family QOL by surveying parents/guardians from UK families containing at least one child aged 6–18 years who was diagnosed with DCD.

Methods

Study design and procedures

Participants were recruited to answer an online questionnaire regarding the economic and other impact of DCD via the Dyscovery Centre's client list; advertisement via the Dyspraxia Foundation's website and local groups; and advertisement by the authors on social media. Participants were aged ≥ 18 years, residents in the UK and the parents/guardians of a child diagnosed with DCD/Dyspraxia who was between 6 and 18 years old.

A mixed-methods study was designed. The online questionnaire consisted of demographic questions, service-use questions, the Family Quality of Life (FQOL) Scale [25], the 12-Item Short Form Health Survey (SF-12) [19] and eight additional questions. Two of these questions were multiple choice (Have you changed anything about your work as a result of your child's DCD/Dyspraxia? If applicable, has your partner changed anything about their work as a result of your child's DCD/Dyspraxia?). Two questions used three-point Likert scales (Do you have a family support network? Do you have a support network of friends?); two used five-point Likert scales (Do you change your family activities as a result of your child's DCD/Dyspraxia? Does your child's DCD/Dyspraxia limit family activities, holidays, meeting with friends and/or meeting with family in any way?); and two were open-ended (Does your child's DCD/Dyspraxia impact your other children? Do you have any other comments?).

The survey ran from February to April 2018, inclusive. Findings regarding the economic impact of DCD will be published elsewhere.

Sample

A total of 328 eligible parents/guardians completed the online questionnaire. Of these, 56.7% were valid responses (Table 1); validity was assessed as having no missing responses to any of the FQOL or SF-12 questions. Valid responses tended to be more often from individuals (parents/guardians) with university education and less often from individuals with only secondary education than non-valid responses (Table 1). In all other respects, they were similar to the non-valid responses.

Variables and instruments

Family Quality of Life (FQOL) Scale

The FQOL is a self-report questionnaire containing five sub-scales: family interaction, parenting, emotional well-being, physical and material well-being and disability-related support [25]. Respondents rate their current satisfaction with 25 items corresponding to these sub-scales using five-point Likert scales. This questionnaire has been reported to have good validity and test–retest reliability [26].

The proportion of respondents rating their family situation as very unsatisfied, unsatisfied, neither unsatisfied nor satisfied, satisfied or very satisfied were calculated. Internal consistency for the scale was high; Cronbach's alpha was 0.931.

Parental health-related Quality of Life (SF-12 and RAND-12)

The 12-Item Short Form Health Survey (SF-12) is a self-report questionnaire derived from the 36-Item Short Form Health Survey (SF-36) that covers two components divided into four sub-sections each: a physical component comprising general health, physical functioning, role-physical and bodily pain, and a mental component comprising role-emotional, mental health, vitality and social functioning [19]. Respondents rate their health with 12 items corresponding to these sub-sections using two- to six-point Likert scales. Questions were asked regarding medium-term health (during the last 4 weeks). The SF-12 has good validity and accuracy [19, 27, 28].

RAND-12 scores were compared with a previously described cut-off for depression [29]. This study re-surveyed a sub-sample of the Australian National Survey of

Table 1 Demographics of respondents

	Valid responses ($n=186$) Mean (95% CI)	Non-valid responses[a] (n = 142)
Respondent age (year)	42.8 (41.9–43.7)	42.0 (40.8–43.3)
No. of children	2.2 (2.1–2.4)	2.4 (2.2–2.6)
No. of children with DCD	1.2 (1.1–1.3)	1.5 (1.3–1.6)
	Valid responses ($n=186$) *N* (%)	Non-valid responses[a] ($n=142$)
Respondent gender		
Female	176 (94.6%)	118 (83.1%)
Male	9 (4.8%)	2 (1.4%)
Other	0 (0.0%)	0 (0.0%)
Prefer not to say	0 (0.0%)	0 (0.0%)
Respondent marital status		
Single	17 (9.1%)	9 (6.3%)
Married/civil partnership	148 (79.6%)	102 (71.8%)
Divorced	9 (4.8%)	4 (2.8%)
Separated	7 (3.8%)	5 (3.5%)
Widow/widower	2 (1.1%)	0 (0.0%)
Respondent highest education level		
Primary or less	2 (1.1%)	1 (0.7%)
Secondary	21 (11.3%)	32 (22.5%)
College (A-levels or equivalent)	47 (25.3%)	27 (19.0%)
Undergraduate degree	49 (26.3%)	30 (21.1%)
Postgraduate degree	54 (29.0%)	23 (16.2%)
Other higher education	13 (7.0%)	8 (5.6%)
Respondent working status		
Working full-time	60 (32.3%)	32 (22.5%)
Working part-time	77 (41.2%)	58 (40.8%)
Not working	49 (26.3%)	31 (21.8%)
Child gender		
Female	50 (26.9%)	18 (12.7%)
Male	135 (72.6%)	87 (61.3%)
Other	1 (0.5%)	0 (0.0%)
Prefer not to say	0 (0.0%)	0 (0.0%)

N.B. Percentages do not add up to 100 as respondents were permitted to not respond to question(s) as they wished

[a]These respondents did not answer the whole FQOL scale and/or did not answer the whole SF-12 survey

Mental Health and Well-being using the RAND-12 mental health component. A MHC score of ≤ 45 was chosen by the authors as the best screening cut-off for depression, yielding sensitivity of 0.87, specificity of 0.83, positive predictive power of 0.18 and negative predictive power of 0.99.

6-dimension short form health survey (SF-6D)

Preference-based measures of health-related QOL are useful in order to provide information for health economic considerations (i.e. in decision analytic models to inform technology or policy adoption decisions). The SF-6D has been demonstrated to have good validity and responsiveness in a variety of populations, including adult mental health populations [30]. The SF-6D was chosen over other preference-based health measures to reduce respondent burden. The values of the SF-6D range from 0 (dead) to 1 (full health). Cronbach's alpha was 0.769.

Parental work life

The proportion of respondents changing their work practices were calculated for all valid responses and for valid

responses from female respondents with partners. Odds ratios were also calculated for the latter.

Data analysis

FQOL scale

Responses for the FQOL scale were analysed by calculating the median score for each sub-scale (family interaction, parenting, emotional well-being, physical and material well-being and disability-related support) for each respondent. The proportion of respondents who were very dissatisfied (median score < 2), dissatisfied (median score < 3 and ≥ 2), neither dissatisfied nor satisfied (median score $= 3$), satisfied (median score > 3 and ≤ 4) and very satisfied (median score > 4) were then calculated.

SF-12 and RAND-12

Physical and mental health summary scores were calculated. There are well-founded concerns regarding the original SF-12 scoring method due to its use of overlapping scales and its assumption that physical and mental health are orthogonal (uncorrelated) factors [31]. Therefore, we calculated physical and mental health component (PHC and MHC) scores following the RAND-12 Health Status Inventory (HSI) method, which does not use overlapping scales and assumes physical and mental health are oblique (correlated) factors [32, 33]. We also provide physical and mental component summary scores following the original SF-12 manual [28, 33], despite their flaws, for the sake of comparison with older literature. Scoring algorithms derived from 1998 USA population were used as there is a high inter-correlation between UK SF-12 data scored with USA- or UK-derived algorithms [27, 34] and use of USA-derived algorithms permitted wider comparison with the literature. Cronbach's alpha was 0.867 for the PHC and 0.789 for the MHC.

SF-6D

SF-6D tariffs were estimated for each respondent from the SF-12 results following standard methods [35, 36].

Parental work life, sibling well-being and family effects

Responses regarding parental work life, sibling well-being and other family effects were analysed by determining the frequency of each response. In the case of parental work life, this was calculated for all respondents and for all female respondents with partners.

Results

Sample

Respondents were predominantly female, almost all of whom were mothers (Table 1). A high proportion of respondents were university educated and married or in a civil partnership. Their children with DCD were aged 6–18 years (Fig. 1) and predominantly male (Table 1); 19.9% had a co-occurring diagnosis of ASD.

Family Quality of Life

Family QOL was assessed using the FQOL Scale. The majority of respondents were satisfied or very satisfied with how their immediate family interacts with itself, with the parenting in their immediate family and with the physical and material well-being of their immediate family (Table 2). Less than 10% of respondents were dissatisfied or very dissatisfied with these aspects of their family QOL.

This is in marked contrast to respondents' satisfaction with their family's emotional well-being. Half of respondents were dissatisfied or very dissatisfied with this aspect of their family's QOL. In particular, respondents were dissatisfied with the statements 'My family has outside help available to us to take care of special needs of all family members' (question 13) and 'My family has the support

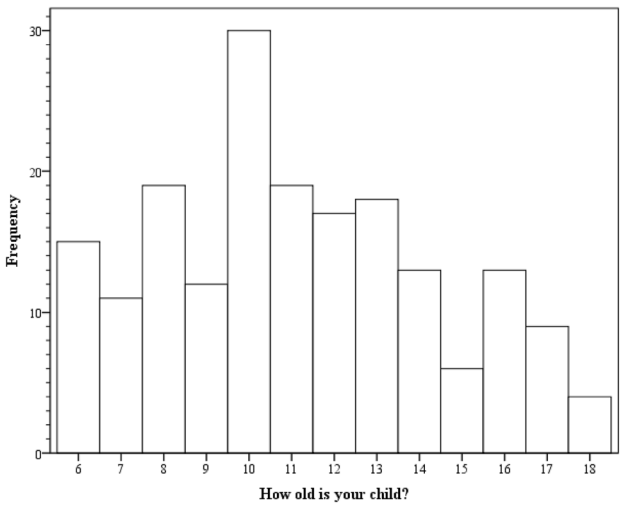

Fig. 1 Histogram of age of children with DCD ($n = 186$). A histogram showing the frequency of each age group of children. All children were between 6 and 18 years old. The majority of age groups (6, 7, 8, 9, 11, 12, 13, 14 and 16 years old) each contained between 10 and 20 children. Most of the older age groups (15, 17 and 18 years old) contained fewer than 10 children. The modal value was 30 children, at age 10 years

Table 2 The effect of a child's DCD on their family's quality of life

FQOL sub-scale	Proportion of respondents who were (%)				
	Very dissatisfied[a]	Dissatisfied[b]	Neither dissatisfied nor satisfied[c]	Satisfied[d]	Very satisfied[e]
Family interaction	1.6	7.0	12.9	54.8	23.7
Parenting	1.1	7.0	15.1	53.2	23.7
Emotional well-being	16.1	33.9	16.1	29.6	4.3
Physical and material well-being	0.5	7.6	11.3	52.6	28.0
Disability-related support	4.8	18.9	9.1	52.1	15.1

[a]Median score < 2 on a 5-point Likert scale

[b]Median score < 3 and ≥ 2

[c]Median score = 3

[d]Median score > 3 and ≤ 4

[e]Median score > 4

we need to relieve stress' (question 3). This was reflected in answers to the open-ended questions:

> Having a child with DCD is very stressful on all aspects of family life. – Respondent 185
> [We're] struggling emotionally and financially. – Respondent 286

Additionally, disability support was an area of concern regarding family QOL. A quarter of respondents were dissatisfied or very dissatisfied with the overall support given to their family member(s) with disabilities. In particular, although 83.9% were satisfied or very satisfied with the support given to help their family member(s) with disabilities accomplish goals at home (question 23), only 51.1% were satisfied or very satisfied with the support given to help their family member(s) with disabilities accomplish goals at school or work (question 22). Furthermore, only 46.8% reported being satisfied or very satisfied with the service providers who helped their family member(s) with disabilities (question 25). Again, this was reflected in the comments:

> I've had almost no support from the NHS and very little from school. It's hard. – Respondent 267
> Completely underwhelmed by the support received throughout the consultations and diagnosis. Following diagnosis we, as a family, have been left to 'fend for ourselves'. We have had to manage and drive our own care plan. – Respondent 302
> There is a distinct lack of support. – Respondent 414

Some respondents indicated that this lack of support was at least partially driving their family's poor emotional well-being:

> This [unsupportive school] has led to a great deal of strain on relationships & anxiety. – Respondent 343

Other respondents noted that there was a particular lack of support, both in the public and third sectors, for older children and young adults with DCD:

> We are finding that there is a gap in finding support for child[ren] going into uni[versity] with DCD. – Respondent 202
> There needs to be so much more support for older children / young adults … [named charity], etc. seem aimed at children only. – Respondent 369

Parental Quality of Life

Parental QOL was assessed by calculating average PHC and MHC scores using the RAND-12. Respondents' average PHC scores were not statistically different ($p = 0.1587$, two-tailed t-test) to that from USA general population norms (Table 3, [19]). UK general population norms are not available. Additionally, respondents' average PHC scores were highly negatively skewed, indicating that comparatively few respondents were in poor physical health.

In contrast, respondents' average MHC scores were highly significantly poorer ($p < 0.0001$, two-tailed t-test) than expected from USA general population norms [19]. Respondents' average MHC scores were symmetrically distributed, indicating as many respondents scored below the already poor average score as scored above the average (and thus approaching or at normal levels). Additionally, 72.6% of respondents met a SF-12 cut-off for depression proposed following a survey of the general adult population of Australia [29]. This, too, was reflected in respondents' comments:

> We [parents] have … lost the will to fight … We are emotionally and physically exhausted. – Respondent 96

Table 3 The effect of a child's DCD on their parent's/guardian's quality of life

	Mean (95% CI)	Median (IQR)
RAND-12 HSI scoring method[a]		
Physical health component (PHC) score	48.9 (47.1–50.8)	53.3 (43.6–59.7)
Mental health component (MHC) score	37.2 (35.4–39.0)	38.0 (27.9–46.4)
Original SF-12 scoring method[a]		
Physical component summary (PCS) score[b]	53.9 (51.9–55.9)	58.5 (49.5–63.1)
Mental component summary (MCS) score[b]	34.9 (32.9–36.9)	36.5 (24.9–45.3)

[a]Both scores are normalised to US population data where the mean PHC/PCS and MHC/PCS scores are 50 and the standard deviations are 10

[b]These scores are provided for reference with prior literature only as there are well-founded concerns regarding this scoring method

> It [child's DCD] has decimated us. My mental health is at rock bottom. – Respondent 205
> This [supporting a child with DCD] takes a significant emotional toll on me for which I have little support. – Respondent 341

Parental preference-based health score

Parental preference-based health was determined using the SF-6D, using data from the SF-12. Respondents' mean SF-6D score was 0.690 (95% CI 0.671–0.708). This is notably lower than norms for populations similar to our respondents (i.e. women aged 40–44 years): mean 0.793, 95% CI 0.785–0.801 [37]. Indeed, this preference-based health score is similar to population norms for individuals with arthritis and lower than population norms for individuals with asthma, hyper- or hypothyroidism, cancer, diabetes, epilepsy or high blood pressure [37].

Parental work life

Having a child with DCD had a marked effect on parental/guardian work life. More than a fifth of respondents had reduced their work hours and high proportions had used flexi-hours, chosen a different job or career, swapped full-time work for part-time work or stopped working altogether in response to their child's DCD (Table 4). However, few respondents reported increasing their work hours, swapping part-time work for full-time or starting work in response to their child's DCD.

The respondents' work life was affected far more frequently by their children's DCD than their partners' work life. This is notable as there was a very high proportion of women among the respondents (Table 1). When only female respondents with partners were considered, these respondents were nearly five times more likely to have swapped full-time work for part-time work than their partners and even more likely to have stopped working or to have reduced their work hours (Table 4). Thus, the effect of children's DCD on their parents'/guardians' work life appears to be gender-dependent.

The proportion of respondents changing their work practices may be affected by the demographics of our sample. Notably, 62.3% of respondents had some form of university education and 79.6% were married or in a civil partnership (Table 1). It is probable that their partners had similar education levels and thus, the sample is likely to predominantly

Table 4 The effect of a child's DCD on their parents'/guardians' work life

Effect on work	All respondents ($n=186$)	Female respondents with partners ($n=147$)		
		Female respondent	Partner	Odds ratio
Reduced work hours	42 (22.6%)	32 (21.8%)	7 (4.8%)	5.6
Increased work hours	0 (0.0%)	0 (0.0%)	1 (0.7%)	0.0
Used flexi-hours	45 (24.2%)	36 (24.5%)	28 (19.0%)	1.4
Chose a different job or career	34 (18.3%)	26 (17.7%)	9 (6.1%)	3.3
Turned down a promotion	15 (8.1%)	9 (6.1%)	7 (4.8%)	1.3
Swapped FT work for PT work	22 (11.8%)	17 (11.6%)	4 (2.7%)	4.7
Swapped PT work for FT work	1 (0.5%)	1 (0.7%)	0 (0.0%)	–
Stopped working	24 (12.9%)	18 (12.2%)	4 (2.7%)	5.0
Started working	4 (2.2%)	2 (1.4%)	0 (0.0%)	–

FT full-time, *PT* part-time

consist of higher income families with two adults' income for whom changing, reducing or eliminating one partner's employment is an option. Among single-parent or low-income families, this option may not be available. This was reflected in some of the comments:

> I am fortunate that I am able to be a full time parent … If I was to return to paid employment I don't believe I would have a marriage. – Respondent 2
> I had to retrain as a childminder. If I hadn't done this I have no idea how I would have got to all the different appointments needed to provide him [child with DCD] with support. – Respondent 49
> I went from earning £50 k [per annum] as a solicitor to £8 k [per annum] as a teaching assistant so I can support him [child with DCD] and attend appointments with him. – Respondent 230
> I work pt [part-time] from home for our own company and can work when I want … I have not returned to ft [full-time] or pt [part-time] work outside of the home because of the demands of looking after my son [with DCD]. – Respondent 348

Family support networks

Two-thirds of respondents said their support networks, both with friends and family, were limited to one or two people. Nearly one-fifth had no family support network (18.8%) while 12.4% had no friends support network. Likewise, more respondents had an extensive support network of friends (22.0%) than of family (17.2%). A lack of family support was also occasionally noted in the comments:

> Some days it can feel so lonely when even your family don't understand his [child with DCD] challenges and judge. – Respondent 411

Sibling well-being

Having a child with DCD had a knock-on effect not only on parents but also on siblings. Of those respondents with more than one child, 87.0% stated their child's DCD had an impact on their other children. When details were given, other children were predominantly affected by receiving less parental time and/or attention than their sibling with DCD, which in some cases caused jealousy between siblings; being unable to do activities they enjoyed but their sibling with DCD was unable or unwilling to do; being embarrassed, frustrated and/or upset by their sibling's DCD, particularly when in the presence of their own peers; and/or being worried for their sibling with DCD.

Family activities

Having a child with DCD impacted generally on family activities. Only 1.6% of respondents stated they never changed their family activities as a result of their child's DCD; 38.0% always or often changed their family activities. Only 8.0% of respondents never found their child's DCD limited family activities, holidays, meetings with friends and/or meetings with family; 34.2% found this happened always or often.

Discussion

Despite previous work in other commonly co-occurring conditions such as ASD, where mothers have reported lower individual and family QOL [38], this paper represents the first UK study assessing the effect of DCD on parental and family QOL. The results demonstrate a significant emotional impact, not only on the parents of a child with DCD but, in many cases, on the whole family. This includes limiting the family's choices of activity and their ability to participate socially. Family and parental emotional well-being appear to be particularly badly affected by childhood DCD, whereas parental physical health, family physical and material well-being, family interaction and parenting are predominantly unaffected.

It is possible that the cohort was potentially able to have more choices over their work settings as nearly two-thirds of respondents reported having had some form of university education and thus family incomes were likely to have been high. Change to working status was frequently reported and included changing careers (with some parents losing significant income), opting for flexible or part-time work, and in some cases choosing to stop working all together. Similar findings have been shown in UK parents of children with ASD [39, 40]. The effect of DCD on parents' work life was modulated by parental gender: female respondents were at least five times more likely to have reduced their working hours or ceased working than their partners. Similar effects on maternal labour force participation have been observed in two-parent families of children with chronic illness [41] and reflect national [42] and worldwide [43] gender inequalities in unpaid care work. This is relevant as there are recognised links between low-quality employment and quality of life [44]. However, this is a bidirectional relationship. It is difficult to determine whether changes in employment are contributing to, or a result of, parental psychological status and/or the demands of supporting their child.

With growing evidence of the long-term physical and psychological impact of DCD, it becomes ever more important that services and appropriate support are available to parents and their offspring at all ages and stages of life, in a similar

way that provision for Diabetics is not considered a childhood service and does not end once the young person moves into adulthood. One in four respondents reported being dissatisfied with the support given to their family member(s) which was especially poor where children were older and approached adulthood. However, it must be noted that two-thirds were satisfied or very satisfied with this aspect of their family's QOL. Some of this may be explained by respondents' high level of satisfaction with the support their family member(s) with disability received to accomplish goals at home. It is possible, however, that this represents support provided by the family or indeed the respondent themselves rather than external support, a hypothesis supported by the fact that far fewer respondents were satisfied or very satisfied with the service providers who helped their family member(s) with disabilities. This could explain why family QOL was overall reasonable but family and respondent emotional well-being were poor.

The observation that nearly three-quarters of respondents met a RAND-12-derived cut-off for depression demonstrates that there is a clear need for greater awareness of DCD by health professionals and recognition of the impact this can have on the whole family. Lack of recognition and support from friends and family may reinforce a sense of isolation. Children with DCD have been noted to experience greater social isolation and less opportunity for social engagement and, as a consequence, have fewer friends [45]. It could be speculated that, with two-thirds of respondents saying their support networks, including friends and family, were limited to one or two people, an impact of their child having fewer friends may result in the parents consequently associating with a smaller group of parents and this resulting in having a smaller support network than parents of typically developing children. It is also possible that respondents lost potential support networks when their child's DCD meant they had to work part-time, change jobs and/or stop working. It is interesting to note that respondents' preference-based health score was similar to or lower than population norms for individuals with chronic health conditions including arthritis, cancer, diabetes and epilepsy [37]. Healthcare professionals working in hospitals and the community need to consider well-being at a whole-family level: if support is provided to one family member this may need to be broadened to other family members who may be equally or more affected. In particular, parental depression may impact on parents' relationships with their child and their ability to support their child practically and psychologically. Preventative techniques such as mindfulness and cognitive behavioural therapy could be considered; however, further research is necessary to determine whether adaptations are required to ensure these techniques are efficacious in this cohort.

The burden of having a child with DCD in the family was reported to impact siblings in most cases, with them often receiving less parental time and/or attention than the sibling with DCD. More than a third of respondents also had to frequently change family activities because of their child with DCD. It is not surprising that respondents reported their other children felt a range of emotions, including jealousy, embarrassment, frustration and concern for their sibling with DCD.

Conclusions

While the social and emotional cost of co-occurring conditions such as ADHD and ASD on the family has previously been recognised, this is the first time that this has been considered in DCD. Health and educational professionals working in the field of neurodevelopmental disorders are increasingly taking a dimensional view of these conditions. It is important that the potential presence and impact of DCD are considered as a standard part of the assessment process in both child and adult services. Additionally, services must ensure the additional psychosocial challenges associated with DCD are fully considered to ensure that they provide person-centred interventions. Raising awareness of DCD in teacher training and among health professionals is also essential so knowledge of and confidence in providing appropriate support can be achieved.

Having a child with DCD has a considerable impact on families' emotional, social and financial well-being. This needs to be recognised by healthcare and other professionals; otherwise, services and support may not be appropriately targeted and the negative sequelae of DCD may ripple beyond the individual with costly social and economic consequences. There is clear need for cross-departmental working, for example, between child occupational therapy to address the primary symptoms of DCD, child and adolescent psychiatry to address the additional symptoms of DCD and adult psychiatry to address the potential effects of a child's DCD on parental emotional well-being. In addition, interdisciplinary working, for example, between health and education, is necessary to ensure children and their families receive holistic support.

Future work is needed to examine this in greater detail to understand the nature of the employment and social limitations of parents of children with DCD and to gain a more in-depth understanding of the siblings' level of mental health.

Limitations of the study

This study employed a convenience sampling method and focused on parents/guardians of children aged 6–18 years. However, the study did not assess co-occurring neurodevelopmental disorders other than ASD and did not collect

information regarding respondents' ethnicity or geographical location within the UK. Additionally, the convenience sampling method resulted in a biased sample: respondents predominantly had a high level of education and were predominantly female, married and between 40 and 45 years old. Respondents' education level is particularly relevant as parents with a higher level of education are more likely to be able to adapt their employment in order to support their child with DCD. These individuals may also be in a better position to obtain professional help for themselves and their families, for example, through greater ability to advocate for themselves and their family due to their own better education and/or through their potentially greater ability to afford private healthcare and education.

A replication study containing a cross-section of respondents and recording all co-occurrence among children with DCD may be helpful to determine if there are greater differences in lower socioeconomic status or particular ethnic groups and whether low family or parental QOL are more common when children with DCD have particular combinations of neurodevelopmental disorders.

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Compliance with ethical standards

Conflict of interest MAMC and PKL declare they have no potential conflicts of interest to disclose. AK is the parent of an adult with NDDs, the chair of Movement Matters UK, patron of the Dyspraxia Association of New Zealand, Advisor to the Dyspraxia Association in the Republic of Ireland, Medical Advisor to the Dyspraxia Foundation in the UK and is on the Hidden Impairment National Group for the Department for Work and Pensions, UK.

Ethical approval This study was approved by the University of South Wales Faculty of Life Sciences and Education Low Risk Ethics Committee and has been performed in accordance with the ethical standards of the institution and the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

Informed consent Informed consent was obtained from all individual participants included in the study.

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