CBT for Anxiety Related to Parenting a Child with a Life-Limiting Neuromuscular Condition: A Single Case Study

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Abstract
Caring for a child with a neuromuscular condition such as Duchenne muscular dystrophy (DMD) presents many challenges, including managing the emotional impact of the diagnosis, managing extended periods of profound uncertainty, navigating the complexities of the healthcare system, managing the child's physical symptoms, and supporting their emotional needs. Although it is encouraging that there is a growing body of research seeking to better understand the medical and treatment needs of those with DMD, the psychosocial needs of individuals and their families have traditionally been considered as ancillary to the child's physical health needs. Consequently, there is limited research investigating the psychological wellbeing of those with DMD, and even less is known about the psychological wellbeing and needs of caregivers, who play a critical role in supporting their child. Caregivers experience multiple stressors and often encounter caring burden and high prevalence rates of anxiety and depression. This paper aims to explore the use of cognitive behavioral therapy (CBT) for comorbid anxiety and low mood in a parent of a child with DMD using a single case design. Results suggest that in the context of multiple stressors and significant life events, CBT was effective in improving mood and reducing symptoms of anxiety. This case highlights the value in offering support to parents of children with DMD and may have clinical implications for other neuromuscular and life-limiting conditions.

Keywords
CBT, anxiety, parent, neuromuscular condition, Duchene's muscular dystrophy

1 Theoretical and Research Basis for Treatment
Muscular dystrophy (MD) is an umbrella term for a heterogeneous group of inherited disorders characterized by progressive muscular weakness (Jacques et al., 2019). The spectrum of dystrophies include Duchenne, Becker, Myotonic, Congenital, Emery-Dreifuss, Facioscapulohumeral, Limb-girdle, Distal, and Oculopharyngeal (NICHD, 2016). Duchenne muscular dystrophy (DMD) is the most common and severe form (Sinha et al., 2017) and is classified as a life-limiting illness. It is a genetically determined, rapidly progressive degenerative disease (Shieh, 2018) and

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has an incidence rate of 1:3,500 male births and 1:50,000,000 female births (Nozoe et al., 2016). DMD is caused by genetic mutations on the “X” chromosome that inhibit production of dystrophin, which is a vital muscle protein (Mohammed et al., 2018). Consequently, muscles weaken and waste over time, resulting in increasing and severe disability (Stein & Cassell, 2016). Inevitable cardiac and respiratory complications result in early mortality (Ryder et al., 2017); life expectancy is currently <30 years, with a median age of survival in the mid-20s (Paramsothy et al., 2018). However, as a result of advances in the management of DMD, age of survival is increasing (Bettolo et al., 2015).

Families have to contend with the reality that there is no curative treatment although progression can be slowed with corticosteroids, but these have significant adverse effects (Matthews et al., 2016). Receiving a diagnosis of any life-limiting illness is an incredibly challenging and stressful time for patients and their families. It is a time of profound and pervasive uncertainty, coupled with feelings of perceived loss, grief, shock and overwhelm (Bally et al., 2018). Families may experience hopelessness when faced with a diagnosis of an incurable genetic disease and the impact on families is often unrecognized and underestimated (Golics et al., 2013).

In DMD, onset of symptoms typically occurs by the child’s fifth birthday (Ciafaloni et al., 2018). In addition to managing the emotional impact of the diagnosis, families are required to share their lives with a multitude of professionals (Chabroi & Mayer, 2015), yet many families encounter problematic experiences of service provision (Smith et al., 2015), with caregivers needing to repeatedly prove their evolving needs to professionals. Many parents are required to take time off work and travel great distances to attend multiple and frequent health appointments. This can increase stress, take its toll on quality of life (Uttley et al., 2018), and impact on relationships and family finances. As Schreiber-Katz et al. (2014) explain, financial costs increase with disease progression and costs can vary from paying for specialist equipment to funding large-scale house adaptations.

The life-limiting nature of DMD strongly affects both patients and parents, who are required to navigate numerous challenges, which may include: fatigue, which can be acute (e.g., following exertion) or chronic (El-Aloul & Campbell, 2017); pain, which is often linked to muscle cramps and joint pain (Jacques et al., 2019); discomfort and sleep disturbance from wearing night splints to manage limb contractures (Apkon et al., 2018); constipation, as a result of limited physical activity (Kraus et al., 2016); loss of ambulation, which occurs by 12 years (Gissy et al., 2017); and late symptoms, which may include difficulties with speech and swallowing (dysphagia) (Toussaint et al., 2016). Approximately 26% of individuals with DMD have an intellectual disability while prevalence rates of ADHD are around 32% (Colvin et al., 2018), and co-occurrence of Autism spectrum disorder (ASD) was found in 21% of cases by Ricotti et al. (2016). In addition to the potential physical and cognitive challenges associated with DMD, there are diverse emotional and behavioral difficulties (Lee et al., 2018), with one in four children estimated to experience internalizing problems (Colombo et al., 2017). There are also social challenges, with some young people encountering bullying and social isolation that impact on wellbeing (Odinaka & Nwolisa, 2014).

Given the rapidly progressive nature of DMD, young people and their caregivers are required to adapt and manage emotional responses to deteriorating health. Bendixen and Houtrow (2017) identified parental concern about their child’s wellbeing, but Beacham and Deatrick (2015) suggest that non-disease specific issues, such as emotional wellbeing, are often overlooked. Times of transition can be especially challenging, particularly when young people become increasingly more dependent upon care (Pangalila et al., 2012). This commonly happens during adolescence when disease progression occurs at the time when most young people are maturing and seeking independence and self-determination (Abbott et al., 2012). It can be particularly difficult for young people when they require increasing personal care (Yamaguchi et al., 2019), and this can result in a high level of caregiver demand (Sullivan & Miller, 2015) that can impact on family functioning and wellbeing.
Various factors predict how families respond to stressful challenges associated with managing DMD. For example, high stress is predicted by low social support, low resiliency and low income (Kenneson & Bobo, 2010). Gocheva et al. (2019) indicate that very high levels of parenting stress is five times more common among families with a child with DMD than the general population, with chronic stress leaving individuals with severely depleted resources (Clifton & Feeny, 2014). Meanwhile, Matud et al. (2019) suggest that gender is an important determinant of health, with elevated stress identified amongst mothers of children with DMD (Nereo et al., 2003). Cultural norms and societal expectation for women to be selfless and put others first is believed to place a disproportionate burden of care on women (Perrin et al., 2015). Unsurprisingly, parental burden is associated with anxiety and coping skills (Pangalila et al., 2012). 70% of caregivers experience anxiety and depression (Landfelt et al., 2016) and parents of children with DMD are more likely to experience a major depressive episode and have significantly lower self-esteem than that of a national control group (Abi-Daoud et al., 2004).

Although there is recognition in the predominantly medical literature that DMD causes significant emotional and caring burden on caregivers (Peay et al., 2015), with high levels of unmet psychosocial needs amongst mothers in particular (Peay et al., 2018), there is an absence of psychological literature addressing recommended interventions for those caring for individuals with DMD. Consequently, when referrals are made for psychology support, clinicians do not have specific guidance on how best to treat the psychological distress of caregivers of children with neuromuscular conditions. There is, however, meta-analytic support for the efficacy of CBT in reducing symptoms in young people with chronic illnesses when parents are involved (Law et al., 2019), with CBT found to be efficacious in treating anxiety and depression in children with chronic physical illnesses (Bennett et al., 2015). Although families experiencing DMD were not included in these studies, there are transdiagnostic parallels, for example, distress and anxiety management. It therefore seems logical to consider CBT as an intervention, particularly as Law et al. (2019) conclude that CBT may improve parenting behavior and therapy may improve parents’ mental health in the context of stressful life experiences. This paper therefore seeks to meet the gap in literature and aims to explore the utility in using cognitive behavioral therapy (CBT) to reduce the psychological distress of a mother of a child with DMD. This study employed a single-case \((n = 1)\) design, with outcome measures taken pre, mid- and post-intervention.

2 Case Introduction

This case study reports the case of “Sarah” (pseudonym), a White British female in her 40s who lives with her husband, “Jack,” and adolescent son, “Sam,” who has DMD. Sarah was a competent and capable individual, who had worked hard to achieve personal and professional success. Sam’s community nurse referred Sarah for therapy with a trainee clinical psychologist for help with managing anxiety about Sam’s condition.

3 Presenting Complaints

Sarah presented with anxiety that was significantly impacting on her wellbeing. Sarah described rumination about Sam’s deteriorating condition, specific worries about the “what ifs?” of Sam’s future, low mood, overwhelm, difficulty sleeping (lying awake at night worrying about Sam’s prognosis), and lapses in concentration when trying to work, where periods of time were lost when anxious thinking took over. Sarah explained that the busy-ness of her life meant she never had time to “switch-off and relax,” which she said was impacting on her relationships. Sarah attributed low mood and increased worry, stress and caregiver demand to Sam’s requirement for more support as he was losing the independence he had previously experienced. In the months before therapy commenced, Sarah’s caregiver role had changed, and she, Sam and Jack were
trying to adjust to a “new normal.” Although Jack was able to help, Sam always asked for Sarah when he required assistance. Sarah described specific worry about Sam’s loss of ambulation, and the physical and emotional effort in supporting Sam with all aspects of personal care (including toileting and showering). Sarah also identified needing to find more time for liaising with school to ensure Sam’s personal care needs could be met there, coordinating other professionals to ensure that Sam had the assistive technology he required (such as a hoist), and providing the emotional support Sam needed as he tried to adjust to his changing capabilities.

4 History
Sarah and Jack met when they were in secondary school. Prior to this, Sarah had encountered bullying but had a small group of close friends. As a strategy to avoid the bullies, Sarah focused her energy on academic work and extra-curricular activities and achieved high standards in both. Sarah’s parents, who valued hard work and success, encouraged high achievement and financial independence. Sarah and Jack had both worked hard to establish and grow good businesses in their respective professions. Although Sarah had previously experienced anxiety, particularly in relation to Sam’s diagnosis, she had not received a formal diagnosis of any mental health condition from a medical practitioner. Sarah had tried counseling in the past but had not previously worked with a psychologist. Sarah encountered numerous challenges in navigating Sam’s neuromuscular condition and life for Sarah was very busy. She was required to juggle multiple demands, including: managing Sam’s changing needs as he required more assistance with daily tasks; managing full-time work, which was especially difficult during the school holidays when Sarah wanted to spend time with Sam but still needed to work; providing emotional support to Sam and to both of her parents, who had been diagnosed with life-threatening illnesses; managing the family home; and trying to find time for family, friends, and Jack. Although the stressors of balancing home and work responsibilities with ageing and sick parents are common among many parents of Sarah’s age, parents of young people with DMD and other neurodegenerative conditions are tasked with additional responsibilities as their child becomes less independent over time.

5 Assessment
A structured CBT assessment and formulation was completed over three sessions. During this time, risk to self and others was assessed. Risk was considered to be low for the duration of therapy. The assessment identified the following specific worries about: work and how to manage without more hours in the day; Sam’s health, parents’ health; how the family will cope; the impact this may have on Sarah’s health, how to stay healthy when there is no time for exercise; and uncertainty about the future. The assessment enabled Sarah to identify the following goals: (i) To have a space to talk in order to understand anxiety, and (ii) To identify ways of managing anxiety in order to “cope better.” A strengths approach was employed during the assessment as it promotes resilience and alleviates distress (Kuyken et al., 2008). There were a number of factors that helped Sarah to cope with the significant stress she was experiencing. Sarah had a good relationship with her partner, Jack, whom she described as being a good listener and her best friend. Sarah was also close with both her parents and her in-laws. As Sarah and Jack were both self-employed, they benefitted from work flexibility, when required to attend Sam’s medical appointments. Having good relationships and work flexibility are considered to be protective factors (Whitton et al., 2018). Sarah also possessed a number of qualities that helped her to manage stressful situations, including resilience and a willingness to try techniques that may help. Sarah was open to psychology support and engaged well in the process.
Measures

In accordance with the requirements of the Community Psychology Service, the following measures were used pre-, mid- and post-intervention to assess the impact of therapy:

The Generalised Anxiety Disorder (GAD-7) scale was administered pre-, mid-, and post-intervention to assess Sarah’s symptoms of anxiety. The GAD-7 is considered a reliable and valid measure of anxiety (Lowe et al., 2008), with good criterion and construct validity (Spitzer et al., 2006) and good internal (α = .93) and retest reliability (0.83) (Mills et al., 2014; Spitzer et al., 2006). According to NHS (2018b) IAPT guidance, clients meet anxiety caseness with scores ≥ 8, although there are cut off scores of 5 (mild anxiety), 10 (moderate anxiety) and 15 (severe anxiety).

The Patient Health Questionnaire (PHQ-9) was administered pre-, mid-, and post-intervention to assess Sarah’s mood. The PHQ-9 is considered to be a reliable and valid measure of depression (α = .89) (Kroenke et al., 2001), with high test-retest reliability (0.94) (Zuithoff et al., 2010), and good construct validity (Martin et al., 2005). Clients meet caseness for depression with scores ≥ 10 (NHS, 2018a).

6 Case Conceptualization

CBT was considered to be the most suitable intervention as evidence-based NICE guidance recommends CBT for treating anxiety (NICE, 2011a), depression (NICE, 2009) and comorbid anxiety and low mood (NICE, 2011b) in adults. Although there is limited literature regarding the therapeutic treatment of parents of children with neuromuscular conditions, CBT was believed to be a useful intervention for managing the psychological distress of caregivers, given that anxiety and depression are common experiences in this population (Landfelt et al., 2016). Moreover, CBT was found to be efficacious in treating anxiety and depression in parents of children with disabilities (Anclair & Hiltunen, 2014).

A longitudinal case formulation was deemed the most suitable approach as it permitted exploration of Sarah’s current difficulties whilst also attending to the developmental origins of her anxiety (Dudley & Kuyken, 2014). The longitudinal formulation utilized in this case was an adapted version of Beck et al.’s (1979) model (refer to Figure 1, below). Although Beck et al. originally developed their conceptual framework for depression, it was employed in this case as Sarah also identified low mood in the context of anxiety. As Beck et al. (1979) recognized, “there is no standard format that can be applied systematically to all clients to obtain the crucial data” required (p. 29), and, in this case, a tailored longitudinal formulation was deemed a better fit than a disorder specific model (Dudley et al., 2010), particularly as Sarah’s assessment indicated caseness for both low mood and anxiety.

As Sarah indicated a preference to make sense of her anxiety, formulation began with the development of a hot cross bun (Padesky & Mooney, 1990), which is the colloquial term for a cross-sectional formulation depicting the intersections between thoughts, feelings, physical sensations, and behavior in a given situation (as depicted at the bottom of Figure 1). This helped provide a shared understanding of Sarah’s anxiety. The triggers (e.g., uncertainty about Sam’s condition) sparked thoughts about not being able to cope, with worse case scenarios happening (i.e., Sam dying), which prompted behaviors such as “pushing people away,” “being a pain to live with,” “keeping everything in” or verbally “taking out frustrations” on Jack. In turn, Sarah described the following physical symptoms: a racing heart, tearfulness, fatigue, a tight chest, and panic that was most prominent at night when there were fewer distractions. Sarah identified feelings of sadness, anger, anxiety, overwhelm, and fear, which she tried to avoid by keeping busy. Through collaborative discussion, Sarah identified the critical incident that perpetuated uncertainty as Sam’s diagnosis of Duchene’s Muscular Dystrophy (DMD).
Once formulation of Sarah’s current difficulties had been explored, attention turned to her early experiences (e.g., parental anxiety and risk aversion, and school bullying), core beliefs (e.g., “I am responsible,” “I am not worthy” and “I am a rule-follower”) and rules/assumptions to live by (including “I must be hard-working,” “I must put others first” and “It is important to keep going”). Sarah recognized “working hard” as her primary coping strategy, as it enabled her to manage the various competing demands on her time, it gave a sense of achievement.
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(which was valued within her family) and it distracted her from the sadness of Sam’s progressive deterioration. The formulation enabled Sarah to see that although hard work was helpful, it was also contributing to reduced emotional and physical wellbeing, as there was no time for her to “be,” to rest and to engage in self-care. The longitudinal formulation fostered collaborative work (Manceil et al., 2012) and facilitated Sarah’s comprehension of precipitating and maintaining influences. It was hypothesized that CBT would be an effective intervention, with reductions in anxiety and depression as witnessed in Sarah’s GAD-7 and PHQ-9 scores.

7. Course of Treatment and Assessment of Progress

Following the three assessment sessions, Sarah engaged in nine 1-hr CBT treatment sessions (outlined in Table 1). This was informed by protocol within the service, which was to offer six sessions, then review, and offer further blocks of three sessions with a review as required. Sarah presented with symptoms of anxiety and depression but did not have a formal diagnosis of either condition from a qualified medic, as required in the UK. NICE (2011b) guidance was therefore followed and a collaborative discussion was had regarding choice of intervention and which symptoms to treat first. It was agreed that the intervention would first focus on anxiety using CBT. Each session comprised a check-in, review of homework, agenda setting, session content that included Socratic questioning and guided discovery (Beck, 1995; Padesky, 1993), summarizing, and setting homework, which provided an opportunity to consolidate skills (Freeman, 2007). The intervention remained client-centered, which strengthened the therapeutic alliance and is considered predictive of outcome (Horvath, 2001).

Following socialization to the model (Padesky & Mooney, 1990), the intervention involved:

- Session 1: Psychoeducation, which is effective in reducing symptoms of psychological distress (Donker et al., 2009). This involved discussing wellbeing, identifying all factors that fill Sarah’s “stress bucket” (Carver et al., 1989), such as worry about family members, health, work, anxiety about the future, competing demands on time etc. and identifying coping strategies, such as using the STOPP technique (Vivyan, 2011a), which involves Stopping and taking a step back, Taking a breath, Observing thoughts and feelings, Pulling back and taking perspective, and Practicing what works.

| Session number | Summary of session content                      |
|----------------|-------------------------------------------------|
| 1              | Psychoeducation—wellbeing, stress bucket, coping strategies, STOPP |
| 2              | Managing anxiety, responsibility pie, breathing exercise, self-care |
| 3              | Problem-solving support issues, coping strategies |
| 4              | Psychoeducation—mood fluctuation, managing tiredness, relationships, coping |
| 5              | Distress tolerance, cognitive restructuring, coping skills |
| 6              | Magic wand, wellbeing, sleep hygiene, self-care |
| 7              | Worry time, mood management, “shoulds”—compassionate response |
| 8              | Review core beliefs, rules for living link to early experiences |
| 9              | Ending, review of therapy, planning for future |

| Table 1. Overview of CBT for Anxiety Intervention. |
thinking (e.g., incidents that highlight the uncertainty of Sam’s condition). Also trying breathing and grounding exercises (Ma et al., 2017; Kennerley, 2000) such as balloon breathing (i.e., imagining there is a balloon in your abdomen that needs fully inflating and deflating with each breath) and using the five senses to attend to things in the immediate environment that can be seen, heard, touched etc. and identify self-care activities, such as gardening, going for a run, and seeing friends, as self-care is often lacking in families of children with life-limiting illnesses (Koch & Jones, 2018).

- Session 3: Problem-solving support issues (Chen et al., 2006), including identifying individuals who could be asked to provide support for Sarah and care for Sam, and identifying previous coping strategies (such as distraction and working hard) to appraise the benefits and consequences of coping strategies and identify new helpful coping strategies.

- Session 4: Psychoeducation to recognize mood fluctuations (as documented in a mood diary), managing tiredness (by recognizing periods in the day where rest would be beneficial, focusing on relationships and prioritizing own needs for connection over work), and exploring possible coping skills (such as practical tasks including delegating work to Sarah’s part-time employee).

- Session 5: Distress tolerance in managing uncertainty (including focusing on things that can be changed and using coping techniques to manage uncertainty, and cognitive restructuring, which is an evidence-based intervention of low mood and anxiety (Clark, 2013) to challenge unhelpful cognitions and core beliefs.

- Session 6: Magic wand (i.e., to identify what life would look like if a magic wand improved things for Sarah), sleep hygiene (to attend to behaviors that help and those that hinder good sleep, for example, drinking alcohol, reading on electronic devices before bed), and self-care (identifying the value in self-care as a necessity rather than a luxury, and completing behavioral experiments to see the impact of self-care on work productivity). Also, recognizing the signs when self-care is not happening, for example, increased work commitments, dips in mood, becoming irritable and experiencing lapses in concentration.

- Session 7: Having allocated worry time, (Hoyer et al., 2009) to reduce the amount of time spent worrying to give Sarah more control over her worries and identifying ways to compassionately responding to “shoulds” (Homan & Sirios, 2017) and Sarah’s inner critic.

- Session 8: Reviewing core beliefs and rules for living (such as the importance of being hard-working to make others proud, putting other people’s needs first and obeying rules, which are indicators of being a good person, and understanding how these link to early experiences. Identifying positive self-talk and coping statements (Vivyan, 2011b), such as “Stop, breathe, I can do this” and “I can use my coping skills and get through this.”

- Session 9: Ending session to review therapy: namely reviewing what helped, what would be good to continue, and planning for the future in order to manage as Sam’s condition changes.

- Homework was included to provide opportunities to practice coping strategies (Kazantzis et al., 2017).

At the start of the intervention, Sarah’s scores on the GAD-7 (score = 8) and PHQ-9 (score = 12) were both considered to be moderately severe (Spitzer et al., 2006; Kroenke et al., 2001) and both met clinical caseness, as specified by NHS (2018a, 2018b). Thus, indicating that Sarah’s symptoms of anxiety and low mood warranted clinical intervention. Although it was decided that the intervention would initially focus on anxiety, Sarah’s depression scores had reduced below the clinical threshold by the middle of the intervention (refer to Figure 2) before implementing any specific depression intervention. During a review session, Sarah identified that the skills she had learnt to manage anxiety had a positive effect on her mood, subsequently stating that she did not feel the need for further therapeutic intervention in relation to managing her mood.
By the end of the intervention, Sarah’s scores had reduced below the clinical threshold on both the GAD-7 and PHQ-9 (scores of 5 on each measure), which are categorized as mild (Spitzer et al., 2006). The reduction in Sarah’s PHQ-9 scores (i.e., ≥6) was considered to be a reliable change (NHS, 2018b). Meanwhile, the reduction in GAD-7 scores from 8 to 5 just fell short of the reliable change index (i.e., ≥4) (NHS, 2018b). According to the NHS (2018b) IAPT guidance, Sarah could not be considered as “recovered” as reliable change needs to be established on both measures for recovery to have occurred. Despite this, by the end of the intervention Sarah described feeling really good about the positive changes she had made; she felt that both of the goals identified at assessment had been achieved. Sarah reported greater insight into her anxiety and greater awareness of the role of past experiences and core beliefs in shaping her anxiety response. When discussing the changes that Sarah had noticed, she identified:

(i) Improved relationships: which resulted from prioritizing time with Jack, Sam and wider family members and working less, which actually resulted in improved work efficiency, motivation and productivity. Sarah noticed she was re-connecting with others to engage in previously enjoyable activities, including running and socializing with friends. (Reviewing core beliefs and understanding rules for living helped Sarah to initiate these changes in her life).

(ii) Improved wellbeing: Sarah noticed she was no longer experiencing unmanageable anxiety, she said she was worrying less what others thought, and she noticed the benefits of being more active—having quadrupled her daily step count. Sarah identified that her wellbeing was improved as a result of being kinder to herself, thinking more about what she needed instead of the “shoulds” that contributed to feeling overwhelmed. (This was achieved by responding more compassionately to her inner critic).

(iii) Improved communication: Sarah noticed she was more able to ask others for support when needed, rather than struggling to do everything by herself. (This was facilitated by the behavioral experiments to ask others for support).

Figure 2. Graph of Sarah’s pre-, mid- and post-intervention GAD-7 and PHQ-9 scores.
(iv) **Improved self-care**: which involved acceptance from Sarah that it was not selfish to consider her own needs, engaging in more regular self-care, including reading fiction and going for lunch or on outings with Jack. (Recognizing the importance of self-care was enhanced by psychoeducation and understanding the stress bucket).

(v) **Improved resilience**: Sarah observed that she was better able to cope with whatever the future holds as a result of practicing the coping strategies discussed in sessions. Sarah anticipated her future coping ability as 8/10 despite uncertain times ahead with Sam and Sarah’s parents’ illnesses.

Sarah confirmed in the final session that she did not require any further psychological support.

### 8 Complicating Factors

In this study, it is not clear why there were greater reductions in PHQ-9 scores with reliable change achieved for depression but not for anxiety, particularly when the intervention focused on anxiety. Other systemic factors outside the therapeutic intervention may have contributed to therapeutic outcomes. For example, during the intervention, Sam had his first successful stay at a children’s hospice, which provided Sarah and Jack with a much-needed weekend away together. Consequently, Sarah reported an improvement in her mood.

This case is, perhaps, limited by the absence of weekly outcome measures; without which it is not possible to know whether the final PHQ-9 and GAD-7 scores were an accurate representation of Sarah’s mood and anxiety, or whether scores were impacted by transient idiosyncratic factors (such as improved sleep) or wider systemic factors (such as increased external support for Sam). On reflection, idiosyncratic measures could have been employed to assess fluctuations in anxiety and mood. This case would also have benefitted from the inclusion of measures of parenting stress, such as Berry and Jones’ (1995) Parental Stress Scale, in addition to pre-assessment outcome measures being taken more than once in order to establish a stable baseline.

### 9 Access and Barriers to Care

Sarah’s access to care was facilitated by the availability of service provision in the region where she lived. In this service, psychologists are embedded in the community nursing team and all parents are eligible to access psychological support if referred by one of the community nurses involved in the child’s care. Other services may not have the resources to offer this support and, as seen in some regions, parents may face lengthy waits to access psychological therapies, and therefore may not be able to access the care at the time they most need it. Access to care was also greatly facilitated by sessions being home-based, to address accessibility issues (Maxfield & Segal, 2008) that would have prevented Sarah from receiving support. Sarah valued having home-visits and appreciated having a protected space in the midst of juggling the multiple demands of full-time work and caring for Sam. Although useful in this case, in-home therapy may be unmanageable for many services.

Sarah was referred for therapy by a nurse in the community team rather than her own family doctor, which created a barrier in accessing information about Sarah’s medical history and previous medical management that could, potentially, have been relevant to her treatment. In this case, the GAD-7 and PHQ-9 measures were completed as Sarah was referred to a psychologist within the multi-disciplinary team. Mental health screening is not routinely completed by other professionals and anxiety and depression would not necessarily be picked up if other services do not have psychologists within the team, which could be a barrier to care. It was not a requirement of the community psychology service to contact professionals outside the service, and, at the start of the intervention, Sarah indicated a preference not to inform her family doctor. She did, however,
give consent to a summary letter being sent to her doctor at the end of therapy. As doctors and community services in the UK often use different systems for recording patient data, difficulties in sharing information is a challenge that is not unique to this case.

10 Follow-Up

The clinician left the service at the end of the therapeutic work with Sarah and was not able to follow-up on her progress. With a lack of follow-up data, long-term change could not be established; it would have been beneficial to establish the stability of change, which would have further increased study validity.

11 Treatment Implications of the Case

This case study sought to establish whether CBT would be effective in treating anxiety and low mood in a parent of a child with DMD. A longitudinal formulation based on Beck et al.’s (1979) work permitted insight into Sarah’s current difficulties in the context of their developmental origins (Dudley & Kuyken, 2014), which was helpful in understanding the unique factors that impact on the wellbeing of caregivers of children with DMD. As evidenced in this case study, the stress of parenting a child with a life-limiting condition is unimaginably difficult to manage, as caregivers cope with the knowledge that their child has a reduced life expectancy. It was no wonder that Sarah was experiencing feelings of overwhelm and anxiety, including both how to manage in the present along with anticipatory anxiety about future uncertainty (Bally et al., 2018).

As a competent and capable individual who had past experience of academic and professional success, Sarah had heightened performance expectations (Poduval & Poduval, 2009) across both her work and caring responsibilities. Having previously adapted the family home to make it accessible for Sam, Sarah understood the high financial costs of having a child with DMD (Flores et al., 2020). Consequently, this motivated Sarah to work even harder in order to ensure financial security. This appeared to be compounded by hard work being a highly valued attribute in Sarah’s family. However, as Sam’s condition progressed, Sarah was no longer able to consistently maintain high expectations of herself and juggle multiple competing demands without support from others. By attempting to work even harder to meet work and caring demands, Sarah noticed she was becoming increasingly more unproductive with lapses in concentration, and was becoming more anxious and tearful. These stressors could have constituted barriers to treatment, which is important to consider as these can result in disengagement (Mian et al., 2020). For example, fatigue, poor concentration, unmanageable demands on Sarah’s time, and work pressures, coupled with high-expectations, could have impacted on Sarah’s ability to engage in CBT. However, Sarah’s readiness for change, motivation to improve her wellbeing, and commitment to engage both in the sessions and with the homework meant that CBT was an appropriate intervention. The structure of the CBT sessions, the space to challenge unhelpful cognitions and the homework opportunities to complete behavioral experiments were helpful for Sarah.

Sarah’s wellbeing was understandably impacted by the stage of transition that she and Sam encountered during the course of therapy; Sam had reached the period in adolescence when ambulation had deteriorated (Gissy et al., 2017), and he required more personal care form Sarah. As suggested in the literature, this transitional stage was challenging (Pangalila et al., 2012), as Sarah was required to find even more time in the day to learn how to use new assistive technology, which took repeated attempts and additional support form an occupational therapist to master. Sarah noticed that Sam required more emotional support during this time, as he adapted to having reduced physical ability, which impacted on Sarah and fed her worst “what if . . .?” fears. Sarah recognized that keeping busy during this time of change was a protective strategy but, as
recognized by Verberne et al. (2019), suppressing emotions left Sarah feeling exhausted, unable to concentrate and anxious, particularly at night when the distractions of work and caring for Sam were removed. It was not until Sarah recognized this avoidance strategy in the therapy sessions that she was able to identify self-care needs that would support her emotional wellbeing. When Sarah started to attend to her self-care needs, she noticed that her anxiety reduced. In turn, Sarah observed that her mood increased. This appeared to be a key mechanism of change (Teachman et al., 2014), and Sarah continued to notice improved wellbeing when she attended to her physical needs (through re-connecting with enjoyable exercise), social needs (through re-connecting with friends and family members) and emotional needs (through communicating more openly with Jack and others).

In conjunction with this, successful behavioral experiments enabled Sarah to test out what it would be like to seek support from others. Although Sarah was initially worried that accepting support might indicate that she was no longer competent and capable, Sarah reported improved wellbeing and strengthened relationships when others were given opportunities to help. As Clifton & Feeny (2014) highlight, augmenting social support is important in improving mood. Sarah’s self-reported mood also improved when Sam had his first independent weekend stay at the children’s hospice, where he enjoyed time with friends away from Sarah and Jack. As Hughes et al. (2019) explain, hospices provide invaluable support to families and contribute to improvements in familial quality of life. The hospice support enabled Sarah and Jack to have a much-needed weekend away together, which Sarah described as being important for their relationship and wellbeing as a couple. Together, the external support coupled with the CBT intervention appeared to have a positive impact on Sarah’s quality of life, which is complex and impacted by having a child with DMD (Uttley et al., 2018).

According to the outcome measures used in this study, there was a clinically significant reduction in depression that was sufficient enough to indicate recovery (NHS, 2018b). This finding is interesting given that the primary focus of the intervention was on anxiety, as requested by Sarah when setting her goals for therapy. It is possible that focusing on wider (transdiagnostic) interventions such as sleep hygiene, self-care, and relaxation exercises etc., had a positive impact on both anxiety and low mood. According to Sarah’s qualitative feedback, the intervention was effective in reducing anxiety, to the extent that Sarah reported not needing any further psychology input despite there being on-going uncertainty around Sam’s condition. However, if the success of the anxiety intervention was judged on the GAD-7 scores alone, reliable change was not indicated despite scores dropping below clinical cut-off. According to NHS (2018b) criteria, Sarah would not be considered to have recovered. One possible explanation is that caregivers of a child with DMD may never be free of anxiety as there are so many stressful challenges to encounter and navigate. Alternatively, one might question the utility of relying on outcome measures alone to assess the efficacy of CBT interventions (NHS, 2018a). As demonstrated in this case, Sarah perceived the intervention as being successful in reducing anxiety, improving mood, strengthening relationships and improving quality of life—factors that were not captured on the outcome measures but were, more importantly, meaningful to Sarah.

This paper highlights the need for psychological support for parents of children with DMD and related conditions, who have to navigate extraordinary challenges at different stages, from diagnosis to periods of transition as children’s needs and abilities change over time. This case demonstrates the utility in using CBT for parents of children and young people with DMD. At present, national organizations such as the Muscular Dystrophy Association in the United States and Duchenne UK offer valuable support to parents via their websites, but research focusing on the psychological needs of parents is lacking. It is hoped that this study will add to the literature and promote interest in future research into the psychological needs of parents supporting children with neuromuscular conditions so that national organizations can begin to disseminate the findings.
12 Recommendations to Clinicians and Students

In accordance with the evidence-base (NICE, 2009, 2011a, 2011b), CBT was a useful intervention in treating anxiety and low mood in this case. However, engagement in the intervention was helped by factors that are recommended to clinicians and students. These include using a flexible approach, such as offering home sessions to remove accessibility issues (Maxfield & Segal, 2008), using a tailored longitudinal formulation that accounts for the complexities in managing life while caring for a child with DMD, rather than a disorder specific model (Dudley & Kuyken, 2014), and being as person-centered as possible, which accommodated a preference for focusing on anxiety first.

Like many parents who are left psychologically depleted from the chronic stress associated with stressful life events (Clifton & Feeny, 2014), Sarah reported high levels of fatigue and difficulties in concentrating, which could have impacted on her ability to engage in CBT. Initially this was not overtly evident as Sarah presented as highly engaged and motivated to make the most of the therapy sessions, fueled by her desire to achieve the goals she had set at the start of therapy. It is recommended that clinicians are mindful of potential barriers to engagement, including either personal traits such as personal drive to achieve or those associated with the complexities of living with a family member with a life-limiting condition. It is also recommended that clinicians attend to times when anxiety or low mood are worse. In this case it was at night-time when free from the distractions of work and caring responsibilities, which left time to ruminate on worse fears about the future. Finally, it is recommended that clinicians are aware of the cultural norms for women, in particular, to place the needs of others before themselves (Perrin et al., 2015), which may conflict with the therapeutic message that time for self-care is important. In this case, psychoeducation played an important role in providing a foundation for coping strategies and, later, self-care that was a key mechanism of change (Teachman et al., 2014).

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Ethical Approval

All procedures contributing to this work comply with the Ethical Principles of Psychologists and Code of Conduct as set out by the APA.

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