Empirical Article

Young Adults and Parents' Coping With Duchenne/Becker Muscular Dystrophy: A Focus Group Study

Emerging Adulthood
2024, Vol. 0(0) 1–13

DOI: 10.1177/21676968241242154
journals.sagepub.com/home/eax
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Abstract

Duchenne and Becker muscular dystrophy (DBMD) are genetic disorders that are characterized by progressive muscle weakness. As such, individuals with DBMD may need constant assistance with medical and physical care, which is oftenE provided by their family members. An essential part of patients' medical management and their parents' care is to develop appropriate coping strategies. This study focuses on young adults in the developmental period of emerging adulthood and parents, aiming to obtain an in-depth understanding of their coping strategies with DBMD. Qualitative methodology was employed and implemented within three focus groups: one group of young adults (ages 18–23) and two groups of parents. The findings of themes related to young adults and parents coping with DBMD included negative emotions alongside positive perceptions, hope, coping with loneliness in the context of being different, and familial adjustments. Our findings revealed similarities and differences in relation to both young adults' and parents' coping strategies, referred to in this study as "adjustments". It may be advantageous to have an interdisciplinary professional team (i.e., physicians, nurses, and psychologists/social workers) intervene with young adults and parents to get a comprehensive understanding of the impact DBMD has on the multidimensional aspects of their daily functioning and the "adjustments" they employ to cope with DBMD.

Keywords

coping, Duchenne/Becker muscular dystrophy, parents, young adult

Highlights

- Young adults with DBMD and their parents experience negative emotions and feelings of being different.
- Hope, resilience, and the development of support networks serve as powerful coping mechanisms.
- Parents make significant life adjustments for their children's well-being in families coping with DBMD.
- The study showed no major differences in 'adjustments' between Becker and Duchenne diseases.

Introduction

Duchenne and Becker Muscular Dystrophy (DBMD) are genetic disorders caused by mutations in the X chromosome; Duchenne Muscular Dystrophy (DMD) is the more severe form, and Becker muscular dystrophy (BMD) is milder (Birnkrant et al., 2018). DBMD is an inherited childhood neuromuscular disorder affecting mainly boys (Bushby et al., 2010). The estimated prevalence of DBMD in Israel is 1: 3500–4000 male births (Health Ministry of Israel, 2021). DBMD is characterized by progressive muscle weakness, and affects the trunk, upper limbs, and oropharyngeal muscles, leading to conditions such as scoliosis, reduced lung function, weakness in the arms, and difficulties in feeding (Liang et al., 2019; Snow et al., 2013). As such, individuals with DBMD may require ongoing support for both basic and instrumental daily tasks (e.g., moving, dressing, eating, and toileting), as well as assistance with managing, arranging, and receiving medical care (Landfeldt et al., 2018). Over time, they often

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become more reliant on others, typically family members (Pousada et al., 2018). In addition to motor disabilities, DBMD might experience more neurodevelopmental and emotional and behavioral concerns (i.e., internalizing symptoms, autism spectrum disorder, attention-deficit hyperactivity disorder, intellectual disability, and challenges in social interaction) compared to the general population (Caspers et al., 2015; Colombo et al., 2017; Colvin et al., 2018).

The disorders demands, along with inherent uncertainty in the disorder progression, are associated with stress in individuals with DBMD (Rahbek et al., 2005; Reid & Renwick, 2001; Simon et al., 2011), and their families (de Oliveira et al., 2020; Gocheva et al., 2019; Landfeldt et al., 2018; Magliano et al., 2014; Nereo et al., 2003; Pousada et al., 2018; Webb, 2005). Specifically, family stress is linked to practical and psychological burdens and the changing nature of caregiving (Bell et al., 2019; Magliano & Politano, 2016). Further, the loss of functional independence is reported as a stressor that affects the quality of life for both individuals with DBMD and their families (Liang et al., 2019).

Within the theoretical framework by Lazarus and Folkman (1984) about the stress concept, assessment of whether the condition is perceived as threatening, damaging, or challenging, and identifying appropriate responses to it, form the foundation for the adaptive abilities of patients and caregivers. In this perspective, coping strategies are hypothesized to be part of those processes moderating the stress in individuals with DBMD and their families. Coping strategies refer to cognitive and behavioral efforts to manage (i.e., minimize, master, tolerate) internal and external demands evoked by stressors (Lazarus & Folkman, 1984). Coping might change over time according to different situations in order to be effective (Lazarus, 1993). Individuals may employ two major types of coping strategies: problem-focused and emotion-focused. *Problem-focused coping* aims to provide resources to control or solve the problem or to actively change one's perception of a stressor (e.g., engagement and positive reframing). *Emotion-focused coping* aims to mitigate emotional tension or manage feelings of distress (e.g., escape-avoidance, denial, and distraction) (Lazarus & Folkman, 1984).

Regarding DBMD, previous studies highlighted parents' perspectives on coping, such as uncertainty, hope, and parent-child interaction (e.g., Bell et al., 2019; Chen et al., 2002; Gocheva et al., 2019). Additionally, more wish-fulfilling fantasies and fewer strategies of emotional expression, self-blame, and information-seeking were utilized by parents (Chen et al., 2002). Similarly, Thompson and colleagues (1992) found that parents' poor adjustment was related to greater use of emotion-focused coping, particularly the use of avoidance, wishful thinking, and self-blame. Nevertheless, regarding individuals with DBMD, studies related to coping are sparse (Palacios-Espinosa et al., 2021; Peay et al., 2022; Rahbek et al., 2005; Tesei et al., 2020). Among the existing studies, only one (Tesei et al., 2020) referred to coping strategies and demonstrated that participants with DBMD (ranging 2–32 years of age) who made a greater use of avoidant coping strategies were more likely to report higher levels of emotional and behavioral problems (i.e., anxiety, depression, aggressive behavior).

The current study aimed to explore coping strategies, specifically among individuals with DBMD in the developmental period of emerging adulthood, and their parents. Arnett (2000) described emerging adulthood as a developmental period lasting from late teens through mid-twenties. This period is characterized by identity explorations (decisions concerning love, work, and ideology), instability (regarding relationships, work, residence), a time of life that is least subject to institutional control, feeling 'in between' (neither adolescents nor adults), and an age of possibilities (hope for the future) (Arnett, 2000). Furthermore, emerging adulthood is characterized by increased autonomy as individuals define their values separate from their families and move away from home (Tanner & Arnett, 2016). Given the challenges posed by a chronic illness like DBMD, emerging adults may face obstacles in developmental tasks such as self-exploration and achieving independence, which can hinder the personal growth typically expected during this period (Houman & Stapley, 2013). A key aspect of identity exploration during this stage is experiencing romantic relationships. Peay and colleagues (2022) found that most males with DBMD, aged 16–30 years, had not been in romantic relationships, yet they expressed a desire for such connections. Furthermore, the dependence on family members for health-related assistance might conflict with their aspirations for growing independence and the typical transition of emotional reliance from parents to peers (Houman & Stapley, 2013). Additionally, failing to develop a strong sense of identity has been associated with maladaptive illness-specific coping strategies and poor integration of the illness into their self-definition (Luyckx et al., 2008). To date, few studies have explored this specific period in relation to DBMD (e.g., Palacios-Espinosa et al., 2021; Peay et al., 2022; Rahbek et al., 2005; Tesei et al., 2020).

The Current Study

The objective of this research was to identify the coping strategies of individuals with DBMD in the period of emerging adulthood and their parents. This understanding may raise awareness among healthcare professionals about the unique aspects of being an individual with DBMD in the period of emerging adulthood and contribute to the design of professional interventions that could support these individuals and their parents.

Methods

Design

This study used qualitative methodology, which is suitable when studying experiences and thoughts. The data collection

method was focus groups, a technique that is fitting when existing knowledge of a subject is inadequate (Powell & Single, 1996). It allows gathering of data not only from the group facilitators' questions, but also from the discussions between participants. Focus groups are particularly apt in the context of healthcare and medical research since most health-related conditions are created by social environments and exist within a social context (Carter & Henderson, 2005). Focus groups are frequently used to obtain knowledge, perspectives, attitudes, and explanations for behaviors (Wong, 2008).

The participants were recruited via a non-profit organization, "Little Steps", the organization of DBMD patients and families in Israel. The criteria for inclusion were being ages 18–29 and having a DBMD diagnosis or being a parent to a person that age with DBMD; fluency in Hebrew; giving "informed consent" to participate in the study by taking part in one focus group meeting via zoom (90 min) which included turning on their camera and being recording during the meeting. The exclusion criteria included comorbidity of disease and age younger than 18. Of the 48 families we identified with individuals diagnosed with Duchenne or Becker Muscular Dystrophy (DBMD) aged between 18 and 29, 11 parents and 7 young adults agreed to participate in the study. After receiving ethical approval, the organization's staff approached all relevant members. All those interested in taking part were then invited to a focus group. More parents expressed interest than young adults.

The use of online focus groups has become more common over the last years due to technological developments and allows for participation of people from diverse geographical regions (Keemink et al., 2022). This was the case in our study, in which the meeting via Zoom allowed people from different regions of the country to participate, including the country's periphery. Moreover, some of the young adults have mobility problems and meeting via Zoom was easiest for them.

Three focus groups were held: two with parents (6 participants in one and 5 in the other, ages 39–46) and one with young adults (7 participants, ages 18–23). With regard to the young adults: five of them were diagnosed BMD and two with DMD. One participant with DMD was confined to a wheelchair and the rest were mobile, including the one female participant. Four of the young adults had parents who participated in the parents' group. All participants agreed on the research terms and to having the meeting audio recorded and later transcribed. In addition to promising confidentiality on the part of the researchers, the participants were asked to respect the other group members' privacy. Each focus group was conducted by two social workers, one working in a hospital and one from academia, using a semi-structured guide. At least one in each pair of facilitators was experienced in facilitating focus groups. After a brief introduction, all discussions were opened with an identical question: "Tell us about life with Duchenne or Becker". Additional questions were asked when clarification was needed or in order to approach a topic that the participants did not bring up themselves. The discussions in the parental focus groups were elaborate and lasted about an hour and a half. The young adults were less forthcoming and the meeting with them took nearly an hour.

The group discussions were recorded, transcribed, analyzed and coded. The selected quotes were translated from Hebrew to English for the purpose of publication. Being aware of the importance of language nuances in qualitative research, special care was taken to represent as accurately as possible the meaning of the quotes used (Goitem, 2020).

Despite the young adults having a harder time elaborating, the themes that arose in their focus group were similar to those that arose in the parents' focus groups. Moreover, the second focus group conducted with parents did not add any new information or new themes, and as such the researchers felt data saturation was achieved (Guest et al., 2006).

Data Analysis

The researchers read the transcriptions and analyzed the data to identify themes in the text (Creswell & Poth, 2016). The analysis was carried out from a perspective that pays attention to the detailed content of the discussion and to the whole story that was presented by each participant (Lieblich et al., 1998). The choice of themes for the analysis was based on the space it took on the text, the repetitions in the discussion regarding the theme and the details the participants added regarding the theme. The analysis included reading and re-reading the text, paying attention to the events that were described and the way they were described, for instance repeating wordings and metaphors.

Analysis was first conducted by each researcher individually. After discussing the themes that each researcher identified, a list of themes was agreed upon. Two pairs of researchers read the transcripts again, searching for text relevant for specific themes, presented the analysis to the other pair, who in turn reviewed the analysis. Each pair was responsible for half of the themes. The analysis was thus carried out within each pair and between the pairs. This was in order to allow peer analysis and strengthen trustworthiness. Few discrepancies were found during this process since coding was generally clear. The few discrepancies were discussed and were either changed or eliminated accordingly. The process of analyzing the texts separately, and by researchers who did not facilitate all the focus groups, and then comparing the analyses, allowed triangulation of viewers (Dadgett, 1998), and what Rodwell (1998) calls "Peer Debriefing" - a process in which colleagues who know enough about the methodology and the subject can control the subjectivity of the interviewer. Using this process, the researchers found connections between topics and organized them as major and sub-major themes (Braun & Clarke, 2006).

Ethical Considerations

Ethical approval was received from the first author's university's institutional review board (IRB). The participants were provided with detailed information about the study and asked to state their informed consent in which it was emphasized they could choose to cease their participation at any time. To ensure anonymity, all identifying information was removed from the transcript and all names were changed.

Results

When describing their lives through the lens of DBMD, both young adults and parents shared a wide range of emotions and coping strategies related to living with the illness. The participants referred to some of their coping strategies as "adjustments", and therefore we will use this term.

Negative Emotions Alongside Positive Perceptions

The conversations with the participants revealed various negative emotions they feel, like anxiety, sadness, and anger. Many parents shared the anxiety they feel daily no matter the age of the child. One source of anxiety is the uncertainty regarding the progression of the disease, and the fear that their child will die young:

> "So it's a lot of anxieties and a lot of worries, that's how we've lived his life and our lives …So, we're still there, worried and anxious, what will happen, what won't happen…that's how we live our lives." (Gali)

These feelings are also accompanied by great sadness:

> "We're sad mothers, we are just trying to project something different. It's a terrible illness, it's living in uncertainty 24/7." (Ariella)

Sadness was shared among the parents and young adults:

> "When I was younger, I was a lot sadder and angrier. There were times when I would barely eat, I didn't have energy to do anything…" (Yair)

Another participant also related to the negative feelings accompanying the illness:

> "It's always negative feelings, why is it me who has this? What did I do wrong?" (Adi)

Negative feelings exist together with positive attitudes. The parents described a process over time; while the initial reaction to the diagnosis were negative feelings such as sadness and anxiety, over time they were able to focus on positive feelings as well. One of the adjustments described by the parents was focusing on the positive aspects of the "here and now", not thinking about the future:

> "What keeps us from falling apart is really routine: getting up, thinking about living in the present, thinking less about what is expected next. Making every day nice and pleasant for us, being happy with what we have now…." (Yael)

Hope

Keeping a positive attitude is related to hope. Parents described how they grieved over the diagnosis but watching their child adjust and eventually make progress, brings them strength.

> "On better days I feel it [the illness] gives me strength, it makes me see the world in a different way and it affects the people close to me because they also see the world in a different way in light of what I have to go through." (Eden)

When asked about the future, both young adults and parents had high hopes. For example, two of the young adults shared:

> "I see my future as being independent, I'll start my own business, build a family and do things that an independent person would do." (Yair)

> "I see success and growth in my future, a good future, no matter what happens, and to leave a legacy behind me." (Ben)

These quotes demonstrate the young adults' aspirations to have success and independence as well as leaving their mark on the world.

The parents also spoke of the hope they feel. One of the fathers said:

> "In my opinion anyone who has experiences difficulties has to build a better future, so that his future will be easier. That's how I see things…and I believe the future will be easier…you can always create more options in order to get to a better and easier path." (Jamal)

Another father hoped that the future will bring a better treatment for the disease:

> "We are people of faith, I'm religious, I believe, and we're hopeful they will find a medication for this disease." (Ezra)

The parents and young adults described various adjustments they made, such as changes in daily routines and family roles, even at the price of financial loss. These adjustments are examples of the flexibility of living and coping with a progressive chronic illness.

Coping with Being Different

The feeling of being different as a result of the illness was a source of frustration for some of the participants. As described by one young adult:

> "On days that are harder for me, I mainly feel disappointed, bitter, and frustrated because there are lot of things I'd want to do differently or different things I would want to do and I know I can't, and I know I can find other solutions that will allow me to do the things I want in a different way, but it's frustrating because I just want to be like everyone else." (Shir)

She further elaborated:

> "… at university I had to be precise about my limitations and difficulties so that they could come up with the best solutions. You need to communicate the difficulties a lot so that people will understand and see what they could do in order to provide help and support" (Shir)

Some of the young adults felt that their loneliness stemming from not knowing anyone else struggling with the same disease:

> "I think that it's hard to deal with this disease by yourself and that there is something comforting in hearing other people who are experiencing something similar, that are your age, that understand your struggles and how you feel, maybe it's not exactly the same but it gives you perspective, it shows you how other people see it. I think it's important to find that group that you can talk to and feel comfortable with." (Shir)

Another participant explained that he has trouble making friends with peers who do not share the same experiences:

> "When it comes to friends, it's harder for people to build a relationship with me. They don't know how to behave, how to act and where we can go out." (Yair)

The parents also reflected on their children's loneliness. Many expressed concern that as their children enter adulthood, they will have difficulty making friends:

"That's what scares me, the lack of social frameworks… [my son] began volunteering in the army, and that lifted his spirits and helped him open up, but I don't know what comes next. That's what I'm worried about…the loneliness, lack of peers, that's what scares me with this disease." (Ezra)

The concern the parents felt for their children as to the depths of their loneliness was emphasized by many of the participants in this study:

> "It's a disease that goes beyond the physical problem, it's an emotional problem, a social problem…I always think about my lonely child, who is fighting for his place…the loneliness is the hardest thing right now…" (Yael).

In addition, many parents felt lonely themselves:

> "I always looked for the other Duchenne and Becker mothers…it was very important to me to be able to discuss these topics with other mothers, because these are things that only we'll understand. A mother who doesn't have a sick child won't understand, she won't understand our frustrations, she won't understand how annoying it is when places aren't accessible, she won't understand how difficult it is for you and that you can't live in a two story house even if the downstairs has a bedroom. It's something that only parents to sick children can understand, this frustration, how frustrating it is…and many parents raise their eyebrows when you say 'I have a child with muscular degeneration' and someone says quietly 'God forbid'." (Ariella).

This mother to a child of Duchenne sought parents to children with either Duchenne or Becker. However, many of the parents to children with Becker emphasized the difference between the diagnoses regarding progression and life expectancy. In addition, Becker is less researched than Duchenne.

In contrast, one parent shared the importance of sharing regardless of similarity:

> "Not just in a support group, but it's good to share, with family, a wife, friends. The moment you share, you slightly ease the burden." (Eli)

It seems that all parents yearned to share their loneliness and ease their burden.

Familial Adjustments

For some of the parents, adjustments included changing perceptions regarding family life. One father described how he allowed his son to have a dog, in spite of his own dislike for dogs, because her understood the importance of the dog for his son:

> "This is an example of how we can adjust ourselves. For instance he loves dogs and I do not love having a dog at home. We brought him a dog eventually, we adjusted the dog to him, the way he wanted it…. We must make adjustments otherwise he is going to have a hard time coping…. So I adjusted myself. I had to adjust myself…" (Jamal)

This example demonstrates the allowances the father made for his son that he wouldn't have made for his other children. He relates to his ill son in a different way, than his other children, and sees it as his duty.

All the parents shared this kind of commitment and understanding that special children need special care:

> "My daughter is the opposite of my son. She is light and he is, unfortunately, darkness. She is the opposite. Just opposite. On the other hand, it is clear that the attention goes to him, there's nothing to do about it…. We know that she is healthy and everything is okay so we worry less. But we are more anxious for him, so we think about him all the time. There's a family joke "you love him more, he's the favorite child, I am second best." (Yael)

Hearing these sentiments from one's child is not easy, even as a sad joke. As a whole, making familial adjustments, either in family daily life or in family dynamics, is not easy and involves frustrations.

Discussion

In this study, through the use of focus groups, we learned from the parents and emerging adults with DBMD about their experiences with these progressive and debilitating genetic conditions. This discussion is centered around the similarities and differences shared by young adults and parents living with DBMD, shedding light on the emotional journey they embark upon and the adjustments they make to lead fulfilling lives despite the challenges posed by the disease. It also explores the theme of being different and the impact of DBMD on familial relationships.

Negative Emotions Alongside Positive Perceptions

The study uncovered a myriad of emotions experienced by individuals and families dealing with DBMD. These emotions encompass anxiety, sadness, and anger, often arising from the uncertainty surrounding the disease's progression and the fear of dying young. This is consistent with findings from Fujino and colleagues (2016), who observed similar anxieties and worries in participants with DMD. It appears that patients with DMD may experience anxiety and depression when faced with health deterioration.

Parents, on the other hand, consistently expressed enduring anxiety, regardless of their child's age. This anxiety remains a constant presence in their lives, a reminder of the formidable challenges they confront. Previous studies (Donnelly et al., 2023; Kenneson & Bobo, 2010; Landfeldt et al., 2016, 2018; Magliano et al., 2014; Pangalila et al., 2012; Tesei et al., 2020) corroborate this, highlighting elevated levels of stress, distress, anxiety, lower quality of life, sadness, and depression among caregivers of patients with DMD.

Parents also shared profound sadness, often portraying themselves as "sad mothers" striving to project positivity despite the constant uncertainty. It's important to note that uncertainty is a significant psychological stressor faced by both patients and families (Bell et al., 2019, p. 677). This uncertainty can adversely affect parental coping, leading to psychological distress, anxiety, depression, and hopelessness (Bally et al., 2018; Truitt et al., 2012).

However, uncertainty can also yield positive outcomes, as individuals' perceptions play a role in their ability to cope with both stressors and uncertainty itself. A positive outlook on their experiences can bolster caregivers' resilience, reduce stress levels, and aid in their adaptation to their child's disease (Tesei et al., 2020).

Furthermore, both young adults and parents experienced deep sadness and anger throughout their journey with DBMD. These negative emotions were not confined to the parents; young adults also grappled with profound questions about why they had to confront this challenging condition. However, amidst this sea of negative emotions, a remarkable aspect emerged - both parents and young adults discovered ways to nurture positive attitudes.

They articulated the importance of focusing on the present moment, consciously avoiding excessive worry about the uncertain future, and finding solace in cherishing the everyday moments they shared. This resilience mirrors the findings of Hinton and Kirk's (2017) study, which shed light on the variability and unpredictability of challenges faced by parents of children with muscular dystrophy. These parents had to reconsider and adapt their everyday routines and question long-held assumptions about their child's future. In doing so, they demonstrated an admirable ability to find strength and positivity even in the face of adversity.

Hope

Hope emerged as a central theme in the lives of those living with DBMD. Parents drew strength from witnessing their children's adjustments and progress. Both young adults and parents held high hopes for the future, envisioning success, independence, and advancements in treatment.

The concept of hope is multifaceted and has been defined and explored across various fields. According to Snyder's Hope Theory (Snyder, 2000), hope is not just a passive feeling but an active cognitive process through which individuals actively strive to achieve their goals. This proactive approach to hope distinguishes it from mere optimism or wishful thinking.

Numerous studies, such as those by Horton and Wallander (2001) and Shikako-Thomas et al. (2013), have emphasized the critical role hope plays in improving mental health, enhancing quality of life, and fostering resilience among families dealing with children with developmental disorders. This highlights the profound impact of hope on the psychological well-being of both caregivers and patients. Furthermore, Zhang and colleagues (2010) have argued that hope has therapeutic value, influencing coping strategies and the ability to effectively adapt to challenging situations. In the medical context, hope and uncertainty are closely intertwined. It can be argued that if the future were certain, hope might have no role in envisioning a positive future because hope is fundamentally about possibilities. Therefore, uncertainty serves as a

prerequisite for hope, as hope thrives in the realm of the unknown, where possibilities exist.

Moreover, hope is often accompanied by a future-oriented perspective among individuals dealing with DBMD and their parents. Generally, maintaining positive expectations about the future contributes to improved health outcomes by acting as a buffer against stressful events, as noted in the research by Rasmussen et al. (2009). Some scholars argue that such positive expectations provide resilience in the face of adversity and enable individuals to cope adaptively and competently (Aspinwall, 2005; Nes & Segerstrom, 2006; Williams et al., 2007). Additionally, Bandura recognized the influential role of future orientation in shaping behavior and goal setting. The anticipation of desirable future events motivates individuals to take actions necessary to achieve their goals (Bandura, 1989). This perspective aligns with the core tenets of Snyder's Hope Theory (Snyder, 2000), emphasizing the proactive and goal-directed nature of hope as a powerful psychological force in guiding individuals toward positive outcomes.

Loneliness

Some of the young adult participants grappled with the sense of being different due to DBMD. Young adults shared feelings of frustration, disappointment, and bitterness because they couldn't engage in activities in the same way as their peers. They highlighted the importance of effective communication about their limitations to access the support they needed, particularly in academic settings.

Participants recognized the value of connecting with others facing similar challenges, finding solace in shared experiences, and emphasizing the importance of forming peer support networks. Loneliness was a common concern among young adults, highlighting their yearning for understanding and companionship from those who could relate to their struggles. Previous studies (Maes et al., 2017; Qualter et al., 2015) echoed these findings, underscoring the vulnerability of medically complex adolescents and young adults to loneliness due to the absence of peers with similar experiences. Additionally, the fact that most individuals with DMD live at home with their parents throughout their lives, as noted by Landfeldt and colleagues (2018), can contribute to social isolation (Gibson et al., 2014).

Parents shared similar concerns about their children's social isolation as they transitioned into adulthood, worried about the lack of social frameworks and the potential for loneliness in their children's lives. This aligns with arguments made by Bailey and colleagues (2021), who pointed out that individuals with disabilities face barriers to participation in the adult world due to prevailing societal attitudes. These concerns were accompanied by a sense of helplessness, as parents struggled to find suitable avenues for their children to form meaningful friendships.

Many parents also shared their own experiences of loneliness, seeking solace in connecting with others who understood the unique challenges of raising children with DBMD. They emphasized the importance of sharing frustrations and burdens with those who could empathize, whether within a support group or among friends and family. Research by Koufaki and colleagues (2019) indicated that parents who take sole responsibility for their children's care may limit their social interactions, leading to heightened social isolation and loneliness.

Familial Adjustments

Parents faced significant adjustments when it came to adapting to life with DBMD. These changes extended to their perceptions of family dynamics and daily life, requiring them to accommodate their child's unique needs, even if it meant making sacrifices or embracing changes they might have resisted under different circumstances. The ability of the family to cope with and adapt to a child's chronic illness depends on the parents' ability to adjust as the child's functional ability decreases and level of dependence on their parents increases as noted in studies by Chen and Clark (2010) and Read et al. (2011).

Furthermore, researchers have advocated for "normalization" as a desirable coping strategy in individuals' and families' adaptation to chronic illnesses and disability (Anderson et al., 2020; Emiliani et al., 2011; McDougal, 2002), as it enables better quality of life and psychological adjustment (Anderson et al., 2020). Specifically, Deatrick and colleagues (1999) identified five attributes of normalization: acknowledgment of the condition and the potential to threaten lifestyle; adoption of a normalcy lens for viewing the child with the condition and the family; engagement in parenting behaviors and family routines that are consistent with a normalcy lens; development of a treatment regimen consistent with a normalcy lens; and interaction with others based on a view of the child and family as normal.

The above was discussed in a study by Gibson and colleagues (2014), which illuminates how individuals with DMD (ages 16–27 years old) strive for normative bodies, lives, and relationships, thereby constructing and maintaining identities of gender normality. Specifically, these individuals endeavor to present themselves as "normal" despite challenges such as fatigue, transportation issues, escalating care needs, loss of physical functions, and changing mobility. These individuals exert considerable effort to align with societal norms of being a "typical guy". While acknowledging their differences, they assert that these differences do not preclude them from being part of their nondisabled peer group. The frequent use of 'normal' in their self-narratives highlights their efforts to be perceived as similar to everyone else, often distancing themselves from other disabled youth and the identity of being disabled. This approach emphasizes the incorporation of

regular aspects into family life while managing the challenges presented by DBMD.

Essentially, normalization focuses on practices that facilitate regular family routines that help integrate the condition and its treatment into everyday life (Emiliani et al., 2011). Likewise, it seems that the parents in this study adopted normalization, which emphasizes the ability to include normal aspects in their family lives and manage the DBMD in the family setting.

Parents demonstrated an unwavering commitment to their children, making allowances and adjustments for their special needs. They recognized that special children required special care and attention, which sometimes meant a different level of attention or accommodation compared to their healthy siblings. The emotional toll of these familial adjustments was palpable, as expressed by one parent who humorously referred to their child as the "favorite" due to the extra care and attention they received. This sentiment, though delivered in jest, underscores the challenges and frustrations that come with making such adjustments.

These findings are consistent with previous studies on DMD (Read et al., 2011; Schwartz et al., 2022), which have shown that DMD can have both negative and positive impacts on other family members. These impacts include unequal parental attention and availability to siblings, as well as positive effects such as increased family cohesion, knowledge, and maturity in siblings.

Moreover, Magliano and colleagues (2014) reported that approximately one-third of parental caregivers of DMD believed that the condition had a negative influence on the psychological well-being and social life of unaffected siblings. Additionally, Schwartz and colleagues (2021) described how DMD parents reported that siblings often sacrificed time with friends, participation in sports, extracurricular activities, and summer camp or travel. These financial and time sacrifices sometimes led to insufficient resources for siblings' activities or schooling. However, parents tended to disagree that DMD in the family had led to a loss of other opportunities for their siblings.

In parallel with the aforementioned challenges, parents in the present study also described positive aspects of their experience with DBMD. They displayed an ability to revise their priorities and perspectives on life in response to their ever-changing reality. Recognizing advantages in their caregiving experience was associated with positive psychosocial functioning (Peay et al., 2016). Magliano and colleagues (2014) found that about two-thirds of parents, both of DMD and BMD, acknowledged psychological benefits in their caregiving experience, particularly in terms of personal growth and an increased sense of strength in facing adversity. It is likely that when parents feel capable of managing the practical difficulties of care, they are better equipped to overcome them and also reflect on the positive aspects of caregiving.

In summary, the experiences of young adults and parents living with DBMD are marked by a complex interplay of emotions, adjustments, and familial dynamics. While negative emotions and the feeling of being different are ever-present challenges, hope, resilience, and the formation of support networks emerge as powerful coping mechanisms. The commitment of parents to adjust their lives for their children's well-being is a testament to their unwavering dedication. Understanding these emotional and practical aspects of living with DBMD is crucial for healthcare professionals, support networks, and policymakers to provide holistic care and support to those affected by these conditions.

Limitations

Several limitations to this study need to be considered. First, the sample included those who consented to participate in the qualitative study via Zoom regardless of their specific diagnosis and were recruited by the psychosocial team of one nonprofit organization in Israel. As such, bias could have occurred, and the study's findings may not be representative of all young adults with Duchenne and Becker Muscular Dystrophy (DBMD) and parents' experiences. Second, among the seven young adults with Duchenne or Becker Muscular Dystrophy (DBMD) who participated in the focus group, five with BMD and two with DMD, there is a notable lack of detailed clinical information for the participants with BMD, and only one of them was female. Given that the gene causing the disease is located on the X chromosome, the condition tends to be more severe in males, who have only one X chromosome. Consequently, females usually exhibit milder symptoms, such as mild muscle weakness and heart muscle damage (cardiomyopathy) (Cohen et al., 2022). Future studies should aim to assess any gender-based differences in coping strategies related to DBMD and make efforts to recruit individuals with DMD and BMD separately. This approach will facilitate a more comprehensive understanding of their distinct needs and challenges. Third, the participants (i.e., young adults and parents) were encouraged to openly express their opinions; however, the focus group format might have been uncomfortable for those who did not wish to express their opinions in a public forum. It should be noted that to create an open discussion, the focus groups were limited to 8 –10 participants. Fourth, the data collected from young adults were gathered during a single Zoom meeting. Consequently, it may not fulfill the principle of saturation. Future research should consider conducting multiple meetings and including quantitative questionnaires that enable anonymous self-reporting. Fifth, the study did not account for past stressors within the research population, nor did it consider characteristics of young adults with DBMD (e.g., current disease severity), or variables related to parents' characteristics (e.g., socioeconomic status, family composition, parenting style, and parent relationship quality). Lastly, the study was conducted in Israel,

which may limit the generalizability of the results to other cultural contexts.

Conclusion

Despite these limitations, the present findings provide insights into the coping strategies of young adults and parents applied in the face of DBMD. Our findings revealed a complex interplay of emotions, adjustments, and family dynamics. Both young adults and parents constantly face challenges such as negative emotions and feelings of being different, while hope, resilience, and the development of support networks serve as powerful coping mechanisms. Our findings did not prominently reflect different "adjustments" between Becker and Duchenne diseases, although there are differences in illness progression and life expectancy. The unyielding commitment of parents to adjust their lives for their children's well-being is a common factor among families dealing with both Duchenne and Becker muscular dystrophies. Future studies should delve deeper into and broaden the scope of how coping strategies are employed in dealing with DBMD, as these strategies, whether temporary or established, may vary depending on the distinct situations of each family and individual young adults with DBMD.

In practical terms, given the diverse challenges reported by participants in this study, an interdisciplinary team of professionals, including physicians, nurses, psychologists, and social workers, should be mindful of challenges in reaching age-appropriate milestones, and remain attentive and proactive with young adult patients and their parents. For instance, they can assist parents in fostering and promoting their child's independence, and provide insights into available resources and vocational services for young adults with DBMD. This approach would assist patients in managing their medical condition and improve their daily coping with DBMD's demands. Additionally, both formal and informal support interventions aimed at patients and their family members should be strengthened to help families attain a sense of normalcy.

Author's Note

We ensure that the work described has been carried out in accordance with The Code of Ethics.

Acknowledgments

The authors thank the young adults and the parents that willingly participated in this study.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

Ethical Statement

Ethical Approval

Ethical approval was received from Tel Hai academic collage ethical committee. Approval number: 9-3/2022.

Informed Consent

The participants were provided with detailed information regarding the study and their participation and asked to sign a form stating their informed consent.

Transparency and Openness Statement

The raw data, analysis code, and materials used in this study are not openly available but are available upon request to the corresponding author. Additionally, no aspects of the study were preregistered.

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Supplemental Material

Supplemental material for this article is available online.

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