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Support Resources in the Lives of Parents of Children with Duchenne–Becker Muscular Dystrophy: An Ecological Approach Perspective

Siwar Makhoul Khoury[1,2], Tali Kaplan[3], and Ayelet Gur[1,2]

Abstract

***Summary*:** This study examines the support resources available to parents of children with Duchenne and Becker muscular dystrophy (DBMD) and their roles in fostering parental coping and resilience. Grounded in Bronfenbrenner's Ecological Model (1979), it explores how individual, familial, and community-level resources shape caregiving experiences. Using a qualitative phenomenological approach, in-depth interviews were conducted with 22 parents (three fathers and 19 mothers) of children with DBMD in Israel. Thematic analysis revealed three primary categories of support: psychological resources, family support, and social support, encompassing both formal services and informal networks.

***Findings*:** Many participants emphasized the critical role of formal support systems in managing the practical and emotional demands of caregiving. While psychological and informal supports were also described as helpful, they were not always sufficient on their own. Faith, optimism, and a sense of purpose emerged as key psychological resilience mechanisms. Informal networks provided emotional companionship and peer validation, particularly through community-based connections. Although some participants mentioned professionals, including social workers, as effective in linking families to

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[1] Social Work Department, Tel-Hai College, Upper Galilee, Israel
[2] Research Center for Innovation in Social Work (RCISW), Tel-Hai College, Upper Galilee, Israel
[3] Little Steps Association, Jerusalem, Israel

Corresponding Author:
Siwar Makhoul Khoury, Social Work Department, Tel-Hai College, Upper Galilee, North District, 1220800, Israel.
Email: siwarmakhoul@gmail.com

formal supports, the findings highlight a broader need for integrated, multi-level interventions to sustain caregiver well-being.
***Applications*:** The study underscores the importance of coordinated collaboration among social, educational, and healthcare services to address the unique challenges of DBMD caregiving and to enhance family resilience and adaptation.

Keywords
Social work, disability, intervention, social support, resilience, parenting

Introduction

While caregiver support has been widely studied in the context of chronic pediatric illness and disability (Boettcher et al., 2020; Hartley et al., 2021), limited research has focused on families of children with Duchenne and Becker muscular dystrophy (DBMD). As a rare and progressive neuromuscular disorder, DBMD presents families with escalating caregiving demands, complex medical routines, and prolonged emotional strain, including anticipatory grief (Landfeldt et al., 2018; Waldboth et al., 2016; Yamaguchi et al., 2019). The rarity of the condition also contributes to limited disease-specific support, fragmented services, and increased caregiver isolation (Schwartz et al., 2021).

Despite these unique challenges, there is a lack of research exploring how families mobilize resources to cope with the cumulative medical, logistical, and emotional demands of DBMD. This study addresses this gap by examining how families raising children with DBMD access and integrate support across individual, familial, and community levels, using Bronfenbrenner's ecological model (1979) as a guiding framework, with a specific focus on the Israeli context.

DBMD refers to two genetically linked muscular dystrophies that progressively weaken muscles, affecting physical functioning and creating significant challenges for affected children and their families. Duchenne muscular dystrophy (DMD) is an X-linked recessive disorder that affects approximately one in 3,500–6,000 male births (Salari et al., 2022). Symptoms typically appear between ages three and five, with rapid muscle degeneration leading to loss of independent ambulation by early adolescence and significantly shortened life expectancy due to cardiopulmonary complications (Birnkrant et al., 2018). In contrast, Becker muscular dystrophy (BMD) follows a milder course, allowing ambulation into midlife and yielding a near-normal life expectancy, although functional limitations often persist (Birnkrant et al., 2018; Verma, 2018). Despite clinical differences, this study uses the term "DBMD" to refer to both disorders collectively, recognizing their shared genetic basis and the overlapping caregiving challenges**.** This unified framework enables a comprehensive analysis of parental experiences in managing progressive muscular disorders.

The diagnosis of DBMD in a child significantly transforms family life, particularly for parents who typically become primary caregivers responsible for daily care, coordinating medical needs, and offering sustained emotional support (Landfeldt et al., 2018). These parents face complex and evolving psychological demands, as the progressive nature of DBMD requires constant adaptation to increasing dependency and medical intricacies. Peaks in parental stress often align with critical disease milestones, such as the initial diagnosis, transition to wheelchair use, initiation of respiratory or feeding support, and the shift into adulthood (Waldboth et al., 2016; Yamaguchi et al., 2019). These moments intensify emotional strain and vulnerability to depression, anxiety, and caregiver burnout.

Coping strategies vary across families. While problem-focused approaches (e.g., organizing care, seeking medical knowledge) are associated with improved psychological adjustment, emotion-focused strategies (e.g., denial, avoidance) can intensify distress (Lott et al., 2021). Resilient caregivers often adopt adaptive coping tools, such as positive reframing, spiritual belief, and social support, to manage the burden of long-term caregiving (Lazarus & Folkman, 1984; Porteous et al., 2021).

The availability and accessibility of multi-level support resources, whether individual, familial, or community-based, play a vital role in sustaining caregiving efforts and promoting parental well-being. Family-level resources such as cohesion, resilience, and supportive dynamics contribute meaningfully to caregiving adaptation. Parents with strong family support networks report improved mental health and greater flexibility in caregiving roles (Hartley et al., 2021; Ortega et al., 2022). Community-based supports, including friendships, extended family, and local peer groups, offer emotional and practical assistance that alleviates the caregiving burden and enhances family well-being (Ortega et al., 2022; Porteous et al., 2021).

In the Israeli context, where universal healthcare is provided, formal social support services are often fragmented, requiring families to navigate a complex and decentralized system. Cultural norms regarding caregiving, help-seeking, and the role of religion and community vary widely across Israeli populations and influence the strategies families adopt. For instance, religious Jewish families may draw on faith-based organizations and communal frameworks, while secular or non-Jewish families may rely more on state-provided services or peer networks, reflecting broader variations in trust, accessibility, and social norms (Arazi et al., 2023). In this context, local nonprofit organizations and support associations (such as *Little Steps*, a national organization supporting families of children with DBMD) serve as critical hubs for emotional assistance, practical information, and peer connections. These non-state actors often play a particularly vital role in assisting families managing rare and complex conditions like DBMD.

Theoretical Framework: Bronfenbrenner's Ecological Model

Bronfenbrenner's ecological systems theory (1979) provides a comprehensive framework for understanding how families navigate the complex and multilayered challenges of raising a child with DBMD. The model conceptualizes human development and adaptation as shaped by multiple, interacting environmental systems, ranging from immediate interpersonal relationships to broader institutional and cultural influences. Bronfenbrenner outlined five core systems: the microsystem, mesosystem, exosystem, macrosystem, and chronosystem.

Microsystem: This innermost level refers to the immediate environment of the individual, family, close friends, and caregivers, where face-to-face interactions occur. Psychological resources such as optimism, emotional regulation, and faith, as well as close family dynamics (e.g., spousal or extended family support), fall within this system.

Mesosystem: The mesosystem captures the interactions between different microsystems, such as those between home and school or healthcare providers. Involvement of schools, medical teams, and support groups shapes the caregiving experience within this level.

Exosystem: This system includes institutions and structures that indirectly affect the individual, such as parents' workplaces, community organizations, and social welfare services. Although parents do not engage with all these systems directly, their influence on caregiving is substantial.

Macrosystem: The macrosystem represents broader cultural, societal, and policy frameworks, including attitudes toward disability, religious traditions, and the organization of healthcare and welfare systems in Israel, a country characterized by diverse ethnocultural groups and a mix of secular and religious populations.

Chronosystem: Introduced in later developments of the theory, the chronosystem tracks changes over time, such as disease progression, developmental transitions, or shifts in family structure or national policy. It reflects both individual life-course changes and broader sociohistorical dynamics.

When applied to the current study, "individual, family, and community resources" map onto specific ecological levels. Individual psychological strengths like resilience or meaning-making align with the microsystem. Family relationships and interpersonal networks extend across the microsystem and mesosystem, while community-based and institutional supports (e.g., healthcare access, education policy, nonprofit services) are positioned within the exosystem and macrosystem. The chronosystem overlays all of these, shaping how resources shift and interact across the caregiving journey.

This layered approach reflects Bronfenbrenner's emphasis on the interdependence and embeddedness of systems in human development (Swick & Williams, 2006). Furthermore, as Neal and Neal (2013) argue, these systems should not be seen merely as nested containers, but rather as dynamic networks of social interaction, allowing support to flow across boundaries and change over time.

Research Objectives

This study adopts an ecological perspective to explore how families in Israel, a culturally diverse society with both Western and non-Western characteristics, cope with the challenges of DBMD caregiving. Drawing on Bronfenbrenner's ecological model, it aims to map multi-level support systems, from psychological strengths and family dynamics to formal services and community structures, that facilitate or constrain resilience.

Although caregiver support has been widely studied, research on parents of children with rare, degenerative diseases like DBMD remains limited. These conditions require prolonged, high-intensity caregiving, often with little guidance or precedent. This study contributes new insights by examining how Israeli families manage caregiving across stages of medical progression, emotional uncertainty, and fragmented service systems.

In the Israeli context, formal services are inconsistently distributed, and faith-based and community-based networks frequently compensate for institutional gaps. This research offers culturally grounded insights into how families in such settings construct adaptive support systems, drawing simultaneously from psychological, familial, and institutional resources to build resilience over time.

Methods

This study employed a qualitative phenomenological approach, aiming to understand the phenomenon of caregiving from participants' subjective perspectives and lived experiences (Giorgi, 2009). The underlying assumption was that in-depth exploration of individuals' narratives would yield a nuanced understanding of caregiving in the context of DBMD (Shkedi, 2003).

Participants

The participants in this study were 22 parents of children diagnosed with DBMD, including three fathers and 19 mothers. Their average age was approximately 45.27 years ($SD = 9.27$). Among the participants, 11 were married (50%), seven were divorced (31.8%), two were cohabiting (9.1%), and one was single (4.5%). The average number of children per family was 2.77, and the average age of the child with DBMD was 14.8 years.

Most families (90.9%, $n = 20$) had one child with DBMD, while one family (4.5%) had three children, and another (4.5%) had two children diagnosed with the condition. Sixteen parents (72.7%) held an academic degree, and 13 (59.1%) were employed, with the rest unemployed or between jobs. Twenty-one participants (95.5%) identified as Jewish, encompassing a range of religious affiliations, including secular, traditional, and religious backgrounds.

Data Collection

Data were collected through semi-structured, in-depth interviews designed to explore parents' experiences following their child's DBMD diagnosis. The interview guide featured open-ended questions, enabling flexible conversation flow and allowing participants to narrate their experiences in their own words. Follow-up probes were used to elicit further detail, and participants were encouraged at the end of each interview to raise additional topics they deemed important (Shkedi, 2003).

The guide was developed with sensitivity to Bronfenbrenner's ecological model and included questions, such as "Can you describe the sources of support you and your family rely on in your daily caregiving?" (microsystem, mesosystem), "How do relationships with schools, healthcare providers, or community organizations affect your caregiving experience?" (mesosystem, exosystem), "Have you noticed any changes in support or challenges over time? What factors contributed to those changes?" (chronosystem)

Additional prompts explored coping strategies, the impact of caregiving on marital and sibling relationships, and the availability and use of formal (e.g., social services) and informal (e.g., community) resources. Although the questions were not explicitly categorized by ecological level during interviews, the data analysis applied the ecological model to systematically map responses.

Procedure

Following ethical approval from the academic institution, participants were recruited through the Little Steps Association for Children with DBMD, a nonprofit Israeli organization that supports families of children with DBMD. The association provides assistance with navigating health and welfare systems, accessing treatments and medications, and offering emotional and practical support.

Social workers affiliated with the organization contacted eligible parents and provided detailed information about the study. After receiving consent, participants signed a consent form either in person or via email. Interviews were conducted via Zoom, recorded with permission, and subsequently transcribed verbatim.

Ethical Considerations

The study received ethical approval from the Institutional Review Board of the authors' academic institution. All participants provided informed consent, and their anonymity and confidentiality were rigorously protected during data collection, transcription, analysis, and reporting.

Data Analysis

All interviews were recorded, transcribed, and analyzed by two independent researchers. Field notes were taken to capture non-verbal cues and researchers' impressions. The analysis followed three stages: Initial holistic reading of each transcript, during which researchers noted personal reflections and tentative codes. Comparison and segmentation into meaning units, followed by clustering into themes and sub-themes. Integration into a coherent thematic framework, aligned with Bronfenbrenner's ecological systems (Shkedi, 2003).

Although Bronfenbrenner's model was not predetermined as the analytic lens, it was adopted post hoc when it became clear that the emerging themes naturally aligned with ecological levels. Accordingly, the thematic analysis was structured around the microsystem, mesosystem, exosystem, and macrosystem.

Data were organized into ecological layers, capturing personal coping mechanisms (microsystem), family and relational dynamics (mesosystem), and institutional and community resources (exosystem and macrosystem). The chronosystem was used to account for changes in resources and challenges over time.

This structure allowed the researchers to present participants' narratives within a multi-layered ecological context, highlighting both distinct and interconnected sources of support. While the broader dataset included themes such as diagnosis, burden, and grief, the current paper focuses exclusively on support-related experiences. These were further categorized into personal, familial, and community-level resources, preserving participants' voices while offering a theoretically grounded representation.

Trustworthiness

To ensure rigor, credibility, and trustworthiness, the researchers implemented several strategies throughout the research process. Transparency was maintained in the data collection and analytic procedures, including clear documentation of recruitment, transcription, and coding processes. A research diary was kept by both researchers to record reflexive insights, impressions, and any potential biases that arose during interviews and analysis. The analysis was further strengthened by the use of extensive participant quotations, which grounded interpretations in the lived experiences of the interviewees and preserved the authenticity of their voices. To enhance analytical validity, two researchers independently coded the data, compared emerging categories, and resolved discrepancies through discussion. These collaborative engagements, which occurred throughout both the interview and analysis stages, contributed to the consistency and depth of the interpretive process, while minimizing the influence of individual researcher bias.

Findings

The analysis of interviews revealed three core types of support resources utilized by parents of children with DBMD: psychological, family, and social support, both formal and informal. Psychological resources included faith, a mindset of actively recognizing the good in life, and optimism. Family resources referred primarily to spousal support and assistance from extended family members. Social support encompassed a wide range of external resources, including community networks, professional caregivers, nonprofit associations, social services, and educational institutions. The following sections describe the key themes that emerged from the interviews, organized according to these categories.

Psychological Resources

Faith and spirituality emerged as significant coping mechanisms in four interviews (18%). Participants described their beliefs as a source of meaning, strength, and emotional structure in facing the challenges of caregiving. Rather than perceiving the condition as a punishment, several parents interpreted it as a divine mission or spiritual purpose. One father shared: “The belief that there is a Creator who determines everything, and He brought this into our lives and no one else… That’s what helped us cope” (Participant 9). He described a pivotal conversation with his rabbi, who had told him: “God entrusts such challenges specifically to those who can handle them… That perspective strengthened me.”

Other parents emphasized their trust in Divine Providence, with one stating: “I strongly believe that I am being guarded from above” (Participant 17), and another sharing: “Many times when I felt like collapsing, someone was always there to lift me up and help” (Participant 2). This belief system fostered a profound sense of gratitude and meaning, as reflected by one mother: “My outlook has shifted significantly toward genuine appreciation for what exists … truly thankful for what is” (Participant 14).

A mindset of actively seeking the good in life was another key theme, noted in four interviews. Parents described a deliberate effort to maintain positivity, even in the face of adversity. One mother reflected: “I look for the good in the bad. I don’t dwell on why it happened, or cry over misfortune. I am a fighter and believe it will be good” (Participant 19). Another parent emphasized the importance of self-care: “Regardless of the challenges, I made time for myself so I could be present with my children, without feeling overwhelmed” (Participant 6). This mindset led to a shift in perspective, encouraging genuine gratitude and a reevaluation of life priorities: “I realized I hadn’t fully valued what I had, but now I appreciate everything… Today my priorities are completely different” (Participant 18).

Optimism, expressed in four interviews, also emerged as a vital psychological resource. Parents intentionally nurtured a hopeful outlook, often drawing on advances in medicine and science. One participant explained: “We try to project more optimism than we feel … conveying it to our child, ourselves, and the researchers… The pace of medical progress is incredible” (Participant 4). Though the emotional toll was acknowledged, maintaining hope for change was viewed as essential. Another mother shared: “I am free-spirited and believe what will be will be, and I remain optimistic” (Participant 6), while another added: “I always hope for change, for new treatments, for improvement” (Participant 15).

Family Resources

Spousal support was identified as a key resource in five interviews. Parents described a fluid partnership, with roles shifting based on each partner’s emotional state. One father shared: “When I felt completely broken, she took charge… She lifted me up when I was truly devastated” (Participant 9). Another participant described their evolving dynamic: “Sometimes we held our emotions inside, other times we cried together… Sometimes I’m strong when he’s down, and other times he supports me” (Participant 4). One mother emphasized that coping together had actually strengthened the marital relationship: “Facing this together preserved our connection and deepened it” (Participant 18).

Support from extended family appeared in four interviews and revealed a mixed picture. Some participants reported ongoing, meaningful support from parents or siblings. One mother described: “My mother visits three or four times a week. She helps physically, emotionally, and even financially. She is still my main conversation partner” (Participant 12). Another expressed confidence in her support system: “My family is inclusive and supportive. I know I can count on them” (Participant 19). In contrast, others described strained or absent family connections. One mother shared painful interactions: “She manipulated me … criticized me… I felt like a burden… Even threats occurred” (Participant 16). Another parent reported: “I have no siblings. I received no help. The father’s side is completely uninvolved” (Participant 2). These narratives underscore the variability and emotional impact of extended family support—or lack thereof.

Social Support Resources: Formal and Informal

Informal community-based support emerged in six interviews as a vital resource. Parents described supportive neighborhoods, religious communities, and peer networks. One father recalled: “The community’s acceptance was amazing. People embraced us and offered help consistently" (Participant 4). Another shared how their rabbi encouraged marital resilience: "He said the most important thing was to maintain our relationship… They even arranged childcare so we could spend time together" (Participant 9). A particularly powerful connection was described by one mother: "A friend connected me with another parent of a child with Duchenne. She truly understood me. It was incredible" (Participant 17).

Professional caregivers were mentioned in seven interviews as transformative figures. One participant noted: "Before, there was no social life or work. Then the caregiver came. Everything changed. I began living again. I could focus on myself" (Participant 2). Another shared: "Our caregiver helps with night-time needs—that's enormous help" (Participant 7). Adjusting to caregivers was gradual for many: "We first called him a housekeeper… Later, he helped with lifting, and now he does personal care" (Participant 4). However, the experience was not without difficulties. One participant described: "The cost far exceeds the allowance we get" (Participant 12), while another remarked: "It's hard having someone in your home—it's an adjustment for the whole family" (Participant 8).

Formal services, including nonprofit organizations, emerged as critical resources. Eight interviews referenced a prominent Israeli nonprofit founded by parents of children with DBMD (referred to here as "the association"). One father described: "X, the social worker, visited us. She pulled us out of the darkness… Connected us to other families… That's when the pain began to ease" (Participant 9). Peer support within the association was emphasized as crucial: "Meeting other parents gave me strength. I wasn't alone anymore" (Participant 18).

The association also provided practical and emotional support, such as vacations, financial aid, support groups, and even a service dog (Participant 4). One parent concluded: "They focus on quality of life—for both children and families. Their work is extraordinary" (Participant 8).

Social services played a role in several cases. One participant described being referred to a family therapy center, where they received couple's therapy, parenting support, and group sessions: "They helped us work on emotional and behavioral aspects" (Participant 9). Another parent noted assistance from a resilience center and support from experienced parents (Participant 6).

Finally, educational institutions were noted in three interviews for their emotional and practical support. One mother highlighted: "The preschool staff knew our situation and were incredibly supportive. It helped me survive" (Participant 17). Another added: "My son receives emotional therapy through his special education preschool—it has been a blessing" (Participant 14).

Discussion

This study aimed to explore the support resources available to parents of children with DBMD and their role in fostering coping and resilience. While previous research has focused predominantly on the burden of treatment and caregiving responsibilities, this study contributes novel insights by examining how multi-level resources are perceived, accessed, and mobilized in the daily lives of caregiving families. Unlike caregivers of children with more stable or less physically demanding conditions, parents of children with DBMD must navigate a trajectory of ongoing loss, anticipatory grief, and increasing physical and emotional dependency. The rarity of DBMD compounds these challenges by limiting public awareness, narrowing available services, and necessitating the pursuit of highly specialized, often fragmented, support.

These experiences differ markedly from those of parents coping with more common conditions, due to the distinct emotional, physical, and systemic demands associated with progressive neuromuscular disease. The findings reflect critiques of the classic nested model of ecological systems, instead supporting a networked conceptualization (Neal & Neal, 2013), in which institutions, individuals, and informal networks interact in dynamic and sometimes disjointed ways. Parents are required to navigate overlapping, contradictory systems rather than progressing neatly through contained layers.

Using Bronfenbrenner's ecological model, the findings were organized across five ecological system levels. At the personal level, faith, optimism, and gratitude emerged as vital psychological resources. These coping mechanisms provided emotional grounding and meaning, helping parents manage ongoing uncertainty. While not universally present across all interviews, faith was a salient theme for some and aligns with prior findings on spirituality's role in coping with childhood illness. In the Israeli context, where religious and secular identities coexist, spiritual coping may be especially pronounced among religiously observant populations. For those participants, faith functioned not only as a microsystemic psychological anchor but also intersected with mesosystemic structures like community or religious institutions.

The role of psychological resilience, including positive reframing, emotional regulation, and meaning-making, aligns with Lazarus and Folkman's (1984) theory of stress and coping. Participants often reinterpreted their caregiving responsibilities as purposeful and value-aligned, reinforcing a sense of agency and coherence. These strategies were also highlighted in prior studies (Boettcher et al., 2020; Hartley et al., 2021), which noted that optimism and cognitive flexibility serve as emotional buffers in unpredictable caregiving contexts.

Familial resources, though less emphasized in this sample, still played an important role. Spousal support and shared caregiving responsibilities offered emotional relief and reduced isolation. However, the intensity and progression of DBMD caregiving often overwhelmed family systems, requiring external buffering from mesosystem and exosystem structures. When these external supports were fragmented or inconsistent, families' internal resources were stretched thin, compounding distress and undermining resilience (Swick & Williams, 2006).

Consistent with Schwartz et al. (2021), progressive caregiving burden impacted multiple domains of health-related quality of life, including mental health, social engagement, and occupational functioning, reinforcing the necessity of external structural support.

At the mesosystem level, relationships with schools, therapeutic services, and nonprofit organizations played a central role. Organizations such as *Little Steps Association* functioned as coordinating hubs, linking families to emotional, social, and material resources. While these institutions were often described positively, integration between them was limited. For example, collaboration between schools, social services, and healthcare was rarely described, suggesting structural fragmentation. This observation echoes Neal and Neal's (2013) claim that system effectiveness depends not just on structure but on the quality of relationships between systems.

At the exosystem level, broader institutions, including welfare services, insurance agencies, and ministry-level policy, shaped access to resources. Parents were often required to navigate multiple disconnected systems, leading to bureaucratic strain and missed opportunities for holistic care. Nonprofits also operated at this level when shaping policy, funding, and systemic design.

The lack of coordination among these systems highlights the limitations of current support frameworks. Previous work (Hartley et al., 2021; Porteous et al., 2021) similarly notes that integrated support networks reduce caregiver burden, whereas fragmentation exacerbates stress and role overload.

At the macrosystem level, societal norms, religious values, and public policy framed caregiving expectations. In Israel, where community ties and religious meaning-making are prevalent in many populations, these macro-level constructs informed both help-seeking behaviors and perceptions of support.

Although not consistently articulated by participants, the chronosystem was evident through references to disease progression, developmental transitions, and shifting resource access. This layer serves as a dynamic, temporal system that influences all others, shaping how families adapt over time to changing caregiving demands (Neal & Neal, 2013; Swick & Williams, 2006).

Limitations of the Study

While this study offers important insights, several limitations must be acknowledged. All participants were engaged with the Little Steps Association, which may have excluded perspectives of families who do not utilize formal services or remain disconnected from such organizations. Therefore, the findings may not represent the full range of parental experiences, particularly among those relying solely on informal networks or avoiding institutional involvement.

The sample was also gender-imbalanced, with 19 mothers and only three fathers, limiting the analysis of paternal perspectives. Additionally, the overrepresentation of Jewish participants (21 of 22) reduced cultural and religious diversity, possibly omitting alternative coping strategies used in other communities.

Finally, the limited reference to social workers in participants' narratives calls for further research into their involvement in caregiving support. Future studies should examine how families perceive and utilize social work services, and what barriers may exist to accessing this professional resource.

Implications for Policy and Practice

The findings hold several implications for social work practice and policy development. First, early involvement of social workers in the caregiving trajectory can be critical.

These professionals can assist families in navigating bureaucratic systems, identifying resources, and offering emotional support. Greater visibility and engagement of social workers within multidisciplinary care teams is warranted.

Second, interventions should address both emotional resilience and practical caregiving support, including expanded access to respite care, peer groups, and therapeutic services. Allocating additional funding and personnel can reduce caregiver strain and enable more sustainable caregiving environments.

Third, policymakers should prioritize inter-system collaboration, particularly among welfare, health, and education sectors. Social workers can play a coordinating role in facilitating these partnerships, ensuring that families receive cohesive and continuous support.

Fourth, cultural sensitivity is vital. The role of faith, tradition, and community in coping must be integrated into intervention design, particularly in diverse populations. Tailoring services to align with cultural and religious values can enhance their accessibility and relevance.

Finally, training and support for informal caregivers, such as extended family and community members, should be institutionalized. This would allow for shared responsibility and increase the family's capacity to cope. Revisiting resource allocation policies to accommodate the unique demands of DBMD caregiving is essential.

Conclusion

This study offers a nuanced, ecologically grounded perspective on how parents of children with DBMD in Israel utilize personal, familial, and community-based resources to cope with caregiving challenges. The findings support the value of Bronfenbrenner's ecological model for mapping support systems and identifying gaps in service provision.

Key takeaways include the need for coordinated support networks, early social worker involvement, and culturally tailored interventions that integrate personal meaning-making and community values. While psychological and familial resources remain central, they are insufficient without accessible, integrated formal support systems.

Future research should examine families not engaged with nonprofit organizations and explore systemic barriers to accessing services. Policymakers and practitioners must work toward multi-level, coordinated responses that reduce fragmentation and enhance resilience in families managing rare, progressive conditions like DBMD.

Ethics

Ethical approval for this study was granted by the Institutional Review Board of Tel-Hai University on the Rise, Israel (approval number: 19-1/2024).

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ORCID iDs

Siwar Makhoul Khoury https://orcid.org/0000-0002-1789-8588
Ayelet Gur https://orcid.org/0000-0002-5764-0653

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