

Research Article

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Family Preparedness for Future Educational and Life Transformations in Caring for Children with Down Syndrome from the Perspectives of Saudi Mothers: A Qualitative Study

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Abstract

Background/purpose. The presence of a child with Down syndrome poses increasing challenges for families, where psychological and social burdens intersect with daily caregiving demands, imposing added pressures on mothers. Although global interest in studying these issues has grown, local research in Saudi Arabia remains limited, particularly regarding family readiness for future educational and life changes. This study therefore explores how Saudi mothers perceive preparedness for future educational and life transitions, within local social and cultural contexts, providing scientific insights to inform family-oriented support programs and enhance overall well-being.

Materials/methods. A qualitative design was employed, based on semi-structured interviews with fifteen Saudi mothers of children with Down syndrome. Data were collected using open-ended questions exploring family preparedness for future educational and life transformations, and were analysed through thematic analysis to identify core patterns and meanings.

Results. Findings revealed that mothers' perceptions of preparedness for future educational and life transformations consolidated into a single overarching theme, from which two sub-themes emerged: the need for supportive community awareness and the call for sustainable family initiatives.

Conclusion. The study highlights that strengthening community awareness and developing sustainable family initiatives are essential to supporting mothers' well-being and thereby improving future educational and life care for children with Down syndrome.

1. Introduction

Down syndrome is the most common chromosomal disorder among live births. It represents a major cause of intellectual disability in children, affecting their academic and social development (Dalrymple et al., 2022). Moreover, its impact extends to multiple body systems, including the nervous and muscular systems, and is frequently associated with congenital heart defects that complicate healthcare (Mahmood & Gul, 2023). In addition, children with this condition often face further challenges, such as sleep apnea, epilepsy, and impaired hearing and vision, requiring comprehensive interventions (Chiracu et al., 2023).

On the other hand, Marchal et al. (2017) emphasized that the distinctive physical traits of children with Down syndrome often attract excessive peer attention, thereby influencing their social adjustment. In contrast, Gashmard et al. (2020) noted that this group faces persistent psychological and social challenges that clearly interfere with their daily participation and affect their emotional balance. Consequently, their slower developmental trajectory compared with peers requires comprehensive and sustainable care that addresses health, educational, and social needs while strengthening opportunities for long-term community inclusion (Soltani & Esbensen, 2024).

Although children with Down syndrome vary in abilities, developmental barriers and health issues often curtail independence and reduce everyday social participation significantly (Alqahtani et al., 2024). Accordingly, Waugh et al. (2025) reported that the severity and persistence of these conditions across stages shape trajectories, creating challenges and caregiving burdens that families must navigate. Based on this, Mohammed Elmwafie et al. (2022) indicated that delayed development requires care and ongoing support, as slow progress hampers functioning and increases reliance on caregivers.

The literature indicates that Down syndrome is recorded globally at nearly ten cases per 10,000 live births, highlighting its prevalence (Shahzad & Manzoor, 2025). In Saudi Arabia, estimates show one case per 554 live births (Alqahtani, 2022). This prevalence in Saudi Arabia is influenced by several factors, notably the religious prohibition of abortion, which sustains pregnancies despite possible diagnoses (Alabri, 2023). Moreover, cultural and social practices encouraging childbirth at advanced maternal ages, particularly into the forties, further elevate prevalence within the community (Yaman et al., 2025).

Furthermore, improvements in healthcare services have reduced infant mortality, including among children with Down syndrome, thereby enabling longer life expectancy and greater survival opportunities (Alabri, 2017). However, alongside this progress, families increasingly face challenges in planning for the future and securing long-term care, particularly given limited resources and specialized knowledge (Goldie et al., 2024). Globally, individuals with Down syndrome experience persistent service and participation gaps, which are intensified by inadequate community awareness and the absence of sustainable supportive initiatives (McGlinchey et al., 2025).

Despite the growing body of international research on Down syndrome, existing studies rarely examine how families prepare for future transitions, particularly within cultural contexts where social norms and community expectations strongly shape caregiving. In the Saudi context, the scarcity of qualitative research exploring mothers' lived experiences creates a notable gap in understanding how families navigate long-term planning, future uncertainty, and the cumulative physical and emotional burdens of caregiving.

This lack of focused investigation creates a clear research gap, particularly concerning how Saudi mothers interpret future responsibilities, anticipate developmental changes, and manage the interplay between cultural expectations, social pressures, and limited institutional support.

Addressing this gap is essential for developing contextually relevant policies and programs that strengthen preparedness and enhance long-term family stability.

Building on the preceding discussion, there is a clear need to prioritize community awareness and sustainable family-based initiatives that support mothers caring for children with Down syndrome, particularly within the unique cultural and social fabric of Saudi society. Although international literature has increasingly addressed this issue, local research remains limited, revealing a persistent knowledge gap that warrants careful exploration from mothers' perspectives. Accordingly, this study aims to examine how Saudi mothers perceive family preparedness for future transitions in their children's care, within contexts that shape both everyday experiences and future expectations. Through this inquiry, the study seeks to generate applied knowledge to inform the development of more effective psychological, social, and rehabilitative support programs, while also producing practical insights to guide policies aimed at improving maternal well-being and ensuring positive outcomes for children and families in the present and the future.

2. Literature Review

The absence of community awareness of Down syndrome creates challenges for mothers, since misinformation perpetuates stereotypes and consistently increases psychological burdens over time. In this context, Alenazi et al. (2025) found that Saudi society holds supportive perceptions, though misconceptions remain, necessitating more consistent, targeted awareness campaigns. Fani et al. (2025) highlighted that higher maternal awareness and faith improve family adaptation, enabling mothers to manage caregiving stress more effectively. Similarly, Steffensen et al. (2024) showed that insufficient community understanding exposes children to harmful labeling, doubling emotional burdens on mothers, and lowering overall quality of life. Ross et al. (2025) emphasized that lacking institutional support heightens psychological stress, limiting mothers' adaptability and hindering effective coping with daily caregiving demands. On the other hand, Alshadfan et al. (2025) reported that limited awareness heightens stress, weakening mothers' participation in teaching responsibilities and overall caregiving tasks. Therefore, Asa et al. (2021) concluded that stronger maternal awareness of laws and resources reduces stress, enhances family stability, and maintains overall household balance.

Community education programs provide a crucial foundation for changing attitudes and behaviors by strengthening awareness, eliminating misconceptions, and promoting long-term understanding. Accordingly, Lima-Rodriguez et al. (2022) emphasized that improved educational achievement enhances mothers' psychological adjustment, confirming learning as a key resource for alleviating stress. Yazicioğlu et al. (2024) showed that greater self-efficacy supports maternal well-being, linking it to higher satisfaction levels and greater stability in emotional functioning. From this perspective, Musyafa'ah et al. (2024) highlighted that community environments broaden mothers' understanding of rights and parenting, thereby creating socially conscious and supportive surroundings. Moreover, Chow et al. (2025) found that awareness programs reduce financial and emotional burdens, enabling mothers to continue adapting and improving their daily lives. In the same context, Shewaikani et al. (2025) emphasized that digital platforms and school initiatives enhance youth awareness, encouraging more inclusive attitudes and broader acceptance. Nevertheless, AbuAlhommos et al. (2025) noted that integrating caregiving with family duties enhances mothers' skills, strengthens their social involvement, and enriches daily experiences.

Moreover, the lack of institutional support heightens mothers' psychological and social pressures, making child care with Down syndrome an ongoing burden. In this regard, McGlinchey et al. (2025) found that negative perceptions associated with institutional gaps limit mothers' access to fair, respectful services. On the other hand, Chiracu et al. (2023) explained that supportive environments and effective coping tools enhance mothers' self-efficacy and improve emotional

balance. Similarly, Shahali et al. (2024) emphasized that limited awareness leads to insufficient services, which significantly worsen families' financial and social burdens. In the same context, Jogu et al. (2023) indicated that limited awareness heightens guilt and isolation, while education programs foster psychological support. It is also evident that parental training and education on future caregiving strengthen adaptive mechanisms, thereby supporting families' roles more effectively (Sharifian et al., 2024). Likewise, Desimpelaere et al. (2024) noted that specialised social support networks reduce isolation and stigma and improve sustained maternal psychological adjustment.

Although community support is crucial, sustainable initiatives provide financial and institutional backing that protects families from excessive pressures and fosters reassurance across time. Zhang et al. (2025) clarified that raising a child with Down syndrome alongside siblings increases stress, necessitating consistent institutional interventions that continuously support mothers effectively. De La Garza et al. (2024) emphasised that caregivers require sustainable, long-term programs that alleviate accumulated burdens, maintain household balance, and strengthen overall family resilience. Ranta et al. (2025) noted that psychological and educational programs reduce maternal stress by offering effective coping strategies that sustainably enhance quality of life. Mendoza-García et al. (2025) highlighted the need to design comprehensive programs that go beyond children's needs to support mothers, thereby reducing strain and promoting sustainable family stability. Stafford et al. (2024) indicated that including individuals with disabilities ensures justice, supports sustainable community development, and consistently enhances families' living standards. Shetty et al. (2023) argued that without sustainable financial initiatives, households encounter greater burdens, facing medical expenses without proper planning or sufficient institutional support.

Moreover, sustainability initiatives that emphasize family interaction and ongoing support help mothers adopt better parenting practices, strengthen bonds, and reduce daily emotional strain. Goldie et al. (2024) highlighted that early future planning during transitional stages consistently improves parental readiness, reduces unmet needs, and enhances overall family stability. Villaescusa et al. (2021) emphasised that a comprehensive, family-centred approach involves all family members, improves quality of life, and effectively reinforces long-term household stability. Nevertheless, Gashmard et al. (2020) found that fostering children's self-reliance decreases caregiving burdens, providing mothers with reassurance about future challenges and greater social adaptability. Similarly, Fucà et al. (2022) indicated that the absence of sustainable family initiatives depletes resources, weakens opportunities for inclusion, and necessitates long-term, supportive programs urgently. In this context, Noroozi et al. (2024) explained that linking mothers' lives to their children reshapes roles, redefines priorities, and strengthens sustained adaptability. Furthermore, Jamir Singh et al. (2023) emphasized that optimism and perceived benefits serve as coping strategies, improving personal growth and relationships, and sustaining positive mental health.

When families lack sustainability programs, including funding, guidance, and respite opportunities, caregiving becomes a constant psychological burden that disrupts healthy household routines. This was shown by Luetke Lanfer et al. (2025), who found that the absence of sustainability correlates with stigma, isolation, and the accumulation of psychological burdens. Marchal et al. (2017) confirmed that sustainable programs supported by effective community networks strengthen family stability and enhance their capacity to manage developmental challenges. Similarly, the lack of sustainable initiatives during transitional life stages leaves mothers unprepared and increases the accumulated social and psychological burdens they face (de Paor et al., 2025). Therefore, Herman et al. (2023) indicated that sustainable community initiatives serve as a foundation for inclusion, promoting equality, fairness, and societal development for families. Since the birth of a child with developmental disability doubles burdens, addressing it requires continuous support systems and practical coping strategies (Shahzad & Manzoor, 2025). Correspondingly, maternal preoccupation

with uncertain futures elevates stress levels and heightens feelings of responsibility, which are intensified by accumulated social and cultural pressures (Mahmood & Gul, 2023).

3. Methodology

3.1. Study Design

A qualitative approach was considered appropriate for research that aims to explore human experiences in depth, uncover individual perceptions, and construct interpretations grounded in the natural contexts of phenomena, thereby providing researchers with greater flexibility in understanding and interpreting reality (Creswell, 2009).

Building on this orientation, the present study employed a qualitative, exploratory design, well-suited to examining complex social and familial experiences that have not been extensively investigated in prior research. This design was selected because exploratory qualitative studies are particularly effective in contexts with limited empirical work, allowing the researcher to explore participants' perspectives without imposing predetermined theoretical boundaries.

The study was situated within interwoven social, cultural, and familial contexts that reflect the nature of these experiences and help clarify their dimensions more comprehensively (Maxwell, 2013).

To guide the analytic process, the study adopted Thematic Analysis as the methodological framework. The use of Thematic Analysis aligned naturally with the exploratory design, as it enabled the identification of patterned meanings across mothers' narratives while still preserving the openness required to capture unanticipated insights.

Semi-structured interviews were employed as the primary data collection tool because they strike a balance between methodological rigour and practical flexibility. This approach allowed participants to express their perspectives freely, yielding rich qualitative data that deepened understanding of the caregiving roles mothers undertake (Cohen et al., 2011).

3.2. Sampling Strategy

This study employed a purposive sampling strategy to recruit mothers through a center for special education and rehabilitation in Dammam, located in the culturally diverse Eastern Province of Saudi Arabia. The approach focused on involving mothers most closely connected to the study's objectives, while ensuring diversity in their social backgrounds to capture varied family experiences, thereby enhancing the comprehensiveness and quality of the data.

The inclusion criteria were developed in coordination with the center's supervisor, specifying that participating mothers must be responsible for the care of a child diagnosed with Down syndrome between the ages of six and sixteen. Additional requirements included the mother's agreement to participate in individual interviews and obtaining spousal consent in line with local social norms. Mothers who did not meet these criteria were excluded to ensure a sample capable of providing rich, relevant qualitative insights.

Mothers were chosen specifically because of their central role in caregiving and household management within Islamic societies (Murray & Lawrence, 2000). Conducting field research with women in Saudi Arabia is often shaped by complex cultural and social considerations; however, the researcher's professional connection with the center's supervisor, combined with prior familiarity with some mothers, facilitated access to participants and fostered the trust essential for effective data collection.

In total, fifteen mothers participated, providing authentic qualitative accounts that reflected realities embedded in the local context. Collaboration with the centre enabled recruitment of

additional participants if needed. However, the fifteenth interview reached data saturation, consistent with Guest et al. (2006), who noted that key themes typically emerge in the earliest interviews and the twelfth interview often achieves that saturation.

3.3. Ethical Considerations

The study commenced following approval from the Ethics Committee at King Faisal University and official authorization from the Center for Special Education and Rehabilitation. To ensure smooth procedures and overcome potential barriers, the researcher coordinated with the centre's administration, which already maintained the mothers' contact information, thereby enabling preliminary phone calls and introductory meetings to explain the study's objectives and clarify the participation process. All mothers provided informed oral consent, as written signatures were deemed culturally inappropriate due to sensitivities associated with official documentation that conflicted with local privacy norms.

Data confidentiality was safeguarded by assigning unique identification codes to each participant and by avoiding the recording of any direct personal information. Mothers were informed that all data would be used exclusively for scientific research purposes, with strict assurances of anonymity. It was also emphasized that participation was entirely voluntary, with the introductory meetings clarifying the study's objectives and the potential benefits for families and the community. Furthermore, mothers were encouraged to raise questions at any stage, and the researcher committed to providing transparent answers, while reminding them of their right to withdraw at any time without consequences.

3.4. Data Collection Procedures

Face-to-face interviews were carefully and systematically conducted with mothers from diverse social, cultural, and educational backgrounds, whose children with Down syndrome varied considerably in terms of gender, health conditions, developmental needs, and psychological status. Semi-structured interviews were deliberately chosen because they offer a well-recognized balance between flexibility and structure, enabling participants to express their experiences and perspectives with greater clarity, comfort, and authenticity. This comprehensive approach yielded detailed, nuanced qualitative data, ultimately providing a robust, reliable foundation for understanding family preparedness for future transformations within the specific local social and cultural context (Patton, 2002).

A total of 12 semi-structured interview questions were used to guide the conversations. In this study, the primary data-collection instrument was a structured interview guide developed directly from the study objectives and reviewed by field experts to ensure clarity and relevance. These questions were organized into four key areas that reflected the core dimensions of the mothers' experiences: (1) their perceptions of community attitudes and daily interactions, (2) the challenges encountered in accessing supportive environments and services, (3) the strategies they employ to strengthen their families' long-term stability, and (4) their expectations for the future and the forms of support they believe are necessary to secure their children's well-being. Additional probing questions were asked when clarification or deeper reflection was needed.

Despite the flexibility offered by this method, the researcher adhered to a structured framework based on guiding questions that explored family preparations, the role of social support, and its impact on the family. Additional probing questions were employed to uncover aspects not initially addressed or that required further clarification, thereby enhancing both the depth and breadth of the data. The shared cultural background between the researcher and the participants further facilitated sensitivity to moments of hesitation and respectful engagement, thus strengthening the credibility of the results and enriching the interpretations drawn from the interviews.

From an organisational perspective, the interviews lasted between 25 and 35 minutes. Due to cultural and personal considerations for some mothers, audio recording was not requested, in line with Patton (2002), who noted that avoiding electronic devices can foster a more comfortable and open atmosphere. Consequently, the researcher documented responses manually and systematically, and participants were allowed to review their transcripts to ensure accuracy and resolve any ambiguities (Chong, 2008). It was also clarified that selected excerpts would later be translated into English and included in the study, thereby reinforcing transparency and trustworthiness.

3.5. Data Analysis

The textual data were transcribed from the mothers' interviews into an electronic file using Microsoft Word. To ensure confidentiality, each participant was assigned a unique identification code instead of personal information. The files were stored securely on the researcher's password-protected computer, with an additional encrypted backup on cloud storage, thereby safeguarding data security and ensuring anonymity throughout all stages of the study.

Thematic analysis was adopted as the primary analytical framework (Hammersley & Atkinson, 2007). The analysis followed the established phases of thematic analysis, including data familiarisation, systematic coding, generating initial themes, reviewing and refining thematic patterns, and producing the final thematic structure, thereby ensuring analytic rigour and transparency. The process of examining transcripts began immediately after each interview, enabling the identification and follow-up on emerging issues in subsequent sessions. This iterative approach facilitated the progressive refinement of preliminary patterns as data accumulated. Repeated engagement with the material further enriched the analytical reading and facilitated the development of findings more closely aligned with the mothers' sociocultural context (Ritchie & Spencer, 2002).

As Hammersley and Atkinson (2007) emphasize, thematic analysis is a dynamic process that requires continuous movement between the transcripts and emergent ideas. This was applied through manual coding, whereby data were categorized into an overarching theme and interrelated sub-themes. This method facilitated the identification of similarities and differences across mothers' experiences and allowed for the testing and progressive refinement of preliminary concepts into more coherent and stable patterns.

To illustrate the analytical process, responses related to community awareness were categorised under the sub-theme The Need for Supportive Community Awareness, while accounts reflecting mothers' perspectives on securing their children's future were placed under the sub-theme The Call for Sustainable Family Initiatives, both of which emerged from the overarching theme Family Preparedness for Future Transformations. Table 1 presents the detailed coding framework, outlining the core theme, its associated sub-themes, and the number of interviewees linked to each sub-theme.

Table 1. Data analysis: coding the data

Core Theme	Sub-themes	Interviewee number
Overarching Theme: Family Preparedness for Future Transformations	Sub-theme 1:	2, 4, 7, 8, 9, 11, 12, 14, 15
	The Need for Supportive Community Awareness	
	Sub-theme 2:	1, 3, 4, 5, 6, 7, 9, 10, 13
	The Call for Sustainable Family Initiatives	

3.6. Qualitative Trustworthiness

This study adopted a qualitative framework, using semi-structured interviews as the primary data collection tool. To ensure the rigor and reliability of its findings, it was guided by the well-established model of Lincoln and Guba (1985), one of the most widely recognized frameworks for assessing quality in qualitative research. This model emphasizes four central criteria: "credibility", "dependability", "confirmability", and "transferability".

To begin with, "credibility" was strengthened through the use of "member checking, which allowed each participant to review, revise, or expand her interview transcript prior to its inclusion in the final analysis. Moreover, the principle of "purposeful diversity" guided the selection of participants, ensuring the involvement of mothers from a wide range of social, economic, and educational backgrounds, and those with both male and female children, thereby reflecting a broad spectrum of experiences.

In addition, "dependability" was maintained by adhering to consistent procedures documented through a detailed "audit trail" that outlined each stage of the research process, from the design of interview questions to data collection and subsequent analysis. Alongside this, and consistent with the practice of "peer debriefing, the interview guide was reviewed by the center supervisor as well as by consultants from comparable institutions, ensuring alignment with the study's objectives and sensitivity to the cultural and social context of Saudi mothers.

Similarly, "confirmability" was enhanced by incorporating "direct quotations" from participants' narratives, thereby supporting transparency and strengthening confidence in the findings. In addition, analytic rigour was strengthened through analyst triangulation, in which coding decisions and emerging thematic patterns were reviewed and discussed with experienced qualitative researchers to ensure consistency and minimise subjective bias. At the same time, "reflexivity" was applied, as the researcher acknowledged his position as a father of a child with Down syndrome, while deliberately minimizing the potential influence of this personal connection and ensuring that interpretations remained grounded in the data.

Finally, "transferability" was increased by providing a "rich description" of the Saudi context, including cultural and social dynamics that shape mothers' lived experiences. Furthermore, the discussion noted the unique contribution of major institutions, such as Aramco, in supporting community initiatives. The inclusion of a "diverse sample"—varying in children's ages, gender, functional abilities, and mothers' backgrounds—further strengthened the applicability of the findings to comparable cultural settings, both regionally and internationally.

4. Results

4.1. Overarching Theme: Family Preparedness for Future Transformations

The future represents a source of both concern and aspiration for Saudi mothers raising children with Down syndrome. Their narratives revealed a growing awareness of the importance of proactive planning and adaptation to potential changes, whether related to the child or to the family as a whole. The accounts also expressed a combination of worries linked to economic and social challenges and a strong desire to build a more stable family life within complex cultural and social contexts.

From this perspective, the present study centers on family preparedness for future transformations as the overarching theme for understanding maternal perceptions. The thematic analysis revealed two sub-themes within this overarching theme. The first highlights the need for community awareness that fosters a more inclusive and informed environment. In contrast, the second emphasizes the need for sustainable family initiatives that enable mothers to navigate future transformations with resilience and confidence.

4.2. Sub-theme 1: The Need for Supportive Community Awareness

Some mothers explained that the community's limited awareness of Down syndrome continues to hinder their children's natural integration. They often encounter looks of pity or neglect, which cause psychological strain, deepen the family's sense of isolation, and reduces opportunities for constructive interaction. *"Society still needs greater awareness of Down syndrome and respect for our children as individuals. While Aramco provides activities that my son enjoys, it is equally important for other parties to share in providing support"* (Mother: 8).

In this regard, some mothers pointed out that weak public awareness of Down syndrome leads to negative situations that reduce their children's opportunities for daily inclusion. At times, they are subjected to ridicule or disregard, leaving painful psychological effects that reinforce the family's social isolation. *"My daughter was sitting outside the supermarket waiting for me when suddenly a group of children laughed at her. I felt disturbed and helpless, unable to intervene; the situation was strange, painful, and left us deeply upset"* (Mother: 11).

Other mothers endorsed this view, emphasizing that the community's lack of understanding of Down syndrome characteristics restricts children's communication and results in frustrating experiences for families. The absence of positive interaction undermines children's self-confidence and places increasing burdens on mothers striving to integrate their children into daily life. *"Sometimes my daughter tries to start a conversation with neighborhood children, but they never respond. I see her joy vanish before my eyes, replaced by sadness and confusion. I feel helpless, unable to ease her painful disappointment"* (Mother: 4).

Based on these accounts, several mothers argued that the absence of official awareness initiatives concerning Down syndrome increases families' isolation and leaves society less prepared for engagement. Limited knowledge restricts opportunities for inclusion and highlights the urgent need for institutional programs that raise awareness and support family stability amid challenges. *"Not many people know about my daughter's condition, and I believe that institutions and municipalities should raise public awareness. Displaying informative boards in the streets to explain Down syndrome to people could significantly change public perceptions"* (Mother: 15).

In another context, some mothers noted that direct dialogue and openness with others can improve societal perceptions of children with Down syndrome. They emphasized that the issue is not intentional rejection but rather lack of understanding, and that openly describing the pressures they face may help shift prevailing attitudes. *"I believe society is kind to my daughter, but the lack of a true picture makes some people misunderstand. If we explain what we experience, I am confident we will receive positive responses and genuine support"* (Mother: 7).

Building on this, some mothers considered that involving children in social activities is an important avenue for challenging stereotypes and boosting their self-confidence. Being present in diverse situations helps break isolation and provides families with opportunities to test societal reactions more realistically and with greater reassurance. *"My daughter participated in National Day activities instead of staying at home, and the experience was remarkable. People welcomed her with smiles; she felt immense joy, and I too felt reassurance and pride in her participation"* (Mother: 9).

In a similar vein, some mothers emphasised that involving children in family gatherings fosters a sense of acceptance and strengthens their connections with relatives. Such gatherings are not simply moments of enjoyment but also reinforce their integration and reassure families about their children's current and future social well-being. *"I took my son to meet his cousins, and he spent a joyful time laughing and playing. These moments bring him happiness and strengthen his belonging, while being deprived turns his joy into sadness and painful frustration"* (Mother: 12).

Some mothers also believed that field-based awareness programs can effectively change negative perceptions associated with Down syndrome, especially among school students. Direct engagement breaks down barriers, creates space for dialogue, raises awareness of children's true abilities, and increases families' confidence in their potential for inclusion. *"I joined other mothers in visiting a school to raise awareness about Down syndrome. The students knew little of my daughter's abilities, and many repeated 'Mongolian.' After the session, they showed empathy and real enthusiasm to participate"* (Mother: 14).

With the same spirit, some mothers emphasized that accepting God's will and trusting in His care provide inner strength to face challenges with resilience. The certainty that having a child is a blessing, combined with reliance on God in all circumstances, fosters reassurance that sustains families and motivates confidence. *"I thank God for my son in my life, for he gives me motivation to continue. I manage my responsibilities with confidence, invest my time in what benefits us, and strive to live in peace and reassurance"* (Mother: 2).

4.3. Sub-theme 2: The Call for Sustainable Family Initiatives

Some mothers believe that true reassurance is achieved when continuity of care is guaranteed even after the parents' presence ends. A stable life for the child depends on having someone who safeguards their interests, stands beside them, and provides full protection—something that alleviates ongoing anxiety about the future. *"I feel a dignified life is not only about the present, but my daughter must have a future that preserves her dignity. What matters most is her care, ensuring she never faces an uncertain fate"* (Mother: 10).

In the same tone, some mothers observed that concerns about the future remain constant in their minds, as they serve as the primary guarantee for their children's comfort when parents are absent. Their insistence on practical solutions and long-term planning reflects their determination to build family stability that reduces anxiety. *"My daughter's future preoccupies me, and I believe every mother in my situation seeks a safe path forward. I strive to provide her with reassurance and security, so she remains well and protected regardless of changing circumstances"* (Mother: 7).

From another angle, some mothers argued that current educational services remain limited, and available alternatives fail to meet children's real needs. They stressed that the absence of comprehensive programs heightens anxiety and makes developing educational institutions essential to ensure a more secure and stable future for their children. *"I believe inclusive schools for children with disabilities do not give my son the support he deserves, as resources are limited. Special institutes were better. I hope for their return, offering clearer opportunities than ineffective inclusion"* (Mother: 13).

In this context, some mothers explained that sustainability can only be achieved through long-term initiatives that ensure continuous support for children. They emphasised that individual programs, however valuable, remain limited, whereas institutional initiatives can ensure services, provide families with stability, and strengthen society's confidence in the future. *"I propose creating an endowment for children with Down syndrome in Saudi Arabia, to support state efforts for a stable life for my daughter and peers. I believe sustainability is achieved when businessmen join official initiatives"* (Mother: 9).

In a related perspective, some mothers expressed their conviction that continuous development is a key factor in reinforcing trust in the future. They highlighted the importance of reviewing policies and ensuring their regular renewal as part of families' demands to build a more stable reality for their children. *"I believe continuous reviews of regulations are essential to give my daughter a stable future and to guarantee children with Down syndrome a dignified life and family support. Such reviews reassure us their rights will not vanish"* (Mother: 4).

In a similar vein, some mothers emphasised that clear, family-oriented legislation represents a pivotal step toward stability. A dedicated legal framework reflects official recognition of challenges, provides practical protection for families, and instills confidence that their future will not remain dependent on individual initiatives or temporary programs. *"I believe family-focused laws are crucial, as they protect our rights and help me care for my son safely. Knowing there is a system that meets his needs and ensures his care reassures me"* (Mother: 5).

In this regard, some mothers stressed that no matter how comprehensive current systems may appear, they still require ongoing renewal, as rapid social changes demand updated solutions. Continuous institutional development ensures greater stability and gives families a sense that their concerns will not remain stuck in rigid procedures. *"I feel disability laws do not make it easy to meet our daily needs, and this exhausts me with my son. We need renewal that clarifies the future and gives us the capacity to adapt, avoiding obstacles"* (Mother: 3).

Accordingly, some mothers noted that reassurance is linked to stable conditions that benefit the entire family. The more a supportive environment fosters comfort, the more families realise that their efforts are meaningful and that their future can hold greater balance and tranquillity. *"My happiness comes from seeing my daughter content in her daily life, which gives me the motivation to continue. Her comfort defines my own, and it reassures me that our family can live in peace"* (Mother: 1).

In a connected expression, some mothers emphasized that the value of family bonds lies in their ability to foster an environment of warmth and support. The affection children receive contributes to their growth and provides reassurance and stability that make families more confident about the future. *"My joy is seeing my daughter with her siblings, receiving their affection and sharing moments of happiness. I hope her life remains free from sorrow and continues in cheerful surroundings that bring me peace and comfort"* (Mother: 6).

5. Discussion

5.1. Family Preparedness for Future Transformations

This discussion aims to provide an in-depth interpretation of the study's findings and situate them within the relevant literature, thereby offering a broader understanding of Saudi mothers' experiences in caring for children with Down syndrome. The discussion expands the implications of the results and highlights their contribution to advancing scholarly knowledge on family preparedness for future transformations and related aspirations. Moreover, the present analysis offers a structured synthesis of the findings, clarifying how mothers' narratives collectively illustrate the multidimensional nature of family preparedness. In addition, the study contributes a culturally grounded perspective that enriches global discussions on family preparedness by highlighting experiences unique to the Saudi context.

Within this overarching theme, two interrelated sub-themes emerged, each reflecting a distinct dimension of the mothers' perspectives. The first concerns the extent of societal interaction with the family and the child, and how this translates into opportunities for inclusion or feelings of isolation. The second centres on pursuing more sustainable pathways that ensure continuity of care and promote family balance and long-term stability. These two sub-themes will be examined in light of the relevant literature. This structured organization of themes further strengthens the interpretive depth of the findings and highlights their alignment with broader conceptual models in the field.

5.2. The Need for Supportive Community Awareness

Findings from this study highlight that a limited societal understanding of the needs of children with Down syndrome, combined with insufficient knowledge about the condition, imposes heavier psychological burdens on mothers, restricts their ability to fulfill daily roles, limits access to

meaningful support, and reduces opportunities for the natural inclusion of their children. This aligns with a recent study showing that parental attempts to place children with severe disabilities in residential care were linked to greater psychological stress and lower social support, emphasizing how the absence of institutional responses heightens families' burdens and weakens their coping capacity (Ross et al., 2025). Additional research reinforces this conclusion, showing that providing supportive environments and equipping caregivers with appropriate coping tools enhances their self-efficacy, strengthens their ability to handle stressful situations, and helps sustain both psychological and familial balance (Chiracu et al., 2023). Taken together, these findings indicate that community awareness functions not only as a social facilitator but also as a psychological buffer, moderating mothers' stress levels and shaping their daily coping capacity. In the same vein, Asa et al. (2021) observed that mothers' awareness of child-disability legislation, alongside access to resources and supportive systems, facilitates adaptation to disability-related realities, reduces unmet needs, alleviates stress, and contributes positively to overall family stability.

Within this context, the mothers' accounts revealed that taking their children with Down syndrome into public spaces was not merely an ordinary practice but a meaningful step that fostered social acceptance, enhanced community awareness, and nurtured greater self-confidence among the children. This pattern is consistent with empirical evidence indicating that higher levels of self-efficacy are positively associated with subjective well-being as reflected in greater life satisfaction and more stable emotional states, thereby underscoring the importance of supporting mothers in managing persistent caregiving demands (Yazicioğlu et al., 2024). Further studies have shown that greater knowledge and understanding are positively associated with improved maternal capacity for psychological and social adjustment, underscoring that awareness and education are essential foundations for empowering mothers, reducing caregiving stress, and sustaining healthier family dynamics (Lima-Rodriguez et al., 2022). In a similar vein, Sharifian et al. (2024) emphasised that parent training and education on disability characteristics, behavioural challenges, and future needs are critical strategies for strengthening coping mechanisms, sustaining family and social roles, and enhancing resilience in the face of chronic demands.

Building on the findings, the narratives of some mothers underscored their contribution to reshaping societal perceptions of children with Down syndrome, a role occasionally connected to religious considerations and reflecting an expanding recognition of the importance of active engagement in fostering acceptance and minimizing isolation. Fani et al. (2025) emphasised that higher levels of religious faith and educational attainment among caregivers enhance their capacity to embrace their children and adapt to the daily demands of caregiving, while also conferring greater resilience in confronting persistent pressures and reinforcing the stability of family life. In line with this, AbuAlhommos et al. (2025) observed that caregivers who intentionally balance household responsibilities with the challenges of raising children with Down syndrome develop educational and social competencies that enrich their quality of life, strengthen positive community participation, and consolidate confidence in their ability to persist. Desimpelaere et al. (2024) corroborated these insights by showing that social support networks and specialised training programs reduce caregivers' isolation and alleviate stigma, thereby improving their satisfaction, sustaining their adaptive capacity across familial and social settings, and fostering greater reassurance about the future. Such patterns reinforce the study's conclusion that awareness efforts must be community-wide and culturally anchored to achieve meaningful and sustainable impact.

5.3. The Call for Sustainable Family Initiatives

It emerged in the mothers' narratives that they were consistently preoccupied with the future of their children with Down syndrome, particularly within the Saudi context, where caregiving responsibilities fall mainly on mothers, exposing them to challenges linked to family role distribution, social expectations, and daily priorities. This is consistent with Zhang et al. (2025), who found that

caring for a child with Down syndrome alongside siblings creates cumulative burdens on mothers and intensifies psychological and physical stress, underscoring the need for institutional interventions that provide effective support, reduce ongoing pressures, and strengthen overall family stability. In a similar vein, Gashmard et al. (2020) highlighted that promoting children's independence alleviates caregiving demands and reduces obligations, thereby fostering mothers' reassurance about their children's futures and reinforcing confidence in their ability to adapt effectively to broader social environments. Aligned with this perspective, Shahzad and Manzoor (2025) observed that the birth of a child with developmental disability heightens overall burdens, while raising such a child to achieve potential intensifies responsibilities, requiring sustained support and practical coping strategies to preserve family balance and ensure long-term stability. Collectively, these insights demonstrate how sustainability-oriented planning directly influences families' sense of security and shapes their long-term decision-making.

The mothers' narratives in this study reflected a growing awareness of the importance of sustainability in securing the future of their children with Down syndrome, linking continuity of care to family stability and the reduction of state burdens, thereby revealing broader social and economic dimensions beyond individual concerns. This finding aligns with Jamir Singh et al. (2023), who emphasized that benefit-finding and optimism function as essential coping strategies, fostering personal growth, strengthening social relationships, enhancing psychological health, and ultimately contributing to sustainable family well-being. Similarly, the results resonate with Marchal et al. (2017), who argued that the development of sustainable programs supported by effective networks of assistance is crucial to meeting children's evolving needs, reducing parental stress, and reinforcing parental awareness, thereby promoting greater family stability and adaptive capacity. From another perspective, the mothers' preoccupation with the future parallels observations by Mahmood and Gul (2023), who reported that future-oriented concerns are strongly associated with heightened psychological stress among mothers in cultural contexts where primary caregiving responsibilities fall predominantly on them, thereby deepening their sense of obligation and amplifying ongoing pressures. This interpretation underscores the unique contribution of the present study by linking mothers' emotional experiences with broader institutional and policy-related dimensions.

The findings highlight that mothers' constant concern for ensuring the comfort and happiness of their children with Down syndrome remains evident, despite recurring daily pressures, underscoring how children's reassurance emerges as a central factor shaping present family decisions and guiding efforts toward stability. This aligns with Noroozi et al. (2024), who observed that a mother's trajectory is closely intertwined with her child's well-being, with caregiving becoming a pivotal factor that reshapes family roles, reorders priorities, and directs maternal energy toward addressing persistent and evolving challenges. These interpretive strands collectively position the study within a growing body of scholarship emphasizing that preparedness is not a single action but a continuous, adaptive family process shaped by emotional, social, and structural determinants. The discussion also resonates with Mendoza-García et al. (2025), who argued that programs for children with Down syndrome should go beyond addressing children's immediate needs to include caregiver support, as this alleviates pressure, strengthens adaptive capacity, and sustains both psychological and social balance within the family. Similarly, Ranta et al. (2025) emphasized the importance of psychosocial and educational training programs that reduce parental stress, provide mothers with practical coping strategies, and offer family counseling to improve mental health, all of which are fundamental to enhancing comprehensive support and promoting family well-being.

6. Conclusion

The findings of this study demonstrate that family preparedness for future transformations constitutes a central concern for Saudi mothers raising children with Down syndrome. The results highlight the need to strengthen community support and the importance of family sustainability

initiatives that ensure continuity of care and reinforce long-term family stability. These insights emphasize that supporting mothers requires a holistic vision that anticipates future challenges and develops practical adaptation strategies.

Based on the overall analysis, this study makes a meaningful contribution by providing an in-depth understanding of how Saudi mothers perceive future responsibilities and the social and institutional factors that shape their preparedness. The findings enrich the literature by situating maternal experiences within the broader cultural and social context of Saudi Arabia.

This study, however, is subject to several limitations. First, the sample consisted of a relatively small group of mothers, which limits broader interpretation of the findings. Second, the study was conducted in a single region, which may not represent the full range of experiences across Saudi Arabia. Third, the data were collected solely through interviews, limiting methodological depth. Fourth, the perspectives of fathers and siblings were not included, narrowing the family lens. Fifth, economic considerations were not directly examined, despite their relevance to long-term preparedness. Sixth, the study focused exclusively on Saudi families, despite the Eastern Province's cultural diversity. Finally, the researcher's personal connection to the topic may introduce bias, despite multiple safeguards to preserve neutrality.

7. Suggestion

Based on the study's findings, two sets of recommendations are proposed. The first set is directed toward policymakers and institutional stakeholders who shape family support systems. The second set is intended for future researchers seeking to expand scientific understanding of family preparedness.

To begin with, national awareness campaigns should be implemented across schools, media platforms, and public institutions in order to reduce stigma and enhance social inclusion. In addition, strengthening partnerships with the General Authority for the Care of Persons with Disabilities and major corporations should focus on developing sustainable endowments that ensure continuous funding for family support initiatives. Furthermore, integrating health, educational, and social services into a coordinated support system would meaningfully ease mothers' burdens and reinforce long-term family stability. Alongside this, specialised training and counselling programs that emphasise coping strategies and stress management skills can empower mothers to manage current responsibilities while preparing for future developmental challenges. Moreover, disability related laws and policies should be periodically reviewed to ensure alignment with families' evolving needs and to maintain adequate protections for children. Likewise, expanding sports, cultural, and artistic programs for children with Down syndrome can foster confidence, strengthen inclusion, and develop essential life and social skills. Finally, digital platforms can be strategically utilized to highlight success stories and positive family experiences, thereby increasing community awareness and reducing societal stigma.

In parallel with these policy-focused recommendations, future research should broaden the scope of inquiry by examining family preparedness across more diverse samples and across different regions and cultural contexts. Future studies should also include the perspectives of fathers, siblings, and extended family members in order to provide a more complete understanding of caregiving dynamics. In addition, researchers may enrich future investigations by adopting various qualitative techniques, including group discussions, document analysis, and extended follow-up designs. These approaches can enhance analytical depth and improve methodological rigor.

Declarations

Author Contributions. The author was solely responsible for the conception and design of the study, data collection, analysis, and interpretation, as well as for writing and approving the final version of the manuscript.

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References

- AbuAlhommos, A. K., Al Hawaj, M. A., Alanazi, A. A., Alrashidi, H. H., Aldawsari, M. F., & Alajmi, R. A. (2025). Quality of Life for Patients with Down Syndrome and Their Caregivers: A Cross-Sectional Study from a Parental Perspective in Saudi Arabia. *Healthcare*, 13(13), 1614. <https://doi.org/10.3390/healthcare13131614>
- Alabri, W. (2017). *The inclusion of children with Down's Syndrome in mainstream primary schools in Saudi Arabia: Understanding the perspective of school principals*, [Unpublished doctoral dissertation]. University of Lincoln.
- Alabri, W. (2023). Maternal perspectives: The needs of Saudi families of children with Down's Syndrome. *Journal of Intellectual Disabilities*, 27(1), 221–237. <https://doi.org/10.1177/17446295211044406>
- Alenazi, S. A., Hanif, I., Alanazi, R. M. K., Alanazi, N. H. K., Alenezi, K. F. R., Alanazi, W. Y. B., Hussain, S., Hassan, S., & Elmorsy, E. (2025). Assessment of the Level of Knowledge and Attitude towards Down Syndrome among the Population of Arar City, Saudi Arabia. *Bahrain Medical Bulletin*, 47(2), 2113–2117. https://www.bahrainmedicalbulletin.com/June_2025/BMB-24-917.pdf
- Alkahtani, F. H. (2022). Down Syndrome and its oral effects in Saudi Arabian region: A review of literature. *Journal of Datta Meghe Institute of Medical Sciences University*, 17(4), 1013–1018. https://doi.org/10.4103/jdmimsu.jdmimsu_433_22
- Alqahtani, A. S., Algabbani, M. F., Alhammad, S. A., Alwadeai, K. S., & Alhusaini, A. (2024). Physical activity status and its association with quality of life among children with Down Syndrome in Saudi Arabia: A comparative cross-sectional study. *PLOS One*, 19(2), e0297111. <https://doi.org/10.1371/journal.pone.0297111>
- Alshadfan, L., Deameh, M., Alhyary, A., Da'meh, M., El-Areidi, K., Sharqi, M., Alkayed, A., Da'meh, K., Ali, O. A., Alkhdour, G., Abu-Shai'rah, R., Akash, B., Alfaouri, M., & Abualhaj, S. (2025). Understanding the caregiver experience: a cross-sectional study of caregiver burden among those caring for chronically ill children in Jordan. *BMJ Paediatrics Open*, 9(1). e003610. <https://doi.org/10.1136/bmjpo-2025-003610>
- Asa, G. A., Fauk, N. K., Ward, P. R., Hawke, K., Crutzen, R., & Mwanri, L. (2021). Psychological, sociocultural and economic coping strategies of mothers or female caregivers of children with

- a disability in Belu district, Indonesia. *PloS one*, 16(5), e0251274. <https://doi.org/10.1371/journal.pone.0251274>
- Chiracu, A., Cosma, G. A., Stepan, A. R., Cosma, M. A., Corlaci, I., Călugăru, E. D. C., Voinea, F., Zăvăleanu, M., Burileanu, H. A., & Avramescu, T. (2023). Psychological capital, quality of life, and well-being in mother caregivers of individuals with down syndrome. *Frontiers in psychology*, 14, 1145104. <https://doi.org/10.3389/fpsyg.2023.1145104>
- Chong, H. G. (2008). Measuring performance of small-and-medium sized enterprises: The grounded theory approach. *Journal of Business and Public Affairs*, 2(1), 1–11. <https://dx.doi.org/10.2139/ssrn.5250565>
- Chow, K., Rezvan, P. H., Kazerooni, L., Nguyen, L., Boyd, N. K., Vogel, B. N., Lucas, M. C., Brown, R., Quinn, E. A., Jafarpour, S., & Santoro, J. D. (2025). Caregiver burden and familial impact in Down Syndrome Regression Disorder. *Orphanet Journal of Rare Diseases*, 20(1), 126. <https://doi.org/10.1186/s13023-025-03644-0>
- Cohen, L., Manion, L., & Morrison, K. (2011). *Research methods in education* (7th ed.). Routledge.
- Creswell, J. W. (2009). *Research design: Qualitative, quantitative, and mixed methods approaches* (3rd ed.). Sage Publications, Ltd.
- Dalrymple, R. A., Somerville, L. H., Hamza, S., & Matta, N. (2022). Fifteen-minute consultation: The review of a child with Trisomy 21 (Down's Syndrome). *Archives of Disease in Childhood-Education and Practice*, 107(2), 88–94. <https://doi.org/10.1136/archdischild-2020-319814>
- De La Garza, E., Scott, A., Hillerstrom, H., Hendrix, J., & Rubenstein, E. (2024). Caregivers' concerns and supports needed to care for adults with Down syndrome. *American Journal of Medical Genetics. Part C, Seminars in Medical Genetics*, 196(1), e32041. <https://doi.org/10.1002/ajmg.c.32041>
- de Paor, E., King, E., McGuinness, S., & Guerin, S. (2025). Transition from School to Adult Life: Scoping Review of Perspectives of Young Adults with Intellectual Disabilities and Families. *Disability & Society*, 1-30. <https://doi.org/10.1080/09687599.2025.2470740>
- Desimpelaere, E. N., De Clercq, L. E., Soenens, B., Prinzie, P., & De Pauw, S. S. (2024). Parenting a child with Down syndrome: A qualitative study on parents' experiences and behaviors from a self-determination theory perspective. *Journal of Pediatric Nursing*, 74, e14-e27. <https://doi.org/10.1016/j.pedn.2023.10.021>
- Fani, O. R., Scheeren, A. M., de Jonge, M. V., Janssen, S. M., & de Vries, M. (2025). Distress and Coping Strategies Among Parents of Autistic Children in Malaysia and the Netherlands. *Neurodiversity*, 3, 1–14. <https://doi.org/10.1177/27546330251353635>
- Fucà, E., Galassi, P., Costanzo, F., & Vicari, S. (2022). Parental perspectives on the quality of life of children with Down syndrome. *Frontiers in Psychiatry*, 13, 957876. <https://doi.org/10.3389/fpsyg.2022.957876>
- Gashmard, R., Ahmadi, F., & Kermanshahi, S. M. K. (2020). Coping strategies adopted by Iranian families of children with Down syndrome: A qualitative study. *Medicine*, 99(28), e20753. <https://doi.org/10.1097/md.00000000000020753>
- Goldie, M. J., Dobson, K. L., Munce, S. E., Killackey, T., Bayley, M., Stapleford, C., Kua, A., Perrier, L., & Kokorelias, K. M. (2024). Future care planning of adults with childhood-onset neurodevelopmental disabilities: A scoping review. *Research in Developmental Disabilities*, 154, 104843. <https://doi.org/10.1016/j.ridd.2024.104843>

- Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods*, 18(1), 59–82. <https://doi.org/10.1177/1525822X05279903>
- Hammersley, M., & Atkinson, P. (2007). *Ethnography: Principles in practice* (3rd ed.). Routledge.
- Herman, C., Eisenberg, Y., Vanderbom, K., Tempio, D., Gardner, J., & Rimmer, J. (2023). Feasibility of implementing disability inclusive evidence-based health promotion. *Journal of Public Health Management and Practice*, 29(1), 82-92. <https://doi.org/10.1097/phh.0000000000001671>
- Jamir Singh, P. S., Azman, A., Drani, S., Mohd Nor, M. I. H., & Che Ahmad, A. (2023). Navigating the terrain of caregiving of children with intellectual and developmental disabilities: importance of benefit finding and optimism. *Humanities and Social Sciences Communications*, 10(1), 1-7. <https://doi.org/10.1057/s41599-023-02211-x>
- Jogu, S., Sharma, R., Gupta, S., Shah, R., Panigrahi, I., & Kaur, A. (2023). Parents of Indian children with Down syndrome: Stigma and health related quality of life. *Indian Journal of Pediatrics*, 90(9), 943. <https://doi.org/10.1007/s12098-023-04693-8>
- Lima-Rodriguez, J. S., de Medina-Moragas, A. J., Fernandez-Fernandez, M. J., & Lima-Serrano, M. (2022). Factors associated with quality of life in relatives of adults with serious mental illness: A systematic review. *Community mental health journal*, 58(7), 1361-1380. <https://doi.org/10.1007/s10597-022-00948-4>
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic Inquiry*. Sage Publications.
- Luetke Lanfer, H., Anderson, E., Bah, F., Krawiec, S., Rossmann, C., & Vines, A. (2025). Experiences of stigma among caregivers of children with disabilities in Freetown. *Scientific Reports*, 15(1), 20236. <https://doi.org/10.1038/s41598-025-07034-1>
- Mahmood, A., & Gul, A. (2023). Parental stress, familial burden and quality of life in parents of children with Down syndrome. *Journal of Professional & Applied Psychology*, 4(1), 61-70. <https://doi.org/10.52053/jpap.v4i1.151>
- Marchal, J. P., van Oers, H. A., Maurice-Stam, H., Grootenhuis, M. A., van Trotsenburg, A. P., & Haverman, L. (2017). Distress and everyday problems in Dutch mothers and fathers of young adolescents with Down syndrome. *Research in developmental disabilities*, 67, 19-27. <https://doi.org/10.1016/j.ridd.2017.05.005>
- Maxwell, J. A. (2013). *Qualitative research design: An interactive approach* (3rd ed.). Sage Publications, Ltd.
- McGlinchey, E., Fortea, J., Vava, B., Andrews, Y., Ranchod, K., & Kleinhans, A. (2025). Raising awareness and addressing inequities for people with Down syndrome in South Africa. *International Journal for Equity in Health*, 24(1), 7. <https://doi.org/10.1186/s12939-024-02349-3>
- Mendoza-García, A., Aparicio, A., Arango, P. S., & Tenorio, M. (2025). Exploring the feasibility and effectiveness of a naturalistic family centered intervention to enhance early interactions in toddlers with Down syndrome. *Scientific Reports*, 15(1), 12077. <https://doi.org/10.1038/s41598-025-96803-z>
- Mohammed Elmwafie, S., Ibrahim Abdalla Ibrahim, A., Hamdy Abd Elmonem, H., Amin Sayed, M., & Ahmed, S. (2022). Effectiveness of coping strategies intervention on quality of life for mothers having children with Down syndrome. *Egyptian Journal of Health Care*, 13(2), 1696-1714. <https://doi.org/10.21608/ejhc.2022.253722>

- Murray, L., & Lawrence, B. (2000). *Practitioner-based enquiry: Principles for postgraduate research*. Taylor & Francis Limited.
- Musyafa, L., Ishaq, M., Dayati, U., & Luar Sekolah, P. (2024). Learning Community for Parents of Children with Down Syndrome to Increase Mother's Awareness in Educating Their Children Better. *Educational Administration: Theory and Practice*, 30 (6), 92–98. <https://kuey.net/index.php/kuey/article/view/5113>
- Noroozi, F., Farrar, Z., Gharibi, T., & Gashmard, R. (2024). Family self-support in managing Down syndrome children: A qualitative study. *The Scientific World Journal*, 2024(1), 9992595. <https://doi.org/10.1155/2024/9992595>
- Patton, M. Q. (2002). *Qualitative research and evaluation methods* (3rd ed.). Sage Publications, Ltd.
- Ranta, K., Saarimäki, H., Gummerus, J., Virtanen, J., Peltomäki, S., & Kontu, E. (2025). Psychological interventions for parents of children with intellectual disabilities to enhance child behavioral outcomes or parental well-being: A systematic review, content analysis and effects. *Journal of Intellectual Disabilities*, 29(2), 500-535. <https://doi.org/10.1177/17446295241302857>
- Ritchie, J., & Spencer, L. (2002). Qualitative data analysis for applied policy research. In A. M. Huberman & M. B. Miles (Eds.), *The qualitative researcher's companion* (pp. 305–329). Sage Publications.
- Ross, S., Jackisch, J., & Almquist, Y. B. (2025). Socioeconomic and psychosocial conditions of parents with children in out-of-home care: a qualitative systematic review. *Children and Youth Services Review*, 170, 108163. <https://doi.org/10.1016/j.childyouth.2025.108163>
- Shahali, S., Tavousi, M., Sadighi, J., Kermani, R. M., & Rostami, R. (2024). Health challenges faced by parents of children with disabilities: a scoping review. *BMC pediatrics*, 24(1), 619. <https://doi.org/10.1186/s12887-024-05104-3>
- Shahzad, S., & Manzoor, I. (2025). Quality of life of mothers having children with Down syndrome. *Journal of Shalamar Medical & Dental College-JSHMDC*, 6(1), 22-27. <https://doi.org/10.53685/jshmdc.v6i1.289>
- Sharifian, P., Kuchaki, Z., & Shoghi, M. (2024). Effect of resilience training on stress, hope and psychological toughness of mothers living with mentally and physically disabled children. *BMC pediatrics*, 24(1), 354. <https://doi.org/10.1186/s12887-024-04828-6>
- Shetty, J., Shetty, A., Mundkur, S. C., Dinesh, T. K., & Pundir, P. (2023). Economic burden on caregivers or parents with Down syndrome children-a systematic review protocol. *Systematic Reviews*, 12(1), 3. <https://doi.org/10.1186/s13643-022-02165-2>
- Shewaikani, N., Al Refaei, A., Khamis, T., Oraikat, M., Abdalgani, N., Shalfawi, M., Abdelghani, F., & Masri, A. (2025). Public Knowledge and Attitude Toward Down Syndrome: A Nationwide Cross-sectional Survey in Jordan. *JAPA Academy Journal*, 3(2), 100-108. https://journals.lww.com/japa/fulltext/2025/04000/public_knowledge_and_attitude_toward_down.5.aspx?context=latestarticles
- Soltani, A., & Esbensen, A. J. (2024). Role of child demographic, executive functions, and behavioral challenges on feelings about parenting among parents of youth with Down syndrome. *Research in developmental disabilities*, 148, 104717. <https://doi.org/10.1016/j.ridd.2024.104717>
- Stafford, L., Novacevski, M., Pretorius, R., & Rogers, P. (2024). The makings of disability-inclusive sustainable communities: Perspectives from Australia. *Urban Governance*, 4(2), 113-121. <https://doi.org/10.1016/j.ugj.2024.03.004>

- Steffensen, E. H., Santoro, S. L., Pedersen, L. H., Vogel, I., & Lou, S. (2024). Encounters with public and professional understandings of Down syndrome: A qualitative study of parents' experiences. *Journal of Applied Research in Intellectual Disabilities*, 37(3), e13221. <https://doi.org/10.1111/jar.13221>
- Villaescusa, M., Martínez-Rueda, N., & Fernández, A. (2021). Support for families of youths and adults with intellectual disabilities: contributions of a program from families' and specialists' perspectives. *Education Sciences*, 11(2), 88. <https://doi.org/10.3390/educsci11020088>
- Waugh, K. A., Wilkins, H. M., Smith, K. P., & Ptomey, L. T. (2025). Charting the future: Current and future directions in translational research for individuals with Down Syndrome. *Journal of Neurodevelopmental Disorders*, 17(1), 38. <https://doi.org/10.1186/s11689-025-09630-8>
- Yaman, F. K., Ezveci, H., Dogru, S., Harmanci, M. S., Bahçeci, P., & Gezginç, K. (2025). The impact of advanced maternal age on pregnancy complications and neonatal outcomes. *Journal of Clinical Medicine*, 14(15), 5387. <https://doi.org/10.3390/jcm14155387>
- Yazicioğlu, T., Yildirim, A. E. S., & Kumaş, Ö. A. (2024). Family stress and self-efficacy in parents of children with special needs: The regulatory role of perceived social support. *Children and Youth Services Review*, 163, 107804. <https://doi.org/10.1016/j.childyouth.2024.107804>
- Zhang, X. N., Zhang, S., Liu, C. Y., Ni, Z. H., & Lv, H. T. (2025). Caregivers' experience of having a child with Down syndrome: a meta-synthesis. *BMC nursing*, 24(1), 66. <https://doi.org/10.1186/s12912-024-02652-y>

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