ORIGINAL ARTICLE

Exploring Caring Motivation Barriers among Mothers of Children with Intellectual and Developmental Disabilities: A Qualitative Content Analysis

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Received: 28 May 2024 Revised: 25 October 2024 Accepted: 29 October 2024

ABSTRACT

Background: Caring a child with intellectual and developmental disabilities (IDDs) presents numerous challenges that can impact the mothers' caring motivation. This study aimed to explore the caring motivation barriers among mothers of children with IDDs.

Methods: This qualitative content analysis study was conducted from July 2023 to March 2024. Twenty-six mothers of children with IDDs were purposefully selected to participate in face-to-face semi-structured interviews. Data collection continued until saturation was achieved. Data analysis was conducted using Mayring's inductive approach within MAXQDA version 20. We utilized Lincoln and Guba's criteria for ensuring rigor.

Results: The mean ages of the mothers and children were 40.34±7.44 years and 9.38±4.33 years, respectively. The analysis identified several main categories and 15 subcategories: (I) Mother's insufficient readiness: low level of competency, decreased maternal strength with child's advancing age, caregiving fatigue, complex health problems, and incompatibility with the child's disability; (II) Perceived lack of support for the mother in caregiving: insufficient family support, inadequate social support, deficient healthcare provider support, lack of spiritual support, and insufficient financial support; and (III) Encountering caring complexity: disappointment with the child's recovery, challenges in providing optimal rehabilitation, multiple physical problems in the child, unintentional behaviors in the child, and priority of personal goals over the care.

Conclusion: The motivation of mothers to care for children with IDDs is influenced by a range of challenges. Future research should take these barriers into account to enhance maternal caregiving motivation. To modify the identified obstacles, a comprehensive plan of actions should be devised.

Keywords: Intellectual disability, Motivation, Mothers, Qualitative research

Please cite this article as: Hosseini SJ, Ramezani M, Ashrafzadeh F, Jamali J. Exploring Caring Motivation Barriers among Mothers of Children with Intellectual and Developmental Disabilities: A Qualitative Content Analysis. IJCBNM. 2025;13(1):77-89. doi: 10.30476/ijcbnm.2024.102470.2490.

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INTRODUCTION

Intellectual and developmental disabilities (IDDs) are neurodevelopmental disorders characterized by an IQ of less than 70 and impaired adaptive functioning that limits the daily life. Conditions such as cerebral palsy, Down syndrome, Fragile X syndrome, and autism spectrum disorders fall under the IDDs.¹ These conditions affect about 2-3% of the general population, with a majority having mild IDDs.²⁻⁴ Children with IDDs rely on their caregivers, who can be categorized as formal and family caregivers.^{5, 6} Among informal caregivers, mothers play a particularly crucial role in supporting children with disabilities.⁷ Maintaining long-term motivation in mothers caring for children with IDDs is vital.8

Motivation is defined as the process that initiates, guides, and sustains goal-oriented behaviors.9 In the context of caregiving, motivation is the driving force that encourages and maintains the caregiver's efforts to provide care, despite the challenges they may face.8 Despite the inherent bond between a mother and her IDD child, some mothers may experience a decline in motivation and quality of care provided over time and consider placing their children in welfare boarding centers. High levels of motivation are associated to enhanced wellbeing and quality of care, while reduced motivation can detrimentally impact both the caregiver and the care provided.8 A study which used a directed content analysis approach categorized caregiving motivation into intrinsic and extrinsic dimensions based on self-determination theory but did not address the barriers impacting this motivation.¹⁰ Also, another study which focused on the experiences of mothers in Iran highlighted caregiving achievement as a main theme, while other studies identified challenges such as time constraints, lack of support networks, and societal stigma.¹¹⁻¹⁵ These challenges can increase caregiving burden and diminish motivation. Given the lack of studies specifically addressing motivational barriers for mothers of children with disabilities further research in this area is warranted. Within the nursing domain, the motivation of caregivers has been examined across various studies, encompassing conditions such as dementia, and advanced breast cancer and less attention has been paid to the mothers with IDDs children.^{16,} In Nanda's nursing diagnosis, both "motivation" and "caregiver" are recurrently cited concepts.¹⁸

Given the lack of evidence concerning the barriers to caregiving motivation among mothers of children with IDDs, especially in Iran, it is imperative to elucidate these barriers through qualitative research. A quantitative study was not feasible for current research due to the limited available information on barriers to mothers' caregiving motivation and the lack of a suitable measurement quetionnaire. As a result, qualitative approach is particularly valuable as it allows for an in-depth understanding of the unique experiences of these caregivers. Given the scarcity of studies addressing motivation in caregivers of children with disabilities, this qualitative study aimed to explore caring motivation barriers among mothers of children with IDDs.

MATERIALS AND METHODS

This qualitative content analysis study was conducted between July 2023 and March 2024 in two cities in Iran: Mashhad and Esfarayen. The research received approval from Mashhad University of Medical Sciences. Given that the concept explored in this study has not been clearly defined in previous research, interviews with participants were conducted to clarify its dimensions. We conducted preliminary screening via in-person meetings to verify the inclusion criteria: mothers of children with Down syndrome, autism, or cerebral palsy with IDDs confirmed by a pediatric neurologist. Additionally, participants needed to be primary caregivers, fluent in Persian, willing to record their interviews, and willing to participate.

The exclusion criterion was unwillingness to continue participating in the study. In the current study, we concentrated on Down syndrome, cerebral palsy, and autism due to their prevalence and the distinctive challenges each condition presents to caregivers. These three conditions collectively represent a significant portion of the IDDs population, enabling us to capture a wide range of caregiving experiences. Furthermore, the insights gained from this focused approach provide a solid foundation for understanding caregiving barriers and can inform future research on other IDDs.

Mothers of children with IDDs attend various environments depending on their child's needs. These children are referred to hospitals due to seizures. In Mashhad, there is a specialized center for neurological issues within the children's neurology department at Ghaem Hospital. Consequently, this center was chosen as one of the sampling environments. Also, mothers typically attend the children's neurology clinic at Ghaem Hospital in Mashhad for regular check-ups, presenting an excellent opportunity for sampling at this location. Mothers frequently bring their children to rehabilitation centers. In Mashhad, several centers provide specialized services for children with disabilities, among which the "Takapo" center was selected as one of the research settings. Additionally, schools serving children with IDDs represent another key environment where mothers regularly take their children. In this study, the 'Shokofa' center in Esfarayen was chosen for its accessibility. To involve mothers who place their children in welfare boarding facilities, we also selected the Center for Unsupervised Children in Esfarayen due to its convenient location and the management's willingness to collaborate.

In this study, a total of twenty-nine interviews were conducted with twenty-six mothers of children with IDDs. To enrich the categories and clarify certain ambiguities, we repeated the first, second, and sixth interviews. Mothers of children with cerebral palsy, autism, and Down syndrome, with different

age ranges, care experiences, and educational backgrounds, were sought to participate in qualitative interviews to ensure diversity among participants. Purposive sampling was conducted and discontinued once data saturation was achieved. In the present study, following the initial screening of participants according to the inclusion criteria, written informed consent was obtained, and the time and place of the interviews were coordinated. The semi-structured and faceto-face interviews based on an interview guide were conducted in three stages: the "initial briefing", the "main interview", and the termination stage.¹⁹ During the "initial briefing", mothers were provided with explanations about the research objectives and the process for approving the study and obtaining an ethical code. The participants were informed that the entire conversation would be recorded using audio recording software to facilitate transcription after the interview. They were assured that the recording would remain confidential and be accessible only to the researcher.

During the "main interview" stage, the participants were asked main open-ended questions from the predetermined interview guide. Examples of such questions in this study include: "Can you describe the experience of caring for your child with disability throughout a day?", "What conditions do you believe influence your motivation when taking care of a child with a disability?", "Could you explain the experience of caring for a child with disability on days when your motivation to care is different from other days?", What circumstances lead to changes in your motivation to care on certain days?". Exploratory questions were incorporated alongside the main inquiries like "Could you explain more about that?" and "Could you provide an example to illustrate your point?". In the third stage of the interview, mothers were invited to offer explanations about barriers to caregiving motivation that the initial questions may not have covered. Finally, the participants were informed that a

follow-up interview could be arranged if any aspects of the interview remained unclear. After each interview session, all recorded conversations were listened to; then, the interview text was transcribed verbatim. Non-verbal messages, such as changes in the tone of speech, emphasis, and pauses noted by the researcher during the interviews, were also recorded. As the study and data analysis advanced, categories were developed that guided the direction of subsequent interviews. In essence, as the study progressed, the interviews became more structured, with questions aimed at enriching the emerging categories. The duration of each interview session varied from 25 to 86 minutes, depending on the caregivers' experiences they wished to share with the researcher.

Data collection was concurrent with data analysis, and the data management was performed using MAXQDA software version 2020. We utilized Mayring's inductive method with eight steps for content analysis (Table 1).²⁰ Initially, the research question is precisely defined to guide the focus of the study. Subsequently, the level of categories to be developed had to be defined. There has to be a criterion for the selection process in category formation. The texts are meticulously examined line by line, allowing for an in-depth understanding of the data. After analyzing 10-50% of the texts, the

categories and coding rules are revised to enhance the accuracy and relevance. The entire material (text) is then reanalyzed to ensure comprehensive coverage. Main categories are subsequently built. To ensure reliability, we conducted both intra-coder and inter-coder agreement checks, verifying consistency in the categorization process. Finally, the results are meticulously reported, providing a detailed understanding of the research question based on the analyzed data.

We utilized Lincoln and Guba's criteria for ensuring rigor, which encompass credibility, dependability, confirmability, and transferability.²¹ We established credibility by thoroughly engaging in the analysis of interviews for over seven months and involving the research team actively in the coding process. We conducted peer debriefing with individuals knowledgeable in qualitative research coding, and participants confirmed the codes. For dependability, an external supervisor meticulously evaluated the data and documentation step by step. Additionally, the researcher underwent systematic training related to qualitative research. Confirmability was ensured by documenting all activities from the initial text search through coding and data extraction, which were then shared with external reviewers for validation. During data collection, interview data were accurately recorded in real time without adding personal bias.

Table 1: Steps of content analysis

Steps	More description
1. Define the research question	- What are the experiences of mothers regarding the motivational barriers
	to caring for children with IDDs?
2. Establishment of category	- We identified the condensed meaning units.
definition and level of abstraction	- The interviews text was ultimately condensed into codes, sub-subcategories,
	subcategories, and main categories.
3. Work through the texts line by line	- Immediately after each interview, content analysis was conducted.
4. Revision of categories and rules	- Each interview was reviewed separately by the research team.
after analyzing 10-50% of texts.	- After conducting five interviews, a fundamental review was conducted to
	match the codes with the sub- subcategories, and subcategories.
5. Final work through the material	- After reaching final agreement on the coding rules, coding for all
	interviews was completed.
6. Building of main categories	- Subcategories that referred to the topic with a higher level of abstraction
	were placed in main categories.
7. Intra-/Inter-coder agreement check	- In case of disagreement between research team in coding process, we tried
	to resolve it with scientific discussion.
8. Report of final results	- The results of the content analysis were presented in a table.

The researchers maintained a neutral attitude during data analysis to accurately reflect the subjects' real experiences. We detailed the participants' characteristics, data collection methods, and analysis processes to provide readers with essential information relevant to the research, ensuring transferability.

The Research Ethics Committee of Mashhad University of Medical Sciences approved the present study with the code IR.MUMS.NURSE.REC.1401.102. Detailed explanations were given regarding the participants' right to choose whether to participate or to withdraw from the study, as well as the principles of confidentiality. The significance of preserving anonymity and confidentiality was emphasized. Upon their consent to participate, written informed consent was obtained, and the time and location of the interview were arranged. During transcription, interview data were anonymized, and the recordings were securely stored to ensure strict confidentiality. Participants were assured that the interview results would be published generically and that details about the interview would remain confidential with the researcher.

RESULTS

In total, twenty-nine interviews were conducted with twenty-six mothers of children with IDDs. The mean age of the mothers was 40.34±7.44 years, and that of the children was 9.38±4.33 years (Table 2). Finally, three main categories and fifteen subcategories were identified, as detailed in Table 3.

1. Mother's Insufficient Readiness

Caregiving for a child with IDD requires a mother to be physically and mentally prepared, with adequate energy, knowledge, and skills. A lack of adaptation to the child's disability, or physical and mental strain, along with insufficient knowledge or experience, can negatively impact her motivation.

Table 2: Participants' basic information

Participants	Mother's age (year)	Mother's degree	Child's age	Child's diagnosis
1	44	Bachelor of science	7	Cerebral palsy
2	32	Diploma	11	Down Syndrome
3	45	Under diploma	4.5	Cerebral palsy
4	55	Under diploma	12	Cerebral palsy
5	42	Under diploma	5	Cerebral palsy
6	39	Under diploma	6	Autism
7	40	Under diploma	8	Autism
8	52	Under diploma	14	Down Syndrome
9	47	Diploma	10	Down Syndrome
10	33	Under diploma	5.5	Cerebral palsy
11	55	Ph.D.	17	Cerebral palsy
12	38	Under diploma	17	Down Syndrome
13	32	Under diploma	6	Autism
14	33	Bachelor of science	6.5	Autism
15	31	Under diploma	7	Autism
16	40	Under diploma	7	Cerebral palsy
17	35	Master of science	1.5	Cerebral palsy
18	40	Diploma	15	Autism
19	36	Under diploma	6	Autism
20	50	Under diploma	18	Cerebral palsy
21	30	Diploma	10	Down Syndrome
22	35	Diploma	7	Autism
23	38	Under diploma	8	Autism
24	50	Under diploma	9	Cerebral palsy
25	41	Diploma	13	Down Syndrome
26	36	Under diploma	13	Cerebral palsy

Table 3: Subcategories and categories generated from the data

Subcategory	Main Category	
Low level of competency		
Decreased maternal strength with child's advancing age	Mother's insufficient readiness	
Caregiving fatigue		
Complex health problems		
Incompatibility with the child's disability		
Insufficient family support Inadequate social support Deficient healthcare provider support Lack of spiritual support Insufficient financial support	Perceived lack of support for the mother in caregiving	
Disappointment with the child's recovery Challenges in providing optimal rehabilitation Existence of multiple physical problems in the child Presence of unintentional behaviors in the child Prioritize personal goals over the care	Encountering to caring complexity	

The category of mother's insufficient readiness includes several subcategories listed below.

1.a. Low Level of Competency

The mother's motivation may be negatively impacted by conditions such as a lack of knowledge, skills, and experience in childcare. One mother said: "Sometimes, while taking care of my child, I encounter behaviors from him that I don't know how to properly manage, and I feel that I lack the necessary knowledge. This diminishes my motivation to provide optimal care." (P22)

1.b. Decreased Maternal Strength with Child's Advancing Age

The mother's motivation weakens due to the child's age and the physical weakness associated with the mother's age. As expressed by a mother: "As my child grows up and gains weight, I find myself getting older and experiencing a decline in physical strength. Consequently, I am considering the possibility of enrolling my child in a welfare boarding center." (P9)

1.c. Caregiving Fatigue

The mother bears a significant burden due to her child's chronic condition, and repetitive behavior in the child, leading to temporary and overwhelming fatigue. These conditions deplete the mother's energy and diminish her motivation to care for the child. As indicated by a mother: "I have been caring for my child for so long that I feel exhausted, unable to manage my tasks, and sometimes lose the motivation to care for my child with disability." (P3)

1.d. Complex Health Problems

The mother's motivation is lessened by both her physical and mental health problems. A participant stated: "I have been struggling with severe depression and I am on medication. My life had reached a point where I contemplated self-harm. I didn't even have the motivation to take care of myself, let alone my child with disabilities." (P12)

1.e. Incompatibility with the Child's Disability

This subcategory suggests that the mother struggles to cope with having a child with disablity at home, and lacks optimism about the future. A mother shared her experience: "I still struggle to accept my child's disability and often question why I have a child with disablity. This negative thought decreases my motivation and ability to provide care." (P9)

2. Perceived Lack of Support for the Mother in Caregiving

A lack of adequate support for mothers caring for children with IDDs poses a barrier

to their caregiving motivation, influenced by insufficient familial, social, financial, spiritual, and therapeutic resources. This category encompasses several subcategories listed below.

2.a. Insufficient Family Support

A decrease in the mother's motivation is evident when family members show a lack of enthusiasm and provide insufficient assistance for the child with disability. This leads to feelings of hopelessness for the mother and a lack of assistance in caring for the child with IDD. A mother stated: "Now my older son says, 'Mom, why are you taking care of this child? Take him to the welfare boarding center." (P25)

The other one said: "My husband says that a child with disablity is very different from a healthy child. He can't be as healthy as a child, and you don't need to take care of him so much." (P9)

2.b. Inadequate Social Support

The mother's motivation diminishes when relatives, neighbors, and other community members fail to accept, support, or encourage her in caring for a child with IDD at home. As expressed by a mother:

"One of my wife's relatives told me to leave my child in the welfare boarding center." (P17)

2.c. Deficient Healthcare Provider Support

The mother's motivation tends to decrease due to the healthcare staff's lack of hope for the child's recovery and their suggestion to place the child in a welfare boarding center. A mother explained that: "When my daughter was in the hospital, some healthcare staff advised me to place her in a welfare center and not bring her home with me to avoid dependence on the child." (P17)

2.d. Lack of Spiritual Support

The mother believes that she lacks support from spiritual sources of inspiration and that a miracle will not occur for her IDD child's recovery. As indicated by a mother: "I have lost hope for a miracle of recovery in my child." (P5)

2.e. Insufficient Financial Support

The significant expenses associated with medication, treatment, and rehabilitation are not feasible on a low income, leading to a decrease in the mother's motivation to provide care. A participant told: "I face increasing financial strain, causing a decline in motivation; I have to reduce the frequency of rehabilitation sessions." (P1)

3. Encountering Caring Complexity

The mothers encounter caring complexity due to their disappointment with the child's recovery, challenges in providing optimal rehabilitation, the presence of multiple physical problems, involuntary behaviors in the child, and the prioritization of personal goals over caregiving.

3.a. Disappointment with the Child's Recovery

This category points to the mother being discouraged by the lack of developmental progress in her child with IDD, regression in developmental stages, and speech impairments, negatively impacting her motivation. This concern was reported by a mother:

"My son has no learning or speech abilities. He shows no awareness of his surroundings. The manager of the rehabilitation center advised me not to bring him back, stating that development was impossible. We placed him in a welfare boarding center when he turned eight." (P19)

3.b. Challenges in Providing Optimal Rehabilitation

The mother faces delays in her child's development due to various factors, including the challenges of accessing rehabilitation services outside the home and the limited availability of rehabilitation and treatment facilities. As indicated by a mother: "My motivation decreases when I find it difficult to commute to and from the rehabilitation

center by public transport because of my child's physical condition, and I can't manage to do this every day." (P16)

3.c. The Existence of Multiple Physical Problems in the Child

Due to the physical problems such as seizure, orthopedic deformity, dysphagia, and severe disability in the child, the mother faces challenges such as frequent hospital readmissions, and feeding the child through alternative methods like gastrostomy. These conditions hinder the developmental progress of the child with IDD, which is the primary goal and motivation behind the mother's care. As expressed by a mother:

"My child faces numerous issues, including increased seizures, muscle spasms, and an inability to communicate. A Percutaneous endoscopic gastrostomy (PEG) tube has been placed for feeding, and frequent hospitalizations are required due to these complications." (P17)

3.d. Presence of Unintentional Behaviors in the Child

Behaviors such as aggression, restlessness, screaming, and self-harm or harm towards others provoke negative responses from caregivers, family members, and others, consequently reducing the motivation to provide care. A participant said: "My son has become increasingly aggressive and harming his brother. It has become challenging to care for him, prompting us to seek a childcare center for assistance." (P4)

3.e. Prioritizing Personal Goals Over the Care

The mother prioritizes her personal goals over the care of her child with IDD. She perceives caregiving and the pursuit of recovery for her child with IDD as obstacles to achieving other significant life goals. As indicated by a mother:

"We wanted to have more children, so we lacked the motivation to keep our child with disability at home and decided to entrust his care to a welfare center." (P20)

DISCUSSION

The present study aimed to explore caring motivation barriers among mothers of children with IDDs. Finally, three main categories emerged including the mother's insufficient readiness, lack of support for the mother in caring, and encountering caring complexity. We found no studies specifically addressing the barriers to caregiving motivation among mothers of children with chronic illness or disability. Consequently, to interpret our findings, we reviewed studies that focused on barriers to caregiving among children's caregivers.

The first category, insufficient maternal readiness, highlights how several factors, including a lack of competency and psychological and physical issues, negatively affect the mothers' motivation to care for a child with IDD. Mothers perform a numerous tasks, such as administering medicine, feeding, caring about oral health, bathing, and rehabilitating. These tasks require sufficient competency including knowledge, skills, and resources to perform effectively. In the same line with the findings of the present study, research on caregivers of children with disability similarly revealed that they lacked sufficient knowledge regarding the principles of their children's oral hygiene.²² Another study on caregivers of children with cerebral palsy found that although these caregivers exhibited good knowledge, generally attitudes, and practices, they were deficient in knowledge related to managing emergencies for their children.²³ The caregivers' lack of necessary knowledgecan lead to decreased confidence, lower readiness, and higher stress which undermine their motivation.²⁴

Mothers in the present study identified physical and psychological problems as factors that decrease their readiness to provide care, which in turn diminishes their motivation. Caregivers of children with health problems are typically twice as likely to experience various health issues, such as depression and reduced physical wellbeing.²⁵ Also, previous studies have shown

that caregivers frequently experience various physical problems, including lower back pain, arthritis, hypertension, gastrointestinal ulcers, and headaches, which was consistent with the results of current research.²⁶ As a result, their motivation and the quality of care they provide are negatively impacted.²⁷

Incompatibility and non-acceptance of a child with IDD by mothers can impede their motivation to provide adequate care. When a mother struggles to accept her child's disability, it often leads to emotional distress and denial, which can manifest as non-compliance with necessary care routines and medical advice.28 This lack of acceptance and compliance diminishes the mother's motivation to engage in caregiving tasks. Research indicates that mothers who do not fully accept their child's condition experience increased stress and decreased emotional resilience, contributing to a cycle of disengagement and reduced caregiving efficacy.29

The second main category is related to the mother's lack of adequate support in caring for a child with IDD. Our findings indicate that mothers in the present study encountered challenges, such as a lack of adequate support from their family members. Some healthy siblings' lack of enthusiasm toward their siblings with disability at home projected these negative feelings onto the mother. Research highlights that the absence of familial assistance not only exacerbates feelings of isolation but also reduces the perceived efficacy of their caregiving efforts, further diminishing motivation. This is in line with thefindings of the current study.^{30,} ³¹ Furthermore, some caregivers in our study reported insufficient support from extended relatives and friends, which negatively impacted their motivation. Without adequate social support, these mothers feel isolated and overwhelmed, leading to reduced self-efficacy and lower engagement in seeking resources or interventions that could benefit their child.32 Additionally, inadequate financial support compelled some mothers to refrain from specific rehabilitation sessions for their children, which is consistent with the findings from previous studies. This finding aligns with the results of previous studies.^{33, 34}

Also, the study emphasizes the detrimental impact of inadequate healthcare provider support on the caregiving motivation of mothers of children with IDDs. Recommendations to reduce maternal involvement, such as placing the child in a welfare boarding center contribute to prolonged emotional distress and diminished motivation for care and follow-up. One study identifies insufficient healthcare provider knowledge as a key barrier to effective caregiver support.³³

In the present study, mothers identified not only the lack of family and social support but also the absence of spiritual support as significant obstacles to their motivation to provide care. In Iran, spirituality and religiosity significantly influence maternal behavior. Previous studies have shown that female caregivers often rely on spiritual beliefs.³⁴ Mothers frequently expect their child's recovery through religious practices and divine intervention. However, unmet expectations can lead to disappointment and negatively impact their caregiving motivation.^{35, 36}

The third main category of caring motivation barriers involves encountering caring complexity. Psychologically, mothers of individuals with neurodevelopmental disorders feel disappointed and dissatisfied with their child's progress and rehabilitation, affecting their well-being and caregiving capacity.³⁷ Recognizing progress in the child is essential for caregivers driven by extrinsic motivation, serving as a reward for their caregiving efforts. Conversely, intrinsically motivated mothers provide care based on their interests, regardless of their child's developmental status. 10, 38 Challenges in accessing appropriate rehabilitation services and insufficient facilities can impede a child's progress and recovery. A study in South Africa found that caregivers of individuals with disability relied on public transportation

for rehabilitation visits and faced long waiting periods, which is consistent with our findings.³⁹

Children with IDDs often have comorbidities such as restlessness, self-harm, aggression, and physical problems, which hinder optimal care. Previous research found that comorbidities and high disability severity among persons with disability were significant obstacles to effective care, in the same line with our outcomes.⁴⁰ Mothers must devote significant time and energy to caregiving, often resulting in job loss, inability to achieve personal goals, and reduced social interactions. This decline in the quality of life negatively impacts their caregiving motivation.⁴¹

Future research should investigate the effectiveness of targeted training programs and resource utilization in enhancing maternal readiness, including strategies to mitigate caregiving fatigue and improve healthcare access. Studies should explore the impact of family and social support systems, healthcare provider support, spiritual support, and financial aid policies on increasing caregiving motivation. Additionally, research should focus on setting realistic expectations for the child's recovery, improving rehabilitation services, addressing physical problems with specialized care, educating mothers on behavior management, and optimizing caregiving schedules to facilitate personal pursuits. These efforts aim to identify practical solutions to enhance support for mothers of children with IDDs.

The study presents significant strengths in its thorough exploration of the barriers that impact caregiving motivation among mothers of children with IDDs. By employing a rigorous qualitative methodology, including purposeful sampling, semi-structured interviews, and Mayring's inductive approach to data analysis, this study provides an in-depth understanding of the complex factors that hinder maternal motivation.

This study has some limitations. We focused on maternal caregivers, but other family members might also be involved in caregiving. Additionally, the generalizability

of our findings in different contexts is limited by the inherent constraints of qualitative research.

CONCLUSION

This qualitative study, conducted to identify the motivation barriers faced by mothers of children with IDDs in Iran, revealed three main categories of caregiving challenges: insufficient maternal readiness, perceived lack of support, and encountering caring complexity. Healthcare and social service professionals must recognize and understand these barriers. Furthermore, targeted interventions should be implemented to address these obstacles and enhance the mothers' motivation to provide care. A comprehensive action plan must be developed to achieve optimal success.

Acknowledgement

We extend our gratitude to the Research Vice-Chancellor of Mashhad University of Medical Sciences for their financial support. We also wish to acknowledge the Clinical Research Development Unit at Ghaem Hospital, Mashhad University of Medical Sciences, for their valuable assistance in this manuscript. Additionally, we appreciate the cooperation of the welfare organizations of Khorasan Razavi and North Khorasan in facilitating this research.

Authors' Contribution

SJH and MR contributed to the conceptualization and design of this study. The data collection was conducted by SJH, MR, and FA. The data analysis and interpretation were carried out by SJH, MR, FA, and JJ. SJH, and MR drafted the initial manuscript. All authors critically reviewed, revised, and approved the final version of the manuscript for publication. All authors take responsibility for the integrity of the data and the accuracy of the data analysis. The corresponding author attests that all listed authors meet authorship criteria and that no others meeting the criteria have been omitted.

Funding Source

This study was funded by Mashhad University of Medical Sciences, which provided essential financial support for the research (Grant number: 4011678).

Conflict of Interest: None declared.

Declaration on the use of AI

We utilized ChatGPT-4 (OpenAI) solely for the purpose of enhancing the clarity, coherence, and grammar of the English language. The authors have reviewed and approved all modifications to ensure accuracy and alignment with the research objectives.

REFERENCES

- 1 van Karnebeek CD, Bowden K, Berry-Kravis E. Treatment of Neurogenetic Developmental Conditions: From 2016 into the Future. Pediatric Neurology. 2016;65:1-13.
- 2 Tural Hesapcioglu S, Ceylan MF, Kasak M, et al. Psychiatric comorbidities of mild intellectual disability in children and adolescents in a clinical setting. International Journal of Developmental Disabilities. 2019;67:151-7.
- 3 Baio J, Wiggins L, Christensen DL, et al. Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2014. Morbidity and Mortality Weekly Report. 2018;67:1-23.
- 4 Singh NN, Hwang YS. Mindfulness-based programs and practices for people with intellectual and developmental disability. Current Opinion in Psychiatry. 2020;33:86-91.
- 5 Raj R, Owen D, Kannan L, et al. Polypharmacy in a Patient With Intellectual and Developmental Disabilities. Cureus. 2022;14:e22019.
- 6 van Wieringen M, Broese van Groenou

- MI, Groenewegen P. Impact of home care management on the involvement of informal caregivers by formal caregivers. Home Health Care Services Quarterly. 2015;34:67-84.
- 7 Hejazi SS, Hosseini M, Ebadi A, et al. Family Caregiver: The Forgotten Savior. International Journal of Community Based Nursing & Midwifery. 2021;9:346-7.
- Dombestein H, Norheim A, Lunde Husebø AM. Understanding informal caregivers' motivation from the perspective of self-determination theory: an integrative review. Scandinavian Journal of Caring Sciences. 2020;34:267-79.
- 9 Zahed S, Emami M, Bazargan-Hejazi, et al. What motivates informal caregivers of people with dementia (PWD): a qualitative study. BMC Palliative Care. 2019;18:105.
- 10 Hosseini SJ, Ramezani M, Ashrafzadeh F, et al. Motivation in caregiving among mothers of children with intellectual and developmental disabilities in Iran: A qualitative study. BMC Pediatrics. 2024;24:472.
- 11 Alaee N, Mohammadi-Shahboulaghi F, Khankeh H, et al. Effective Factors on Caring Role of Parents of Children with Cerebral Palsy. Avicenna Journal of Nursing and Midwifery Care. 2019;27:55-63. [In Persian]
- 12 Naghdi N, Ghasemzadeh S, Ghobari bonab B. Phenomenology of Lived Experience of Mothers of Children with Down Syndrome (DS). Journal of Applied Psychological Research. 2019;10:105-18. [In Persian]
- 13 Khougar A, Asgharnejad A, Ranjbar H, et al. Lived Experience of the Social Suffering of the Parents with Autism Spectrum Disorder (ASD) Child. Social Welfare Quarterly. 2019;19:243-82. [In Persian]
- 14 Bahador RS, Farokhzadian J, Rafiee Sarbijan Nasab F, et al. Experiences of family caregivers of people with intellectual disabilities from rural areas in southeastern Iran: a qualitative study.

- BMC Psychiatry. 2023;23:613.
- 15 Corman MK. The Positives of Caregiving: Mothers' Experiences Caregiving for a Child with Autism. Families in Society. 2009;90:439-45.
- 16 McDonnell E, Ryan AA. The experience of sons caring for a parent with dementia. Dementia (London). 2014;13:788-802.
- 17 Kusi G, Boamah Mensah AB, Boamah Mensah K, et al. Caregiving motivations and experiences among family caregivers of patients living with advanced breast cancer in Ghana. PLoS One. 2020;15:e0229683.
- 18 Ackley BJ, Ladwig GB, Makic MBF, et al. Nursing Diagnosis Handbook, Revised Reprint with 2021-2023 NANDA-I® Updates-E-Book. 12 th ed. Netherlands: Elsevier Health Sciences; 2021.
- 19 Dunwoodie K, Macaulay L, Newman A. Qualitative interviewing in the field of work and organisational psychology: Benefits, challenges and guidelines for researchers and reviewers. Applied Psychology. 2023;72:863-89.
- 20 Mayring P. Qualitative content analysis: theoretical foundation, basic procedures and software solution. UK: SSOAR; 2014. [Cited15 August 2024]. Available from: https://www.ssoar.info/ssoar/bitstream/handle/document/39517/ssoar-2014-mayring-Qualitative_content_analysis_theoretical_foundation.pdf?sequence=1&isAllowed=y&lnkname=ssoar-2014-mayring-Qualitative_content_analysis_theoretical_foundation.pdf
- 21 Forero R, Nahidi S, De Costa J, et al. Application of four-dimension criteria to assess rigour of qualitative research in emergency medicine. BMC Health Services Research. 2018;18:120.
- 22 Liu HY, Chen JR, Hsiao SY, et al. Caregivers' oral health knowledge, attitude and behavior toward their children with disabilities. Journal of Dental Sciences. 2017;12:388-95.
- 23 Almosallam A, Qureshi AZ, Alzahrani B, et al. Caregiver Knowledge, Attitude,

- and Behavior toward Care of Children with Cerebral Palsy: A Saudi Arabian Perspective. Healthcare. 2024;12:982.
- 24 Tan GTH, Yuan Q, Devi F, et al. Factors associated with caregiving self-efficacy among primary informal caregivers of persons with dementia in Singapore. BMC Geriatrics. 2021;21:13.
- 25 Brehaut JC, Kohen DE, Garner RE, et al. Health among caregivers of children with health problems: findings from a Canadian population-based study. American Journal of Public Health. 2009;99:1254-62.
- 26 Hartley J, Bluebond-Langner M, Candy B, et al. The Physical Health of Caregivers of Children With Life-Limiting Conditions: A Systematic Review. Pediatrics. 2021;148:e2020014423.
- 27 Smith GR, Williamson GM, Miller LS, et al. Depression and quality of informal care: a longitudinal investigation of caregiving stressors. Psychology and Aging. 2011;26:584-91.
- 28 Ben Thabet J, Sallemi R, Hasïri I, et al. [Psycho-emotional impact of a child's disability on parents]. Archives de Pédiatrie. 2013;20:9-16. [In French]
- 29 Pelchat D, Levert MJ, Bourgeois-Guérin V. How do mothers and fathers who have a child with a disability describe their adaptation/transformation process? Journal of Child Health Care. 2009;13:239-59.
- 30 Bristow SM, Jackson D, Power T, Usher K. "Rural mothers' feelings of isolation when caring for a child chronic health condition: A phenomenological study". Journal of Child Health Care. 2022;26:185-98.
- 31 Resch JA, Elliott TR, Benz MR. Depression among parents of children with disabilities. Families, Systems, & Health. 2012;30:291-301.
- 32 Dembo RS, Mailick MR, Rudolph AE, et al. Social Network Diversity and Mental Health Among Mothers of Individuals With Autism. American Journal on Intellectual and Developmental Disabilities. 2023;128:101-18.

- 33 Wangler J, Jansky M. Support, needs and expectations of family caregivers regarding general practitioners results from an online survey. BMC Family Practice. 2021;22:47.
- 34 Zhang Y, Yuan Z, Cheng T, et al. Intrinsic drive of medical staff: a survey of employee representatives from 22 hospitals in China. Frontiers in Psychology. 2023;14:1157823.
- 35 Kurtgöz A, Edis EK. Spiritual care from the perspective of family caregivers and nurses in palliative care: a qualitative study. BMC Palliative Care. 2023;22:161.
- 36 Delgado-Guay MO, Parsons HA, Hui D, et al. Spirituality, religiosity, and spiritual pain among caregivers of patients with advanced cancer. The American Journal of Hospice & Palliative Care. 2013;30:455-61.
- 37 Hemati Alamdarloo G, Majidi F. Feelings of hopelessness in mothers of children with neurodevelopmental disorders. International Journal of Developmental

- Disabilities. 2022;68:485-94.
- 38 Deci EL, Ryan RM. Intrinsic motivation and self-determination in human behavior. Germany: Springer Science & Business Media; 2013.
- 39 Maddocks S, Moodley K, Hanass-Hancock J, et al. Children living with HIV-related disabilities in a resource-poor community in South Africa: caregiver perceptions of caring and rehabilitation. AIDS Care. 2020;32:471-9.
- 40 Ghazawy ER, Mohammed ES, Mahfouz EM, et al. Determinants of caregiver burden of persons with disabilities in a rural district in Egypt. BMC Public Health. 2020:20:1156.
- 41 Natvig C, Mikulich-Gilbertson SK, Laudenslager ML, et al. Association between employment status change and depression and anxiety in allogeneic stem cell transplant caregivers. Journal of Cancer Survivorship. 2022;16:1090-5.