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Meta-synthesis of the motherhood-related needs of women with multiple sclerosis

Elaheh Mansouri Ghezalhesari¹, Abbas Heydari², Hosein Ebrahimipour^{3,4}, Mohammad Ali Nahayati⁵ and Talat Khadivzadeh^{2,6*}

Abstract

Background The treatment of multiple sclerosis, an autoimmune disease that predominantly affects women of reproductive age, has undergone considerable advancements. Nevertheless, their unique needs, particularly those related to motherhood, continue to be disregarded. This study aims to ascertain the needs of women diagnosed with MS about motherhood.

Methods Using the Noblit and Hare methods, meta-synthesis research was conducted on 10 qualitative studies. The relevant studies were obtained by conducting a comprehensive search using keywords in the PubMed, Scopus, Web of Science (ISI), and ProQuest databases without any time limitations until June 2023. The CASP checklist was used to assess the quality of the articles, while the technique of Brown and Clark (2006) was utilized for data synthesis.

Results Four key themes emerged from this meta-synthesis, highlighting the significance of a support system, psychoeducational counseling, knowledge promotion, and continuous, comprehensive, and unique care.

Conclusion Identifying the needs of women diagnosed with MS and addressing these needs concerning motherhood can enhance the quality of services rendered and enhance women's contentment with their choice to embark on motherhood. Furthermore, recognizing these needs during subsequent stages can be utilized in formulating tailored programs catering to this specific cohort of women.

Keywords Need, Multiple sclerosis, Motherhood, Meta-synthesis, Qualitative studies

Background

Multiple sclerosis (MS), the third most common cause of neurological disability, is a chronic autoimmune disease that is known as the most common neurological disorder among young adults [1–3]. According to a report from the Multiple Sclerosis International Federation (MSIF), in 2020, approximately 2.8 million people with this disease were identified worldwide, which is 30% more than the number reported in 2013 [4].

MS is a persistent, advanced, and incapacitating neurological disorder marked by autoimmune harm to the white and gray matter of the brain, spinal cord, and optic nerve [5]. Individuals afflicted with this disease encounter an extensive range of sensory, motor, and visual

*Correspondence:

Talat Khadivzadeh
tkhadivzadeh@yahoo.com

¹Candidate of Reproductive Health, Student Research Committee, Faculty of Nursing and Midwifery, Mashhad University of Medical Science, Mashhad, Iran

²Nursing and Midwifery Care Research Center, School of Nursing and Midwifery, Mashhad University of Medical Sciences, Mashhad, Iran

³Department of Health Economics and Management, School of Health, Mashhad University of Medical Sciences, Mashhad, Iran

⁴Health Sciences Research Center, Torbat Heydariyeh University of Medical Sciences, Torbat Heydariyeh, Iran

⁵Department of Neurology, Ghaem Hospital, Mashhad University of Medical Sciences, Mashhad, Iran

⁶Department of Midwifery, School of Nursing and Midwifery, Mashhad University of Medical Sciences, Mashhad, Iran



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impairments due to significant inflammation in the central nervous system, which subsequently disrupts the transmission of nerve impulses [6, 7]. MS has a detrimental effect on the social life of individuals, which in turn negatively impacts their quality of life and restricts their ability to participate in health-related activities. Studies have consistently shown that MS patients have a reduced life expectancy by an average of 10 years [8, 9].

The disease is more prevalent in women, with a ratio of 3 to 1, than in men [10]. Moreover, it has been observed that women of reproductive age who are at the peak of their sexual and reproductive activities are more susceptible to this disease, leading to its rapid spread [11, 12]. Dysfunction of the pelvic floor muscles in the form of urinary incontinence and bowel problems, menstrual disorders, reduced sexual desire and satisfaction, and annoying mental and mood problems such as irritability, anger, decreased self-esteem, individual independence, and increased anxiety and depression have been reported only as a part of the problems and challenges faced by these women [8, 13–15].

In addition to having physical and psychological effects on women, MS also affects their fertility [16]. Before the 1990s, many women with this disease chose not to have children due to limited knowledge about how pregnancy and MS might interact [17, 18]. Recently, significant progress in the treatment of incapacitating illnesses such as MS has allowed women to experience motherhood, similar to their counterparts [19]; as indicated by recent studies, the advancement of MS over five years has been observed to be slower in women who have at least one child than in those who are single or without children [20–22]. Nevertheless, the number of women who become pregnant after the diagnosis of the disease is small, and in several studies, this percentage range is reported to be approximately one-third to one-fifth [23, 24].

The challenges and unmet needs of women appear to have a significant impact on reducing the desire for pregnancy and the experience of motherhood. The physical burden and problems of taking care of the infant, the lack of access to the required information, and the lack of appropriate emotional and social support are part of their challenges and unmet needs in the field of pregnancy and motherhood [17, 25–28].

Despite the recent focus on the medicinal regimens of women in this specific group during their reproductive period, their needs and challenges in the domain of motherhood and reproductive age remain disregarded [29]. Few studies have examined the needs and obstacles associated with pregnancy, childbirth, breastfeeding, and motherhood in women with MS. Likewise, existing studies have approached these needs and challenges in a sporadic and one-dimensional way [25, 30]. However,

identifying the needs and challenges of these women can be highly effective in formulating suitable programs and interventions to enhance their quality of life [31].

Qualitative studies, as a part of health studies, with a more complete understanding of the concerns of women with MS, can achieve a deep understanding of the main factors affecting health behaviors [31, 32]. Meta-synthesis, as a method for systematically reviewing qualitative studies, yields a novel and comprehensive interpretation of findings within a specific field. Consequently, these studies hold significant value [32]. Given the significance of recognizing the needs of women with MS during motherhood and the absence of meta-synthesis conducted in this area, the present study was designed and implemented to achieve an organized in-depth analysis of the needs of women with MS regarding motherhood.

Methods

Meta-synthesis, as a type of qualitative study, utilizes data from other qualitative studies in a specific field related to the researcher's question. In meta-synthesis, the researcher's goal is to combine and synthesize the findings of qualitative studies to achieve a new interpretation of the phenomenon. This method is not a secondary analysis of primary data from selected studies but rather an analysis of the findings of these studies [33, 34].

For this study, the meta-ethnography synthesis method proposed by Noblit and Hare (1998) was utilized to gain new insights into the needs of women with MS about motherhood. The method developed by Noblit and Hare involves seven distinct steps.

The first step is to set the research question. To set the research question, characteristics such as the studied community and what, when, and how the method is used need to be considered. The second step is the selection of eligible studies for the meta-synthesis. In this step, a systematic review of the existing studies related to the desired questions is performed. In the third step, the selected studies are carefully read to identify their key concepts and themes. The fourth step is text extraction. At this stage, the researcher examines the relationship between the studies and extracts the content of the studies related to his research question. The fifth stage is the translation of studies to each other. The purpose of translating studies to each other is to convert their key concepts to each other. At this stage, the key concepts of each study are compared with the key concepts of other studies. The sixth stage involves creating a "whole" from the initial studies. This whole, which is the final result of the meta-synthesis, is an interpretation that goes beyond the results of each of the initial studies and at the same time includes them all. The seventh step is the publication of meta-synthesis findings. In this step, the findings

from the previous steps are presented in the form of a conceptual model [34, 35].

The initial stage of this approach involves identifying the research question. In the present study, the following research question was established: What are the needs of women with MS about motherhood?

To formulate the study question in alignment with the research objective, the Population, Phenomenon of Interest, and Context (PICO) framework from the Joanna Briggs Institute was utilized [36]. (Population: Women with MS, Phenomenon of Interest: The needs of women about motherhood, Context: No location restrictions).

Research strategy

By the second phase of the Noblit and Hare approach, an extensive search was conducted in the PubMed, Scopus, Web of Science (ISI), and ProQuest databases, without time limits until the end of June 2023, using Boolean operators with 4 groups of words: Key (“multiple sclerosis”) OR (“multiple-sclerosis”) AND (motherhood) OR (mothering) OR (maternity) OR (“pregnant women”) OR (parent*) AND (qualitative) OR (phenomenology) OR (“grounded theory”) OR (“content analysis”) OR (“mixed method”) OR (ethnography) AND (needs*) OR (Experience) OR (perception) OR (Attitude) OR (View*) OR (Feeling*) OR (Opinion). Furthermore, apart from conducting searches on the aforementioned databases, a manual check was carried out on all the references cited in the acquired articles.

Inclusion and exclusion criteria

The inclusion criteria for the current study included all qualitative studies focused on motherhood-related needs in women with MS at various stages of life (women in the pre pregnancy period, pregnant women, and women with children), without regard to the disease stage, and studies with access to the full text of the article. Studies with a quantitative design, meta-synthesis, studies focusing on both genders (men and women with MS), studies that did not specify the gender of participants, and non-English language studies were excluded.

Study selection

The articles identified by two researchers (EMG, MAN) were investigated in multiple stages to ensure the retrieval of the most relevant articles about the research question. The primary stage of the process entailed examining the title and abstract of all the articles that were searched, and then, the full texts of the articles that were relevant to the research question were evaluated. A total of 381 articles were identified during the initial search, while an additional 11 articles were identified through the manual search. After analyzing the title and abstract of each acquired article and disregarding 337 articles that

lacked semantic connections, the complete texts of 21 articles were evaluated, and 10 articles were ultimately incorporated into the present meta-synthesis.

Quality assessment

To assess the quality of the studies based on the third stage of the Noblit and Hare method, the CASP tool was used. Despite the absence of unanimous agreement on the most effective evaluation tool for qualitative studies, this particular tool has been utilized in several studies to appraise the quality of articles [37–39]. This tool consists of three parts and 10 questions that can be responded to with a yes, unclear, or no. Two researchers (EMG, TKH) individually assessed the quality of each article included in the meta-synthesis utilizing the tool mentioned above, and in cases of disagreement, the final decision was made via the consensus of the authors through discussion with a senior reviewer (TKH). After the research team's agreement, this tool employs a scoring method where each affirmative option is assigned a score of one, the unclear options are assigned a score of half, and the negative options are assigned a score of zero. The tool's maximum score is 10, while the minimum score is zero.

Since the present study aimed to meet the needs of women with multiple sclerosis, none of the articles based on their quality were excluded from the present meta-synthesis (Table 1).

Data analysis

The present study utilized a combination of classical meta-synthesis or meta-ethnography proposed by Noblit and Hare (1998) [35] and the thematic analysis approach introduced by Brown and Clark (2006) [40] to achieve synthesis. The rationale behind opting for this solution was the absence of a comprehensive explanation of the practical process involved in executing the approach, particularly the steps mentioned in steps 4 to 7 [37]. Brown and Clark's six-step approach was utilized for analysis. Previous studies have also demonstrated the successful implementation of this combination [37, 38, 41]. Brown and Clark's thematic analysis comprises six stages: (1) becoming acquainted with the data, (2) extracting primary codes, (3) identifying themes, (4) examining themes, (5) defining themes, and (6) creating a network of themes. To adhere to the six-step model, the researchers initially perused the text of the studies encompassed in the current meta-synthesis multiple times to acquaint themselves with the data of each study. The primary codes that aligned with the research question were extracted from the text of each study. The extracted initial codes were compiled into a list, and subsequently, any extraneous, incomplete, or repetitive codes were eliminated, followed by a reevaluation of the remaining codes. In the subsequent phase, comparable codes that

Table 1 The results of the critical appraisal of the included studies

study	Research question		appropriateness of the methodology		appropriateness of the methodology		Recruitment strategy	Data collection	Reflexivity	Ethical issues	Data analysis	Findings	Contribution to knowledge	score
	+	-	+	-	±	-								
Smeltzer, S.C. et al. [30]	+	+	+	-	±	+	+	-	+	+	+	+	+	7.5
Prunty, M. et al. [27]	+	+	+	-	±	+	+	-	-	-	-	±	+	5
Payne, D. et al. [17]	+	+	+	+	+	+	+	+	+	+	+	+	+	9
Kosmala-Anderson, J. et al. [82]	+	±	±	-	±	+	+	-	+	+	+	+	+	7
Willson, C.L. Et al. [83]	+	+	+	+	+	+	+	+	+	+	+	+	+	10
Parton, C. et al. [73]	+	+	+	-	±	+	+	-	+	+	+	+	+	7.5
Parton, C. et al. [111]	+	+	+	-	+	+	+	-	+	+	+	+	+	8
Ghafoori, F. et al. [25]	+	+	+	+	±	+	+	-	+	±	±	+	+	8
Carlino, M. et al. [112]	+	+	+	+	+	+	+	-	+	+	+	+	+	9
Colacci, S. et al. [29]	+	+	+	+	+	+	+	-	+	+	+	+	+	9

conveyed analogous requirements were grouped and constituted subthemes. By arranging subthemes of the same gender in immediate proximity, the main themes were established. The principal themes underwent a thorough reassessment and modification. The presence of all authors was ensured throughout the entirety of the data synthesis process, and the use of MAXQDA version 20 software was employed.

Results

Out of the 392 studies that were analyzed, only 10 studies with a combined sample of 316 participants were deemed suitable for inclusion in the current meta-synthesis. In the final search, three studies were excluded from the present meta-synthesis because they included men in the study and did not segregate the results by sex [26, 42, 43]. One study was also excluded because it did not precisely mention the gender of the participants [44]. The details are reported in Fig. 1.

Characteristics of the included studies

The data from the above studies were collected through face-to-face interviews, telephone interviews, focus groups, and open-ended questions. Of the 10 studies included in the present meta-synthesis, three were conducted in Australia, three in Italy, one in New Zealand, one in Iran, one in England, and one in Canada. The age range of the participants in these studies was between 20 and 54 years, with an average age of 33 years. Only one study did not mention the age range of the participants. The majority of participants had relapsing-remitting MS type (RRMS). However, one study did not report the MS type of the participants. Three studies focused on pregnant women, while two studies did not specify the type of participants (pregnant or non pregnant). These studies addressed various aspects of the Motherhood-Related Needs of women with MS (Table 2).

Synthesis of findings

The synthesis of the findings led to the creation of four main themes and 15 subthemes. The four themes of this synthesis are the need for a support system, the need for psychoeducational counseling, the need for knowledge promotion, and finally, the need for continuous, comprehensive and unique care, which are reported in detail in Table 3.

The need for a support system

The emergence of special support needs can be attributed to the duration of MS disease and the complexity of its course. Individuals who have recently been diagnosed with MS face a range of challenges that necessitate tailored support. The duration of the disease and its course can exacerbate these challenges, leading to the emergence

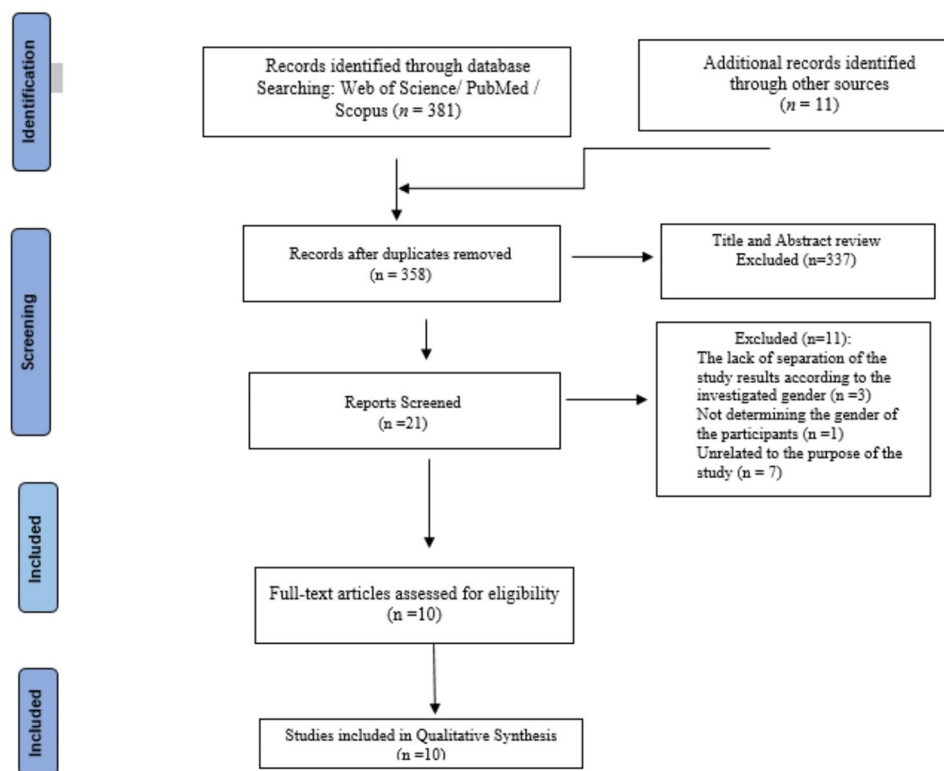


Fig. 1 PRISMA flow diagram for the selection process of the articles

of unique support needs. As women embark on the path of motherhood, they encounter unique circumstances that necessitate tailored assistance and guidance. The support requirements that individuals may perceive can manifest due to a range of factors, encompassing the development of novel conditions after pregnancy and childbirth, the provision of care for newborns, physical and psychological complications after giving birth, and the recurrence of illnesses postpartum. The current meta-synthesis findings indicate that women require a distinct support system to aid them in their path to motherhood. This theme consists of four subthemes: the need for physical support, the need for financial support, the need for job support, and the need for social support.

The need for physical support

A considerable number of the examined mothers highlighted various physical challenges encountered during the postpartum phase, including exhaustion, sleep disturbances, and hindered ability to carry out routine activities. Fatigue symptoms can be characterized by manifestations such as tiredness, a propensity for premature fatigue, diminished energy levels, and an insuffering state of lethargy. Waking up frequently during the night to breastfeed the baby, reducing the quality and quantity of sleep, changing the lifestyle after the birth of the baby, and taking care of the baby are among the factors

influencing the fatigue of mothers in the postpartum period. On the other hand, fatigue and insomnia after childbirth can contribute to the recurrence of the disease after childbirth and cause disease attacks during this period, which in this case makes breastfeeding and taking care of the baby difficult. For example, it was reported in study (8):

"But what can I expect after giving birth? I am afraid it will worsen my illness as I must cope with the lack of sleep due to feeding times and at the same time deal with the usual pains. These will give me additional stress which may trigger an MS relapse"

The need for financial support

The prolonged effects of MS ultimately lead to a substantial economic burden for individuals living with the condition. The economic consequences of the disease can vary depending on several factors, including the stage of the disease, the employment status of the individual, and their life stage. These variables contribute to the diverse range of economic effects experienced by individuals affected by the disease. The financial strain on patients encompasses a range of expenses, such as hospitalization costs, medical tests, prescribed medications, essential supplements, consultations with healthcare

Table 2 Characteristics of the included studies

Ref. no.	Country	Methodology	Data collection methods	Participants	Type of Disease	Mean of ages	Result
1	Canada	Qualitative descriptive	Semi structure interview	15 women: (12 women: pregnant (5th and 8th month of pregnancy) 3 women: Post-Partum periods)	12 women with relapsing-remitting course and 3 women with chorionic progressive MS	32 years Range (20–40)	Concerns that were identified focused on pregnancy itself, labor and delivery issues, breast-feeding, and short- and long-term parenting issues.
2	Australia	qualitative study	Focus group interviews	20 nonpregnant women (5 participants: doubts about pregnancy 5 participants: definitive decision for pregnancy 6 participants: definitive decision not to get pregnant 4 participants: They had children before and did not want children anymore)	60% relapse–remitting MS, 10% secondary progressive and 10% primary progressive 20% not mentioned.	30.3 years Range (24–40)	The themes emerging most frequently during the decision-making process were: a) concerns about the mother's own health and well-being; b) well-being of the child; c) coping with parenting; d) societal attitudes; e) experiencing parenting and f) timing and pressure of the decision
3	New Zealand	Qualitative interpretive descriptive	Semis-structured interviews	9 women (age of youngest Child:3 months)	8 women with relapsing-remitting course and 1 woman with Secondary progressive MS	Range 20–45 years	Analysis of interviews produced six key themes: becoming a mother as a public private experience, keeping the baby safe; support; conserving energy; being the ideal mother; and back-grounding of their MS
4	England	Qualitative study	Semi structured interviews	9 women (3 women pregnant, 3 women were currently pregnant (3, 5 and 7 months) and 3 woman recently had a baby (2, 6 and 8 months ago))	8 women with relapsing-remitting course and 1 woman with Secondary progressive MS	mean ages: 30.6 years (range 23–37 years)	Three major themes emerged from the interviews: "Concerns about MS and pregnancy, Lack of information about MS and pregnancy, Others' opinions about child-birth choices"

Table 2 (continued)

Ref. no.		Country	Methodology	Data collection methods	Participants	Type of Disease	Mean of ages	Result
5	The impact of multiple sclerosis on the identity of mothers in Italy [83]	Italy	Interpretative Phenomenological Approach	In-depth interviews	16 women (age of youngest Child:2 years)	6 women with low movement disorder and no need for help, 5 women with moderate movement disorder, 5 women with severe movement disorder and needing a wheelchair)	Not Mentioned	Analysis of interviews produced Three key themes: Self and identity, Challenges and support within society and Relationships with others
6	Being a mother with multiple sclerosis: Negotiating cultural ideals of mother and child [73]	Australia	Thematic decomposition	The semi-structured interviews	20 women (age of youngest Child:7 months)	90% relapse–remitting MS, 10% secondary progressive .	Mean ages: 37.5 years (range 26–54 years)	Two main themes were identified: “Performing motherhood in the context of MS” and “Bringing up a ‘good’ child”.
7	‘Normal’ and ‘failing’ mothers: Women’s constructions of Maternal subjectivity while living with multiple sclerosis [111]	Australia	Thematic decomposition	The semi-structured interviews Telephone interviews	20 women (age of youngest Child:7 months)	90% relapse–remitting MS, 10% secondary progressive .	mean ages: 37.5 years (range 26–54 years)	Three main themes were identified: ‘The Failing Mother’, ‘Fear of Judgment and Burdening Others’ and ‘The Normal Mother’.
8	Pregnancy and Motherhood Concerns Surrounding Women with Multiple Sclerosis: A Qualitative Content Analysis [25]	Iran	Content Analysis	In-depth semistructured face-to-face interviews	25 women (13 women without child and 12 Women with at least one child)	Mean severity of disability, according to the expanded disability status scale (EDSS) : 4.7 ± 2.3	Mean ages: 31.7 years (range 20–47 years)	The main themes identified in this study was “Pregnancy concerns”, “Fear of failing as a parent”, “Feeling of threatened fertility”, and “Lack of social support”.
9	Multiple Sclerosis and Maternity: A Psychological Explorative Qualitative Research [112]	Italy	Psychological Explorative Qualitative Research	Interview	20 women	100% women with relapse–remitting MS	Mean ages: 34.5 years (range 25–40 years)	The main themes identified in this study was “Family Role, Daily Pain, Relationship with Health Care Services and Closing the Circle
10	‘A sleeping volcano that could erupt sooner or later’. Lived experiences of women with multiple sclerosis during childbearing age a motherhood: A phenomenological qualitative study [29]	Italy	Descriptive phenomenological	Semis-structured interviews	16 women (3 women pregnant, 13 women not pregnant (10 women with children < 2 years))	Not Mentioned	Mean ages: 35.8 years (range, 29–48 years)	The following 6 deductive themes emerged: (1) experience with diagnosis of MS; (2) relationship with the partner, children, and family; 3) pregnancy; 4) delivery; 5) puerperium; 6) care pathway.

Table 3 Themes and subthemes that emerged from the analysis

Primary codes(study number)	Subtheme	Main theme
The need to limit activities after delivery [2–4, 8, 10]	The mother's need for physical support	The need for a support system
The need for a companion to take care of the mother in the days following the delivery [3, 8]		
The need for financial support in connection with the baby's care [4]	The need for financial support	
The need for financial support during the postpartum period [2, 6]		
The need for financial support to cover expenses such as diagnostic tests during pregnancy [10]	The need for work support	
The need for flexible working hours and improving working conditions [4, 6]		
The need for employers to support the spouse's employment [2, 3]	The need for social support	
Need for emotional support from spouse and family [3, 10]		
The need for social support following childbirth [3, 6–8]		
Needing help with household chores [2, 9]		
The need for a companion to take care of children [1, 3, 6–8]	The individual's need for psychological counseling	The need for psychoeducational counseling
The need for psychological counseling for disorders during pregnancy and after birth [6, 7, 10]		
The need for psychological counseling during the treatment process [10]	The need of family members for psychoeducational counseling	
The need for counseling to accept the role of mother with illness [3, 5–7]		
The need for counseling family members to effectively deal with affected mothers [10]		
The need for family counseling in relation to the impact of illness on a woman's ability to be a mother [2]		
The need to be aware of the consequences of medications on the fetus, infant, and child [1, 3, 4, 8]	The need to acquire knowledge about the effects of medication during pregnancy and after delivery	The need for knowledge promotion
The need to be aware of the impact of medications on the mother's health [1, 3]		
The need to be aware of the effect of medications on the mother's health [1, 4, 9, 10]	The need to acquire knowledge about the hereditary aspect of the disease	
The need to understand how the condition is inherited by children [4, 8]		
The need to recognize the rates of disease transmission during pregnancy and lactation, as well as drug usage [1]	The need to acquire knowledge about with knowing the nature of the disease during pregnancy, childbirth, and breastfeeding	
The need to be aware about the effect of the disease on the stages of pregnancy, delivery, and breastfeeding [1, 4, 10]		
The need of awareness in distinguishing the natural symptoms of pregnancy from the disease [1]	The need to acquire knowledge about labor care, childbirth, and breastfeeding	
The need for awareness in connection with the effects of pregnancy and childbirth on the rate of disease progression and the risk of recurrence [4, 8]		
The need for awareness in selecting the most appropriate delivery method and related care [10]	The need for available, comprehensive, and reliable information sources	
The need for awareness about the type of analgesia administered during labor [3, 10]		
The need for awareness regarding breastfeeding and weaning the baby in cases of disease recurrence and the need to take medicine [1, 10]		
The need to have access to a source of information on the disease and childbearing [4]		
The need to access information sources related to MS drugs and childbearing [10]		

Table 3 (continued)

Primary codes(study number)	Subtheme	Main theme
The need to have uniform guidelines about labor, anesthesia, and delivery [10]	The need to develop specific guidelines	The need for continuous, comprehensive, and unique care
The need for collaboration among HCPs to provide pregnancy recommendations [1, 3]		
The need to improve HCPs' awareness regarding the nature of the disease [3]	The need to access well-informed HCPs	
The need for educating HCPs on the impact of disease on the pregnancy, delivery, and breastfeeding processes [1, 8, 10]		
The need for HCPs awareness regarding the effects of the disease on women's well-being, mentality, and psyche [6, 7]	The need for visits and special follow-ups during pregnancy and after delivery	
The need to improve HCPs' communication and counseling skills [10]		
The need for home visits during the postpartum period [3]	The need for special care	
The need to expedite the scheduling of appointments and check-ups for women during their pregnancy and postpartum period [10]		
The need for MS nurses to be available in times of disease recurrence and symptoms [3]	The need for special care	
The need to adopt a unique approach in dealing with the needs of women during pregnancy and after childbirth [3, 8]		
The need to access a professional team of healthcare providers during pregnancy, delivery, and postpartum [3, 10]		
The need for child health care programs [8]		
The need for a unique mother's care program [8]		

professionals, the acquisition of medical equipment, and the responsibility of caring for dependent children. Financial assistance was identified by women diagnosed with MS as an integral component of the support they needed. The support mentioned pertains to indispensable outlays such as consultation appointments, diagnostic assessments, assisted reproductive procedures, expenses for infant care, acquisition of necessary equipment such as wheelchairs, and home alterations to adjust to postpartum circumstances. For example, the following was reported in study (2):

"I know that we want to be financially stable before we sort of move into having kids, just in case...all the what-ifs I get sick "

The need for work support

As a consequence of the progressive nature of MS, a significant number of patients are bound to experience a gradual decline in their employment capacity. Factors leading to leaving work have been attributed to fatigue, movement disorders, cognitive deficits, and medical advice from doctors. On certain occasions, individuals are compelled to leave their jobs not by their own choice but by the actions of their employers. A reduction in income that occurs without one's intention can lead to a stressful experience. Work support is necessary for women because they embark on the path to motherhood. Work support perceived by women is divided into two categories: women's work support and spouses' work support. To ensure optimal work support during pregnancy and after childbirth, it is crucial to consider

the physical conditions of women. This can be achieved by reducing working hours, providing lighter work positions, and offering support to employers. For example, one of the women in the study (8) expressed her working hours despite little social support while caring for a young child and experiencing fatigue due to MS:

"By afternoon, one-o'clock, lunchtime, I'm very tired and my shoulder aches. I'm totally exhausted"

In addition to providing work support for mothers, it is also imperative to provide job support to spouses. During the postpartum phase, the mother undergoes immense physical and mental stress, and the support of her spouse in taking care of her and the newborn is crucial. Support and flexibility in the workplace and awareness of employers in relation to the nature of MS and the support needed by the mother are considered part of the work support proposed for the spouse. In this context, the following was reported in study (2):

"My husband will have to quit work if I'm truly too exhausted to care for a child, which worries me because it is so expensive."

The need for social support

The highest rate of MS relapse is documented during the initial three to six months after childbirth. In light of the prevailing conditions, it is crucial to provide mothers with an extensive amount of social support. The concept of social support entails a complex structure that involves the provision of emotional, informational, or instrumental aid by individuals within one's family, friends, or work associates [45]. The provision of social

support is determined by the severity of the illness, and the mother's state. Mother's social support can be fulfilled first by family members such as spouses and parents and then by peer groups and governmental and nongovernmental institutions. However, the mother's source of support depends on who is close to her social circle. Most of the participants mentioned social support from family and close friends as a basic need in the postpartum period and considered it their first source of support. For example, one of the participants in study (8) reported the following:

"I lost my mother two years ago, and I have no one to help me. How am I supposed to care for my child on my own? It is important to have someone to help you after the pain and loss of blood from giving birth and during the first days after delivery"

Peer groups can offer the necessary social support that mothers require at times. Sharing the experiences of mothers about how to take care of themselves and their children, the challenges ahead, benefiting from their opinions and physical help in taking care of children can be useful. The government can provide social support to individuals in various ways, including financial or physical support. This support can come in the form of a person's presence at home to assist with household tasks such as cleaning, washing, and caring for children and mothers. Additionally, the government can offer physical support, such as installing fences and furnishing homes.

The need for psychoeducational counseling

Women who have been diagnosed with MS often experience significant emotional distress, characterized by heightened levels of anxiety and depression, during pregnancy and the postpartum period. After childbirth, women may struggle to grasp the true essence of their role as mothers due to the limitations imposed by the disease. As a result, they may perceive themselves as unsuccessful or inadequate caregivers, harboring feelings of failure. The fear and unease surrounding the unknown future following pregnancy and childbirth, combined with the feelings of guilt associated with potentially transmitting the disease to the child and the inclination to impose strict expectations upon oneself to exemplify flawless motherhood, can heighten the severity of mental disorders experienced by these mothers. Undoubtedly, in this particular scenario, mothers' performance and social activities may undergo modifications. Consequently, not only will the upbringing of the children be disturbed, but the mother will also experience heightened levels of tension and fatigue and a decline in her overall quality of life. This primary class encompasses three subordinate classes that address various counseling requirements of

mothers. This theme, which consists of two subthemes, expresses different aspects of the counseling needs of these mothers. These subthemes include individual need for psychological counseling and family members' need for psychoeducational counseling.

Individual need for psychological counseling

Women diagnosed with MS often encounter a range of adverse emotions as they navigate the path to motherhood. These emotions may encompass feelings of guilt, shame, anxiety, fear, worry, and psychological tension. One of the emotions recognized by this mother was the sense of guilt and shame that arose from transmitting the disease to her child. In a number of studies examined in the present meta-synthesis, mothers stated that when they saw the smallest symptom in their child, they thought that they had transmitted the disease to him/her and thus they constantly blamed themselves. On the other hand, mothers were worried about the uncertain future and possible disabilities due to the unpredictable nature of the disease and its behavior after pregnancy. These women were afraid of becoming weak and dependent on others and unable to meet the needs of their children. By comparing themselves with other healthy mothers and observing their inability to meet the physical, mental and emotional needs of their children, these mothers lost the self-confidence necessary to accept and play the role of mother and felt that they were failed mothers in meeting the needs of their children. For example, one of the participants in study (6) stated:

"My friends, they're fine, they can go out. So that's where I feel he misses out a lot on that sort of thing. In addition, that's shift. There's no one else to blame but me in that sort of situation"

The need for family members for psychoeducational counseling

The findings of several studies have demonstrated that women have conveyed their discomfort with the limitations imposed upon them by their husbands and parents in fulfilling their daily tasks and maternal duties. The women who shared their experiences expressed their anxieties regarding their perceptions of them as disabled mothers and the potential ramifications of losing some or all of their roles as mothers. Moreover, the excessive support provided by husbands and parents to mothers has caused women to experience discomfort and doubt their suitability for the role of motherhood. In this context, one of the study's (6) participants stated:

"My mother and my husband's mother thwarted a lot... They treat me like a disabled person... They

lead me to feel bad, agitated, and stressed; we often have discussions. My three children have always been a mistake for my mother, one mistake after another”

The need for knowledge promotion

To navigate their path to motherhood, women living with MS need access to comprehensive and trustworthy information encompassing the realms of medicine, pregnancy, childbirth, breastfeeding, and the reciprocal impact of the disease and the processes of pregnancy and childbirth on one another. The provision of information to women in this specific direction has the potential to alleviate their anxiety and concerns, enabling them to make more informed decisions and improve their self-esteem and general well-being through active engagement in their affairs. This theme is composed of five subthemes: the need to acquire knowledge about the effects of medication during pregnancy and after delivery; the need to acquire knowledge about the hereditary aspect of the disease; the need to acquire knowledge about the nature of the disease during pregnancy, childbirth, and breastfeeding; the need to acquire knowledge about labor care, childbirth, and breastfeeding; and the need for available, comprehensive, and reliable information sources.

The need to acquire knowledge about the effects of medication during pregnancy and after delivery

Understanding the implications of drug usage during pregnancy, postpartum, and breastfeeding was a primary concern for many mothers in the present meta-synthesis. A few women had to adhere to their medication schedule during pregnancy as a result of their medical conditions and bouts of disease relapse before becoming pregnant. To prevent the disease from recurring, several women had to resume the administration of medications shortly after giving birth and continue taking them throughout the breastfeeding phase. In this particular scenario, women need to possess this knowledge regarding the potential impacts of the drugs administered on the fetus, the newborn, and their well-being. In the same context, the following was reported in the study (8):

“I have heard that breastfeeding makes children stronger and boosts their intelligence, but I cannot breastfeed due to my illness. I fear my child will not be healthy because of all the medications I take. I think only healthy mothers should plan to become pregnant.”

Several women who were part of the study indicated that they ceased taking their medications during pregnancy as a result of the stabilization of their disease conditions.

However, they resumed their medication regimen after giving birth to prevent any potential relapse. In the given circumstances, the mothers expressed their concerns about ceasing medication during pregnancy and the subsequent progression of the disease after discontinuation. They sought reassurance regarding the possibility that discontinuing medication during this period may lead to disease progression in later stages or a recurrence of the condition after giving birth. According to the findings reported in the study (3):

“Before I started injections, I had 3–4 major relapses a year. I am very scared that this will happen again when I stop taking them”

The need to acquire knowledge about the hereditary aspect of the disease

Although there are only a few studies on the transmission of diseases to children, women need to be knowledgeable about the modes of transmission and the likelihood of transmission during pregnancy and breastfeeding. For example, it was stated in study (4):

“My maternal grandmother’s sister had MS, and my husband’s cousin has it too. I’m very worried that my baby will have it too, but there is no way of knowing before the baby is born, is there?”

The need to acquire knowledge about the nature of the disease during pregnancy childbirth and breastfeeding

Mothers diagnosed with MS need to be knowledgeable about the characteristics of the disease and its impact on pregnancy, labor, and breastfeeding. Moreover, primiparous mothers who were new to the experience of motherhood required precise information to differentiate between the typical signs of pregnancy, such as tiredness, frequent urination, and muscle cramps, and indicators of disease relapse or the emergence of new symptoms. A few of the women who were examined revealed that their inadequate understanding of the matter led them to mistake the typical symptoms of pregnancy for a fresh indication of disease relapse during or after childbirth, resulting in heightened levels of stress and anxiety. In research (1), for example, it was stated:

“That is the thing that I can’t distinguish... fatigue because of my pregnancy or fatigue from the MS. but it’s truly hard any time to distinguish if you’re truly getting sick or if it is your MS. Whether or not to make an appointment with the doctor and go in or whether it’s a matter of waiting a while and resting. It is truly hard to distinguish”

During motherhood, it is imperative for women diagnosed with MS to have a comprehensive understanding of how the disease can influence the processes of pregnancy, childbirth, and breastfeeding. They should be aware of the reciprocal effects between MS and these stages, including the hormonal changes that occur during pregnancy and after childbirth, as well as the potential stresses and strains encountered during labor and delivery. By being knowledgeable about these factors, women can better assess the likelihood of disease recurrence and progression. For example, a study (8) on the need for information about the effects of pregnancy on the disease and the possibility of its recurrence during pregnancy and after delivery reported the following:

"I know the pregnancy itself does not cause an MS relapse and may even have a positive effect, but what can I expect after giving birth? I am afraid it will worsen my illness..."

The need to acquire knowledge about labor care, childbirth, and breastfeeding

Selecting the type of delivery for women with MS is a very challenging issue. Vaginal delivery can be stressful for the mother due to the need for the mother's efforts to get the fetus out in the second stage and the resulting fatigue. However, to determine the most suitable type of delivery, it is necessary to provide very detailed information about each type of delivery, their benefits, the state of their illness, and its physical effects. The results of the present meta-synthesis showed that women with MS needed to learn about the most appropriate type of delivery, necessary care during labor, and pain relief options during labor and delivery. Study (1) stated the following:

"I've heard that if you have MS, you can't have an epidural"; "The midwife told me that I truly should have a cesarean section, as natural delivery is too risky for my baby"

Breastfeeding has the potential to act as a safeguard against disease recurrence in the postpartum phase [46]. Nonetheless, women may cease breastfeeding due to specific factors, such as the resumption of medication intake. The findings of the research conducted on women with MS indicated that they required education on breastfeeding, including its significance, indications and contraindications, and the proper method of weaning the baby in case of disease recurrence or the need to switch to formula milk. For example, it was reported in study (1): "Breastfeeding is the one thing I will not do. I probably would never have done it anyway. However, especially because I have MS... "

Needs for available, comprehensive, and reliable information sources

The studies conducted indicate that women primarily turn to the internet for information on drugs, pregnancy, childbirth, breastfeeding, and disease transmission to their offspring, with books, friends, and peer groups being secondary sources in later stages. For women, obtaining access to this information has proven to be a tiresome and time-consuming endeavor. Furthermore, in certain instances, it has led to increased confusion due to limited and conflicting information, thereby impeding their decision-making capabilities. Consequently, this situation has proven distressing, exacerbating individuals' levels of stress and anxiety. Access to reliable and comprehensive information sources is crucial for mothers, as it fulfills their need for accurate information.

The need for continuous, comprehensive, and unique care

The path to motherhood for those with MS necessitates consistent, comprehensive, and tailored care to meet their unique needs. The multifaceted nature of MS has wide-ranging implications for maternal health. In this scenario, employing a team-based approach to meet the needs of mothers and provide them with adequate care fosters effective coordination of services and ensures continuity of care. This theme of four subthemes includes the need to develop specific guidelines, the need to receive services from health care providers (HCPs) aware of the disease, the need for special visits and follow-ups during pregnancy and after delivery, and the need for special care.

The need to develop specific guidelines

Women diagnosed with MS often encounter the challenge of navigating through varying perspectives from healthcare providers. The diverse opinions surrounding pregnancy, the administration of medications during pregnancy, the choice of delivery method and anesthesia, breastfeeding, and the postpartum period can cause women to feel confused and uncertain, impeding their ability to make informed decisions regarding these impending concerns. The decision to become pregnant was found to be a topic of varying opinions among healthcare providers, as reported in the study (3).

"The way he (the overseas doctor) diagnosed me everything was a truly big drama, 'You shouldn't have kids because of that yo-yo effect. It's too much risk.' In addition, then when I came to New Zealand, the attitude changed; the neurologist said, 'No, 'if you want to have kids, have kids. Be aware of the risks. Therefore, yes, I should be fit and healthy and young enough to go through it'"

The need to access well-informed HCPs

The outcomes of our meta-synthesis highlight the necessity for HCPs to improve their knowledge and awareness regarding the specific concerns of women with MS during the reproductive and motherhood periods. This includes understanding the nature of the disease and its effects on pregnancy and childbirth. In this regard, the following was noted in study (3):

"I do remember asking them about that (interferon harming the baby). Whether or not that was going to be a problem with me still taking interferon as well as trying to become pregnant and conceive. They couldn't answer a lot of questions on that, and they said 'However, as soon as you fall pregnant that's when you must come off it'"

The need for visits and special follow-ups during pregnancy and after delivery

The outcomes of the meta-synthesis conducted in this study highlight the necessity for women to receive specialized care during pregnancy and postpartum, emphasizing the need to prioritize expedited appointments during these visits. Following childbirth, women may require specialized home visits instead of attending clinics or medical centers, depending on their physical well-being. Conversely, several individuals involved in the examined research expressed the significance of unhindered and convenient communication with nurses or personnel responsible for MS treatment, particularly in sensitive situations such as experiencing recurring symptoms or the emergence of new symptoms. This allowed them to seek clarification on their concerns and receive the necessary care. For example, according to study (10):

"I feel abandoned to myself because I want another child, but I don't get pregnant, and I don't know who to talk to... the waiting times for a neurological visit are very long, and if I have a doubt, I don't know who to call... I answer myself because I am a nurse, but it is not right for those who are not doctors and nurses"

The need for special care

Women diagnosed with MS necessitate unique attention during pregnancy and postpartum, contingent on the advancement of the disease, their physical state, and specific requirements throughout the different phases of motherhood. A multitude of studies have emphasized the significance of adopting a specialized approach that takes into consideration unique circumstances and prioritizes the physical, psychological, and emotional needs of individuals.

By assembling dedicated teams of healthcare professionals comprising neurologists, gynecologists, midwives, anesthesiologists, nurses, psychiatrists, and consultants, a tailored approach can be adopted to provide specialized care for this specific group of women. This approach involves understanding the intricacies of the disease and addressing the unique requirements of women. In the study (10), the following statement was reached:

"If I want to have a child ... I don't know if I have to refer to a gynecologist expert in neurology or a neurologist expert in gynecology, there is no team ... and therefore we should create a path for mothers or future mothers with MS ... This aspect should be improved as well as the cohesion between gynecologists and neurologists..."

Discussion

The current meta-synthesis represents a groundbreaking study to delve into the needs of women with MS as they navigate the path to motherhood. The findings of this meta-synthesis reveal four overarching categories of support, counseling, information, and care needs. Each of these needs consists of subclasses that ultimately encompass the needs of women during this particular phase.

The first weeks and months after childbirth create challenging changes in women's lives. Sleep disorders, mood changes, fatigue, stress, and physical symptoms such as pain and breastfeeding can affect the physical and mental health of women [47]. Emotional, material, and practical support is vital during this period, and without it, women may become isolated [47–52]. In women with disabilities or chronic diseases, these challenges are more complicated [47]. The results of the present meta-synthesis showed that women with MS need much support in the postpartum period to take care of themselves and their children. This support can be provided by family, friends, peer groups, and even the government.

The first three to six months after childbirth are considered a critical period for women with MS. During this time, the mother experiences increased fatigue due to frequent waking to breastfeed, the physical and mental strain of caring for a newborn, and hormonal imbalances. This can potentially trigger disease attacks [53]. Özkan et al. conducted a study to investigate the motherhood experiences of women with MS. The findings revealed that a majority of these women experienced fatigue and a sense of helplessness due to the demands of breastfeeding, insomnia, and caring for their infants. Consequently, they expressed the necessity for support from their family members [32]. It should be emphasized that offering practical aid during the postpartum period, such as having a caregiver for the infant or assistance with domestic

duties, provides the opportunity for the woman to have more time to enjoy her role as a mother and, at the same time, focus on her health and engage in activities related to improving her health [54].

Through a comprehensive meta-synthesis, the systematic review conducted in this study demonstrated that the support received from family and relatives is predominantly of superior quality. Conversely, the assistance provided by peer groups and the government is comparatively insufficient. Nevertheless, the assistance provided by the family was met with certain constraints, including the lack of postnatal leave for partners or the unavailability of parents due to geographical distance. For mothers to receive financial and social support from the government, their eligibility must be recognized. Alternatively, the government should predefine and specify the desired support for mothers within the healthcare and treatment system, as well as in relevant government organizations. Meanwhile, the recognition of support from individuals within one's social sphere and society at large can facilitate the enhancement of health and well-being by diminishing the intensity of stress [48]. Tefera. et al. conducted a study in Ethiopia to explore the challenges faced by disabled women in their experience of motherhood. The findings revealed that disabled women expressed difficulty with motherhood without the support of another person [55]. Thomas. et al. conducted a study to explore the reproductive experiences of disabled women. After interviewing 17 women with disabilities, she concluded that the support offered to them in the context of motherhood was either inadequate or inappropriate. Furthermore, she observed that no one had consulted these women about their specific needs and preferences regarding support [56].

The results of the present meta-synthesis indicated that the primary source of support for women affected by certain issues comes from their families, with many participants highlighting the importance of support from their spouses. This support encompasses both psychological and physical aspects, including assistance with household tasks, childcare, and creating opportunities for the mother to rest and alleviate the pressures of her role. Particularly in cases where women face physical limitations, the need for practical and physical support from their spouse or partner becomes even more crucial [57]. In MS patients, social isolation and physical and emotional disturbances due to the disease make support from one's spouse an important prognostic factor [57]. However, some husbands may not have a proper understanding of the woman's condition due to the symptoms of the disease and her progress in caring for the newborn baby and doing housework [17]. This lack of understanding of mothers' conditions may cause differences and, as a result, many challenges in women's roles as mothers [58].

In this situation, it is necessary to provide the necessary training to understand the special conditions of women to their spouses [57].

Although the need for support from one's spouse is reported to be one of the most important needs of women in this period, it is important to mention that many laws enacted by legislators are effective in estimating or emphasizing this need. For example, paternity leave, which is exclusive to fathers and is considered for a very short period after the birth of a child, has been approved in Iran for only three days in the public sector and 14 days in the private sector after the agreement of the employer [59, 60]. In Australia, men who have been in paid employment for 10 months before birth can have access to 14 days of paid state paternity leave [61, 62]. In addition to the different durations and conditions of this paternity leave from one country to another, even within the states of the same country, its duration and benefits can vary. For example, in the provinces of Canada, the time considered for this leave and the terms of payment of salaries and privileges differ from one province to another [63]. In one of the studies examined in the present meta-synthesis, according to the laws of New Zealand granting leave to parents for up to two weeks, the participants expressed satisfaction with the support of the spouse as the main source of support. In this case, women were able to benefit from their husband's support to take care of the baby and prepare to accept new conditions [17]. The husband's presence in the first days after giving birth and participation in matters related to mother and child care can be effective in improving women's health and creating constructive interactions among parents [64, 65]. It seems that drafting laws related to women's needs can be effective in reducing the challenges faced by these women in relation to motherhood.

The second need identified in women with MS in connection with motherhood is the need for psychoeducational counseling. These women are more prone to mood disorders than other women are, especially in the postpartum period [66, 67]. Egger. et al. highlighted the necessity of offering counseling services to patients suffering from MS to effectively address cognitive disorders. This counseling is crucial because it takes into account the influence of health status, medications, and patients' ability to cope with the limitations they may encounter [68].

Many of the participants in the current meta-synthesis stated that they are afraid of transmitting the disease to their children, of the negative effects of the disease, such as fatigue and physical disabilities in the care of children, and of the uncertain future after childbirth. Uncertainty about the future, especially in the postpartum period, and the fear of disease progression and deterioration of the mother's health were such that one of the participants

compared this situation to a volcano that could erupt at any time [29]. The volcano on the verge of eruption, the disease gone crazy, etc., were examples of the participants' interpretations of fear and worry related to the future of the disease in the postpartum period. The uncertainty created in women's minds from the postpartum period and drawing a dark future from the disease due to its unpredictable nature caused several participants to hesitate about their motherhood decisions. These women reported that due to the unpredictable nature of the disease, especially in the postpartum period, it is very difficult to make decisions about pregnancy and even unpredictable about whether they may need to seek help after childbirth [27]. The fear of recurrence after childbirth and doubts about the conditions after childbirth can affect the planning for pregnancy, the continuation of treatment, and even the choice of breastfeeding [69]. Like the participants in our meta-synthesis study, women with epilepsy also expressed concern about the adverse effects of the disease on child care. Unpredictable seizures, inability to control the situation during a seizure, and fear of harming children are examples of the worries and fears of these women [70].

In addition to fears, ambiguities, and worries, guilt was also reported by participants in relation to transmitting the disease to their children and the inability to fulfill the role of a mother. This sense of guilt caused women to encounter challenges in accepting the role of motherhood, especially when comparing themselves to healthy women. The deficiencies and limitations brought about by the disease made them feel distant from society's norms for an ideal mother. However, this feeling of guilt is not exclusive to women with MS, as it has also been reported in women without MS. This guilt arises from the discrepancy between the ideal cultural expectations of motherhood in society and the actual circumstances faced by women as mothers. This mismatch between ideal and real conditions can result in psychological distress for women [71, 72].

Society's view of women with physical disabilities and the stigma of not being a good mother due to the limitations created by the circumstances caused many participants to try beyond their ability to perform the role of a mother properly. In this case, the needs of the husband and children were the main focus of care, and self-care and health status were marginalized. Therefore, in one of the studies, the theme of the self-sacrificing mother was a good representation of the situation of women [73]. Some participants even felt ashamed of their inability to meet the needs of their children. These reports are consistent with Bury's (1982) framework regarding biographical disruption. In this framework, it is suggested that disorders in people's minds about themselves and their expectations of a normal life after suffering from a

chronic disease are associated with emotional distress [74]. The results of Grue's study on the experience of motherhood among 30 women with physical disabilities showed that these women strongly felt the need to make a double effort compared to other healthy mothers about the care of their children to convince others that they are worthy mothers. One way to do this was for them to be super moms. The fear of being judged by others and labeled incompetent by others was one of the mental concerns of these mothers. In the meantime, playing the role of super mum was a very difficult task for mothers who lacked material, personal, and social support [75].

In some studies, the participants stated that they wanted to be able to be a perfect mother to their children, such as healthy women, or even to be able to participate in all matters related to their children, similar to the conditions before their illness. The prevailing view about disability states that disabled women are considered only recipients of services and not people who are capable of taking care of themselves [76]. In this case, some participants reported that they wanted to avoid the judgments of society resulting from the recognition of these women as failed and abnormal mothers. Society looks at a mother as a person who devotes herself to the needs of her children [77–79]. However, several participants stated that the restrictions created due to illness and the prevailing view of society about the ideal mother had created this mindset in the family that they do not have enough competence to take care of their children and take on the role of a mother. In this case, a part or a large part of the mother's duties were taken away from the woman, which intensified the feeling of ineffectiveness and failed mothers in women. The fear of losing children due to not fulfilling the role of a mother following the norms of society was also reported in Guru's study. In this study, women with physical disabilities were afraid that they would lose their children if they could not meet the expectations of others about maternal duties [75]. Trying to be a good mother creates a very complex challenge for disabled women, which can be associated with many problems in the long run if conflicts are not resolved [80].

The severity of women's helplessness in playing the role of a mother depends on the severity of the disease and the resulting disability. A mother with severe physical disorders, such as an imbalance in walking, faces more complex challenges than a mother without movement disorders [81]. In most of the articles included in this meta-synthesis, the type of MS of the participants was reported as relapsing-remitting, and none of the reviewed articles mentioned the type of MS participants as atypical. However, in one study, the type of MS of the participants (normal or abnormal) was not mentioned [29], and in the other two studies, the Expanded

Disability Status Scale (EDSS) was used to report the severity of disability of the participants [25, 82]. In another study, to capture a wide range of women's experiences related to motherhood, three groups of women with different degrees of mobility disability (limited disability, moderate disability, and severe disability requiring the use of a wheelchair) were examined [83]. The study also did not report whether women with different severities of disability have different maternal experiences than women with less severe illness. In fact, in this study, the difference between the restrictions created for women in the three studied groups was not clearly explained.

The results of Barker-Collo et al.'s study on 16 people with type MS primary progressive syndrome (PPMS) and RRMS showed that, in contrast to the slowly progressive nature of PPMS, women with RRMS experienced some degree of relative normalcy and were able to perform tasks associated with motherhood [84]. In women with advanced cases of the disease, where the severity of the disease was very low at the beginning of the disease and progressed over time and this severity also increased, the problems and issues related to their ability to perform maternal duties were much greater than those before the disease progressed [83]. Although in the studies examined in the current meta-synthesis, the exact amount and severity of the disabilities of the participating women and their experiences in cases of extensive disabilities were not precisely stated, some participants reported that the movement disorders caused by the disease can play a role in motherhood and even limit the scope of a mother's activities. In contrast, some participants stated that when the symptoms of the disease are very limited and even improve, the disease has very little impact on their ability to perform daily tasks and play the role of a mother. However, when the symptoms of the disease worsen compared to when the symptoms are stable or when the mother's disability is greater, the woman's range of motion is limited, and the amount of maternal physical affection decreases [85].

In recent years, significant progress has been made in identifying the drugs used for treating MS patients. In October 2018, the US Food and Drug Administration (FDA) approved 15 drugs for the treatment of multiple sclerosis, all of which were approved for the treatment of relapsing-remitting MS. The mechanism of action of these drugs is such that they reduce the possibility of new brain white matter lesions, clinical relapses, and the gradual accumulation of disability to different extents [86, 87]. This evolution in MS drugs has increased the treatment options available for patients and provided the opportunity to provide care for people based on the patient's condition [88]. It seems that the new generation of these drugs can be effective in reducing the challenges caused by the recurrence and progression of the disease during

pregnancy, after childbirth, and during breastfeeding by reducing the progression of the disease and the resulting disability [69, 89, 90].

The studies included in the present meta-synthesis were reviewed from 1994 to 2021 without a time limit and based on inclusion and exclusion criteria. Among them, seven of the reviewed articles were published between 1990 and 2017, and only three articles were published between 2018 and 2021. In most of the articles published before 2018, the main concern of the participants was related to the possibility of disease recurrence due to the discontinuation of drugs during pregnancy, the effects of drugs on the health of the fetus-newborn, and the fear of the disease progressing after delivery. In these studies, participants were concerned about how their health would be affected if they stopped taking the drug during pregnancy and breastfeeding. In the three studies examined in the present meta-synthesis after 2018, although concerns related to the effects of drugs on the fetus-child relationship had faded, in Ghafoori et al.'s study, women were still worried about the effects of drugs during pregnancy and after delivery on the health of their fetuses and infants [25]. The results of the current studies show that over time and with the development of new drugs related to the control of MS disease and more assurance from doctors related to the safety of drugs during pregnancy and after delivery, to some extent, women's concerns related to the effects of drugs and their safety have decreased, but the fear of disability and the progression of the disease and the fear of the recurrence of the disease in the postpartum period are still strong. However, the volume of our studies is not suitable for such a precise conclusion because the number of studies reviewed and included in the current meta-synthesis after 2018 was only three, and this small number of studies may influence the bias of the results.

The process of actively searching for pertinent information in the field of health is essential for individuals to make informed choices regarding their health-related concerns and achieve an optimal state of well-being [91]. Enhancing individuals' understanding in the realm of health has the potential to empower them [92]. The present study's results demonstrate that women who participated in the qualitative research were exposed to limited and sometimes contradictory information regarding the effects of drugs and diseases on pregnancy, childbirth, and the postpartum period. Providing postpartum women with timely medical information to address potential health issues is imperative. The need for medical information is equally significant for both primiparous and multiparous women, regardless of their previous childbirth experiences [54]. The findings from the qualitative studies indicated that women encountered challenges in obtaining the information they sought due

to various factors. These included the brief duration of their visits, insufficient knowledge of healthcare providers, and the unavailability of desired information. Consequently, they turned to alternative sources such as the internet and friends for assistance. According to Hughes. In a qualitative study, which was conducted to examine the experiences of women with physical disabilities in finding health information, the internet emerged as a prevalent source of information for this group [91]. While the internet serves as a vital platform for accessing information regarding pregnancy and childbirth, the available information is often inconsistent and fragmented [93]. The provision of unambiguous and top-notch information to patients with MS, right from the point of diagnosis, is crucial for empowering them to effectively manage the disease [94].

Due to the intricate nature of MS, patients with this condition require a broad range of healthcare services. The effective control of diseases is contingent upon the provision of healthcare, emphasizing the critical role played by communication between patients and healthcare providers. Patients have various needs that must be addressed to provide comprehensive and holistic care. These needs may include access to information about their disease and treatment options, rehabilitation services, social support, medical treatments, and home care services. Healthcare providers can ensure that patients receive the best possible care by catering to all of their needs [95]. The results of the present meta-synthesis showed that by meeting the two needs of developing specific guidelines and access to well-informed HCPs, the infrastructures for special visits and follow-ups during pregnancy and postpartum and specific care will be provided, and in this way, part of the needs of women with MS during the motherhood period will be fulfilled. Additionally, the need for continuous, comprehensive and unique care can directly affect the need for knowledge promotion and the need for psychoeducational counseling. If the counseling and informational needs of mothers with MS are identified and met by the development of specific guidelines or special care for them and if they have access to HCPs with sufficient knowledge and skills in those regards, their needs for knowledge promotion and psychoeducational counseling will also be met (Fig. 2).

The findings of the recent meta-synthesis revealed that a significant number of participants observed a disproportionate focus by healthcare providers on the physical dimensions of the disease, primarily its control, while disregarding the psychological and emotional consequences experienced by mothers. Many healthcare providers displayed a limited willingness to provide the necessary information and counseling concerning the decision to motherhood and the challenges it entails.

Insufficient knowledge and communication skills, coupled with HCPs' failure to acknowledge mothers' needs, led mothers to feel neglected, and routine visits were the only form of communication. A study conducted by Malouf et al. sought to examine the accessibility and quality of maternity care for women with disabilities. The findings revealed gaps in the provision of care for this population, particularly in the interpersonal aspects of care. These include the need to feel heard and supported, participation in decision-making, and the presence of a respectful and trustworthy relationship with healthcare providers. The participants strongly desired to enhance their interaction with healthcare workers during the postpartum phase [96]. Furthermore, the study of Yazdannik et al. shed light on the lack of attention given by healthcare providers to the specific requirements of individuals with MS, resulting in patients seeking assistance from various doctors to address this challenge. The study findings highlighted that patients expressed satisfaction with healthcare providers who demonstrated a profound understanding of their needs and exhibited empathy toward them [95].

Ensuring a cohesive set of guidelines for managing diseases throughout pregnancy and postpartum is of utmost importance. By providing comprehensive services tailored to the specific needs of mothers, healthcare professionals can effectively enhance the quality of care and boost maternal satisfaction with the received services. According to the study of Hansen et al., women diagnosed with chronic diseases reported receiving contradictory information from their healthcare providers. According to the women's reports, the specialists provided information without considering the mother's condition and solely based on their healthcare expertise. Moreover, the information provided by different specialists is sometimes contradictory. This investigation highlights the self-perception of women as messengers that serve as conduits for the exchange of information among experts. Moreover, women were occasionally tasked with the responsibility of synthesizing conflicting information and formulating comprehensive conclusions, thereby assuming an active role in the process [97].

The goal of all health systems is to maintain, provide, and improve the health of people in society [98, 99]. However, health policies and programs may vary according to health priorities and the population covered [100, 101]. The existence of health programs and the quality of their implementation are effective in estimating the needs of the involved groups. The articles included in this meta-synthesis are from countries with different health systems. This difference in the structure of the health system can impact the creation or fulfillment of the needs of patients with MS. For example, in Iran, one of the countries under investigation, the country's guide to providing

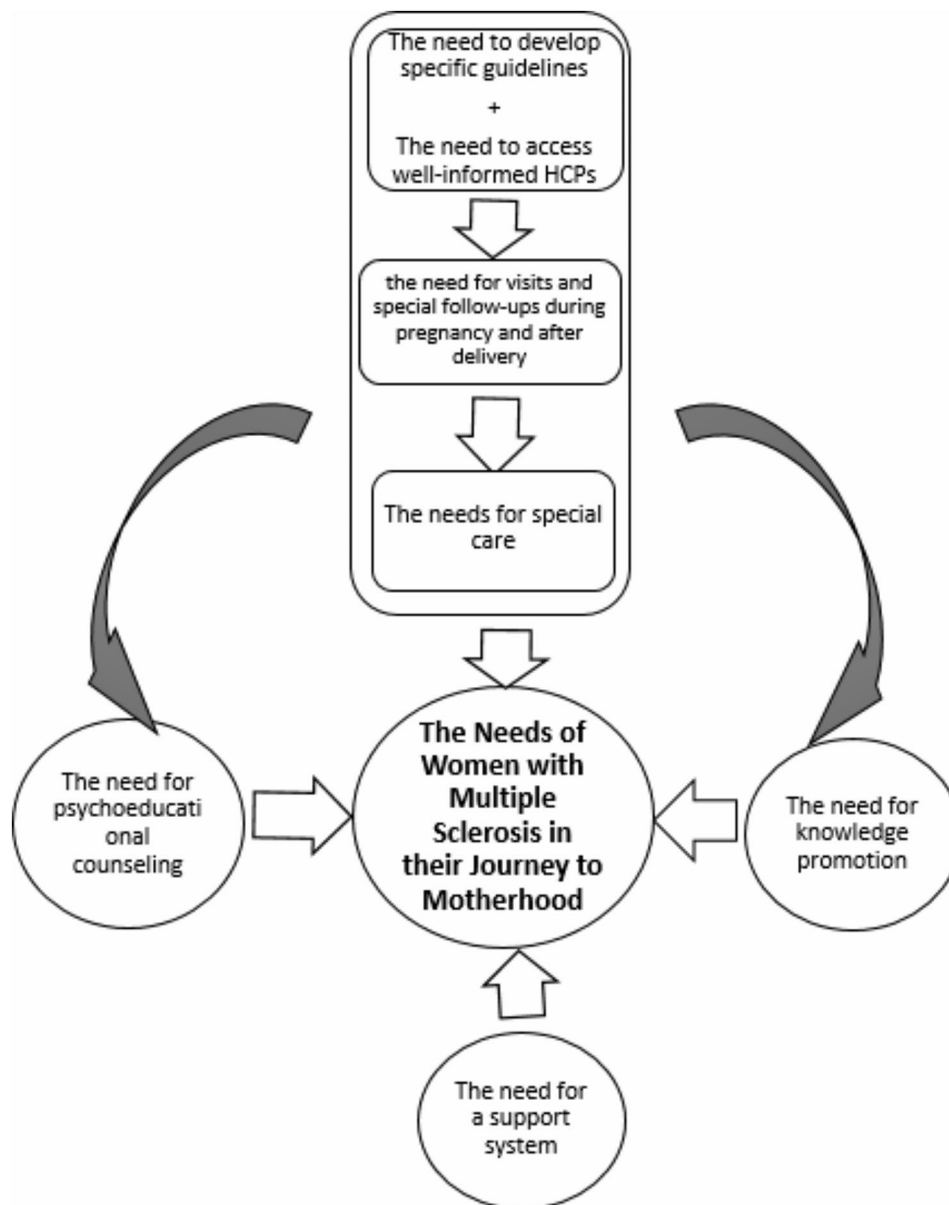


Fig. 2 Conceptual model of the needs of women with multiple sclerosis in their journey to motherhood

midwifery and delivery services does not include specific care for women with MS. Only a brief reference to consultation with a relevant specialist is mentioned for pregnant women [102]. In contrast, the postpartum care program in England includes a comprehensive evaluation of the health and support needs of women and their babies, with the first visit occurring 36 h after delivery [103]. This visit helps identify the needs and support required and create a personalized care plan for each individual. Regarding financial support for MS patients, while in Iran, the government provides free use of certain consumable drugs [104], Australia has the National Disability Insurance Plan to support MS patients with mobility disabilities [105, 106]. In Canada, the MS Association

offers a quality of life program that provides financial support and necessary facilities for patients, such as wheelchairs and medications [107]. Specialized guidelines and consensus recommendations related to pregnancy and postpartum periods in England and Italy [108, 109], as well as a patient registration program in Italy [110], demonstrate the resources available in these countries to enhance care quality and allocate resources for treatment and support.

In this meta-synthesis, we identified existing needs related to motherhood in women with MS. These needs may vary across different health systems. A need in one country, such as increased access to financial support and services, may not be a priority in another country

with quality programs. Understanding the existing situation and considering the support systems, policies, and health system structure of each country are essential when interpreting the needs of affected women about motherhood.

In the current study, we aimed to explore the needs related to motherhood in women with MS. Therefore, all the participants in the reviewed articles were women with MS, and studies that included men with MS were excluded. With respect to parenting and caring for children, each parent with MS has challenges. For a parent with MS, the physical assistance provided by the spouse can play a crucial role in fulfilling parental responsibilities. When only one parent suffers from MS, a healthy parent can be effective at performing duties and reducing parental pressure on the other person. This enables them to take charge of sensitive and critical situations [42, 43, 57, 85]. Several participants in the present meta-synthesis emphasized the need for support from their spouses during disease relapses or the postpartum period. Women expressed the importance of receiving physical support from their husbands in tasks such as childcare, newborn care, and household chores to ease the pressure of the new motherhood role and prevent disease exacerbation due to fatigue and physical strain. However, if the husband also has MS, the severity of the disease and physical limitations may hinder the affected woman from receiving the expected support. This situation can intensify the challenges of motherhood, particularly for women experiencing motherhood for the first time.

Conclusion

The findings of the current meta-synthesis reveal that women encounter numerous needs related to motherhood, which can be categorized into four distinct domains: support, counseling, information, and care needs. Addressing these needs effectively can significantly enhance the level of care offered to these mothers, fostering their contentment as they navigate the path to motherhood. Conversely, acknowledging recognized needs can serve as a valuable tool in developing the requisite plans and policies that cater to the specific needs of this cohort of women.

Abbreviations

MS	Multiple Sclerosis
MSIF	Multiple Sclerosis International Federation
HCPS	Health Care Providers
RRMS	Relapsing-Remitting Multiple Sclerosis
PPMS	Primary Progressive Multiple Sclerosis
FDA	Food and Drug Administration

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Author contributions

Each of the authors of this manuscript participated in all stages of writing the manuscript. T.KH and EMG formed the initial idea. E.MG and M.A.N cooperated in the search and study selection. T.KH and E.MG did the quality assessment of the articles. Data extraction was done by M.A.N, H.E, and E.MG. Data analysis and interpretation were done by T.KH, AH, and E.MG. All the authors have been involved in all stages of writing the manuscript. All authors have read and approved the final manuscript.

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Data availability

No datasets were generated or analysed during the current study.

Declarations

Ethics approval and consent to participate

Not applicable.

Consent for publication

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Competing interests

The authors declare no competing interests.

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