

# ORIGINAL ARTICLE

## Pregnancy and Motherhood Concerns Surrounding Women with Multiple Sclerosis: A Qualitative Content Analysis

Faezeh Ghafoori<sup>1,2</sup>, PhD; Nahid Dehghan-Nayeri<sup>3</sup>, PhD; Zohreh Khakbazan<sup>1</sup>, PhD; Mahmoud Hedayatnejad<sup>4</sup>, PhD; Seyed Massood Nabavi<sup>5</sup>, MD

<sup>1</sup>Department of Reproductive Health, School of Nursing and Midwifery, Tehran University of Medical Sciences, Tehran, Iran;

<sup>2</sup>Ministry of Health and Medical Education, Tehran, Iran;

<sup>3</sup>Department of Nursing Management, School of Nursing and Midwifery, Tehran University of Medical Sciences, Tehran, Iran;

<sup>4</sup>Department of Psychology, Shahed University, Tehran, Iran;

<sup>5</sup>Department of Brain and Cognitive Sciences, Royan Institute for Stem Cell Biology and Technology, Royan Institute, Tehran, Iran

### Corresponding Author:

Faezeh Ghafoori, PhD; Department of Reproductive Health, School of Nursing and Midwifery, Western Nosrat St., Tohid Sq., Postal Code:14197-33171, Tehran, Iran.

**Tel:** +98 21 66943187; **Fax:** +98 21 66941668; **Email:** faezeh.ghafoori@yahoo.com, f.ghafoori1366@gmail.com

**Received:** 1 March 2019    **Revised:** 24 July 2019    **Accepted:** 26 July 2019

### ABSTRACT

**Background:** There is a high prevalence of multiple sclerosis (MS) among Iranian women of reproductive age. However, very few studies have been conducted in Iran to assess the experiences with and concerns about pregnancy and motherhood of such patients. The present study was conducted to better understand the experiences and concerns of women with MS about pregnancy and motherhood.

**Methods:** The present qualitative study was conducted from August 2016 to January 2017 among Iranian women with MS visiting the Iran MS Society in Tehran, Iran. The purposive sampling method was used to recruit the participants and the sampling was continued until data saturation. Based on the inclusion criteria, a total of 25 women with MS were recruited in the study. The data were collected by in-depth semi-structured face-to-face interviews and analyzed using the MAXQDA 10 software.

**Results:** The analysis of the interview data resulted in four main categories, namely “Pregnancy concerns”, “Fear of failing as a parent”, “Feeling of threatened fertility”, and “Lack of social support”. The results showed that Iranian women with MS avoided pregnancy due to the negative effects of the disease on their physical abilities and on life in general. They were also concerned about possible infertility, the effect of MS medications on their menstrual cycle, and the limitations of infertility treatments due to the presence of MS. These concerns led them to postpone pregnancy and lose time or opt for voluntary childlessness and consequently miss out on the experience of motherhood.

**Conclusion:** MS poses a serious challenge to women who consider getting pregnant and wish to experience motherhood. Health care professionals should support such patients to overcome their concerns and indecisiveness by providing appropriate information and counseling.

**KEYWORDS:** Multiple sclerosis, Fertility, Pregnancy, Concerns, Women

**Please cite this article as:** Ghafoori F, Dehghan-Nayeri N, Khakbazan Z, Hedayatnejad M, Nabavi SM. Pregnancy and Motherhood Concerns Surrounding Women with Multiple Sclerosis: A Qualitative Content Analysis. IJCBNM. 2020;8(1):2-11. doi: 10.30476/IJCBNM.2019.73900.0.

## INTRODUCTION

Multiple sclerosis (MS) is a disease that attacks the nervous system causing various physical and cognitive impairments.<sup>1,2</sup> Such impairments, along with the side effects caused by medical treatments, can directly or indirectly affect the patients' fertility and pregnancy.<sup>3,4</sup> MS is more prevalent in women than men, particularly during their childbearing age, with onset usually occurring between the ages of 20 and 40.<sup>5,6</sup> In the past, challenges associated with MS led women to avoid getting pregnant.<sup>7</sup> However, recent advances in medical treatments have enabled many women with chronic illnesses and disabilities to get pregnant and experience motherhood.<sup>8</sup> Despite the fact that pregnancy is safe for women with MS and does not affect the child, research has shown that premature termination of the pregnancy and voluntary childlessness are more common among such patients.<sup>9,10</sup>

Some studies have addressed the perceptions and experiences of women with MS on pregnancy and the challenges associated with motherhood. A study conducted in New Zealand reported that pregnant women with MS had been concerned about getting pregnant.<sup>7</sup> In a study conducted in Australia, female MS patients emphasized that the issues related to fertility and childbearing must also be taken into account by the rehabilitation team.<sup>11</sup> Another study conducted in the United States reported that women with MS, as well as their partners, regarded having children as an irresponsible act.<sup>12</sup> In contrast, another US study reported that women with MS tend to downplay the importance of pregnancy and motherhood related issues. The participants of that study did not express any concern about their pregnancy and had a fatalistic attitude towards their illness, and felt as if nothing could be done about the illness anyway. They had reconciled themselves with the reality and consequently had no additional requests from the rehabilitation team.<sup>13</sup> Some studies have stated that although MS often has an unpredictable prognosis, female

patients still opt to get pregnant despite these uncertainties.<sup>14,15</sup> This is an area that should be addressed by health care professionals when helping women with MS.

The prevalence of MS in Iran is estimated to be around 89 cases per 100,000 persons with a gender ratio of 3.12.<sup>5,16</sup> However, despite a relatively high prevalence of MS among Iranian women, very few studies have been conducted in Iran.<sup>1,6</sup> Moreover, to the best of our knowledge, there have been no qualitative studies in Iran to investigate pregnancy and motherhood among women with MS. The choice for a qualitative study based on the conventional content analysis approach stems from its effectiveness in obtaining the perceptions and experiences of people with health issues and to understand their concerns and feelings.<sup>17</sup> This method is suitable to study context-based subjects and to understand the meaning from the content of text data.<sup>18,19</sup> In conventional content analysis, theory or research literature on a phenomenon is limited. Therefore, codes and categories are directly extracted from the text data without considering presumptions and existing theories.<sup>20</sup>

The provision of support and interventions for women with MS requires a good understanding of their experiences and concerns and is a requisite to optimally respond to the emerging needs of such patients. Given the effect MS has on women of reproductive age and the context-specific nature of their experiences, the present qualitative study was conducted to better understand the experiences and concerns of women with MS about pregnancy and motherhood.

## PATIENTS AND METHODS

The present qualitative study was conducted from August 2016 to January 2017 at the Iran MS Society in Tehran, Iran. The target population were Iranian women with MS referred to the Iran MS Society center. A maximum variation purposive sampling was used to recruit information-rich candidates with diverse

characteristics relevant to the phenomenon.<sup>21</sup> Data analysis was performed concurrently with the data collection and the sampling was continued until data saturation was reached, i.e., until no new categories emerged and the obtained categories were saturated in terms of features and dimensions. The inclusion criteria were women of reproductive age (15-45 years old), married women with a definite diagnosis of MS by a neurologist, suffering from no other chronic illness except MS, suffering from the disease for at least (the last) one years, and willingness to participate. The exclusion criteria of the study were lack of willingness to continue participation in the study. The demographic characteristics of the participants included age, education, occupation, duration of the marriage, number of children, MS phenotypes and duration, type of drugs, and severity of the physical disability.

#### *Data Collection*

The data were collected through in-depth semi-structured face-to-face interviews. A total of 25 individual interviews were conducted by a research team member (FG) in a calm and relaxing atmosphere in a private room at the Iran MS Society. The interviews lasted between 35 to 90 minutes.

The interviews started with general questions such as “*What are your thoughts and feelings about pregnancy and motherhood?*”, “*How do you describe pregnancy and becoming a mother while suffering from MS?*”, “*How did you experience motherhood after being diagnosed with MS?*”, “*How has motherhood changed your life?*” and “*How do you picture yourself as a mother suffering from MS?*” Open questions such as “*What do you mean?*” and “*Please expand*” were used to extract more clear and detailed responses. With the permission of the participants, an audio recording of the interviews was made.

#### *Data Analysis*

The data were analyzed using conventional content analysis as described by Lundman and Granheim. At the end of each interview,

the audio recordings were meticulously transcribed verbatim. Following multiple reviews of the transcriptions, initial semantic units (primary codes) were identified. The extracted codes were then classified in terms of similarities and differences based on which the sub-categories were defined. These were then reviewed, compared, and grouped to determine the main categories. Data analysis was performed using the MAXQDA 10 software.

#### *Rigor*

The accuracy of the findings was assessed using the four criteria proposed by Goba and Lincoln; namely credibility, dependability, confirmability, and transferability.<sup>17, 22, 23</sup> The credibility criterion was achieved through prolonged engagement, adequate time allowance for the collection and analysis of the data, and member checking. The dependability criterion was achieved through feedback from two experts and a review of the text by team members and 17 participants. Confirmability was ensured by keeping an audit trail through careful registration of each step of the data collection and analysis to facilitate the scrutiny of the research activities by external observers. To ensure the transferability of the data, we provided a full description of the categories, characteristics of the participants, data collection and analysis methods, and from the participants' full quotes.

#### *Ethical Considerations*

The present study was approved by the Ethics Committee of Tehran University of Medical Sciences, Tehran, Iran (code: IR.Tums.Rec.1395.98.9221151003). The managers of the Iran MS Society willingly facilitated the study. Prior to the interviews, the participants were informed about the research goals, confidentiality of any disclosed information was guaranteed, and voluntary participation was emphasized. The participants were permitted to withdraw their participation at any time without any consequences or negative impact on the

services provided by the Iran MS society. Written informed consent was obtained from all the participants.

## RESULTS

The mean age of the participants was  $31.7 \pm 3.1$  years and the mean duration of the marriage was  $10 \pm 4.1$  years. The participants were mostly unemployed 18 (72%) and had a higher education 15 (60%). The mean duration of MS among the participants was  $6.2 \pm 3.5$  years and the mean severity of disability, according to the expanded disability status scale (EDSS) was  $4.7 \pm 2.3$  (Table 1).

The four extracted main categories from the interview data were “Pregnancy concerns”, “Fear of failing as a parent”,

“Feeling of threatened fertility”, and “Lack of social support” (Table 2).

### 1. Pregnancy Concerns

#### 1.a. Personal Health

The majority of the participants expressed their fear of getting pregnant due to its potential negative side effects on their personal health. A participant stated: “*Although I really would like to have a child and the time is right, but I am concerned about getting pregnant. I do suffer from backaches and I am afraid that a pregnancy would exacerbate the pain to the extent that I may not even be able to get out of the bed.*” (P2) Similarly, another participant stated: “*Since suffering from MS, I have a calcium and vitamin D deficiency and suffer from serious dental problems. I am afraid that*

**Table 1:** Demographic characteristics of the participants (n=25)

Participant	Age (years)	Education	Occupation	Marriage duration (years)	Number of children	MS duration (years)	EDSS <sup>a</sup>
1	33	PhD	University lecturer	1.5	0	18	6.5
2	26	BSc	Midwife	3	0	7	3.5
3	28	Diploma	Housewife	6	1	1	2.5
4	22	BSc	Housewife	5	0	1	1.5
5	40	Middle school	Housewife	11	0	14	7.5
6	35	Diploma	Housewife	9	1	2	8
7	37	BSc	Housewife	8	0	20	5.5
8	45	Diploma	Housewife	17	1	11	4.5
9	47	Primary school	Housewife	25	3	17	6.5
10	21	BSc	Housewife	2	1	3	7
11	39	MSc	Employee	22	2	5	8
12	20	Diploma	Dental assistant	<1	0	1	1.5
13	31	Diploma	Shopkeeper	10	0	2	1.5
14	22	BSc	Housewife	1	0	3	2
15	26	BSc	Housewife	3	0	1	1.5
16	24	BSc	Tailor	2	1	5	4.5
17	37	BSc	Housewife	7	1	2	3
18	20	BSc	Housewife	<1	0	1	1.5
19	42	Middle school	Housewife	21	3	8	5.5
20	39	BSc	Housewife	5	3	5	5
21	40	Primary school	Housewife	15	2	12	7.5
22	21	BSc	Housewife	2	0	3	7
23	34	BSc	Nurse	5	1	5	5
24	35	Diploma	Housewife	8	1	7	3.5
25	30	MSc	Housewife	7	0	2	8

<sup>a</sup>Expanded disability status scale : Examined by a neurologist to assess pyramidal, cerebellar, brainstem, sensory, bowel and bladder, visual and mental functions; scores range from 0 to 10

**Table 2:** Extracted categories and sub-categories from the interview data

Example of codes	Sub-categories	Categories
Coping with multiple physical problems during pregnancy Fear of postpartum MS relapse	Personal health	Pregnancy concerns
Negative effect of medication on the fetus The effect of MS on the fetus Genetic risk of passing on MS	Harm to the fetus	
Inability to meet the infant's needs lactation failure	Challenges in the care for infants	Fear of failing as a parent
Inability to meet the needs of a child Inability to keep a child entertained Inadequate provision of care in general	The physical burden of caring for a child	
Spotting Irregular menstruation Early menopause	Interrupted menstrual cycle	Feeling of threatened fertility
The impact of the disease on fertility The impact of medication on fertility Hormone therapy reduces the effect of MS medications The negative effect of infertility treatments on MS	Negative effects of MS on fertility Limitations of infertility treatment due to the presence of MS disease	
The need for more support by the family and spouse Lack of coaching and fertility counseling Lack of attention paid to fertility needs after MS diagnosis Lack of child care services	Neglecting support needs of women with MS on fertility and pregnancy	Lack of social support

*a pregnancy would worsen the problem and will lose all my teeth.” (P3)*

The majority of the participants stated that the reason for avoiding pregnancy was the fear of a post-pregnancy MS relapse. A participant stated: *“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 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. I do not even wish to imagine having to take care of an infant while having a relapse and being hospitalized for 5 days.” (P12)*

### *1.b. Harm to the Fetus*

Concerns about harm to the fetus was an important factor in avoiding pregnancy. A participant stated: *“I sometimes think that I should have another baby before my condition worsens. But, considering all the medications I must take every day, I am afraid that I will not be able to give birth to a healthy child. In addition to the steroids I take when I am having an attack, I take three*

*pills daily. All these drugs would certainly harm the fetus.” (P1)*

The fear of passing on the MS gene to the child was another reason for avoiding pregnancy. A participant stated: *“I have MS and there is a genetic risk to pass it on to my child. 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 get pregnant.” (P3)*

## *2. Fear of Failing as a Parent*

### *2.a. Challenges in the care for infants*

The participants believed motherhood was associated with the ability to meet various needs of an infant, including preparing food, feeding, bathing the infant, and providing a hygienic environment. Since the participants were unable to perform many of these tasks, they feared the social stigma of not being a good enough mother. This fear was to the extent that some participants refrained from getting pregnant. A participant stated: *“How can I have a child when I cannot even take*

*care of myself. Taking care of a baby is a full-time job and I would need someone to help me. Children need a higher level of care and attention when they get older. Considering my physical condition, how am I supposed to take my child to a park or play? How should I respond if at one point my child questions my decision to become pregnant despite my illness?” (P21) Another participant stated: “There is more to bringing a child into this world. Considering my illness, how can I take care of a child and get the vaccinations done?” (P6)*

### *2.b. The Physical Burden of Caring for a Child*

With a specific focus on physical disabilities due to MS, a participant stated: *“I am worried about the future of my child as I cannot physically cope with activities such as long walks or jogging. How am I supposed to take my child to school? If my child wishes to run together, I will not be able to keep up the pace.” (P24) Another participant stated: “Due to my illness, I cannot take my child to school, participate in a school meeting, or even teach my child how to ride a bike.” (P23)*

## *3. Feeling of Threatened Fertility*

### *3. a. Interrupted Menstrual Cycle*

The participants stated that MS would negatively affect their fertility. Some participants experienced an interrupted menstrual cycle due to MS medications. Hormone therapy in combination with MS could cause early menopause and even infertility. A participant stated: *“My MS started in my teens when I had my first period. I had an irregular menstrual cycle when I was in high school. My physician associated irregular menstruation with medications such as Mitoxantrone and stated that nothing could be done about it.” (P1) Another participant who experienced early menopause stated: “For about 3 years I had an interrupted menstrual cycle and at times I had severe bleeding to the extent that I could not walk. When I was 31, I had excruciating pains and had to go to the hospital. The physician*

*diagnosed ovarian torsion and my ovaries had to be removed. He could not prescribe hormone therapy because of my disease. I lost my ovaries due to enlarged cysts. I have not had any menstrual period since.” (P17)*

### *3.b. Negative Effects of MS on Fertility*

The participants expressed their concerns about the negative effects of MS and the associated medication on fertility. A participant stated; *“I am under the impression that MS causes ovarian insufficiency or cysts. Many patients at the Iran MS society have cysts or polycystic ovary syndrome. MS certainly affects the nervous system, but I think it also affects other organs. Apparently, MS is unlikely to be the cause of ovarian cysts. But, these cysts make it harder to get pregnant.” (P18) Another young female participant stated: “In my opinion, daily use of multiple drugs impairs your bodily system over time. Therefore, it is not strange that ovaries also become impaired. Even daily use of over-the-counter drugs eventually affects the body negatively. It is not possible or, at least, it is hard to get pregnant with an unhealthy body. I have heard that ovarian cysts are caused by certain medications such as Teriflunomide; the medication I have been taking for a long time.” (P1)*

### *3.c. Limitations of Infertility Treatment Due to the Presence of MS Disease*

The limitation of infertility treatments in the presence of MS was another factor that made the participants fearful of infertility and the inability to have children. A participant stated: *“We have been trying to conceive for 6 months without success. Because of the disease, I cannot get pregnant with IVF or similar methods. My physician, although he did not know for sure, claimed that it is very likely that I could have an MS relapse because of the strong hormone therapy. He mentioned that medical treatments cause stress to the body and in turn, any type of stress can trigger an MS attack.” (P13) Another participant stated: “In my opinion, there is no remedy for infertility. I*

*have heard that hormone therapy reduces the effect of MS medications, and thus increases the possibility of an MS attack.” (P12)*

#### *4. Lack of Social Support*

##### *4.a. Neglecting Support Needs of Women with MS on Fertility and Pregnancy*

All participants emphasized on the need of MS patients for full support of the family, spouse, and support organizations. They felt that the rehabilitation team solely focused on their physical problems and ignored other aspects, such as infertility and getting pregnant. They also pointed out the lack of counseling and limited coaching on infertility and pregnancy after being diagnosed with MS. A participant stated: *“Nobody told us about potential fertility problems. Even when we mentioned the subject to the rehabilitation team, they immediately associated infertility with MS. Their focus was to control the disease and it seemed they were not interested in our desire to have a child and experience motherhood.” (P15)*

The participants stated that the early postpartum period is the most important time to receive social support because of the probability of an MS relapse. A participant stated: *“Due to a higher risk of an MS relapse after giving birth, social support during the first 6 months is more important than at any other time. Next to physical issues related to giving birth and the stress associated with the delivery, one must also deal with taking care of an infant and cope with sleepless nights. These stresses may trigger an MS relapse and therefore we need more support. The health care system should take note of such needs and plan accordingly.” (P3)*

Some participants expressed their dismay with the lack of child health care provided by the health care system. They perceived this as indifference to their needs for a dedicated care program. A participant stated: *“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. Regrettably, there is no child health care support program in our country for people like us.” (P6)*

## **DISCUSSION**

The present study aimed to identify the perspectives and experiences of female patients with MS about getting pregnant and motherhood. Four main categories were extracted from the interview data, namely “Pregnancy concerns”, “Fear of failing as a parent”, “Feeling of threatened fertility”, and “Lack of social support”. In line with our findings, various other studies also indicated the concerns of women with MS about pregnancy.<sup>24, 25</sup> A study conducted in the United States reported that female patients with MS viewed pregnancy as precarious and feared that getting pregnant would exacerbate their disease and cause an MS relapse.<sup>12, 25</sup>

A qualitative study in Australia examined the perceptions of women with MS about motherhood.<sup>26</sup> They reported that women with MS were, on the one hand, more self-centered, but on the other hand, felt guilty for not considering the welfare of their children when they did get pregnant. They were concerned about the harmful effect of their physical and mental limitations, caused by the disease, on the upbringing of their children. The participants in our study expressed their fear of failure as a parent by not fulfilling maternal duties. They were also concerned about the genetic risk of passing on MS to their child and thus viewed themselves as a risk factor. Some other studies also reported similar concerns of women with MS about pregnancy in terms of genetic risks and challenges associated with infant care.<sup>11, 24</sup>

Feeling of threatened fertility was another main category extracted from the interview data. While some studies have indicated that MS had no effect on fertility,<sup>27, 28</sup> a study conducted in Iran reported that the prevalence of irregular menstruation, oligomenorrhea, and amenorrhea were higher in MS patients

who used interferon betas.<sup>29</sup> Another study examined the ovarian reserve in 76 women with MS at their fertility age by measuring the serum levels of the anti-Mullerian hormone (AMH). They reported that AMH levels were significantly lower in women with MS compared to the 58 healthy women in the control group.<sup>30</sup> Such a decrease has been associated with MS medications such as cyclophosphamide and Mitoxantrone.<sup>31</sup> However, another study associated the decrease in AMH levels with autoimmune disorders and the neuroendocrine effects of MS itself.<sup>32</sup> Some studies have associated lower fertility rates with a higher prevalence of psychological disorders and sexual dysfunction in women with this disease.<sup>31, 33</sup> Further research is required to confirm the correlation between MS, reduced fertility and related medications.

In the present study, the participants expressed their concerns about the harmful effects of infertility treatments in the presence of MS. They feared that undergoing assisted reproductive technology (ART) to treat infertility would exacerbate MS symptoms and trigger attacks. A study in Scandinavia (2018) reported a significant increase in the incidence of MS attacks among patients who went through IVF.<sup>34</sup> The mechanism underlying increased MS attacks after ART is not fully understood yet. However, the discontinuation of MS medications prior to ART, a sudden increase in hormone levels in the body during ART, and the effect of hormones on the activity of various immune cells have been hypothesized.<sup>35</sup> Overall, our findings indicated that women with MS were not only concerned about getting pregnant and having children, but also worried about the effect of the disease on their fertility. These concerns led us to believe that childlessness in such patients is not voluntary but stems from their indecisiveness to bear a child. As a direct result, they may lose time and subsequently the opportunity to experience motherhood.

The lack of social support was also extracted as a main category from the

interview data. The main concerns of the participants were related to the lack of counseling on pregnancy, fertility, and the disregard by the rehabilitation team of their desire to experience motherhood. Several other studies have also reported little or no education during the rehabilitation process for pregnant women with MS.<sup>7, 11, 12</sup> In line with our findings, a study also indicated that rehabilitation teams should improve their understanding of the problems and needs of pregnant women with the disease.<sup>7</sup>

The main limitation of the present study was the participation of a limited number of women with MS and the fact that they were recruited from a single center, which undermined the generalizability of our findings. Note that we did our utmost to reduce the effect of these limitations through maximum variation sampling, e.g., patients with different MS phenotypes, duration of MS, and different ages. It is recommended that future studies include the spouses of women with MS to complement the interview data.

## CONCLUSION

Iranian women with MS avoided pregnancy since they believed it could undermine their personal health, harm the fetus, and that they may fail to adequately provide for the physical needs of the child. In addition, they were apprehensive about becoming infertile, the effect of MS medications on their menstrual cycle, and the limitations of infertility treatment due to the presence of the disease. These concerns led them to opt for voluntary childlessness and consequently, lose time and the opportunity to experience motherhood. Lack of social support also increased their indecisiveness to have a child. The provision of appropriate information, counseling, and support would have a positive effect on the health and quality of life of both the patients and their spouses.

## ACKNOWLEDGMENT

The present manuscript was extracted from the



Ph.D. thesis on reproductive health by Faezeh Ghafoori. The study was financially supported by the Tehran University of Medical Sciences, Tehran, Iran (grant number: 9221151003). We would like to thank the managers and personnel of the Iran MS Society for their cooperation. We also would like to express our gratitude to the patients for their active participation in the study and providing their valuable experiences.

**Conflict of Interest:** None declared.

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