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Article abstract

Chronic illness in children causes more mental health risks for parents than for other family members. Therefore, exploring the experiences of parents who have a daughter with multiple sclerosis (MS) and presenting them to health care planners and managers can have a positive impact on community health. This phenomenological study involving 12 participants in Iran aimed to explore the experiences of parents of young women (aged 17 to 40) with MS. The data collected from semi-structured interviews were analyzed using Colaizzi's method. Open coding resulted in 450 codes, and after several stages of analysis and integration of similar codes, five main themes containing 21 subthemes were produced. The main themes were mental distress, feeling trapped, adaptation issues, reaction to the disease, and coming to terms with the disease. This study showed that having a daughter with MS affects all dimensions of the parents' life, and can lead to experiences that are new to them and may confuse them. These findings provide a path towards improving effective parental care for their daughters with MS, and ultimately reducing the burden of disease on the family, the health system, and the community.

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Abstract: Chronic illness in children causes more mental health risks for parents than for other family members. Therefore, exploring the experiences of parents who have a daughter with multiple sclerosis (MS) and presenting them to health care planners and managers can have a positive impact on community health. This phenomenological study involving 12 participants in Iran aimed to explore the experiences of parents of young women (aged 17 to 40) with MS. The data collected from semi-structured interviews were analyzed using Colaizzi's method. Open coding resulted in 450 codes, and after several stages of analysis and integration of similar codes, five main themes containing 21 subthemes were produced. The main themes were mental distress, feeling trapped, adaptation issues, reaction to the disease, and coming to terms with the disease. This study showed that having a daughter with MS affects all dimensions of the parents' life, and can lead to experiences that are new to them and may confuse them. These findings provide a path towards improving effective parental care for their daughters with MS, and ultimately reducing the burden of disease on the family, the health system, and the community.

Keywords: lived experiences, multiple sclerosis, parenting, phenomenology

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Multiple sclerosis (MS) is the most common neurological disease among young adults, affecting more than two and a half million people worldwide (Gafari et al., 2017). In the United Kingdom, more than 100,000 people are affected, with a ratio of 1:3 male to female (McClurg et al., 2019), and in the United States, about 400,000 people (Dilokthornsakul et al., 2016). In Iran, approximately 60,000 people are affected, a number that seems to be increasing (Eskandarieh et al., 2019). For instance, in a systematic review that examined the prevalence of MS in different parts of Iran as well as other countries, Heydarpour et al. (2015) reported an increase in the prevalence of MS in Tehran from 51.9 per 100,000 in 2008 to 74.28 per 100,000 in 2011. It seems likely, however, that this rapid increase, at least to some extent, reflects methodological variations as well as possibly improved diagnosis and reporting. The number of people with MS in the 13-to-18 age group in Iran was reported to be 16.20 per 100,000 people in 2017; the ratio of women to men was 3.69 to 1 (Eskandarieh et al., 2019). Maghzi et al. (2010) found a significant increase in the incidence of MS among females over the last decades in the Isfahan province of Iran.

Obtaining a definitive diagnosis of MS can be difficult; once the diagnosis is received, rehabilitation is considered medically necessary (Rao et al., 2009). Diagnosis is based on the presence of clinical symptoms and signs, and the results of an MRI scan, which provides highly sensitive detection of the lesions characteristic to MS (Brownlee et al., 2017). Most patients suffer from multiple problems, which can include spasticity, tremors, tiredness, sensory disorders, cognitive and sexual disorders, double vision and balance disorders, bladder and intestinal dysfunction, and difficulty swallowing and speaking. Moreover, the disease can lead to changes in professional and family life, and psychosocial problems (Kapucu et al., 2011). The effects of MS vary unpredictably from person to person; for any individual, the prognosis too is unpredictable (Asadi Haghighat et al., 2019). Most patients with MS need corrective treatments and rehabilitation due to their debilitating symptoms; however, rehabilitation strategies are limited (Lipp & Tomassini, 2015). People with MS may become desperate enough to try unapproved treatments. Although a neutral observer might see them as having fallen victim to "medical racketeers peddling false hope", the patients often view themselves as "empowered citizens who have taken an informed decision to pursue an experimental therapy" (Mazanderani et al., 2018, p. 232). Patients with MS often experience negative prejudice, judgemental attitudes, and social exclusion because of their disease (Rao et al., 2009). This feeling of "having an attribute that marks them as different and leads them to be devalued in the eyes of others is conceptualized as stigma" (Major & O'Brien, 2005, p. 395).

Most people affected by MS are young women at their peak of social responsibility (Qaderi & Merghati Khoei, 2013). In a study of 70 MS patients in Iran, Masoodi et al. (2013) found that the burden of the disease on the caregiver seems to be of both primary and secondary types: the primary one of providing direct physical care and coping with psychological stresses caused by the stigma, and the secondary one of taking on the role of caregiver. Parents who are primary caregivers must adopt new roles and responsibilities that require adjusting the family's routine and other life commitments (Jones et al., 2016). As with the birth of a new baby, the emergence of a chronic disease in the family brings with it a commitment to provide years of care and nurturing (Brola, 2018).

When they live with a child who has a chronic disease, parents are not only the primary caregivers, but are also key members of their child's health care team (Fairfax et al., 2019). Chronic diseases of a debilitating nature, such as MS, affect not only the physical, social, psychological, cognitive, and emotional aspects of patients, but also of their families (Silvestri et al., 2018). In a study of spousal caregivers, Cheung and Hocking (2004) argued that the overwhelming nature of the caregiver's role — juggling health concerns while maintaining their spousal relationship, often with insufficient support — can lead to the internalization of mental stress. Caregivers of children with chronic illnesses experience challenges that can affect their own health (Magliano et al., 2015), as other researchers have found. For instance, chronic illnesses in children create more mental health risks for parents than for other members of the family (Jones et al., 2016). Flury et al. (2011) stated that parents of children with cancer experience a "huge amount of new and changed tasks" (p. 143) while caring for their children at home. Nygård and Clancy (2018) explored the experiences of parents of children with special health problems who were caring for them at home, stating that the burden of care can lead to reduced parental ability, which in turn can affect parental health and family functioning. Therefore, exploring the experiences of parents living with young women who have MS and presenting the findings to health care managers can have a positive impact on the health of the community. To achieve family-centered compassionate care, it is critical that health care professionals become knowledgeable about parental experiences.

The Descriptive Phenomenological Approach

Previous MS studies conducted in Iran that have focused on the epidemiology of illness and perceptions of carers and their quality of life have been done quantitatively (e.g., Alonso et al., 2011), and thus did not explore the carers' experiences. This paper, in contrast, uses a phenomenological approach. Phenomenology is essentially the study of lived experiences (Sigaroodi et al., 2012). It is a qualitative research method that is suitable for understanding the depth of a participant's experience with, and their concept of, a phenomenon. According to Thorne, phenomenology is a good way to explore broad concepts, including care (Shahgholian & Yousefi, 2018). After hearing a person describe their view of a phenomenon — the role it plays in their inner world —researchers must draw conclusions without imposing their own interpretations or assumptions about that person or the phenomenon (Heidari et al., 2020). Drawing on participant experiences to help gain a better understanding of the psychological, social, and cultural contexts in which the experiences took place, the present researchers decided to use the descriptive phenomenological method to explore the physical, psychological, social, cultural, and economic experiences (Ebrahimi et al., 2021) of parents living with daughters who have MS. An examination of the literature shows that this research is the first in the world to explore the experiences of parents of young women with MS.

Method

Ethical Considerations

This study was designed to conform to the code of ethics from the Ardabil University of Medical Sciences. Permission to conduct this research was obtained from the university's ethics committee under the ethics code R.ARUMS.REC.1395.114. Before signing a consent form, participants were informed of their rights, including the right to withdraw at any time, and were assured that their statements and opinions would be treated as confidential. Participant names are not used in this paper, and all analyses were based on codes. All the recordings were deleted after transcription, and transcripts were stored in a locked cabinet in the researcher's office.

Trustworthiness

To validate the findings, four criteria attributed to Lincoln and Guba (1985) were used: credibility, transferability, dependability, and confirmability. To achieve credibility under this framework, two techniques were applied: long contact (10 months) with the research environment to build participants' trust, and self-review by each researcher through repeated study of the interview material they had recorded in order to ascertain the exact meaning of the participants' statements as nearly as possible. For transferability, a rich description was used; that is, an attempt was made to fully describe all the details of the research from sampling to the process of data collection and analysis, and to present our findings concerning the postures and body language of the participants. To achieve dependability, the peer checking method was used: the coding, which was designed in the form of tables, was provided to two faculty members of the Ardabil School of Nursing and Midwifery. For confirmability, we used the triangulated interview method, in which the researcher uses two or more questions to examine the phenomenon under study.

Participants

Eligible participants were parents of a daughter who had MS but no other chronic illness. Daughters of the participating parents were all members of the MS Association of Ardabil, Iran. Participants were chosen using a purposeful sampling method based on their experience caring for a daughter with MS, and their ability to express themselves. Seven of the parents were living with their daughters; the daughters of the rest were married and lived separately, but their parents still felt responsible for helping them cope with their illness. The data were collected from February 19 to December 5, 2018. Data saturation was achieved with a sample size of 12. Nine mothers and three fathers participated; their ages ranged from 42 to 78 years (*M* = 56.41). The demographic characteristics of the participants in the study and their daughters with MS are presented in Table 1.

Table 1. *Demographic Profile of the Participants and Their Daughters with MS*

Parent				Daughter			
Role	Age	Education	Occupation	Age	Duration[a]	Education	Occupation
Mother	38	Middle school	Housewife	17	7	Diploma	Unemployed
Mother	48	Elementary	Housewife	19	30	Diploma	Housewife
Mother	42	High school	Housewife	23	48	Undergraduate student	Student
Mother	63	Illiterate	Housewife	38	48	Diploma	Housewife
Mother	60	Illiterate	Housewife	40	72	Associate degree	Housewife
Mother	48	Elementary	Housewife	26	84	Undergraduate student	Student
Father	68	High school	Plumber	31	96	PhD student	Translator
Mother	58	Elementary	Housewife	28	108	Bachelor degree	Housewife
Mother	60	Associate degree	Retired teacher	38	120	Bachelor degree	Computer services
Father	78	Elementary	Vendor	33	120	Middle school degree	Unemployed
Mother	61	Elementary	Housewife	35	144	Diploma	Housewife
Father	53	Middle school	Driver	29	168	Diploma	Housewife

[a] Time in months since MS diagnosis

Data Collection

The data were gathered using in-depth interviews, and the researchers tried to extract the unfiltered experiences of the parents in their own language. After obtaining verbal and written consent from the participants, a digital voice recorder was used to record the interviews. Throughout each interview, the researcher applied “bracketing” — putting aside, as far as possible, all feelings and preconceptions about the subject of the study. The interviews were conducted in quiet locations convenient for the interviewee: the MS Society, the workplace of the parents, the interviewee’s home, or a nearby park.

The interviews began with general prompts: “What experiences do you have with your daughter with MS? What is the effect of your daughter’s illness on your life? Talk about what happened to you after your daughter started suffering from this disease.” In addition, when participants experienced difficulty in describing their experiences, the researcher put forward follow-up questions for clarity. The follow-up questions varied, as they were based on participant responses and the results of the analysis of earlier interviews. The duration of the interviews ranged from 45 to 120 minutes. Each interview continued until the participant had finished describing his or her experiences and the researcher had decided that no further clarification was needed. The participants' speeches were translated into English by the first author, then reviewed and modified by the other authors.

Analysis

The analysis was performed simultaneously with data collection. Since the aim of the study was to achieve a comprehensive description of the parents’ lived experiences, Colaizzi’s seven-step method of data analysis was used (Morrow et al., 2015). The first step, collecting participants' descriptions of the phenomenon under study, was accomplished by making digital recordings of what the participants said during their interviews. Second, all interviews were transcribed verbatim; after reading an interview several times, we tried to extract the meaning of each statement. Third, after reading all transcripts, the meaningful information and comments associated with the subject under study were underlined, and the essential sentences were noted. Fourth, the researchers tried to extract a concept from each statement that expressed the meaning of the interviewee. Fifth, the concepts were categorized into subthemes based on similarity, then considered as a whole to ensure that we had as full a description as possible of the phenomenon under study; the subthemes were then grouped into general themes. Sixth, we wrote a comprehensive description of the phenomenon, with the aim of making it as clear and unambiguous as possible. The seventh and final step was accreditation of the findings, in which eight of the participants confirmed the codes and themes. An example of the analysis process for five of the subthemes is presented in Table 2.

Table 2. *Analysis Process*

Quote	Code	Sub theme
I think to myself, God, will my daughter be cured or not?	The unpredictability of the daughter's disease status in the future	Uncertain future
After my daughter's illness, the stress caused a hearing problem in me, and I got diabetes.	Getting sick due to daughter's illness	Burnout
Always, I say, God, what is this disease?! Why me? Look now, how many people are there?! From all around, why only me?!	Why me?	Bargaining
I think that the problems of life, both economic and financial, have caused the disease to come to light	Hypothesis about the daughter's illness	Hypothesizing the cause of the illness
We did not go to places where we could not take her!	Constraints on socialization due to daughter's illness	Change in lifestyle

Measures taken to achieve consistency included allowing sufficient time for data collection (about 17 months), establishing adequate and appropriate rapport with participants, having eight participants confirm the extracted codes and categories, and reviewing the interviews, codes, and themes with the aid of faculty members. The sample was diverse in terms of gender (mothers, fathers), age (38–78), disease history (7–168 months), and education (illiterate to associate degree).

Results

Open coding led to extraction of 450 codes. These were classified into 22 subthemes from which five themes were obtained: mental distress, feeling trapped, adaptation issues, reaction to the disease, and coming to terms with the disease (see Table 3).

Table 3. *Themes and Subthemes*

Subtheme	Theme
Worry and fear Sadness Uncertain future Mental preoccupation	Mental distress
Desperation Burnout	Feeling trapped
Ups and downs of diagnosis Economic burden Problems with the treatment process	Adaptation issues
Denial Bargaining Concealing the disease Resort to appeals to God through prayer Interpretation of the disease	Reaction to the disease
Accepting Hypothesizing the cause of the disease Family mobilization Managing people around daughter Change in lifestyle Discovering resources and techniques	Coming to terms with the disease

Mental Distress

The four subthemes of worry and fear, sadness, uncertain future, and mental preoccupation combine to make up the theme of mental distress. Participants expressed that, because of the unpredictable nature of MS and uncertainty about future conditions and responsibilities, they had a constant concern about what the future might bring, causing mental distress. A 60-year-old mother said, “I’m worried. For example, I say what will happen to my daughter after my death?”

The inconveniences and frustrations participants felt were sometimes due to the unpredictable nature of the disease. However, some participants expressed that their mental distress resulted from their child’s attitude to the illness, a lack of understanding of their child’s condition on the part of others, or the additional demands placed on them because of their child’s illness. For example, a 48-year-old mother said:

> Now, it is ten days since our relatives learned of my daughter’s illness; they keep ringing and asking how she is. I say she is fine. They learned of it after two and a

> half years, but if they had known before that, they would have been calling every day. I'm upset with their behavior.

The recurrent nature of the disease, the unpredictability of when an attack will occur, and the lack of certainty regarding treatment outcomes all cause instability in the lives of patients and families. Participants were often preoccupied with their child's predicament, and worried about an uncertain future. Some parents voiced concerns about their daughters' futures in terms of career, marriage, and schooling. For instance, a 38-year-old mother said, "Questions like these have been put forward: 'Whom will I marry? When will I be married?' Oh my God, what can I say to her?"

Feeling Trapped

Participants stated that, because of the new responsibilities imposed on them, they could no longer be present in the community; they felt trapped, and had a sense of helplessness. This theme comprises two subthemes: burnout and desperation.

Some parents said they had made repeated unsuccessful attempts to help address their daughter's medical condition, and were left with a sense of helplessness and desperation:

> I did everything. I took her to the best doctors in Tehran, I took her to an herbalist, I took her to the bee therapy, and I do not know what I am going to do now? We cannot do anything? (53-year-old father)

One of the effects of their daughters' illness on participants was burnout, whether physical or mental. A 60-year-old mother said, "When they told me that my daughter is ill, I became ill too, I could not raise my head, and doctors said it is because your daughter got sick!"

Adaptation Issues

As noted above, obtaining a definitive diagnosis of MS can be difficult, and once the diagnosis is received, rehabilitation is considered necessary. Throughout the process of diagnosis and rehabilitation, some hindering issues may emerge. In our analysis of the participants' statements, we grouped these issues into three subthemes: ups and downs of diagnosis, economic burden, and problems with the treatment process.

The subtheme "ups and downs of diagnosis" reflects the fact that the uncertainty of diagnostic tests, lack of access to skilled physicians and diagnostic facilities, and the resulting likelihood of an incorrect diagnosis potentially increase the challenges of the disease. For instance, a 38-year-old mother described the difficulties of obtaining a diagnosis:

> She had nausea and vomiting, her legs were paralyzed, I was not at home, and her dad had no idea, then we went to the doctor, they did not say what it was. Later she was hospitalized; [but the] CT and MRI machines were broken down. After that the doctors sent us to Tabriz [a metropolitan city], where they diagnosed, hospitalized, and injected cortisones into my daughter.

When a child has MS, parents often encounter economic problems as they must pay for any costs associated with diagnosis, treatment such as drugs and supplements, and hospitalization. These problems were more pronounced in participants with lower incomes, for whom even the cost of food can became an issue. A 42-year-old mother said, “I cannot completely take care of my daughter, but I am trying to reduce the cost of nutrition or recreation of myself or my husband to fully supply the cost of medication for my daughter.”

Reaction to the Disease

Parents perceived each successive stage of the disease differently from the previous one, and their response to the illness varied according to their present understanding. We named this theme “reaction to the disease”. It was obtained by combining five subthemes: denial, bargaining, concealing the disease, resort to appeals to God through prayer, and interpretation of the disease. These reactions were conveyed in participant statements like the following:

> Because this disease was unexpected to me, I did not believe it, and I did not accept it, I could not believe it, of course, still after years now, I do not really accept that my daughter has this problem. (42-year-old mother)
>
> We took our daughter to Tabriz, we said that maybe the MRI has a problem, maybe they are lying to us, and maybe they had made a mistake. (60-year-old mother)
>
> Except my children, nobody knows about my daughter’s illness. We know it [MS] can be bad, but thanks to God, right now she’s good, like ordinary people. (61-year-old mother)

Coming to Terms With the Disease

After a while, most participants accepted their daughters’ illness. Parents learned how to look after their daughters and to manage altered social relations. They also changed their lifestyles to make their daughters more comfortable and better able to cope with the disease. This theme consists of seven subthemes: accepting, hypothesizing the cause of the disease, family mobilization, managing people around daughter, change in lifestyle, and discovering helpful resources and techniques. Representative participant statements included:

> At first, we said the diagnosis might not be correct, we did not believe it, but then we saw the symptoms, and we believed it … (61-year-old mother)
>
> I asked myself what kind of disease this is. Why did this happen to us? Maybe it happened because our financial situation was not good. Perhaps this happened because we did not eat good food. This disease is like a cold, does it have a virus? I have MS. Did my daughter have a higher chance of having MS? (38-year-old mother)

Some participants came to accept their situation, even though, prior to their daughters' illness, they could never have imagined being able to cope with it:

> The reaction of my daughter's friends was perfect; none of them made my daughter upset! (48-year-old mother)
>
> My daughter's illness affected my life badly, for example, I could not have a child again, I had stress, I said, "I have to raise her, it is costly!" (53-year-old father)

Participants found that the onset of chronic illness was the start of a long struggle with practical aspects of their daughters' care, such as a special diet, medications, and rehabilitation. Gradually they discovered and became familiar with resources that made their lives easier:

> It was very hard at the beginning, and we did not know where we can get her medicine or how to get it, we did not know the Red Crescent helps for providing the family with the drugs, we bought it from the ordinary pharmacy. Now, it is better, we have much more knowledge in this regard. (60-year-old mother)

Discussion

Upon receiving the diagnosis, parents are often overwhelmed with such sadness, worry, and fear that they can become preoccupied with their daughters' illness, and distressed over the unpredictability of its future course. Their concerns about the progress of the disease, the treatment process, the reactions of others to disclosure of the illness, and their daughter's future life could be minimized if they received appropriate emotional and spiritual support. In a study of parents whose children had been diagnosed with congenital heart disease, Barreto et al. (2016) reported similar parental reactions and concluded that the development of a supportive network was crucial to mitigating parental distress. In line with our study, Salehi et al. stated that mothers with disabled children experience many psychosocial concerns and painful experiences in caring for their disabled child; they also emphasized the need for specialized support (Salehi et al., 2022).

Mental distress and improper management can result in the parents becoming destitute and exhausted, making them feel trapped. The effects on parents of their daughter's chronic disease may cause physical and mental changes that can worsen over time and endanger their social and even physical activities. Consistent with the present research, Ali et al. (2012) stated that parental stress associated with problems, difficulties, and complications arising from their child's disease negatively impacted parents' lives, with lack of support leading to individual isolation and loneliness. MS is not only a great stressor for the patients but also for their families. Vorobeychik et al. (2020) stated that stressors can be physical, psychological, social, or financial, and that "the uncertainty and unpredictability of the disease course can … contribute to major stress" (para. 11). Consistent with the present research, Johnson et al. (2019) stated that when, as sometimes happens, a positive cystic fibrosis screening result in infants is accompanied by an inconclusive diagnosis, the uncertainty and lack of clear information from health care professionals had an ongoing negative psychological impact on parents. Banitalebi et al. (2020) also found that family caregivers of MS patients are severely stressed.

When a child is diagnosed with a chronic illness, parents strive to accept and adapt to the situation, but our findings show that they may then face such obstacles as the ups and downs of diagnosis, economic burdens, and problems arising in the treatment process. Consistent with our study, Jadid Mylani et al.'s (2012) study, which was "conducted to evaluate the effectiveness of peer groups on promoting physical health status in MS patients" (Abstract), also reported problems in the initial diagnosis. Most of the patients had been referred to a physician for symptoms such as anorexia, weight loss, and pallor, but underestimation of the seriousness of symptoms and incomplete testing caused the disease not to be diagnosed at the beginning. As a result, the disease progressed and the opportunity for early treatment was lost.

In a study of children with congenital heart disease, Barreto et al. (2016) stated that factors that interfere with the recognition and proper management of the disease included "the child is the first child, [and] the need for reorganization of family and financial routines" (p. 131). They showed that, alongside other factors, a lack of professional support from specialists makes it more difficult to obtain a correct diagnosis, and for parents to cope with the child's illness. Dung (2020) described the key problems parents of children with autism faced when taking their children to psychiatric clinics for diagnosis, which included financial problems and fatigue.

Our study found that with the onset of symptoms, some parents deny their child's illness, some complain about the situation, some prefer to conceal their daughter's disease, and some, on learning that there is no cure, resort to appeals to God through prayer. Uccelli's (2014) review of 30 studies of families who had a member with MS found that families are widely affected: even 5 to 10 years after the initial diagnosis, there are significant changes in normal family functioning. Barreto et al.'s (2016) study of parents of children with congenital heart disease pointed out that the anxiety and fear parents feel from the moment they learn of their child's diagnosis, and the long-term challenges that follow, lead to frustration related to their insecurity and lack of power. Baumbusch et al. (2018) also reported feelings of loneliness and isolation in parents of children with rare diseases.

Each participant had a unique comprehension of their daughter's illness: some viewed it as a natural part of life, while others found it an almost intolerable challenge. Parents' reactions varied depending on their background and their current condition; some reported reacting with shock, crying, and sleepless nights after learning of their daughter's diagnosis. Nikfarid et al. (2017) reported similar reactions in Iranian mothers of children with cancer: although they felt that their child's illness had strengthened them, thoughts of their child's future illness were shocking to them, leading to a sense of insecurity and chronic sorrow. Karami Nejad et al. (2020) also reported that the parents of children with Down syndrome experienced initial shock, then sadness, avoidance, guilt, confusion, and frustration.

After the early stages of diagnosing and confronting the disease, the participants accepted their daughter's illness. Although they wanted to know what caused the illness, they accepted their new circumstances and concentrated on improving conditions, enlisting the help of all members of the family. They learned how to handle the people around their daughters, adapted their lifestyles to their daughter's changing needs, and gradually discovered resources and techniques to help them deal with the disease. In short, they came to terms with the new situation, and were able to help their daughters do so as well. This enforced lifestyle change did not mean that parents were unable to recognize problems or were in a state of denial, but was a positive indication that they wanted to make a success of life in their new situation.

Strickland et al.'s (2015) investigation of the experiences of those supporting people newly diagnosed with MS mentioned that participants used the term "shared journey"; that is, a shared experience is created between the person with MS and the one supporting them as they help each other deal with emotional problems that arise, such as fretfulness, fears, and distress.

Limitations

This study took place in Ardabil, with parents of young women who were members of the MS Association there. The findings cannot be generalized to other regions, although the results may be similar to outcomes in studies performed elsewhere.

Conclusion

MS is a chronic and costly illness that challenges the continuous and orderly process of life. The experiences of the parents of daughters with MS show that each parent's understanding of his or her daughter's disease is unique. Parents' understanding of the disease, whether it seemed a natural part of life or an almost intolerable challenge, impacted how it affected them. These disparate understandings can lead to unique responses and confusion about how best to adjust. Parents are forced to make changes to their lifestyles as they learn how to manage and treat not only their daughters, but other relatives and friends who have their own ideas about MS.

Parents are the most essential carers of daughters with MS. It is therefore crucial that health care planners and managers develop a greater understanding of parental experiences in order to effectively address their problems. Ensuring that parents are properly supported could also reduce the burden of disease on the family, the health system, and the community. Furthermore, the present study can be a resource for future studies related to the experiences of parents of men with MS as well as the experiences of spouses of people with MS. In addition, we suggest that the present study be replicated in other cities to study the influence of culture on the experiences of parents of daughters with MS.

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