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## Living with Multiple Sclerosis: A Phenomenological Study of Worries, Concern and Psychological Problems in Iranian Patients with MS

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### Abstract

Multiple sclerosis (MS), as a progressive and degenerative illness, has an impact on different aspects of individual lives and may lead to difficulties, concerns, and worries in patients. The aim of the present study was to investigate concerns, worries and problems in patients with MS. We used a descriptive phenomenological qualitative approach. Participants were volunteers purposively selected based on their availability. We carried out deep interviews with 15 MS patients and analyzed the detailed information obtained from these interviews by using Colaizzi's method. We extracted six essential themes and thirty-four sub-themes associated with MS from the content of the interviews. The main themes were labelled "Confronting existential concerns," "Crisis of facing up with the illness," "Suffering from the illness," "Relationship," "Confrontation with spirituality and religion," "Searching for tranquility." Results of the present study also reiterated the following: Patients with MS seem to lose meaning of life and this together with problems in dealing with existential concerns, may lead to the "disintegration of self," hence resulting in considerable psychological disturbance and distress. It is concluded that the illness evokes psychological injury such as existential anxiety, relationship disturbance and hopelessness, and these psychological injuries can lead to relapsing of MS.

### Keywords

Existential Concerns, Multiple Sclerosis, Phenomenology, Qualitative Approach, Self

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## Living with Multiple Sclerosis: A Phenomenological Study of Worries, Concern and Psychological Problems in Iranian Patients with MS

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*Multiple sclerosis (MS), as a progressive and degenerative illness, has an impact on different aspects of individual lives and may lead to difficulties, concerns, and worries in patients. The aim of the present study was to investigate concerns, worries and problems in patients with MS. We used a descriptive phenomenological qualitative approach. Participants were volunteers purposively selected based on their availability. We carried out deep interviews with 15 MS patients and analyzed the detailed information obtained from these interviews by using Colaizzi's method. We extracted six essential themes and thirty-four sub-themes associated with MS from the content of the interviews. The main themes were labelled "Confronting existential concerns," "Crisis of facing up with the illness," "Suffering from the illness," "Relationship," "Confrontation with spirituality and religion," "Searching for tranquility." Results of the present study also reiterated the following: Patients with MS seem to lose meaning of life and this together with problems in dealing with existential concerns, may lead to the "disintegration of self," hence resulting in considerable psychological disturbance and distress. It is concluded that the illness evokes psychological injury such as existential anxiety, relationship disturbance and hopelessness, and these psychological injuries can lead to relapsing of MS. Keywords: Existential Concerns, Multiple Sclerosis, Phenomenology, Qualitative Approach, Self*

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Multiple sclerosis (MS) is known as a chronic and progressive inflammatory autoimmune disorder (Boeschoten et al., 2012). Demyelination and damage in the central nervous system bring about a variety of disabling neuro-physiological as well as psychological and psychiatric symptoms (Backus, 2016; Holden & Isaac, 2011), which may have a widespread impact on the patient's life (Samios, Pakenham, & O'Brien, 2015). MS, with a broad, anonymous and multifactorial etiology (Costa, Marques, & Calheiros, 2013; Pakniya et al., 2015), is a relatively common degenerative illness believed to affect over 2.5 million people across the world (Multiple Sclerosis International Federation, 2013).

Patients with MS experience progressively worsening disability during their lifetime (Chruzander et al., 2013). The quality of life and psychological well-being in patients with MS are mainly affected by illness symptoms (Olsson, Lexell, & Söderberg, 2008). Previous studies have shown that psychological quality of life is strongly predicted by physical disability, self-reported fatigue, cognitive impairment, and depression (Mohammadi et al., 2016). Fatigue as one of the most debilitating symptoms affects approximately 80% of MS patients (Blikman et al., 2013; Cook et al., 2013). This symptom can directly reduce self-efficacy (Nowaczyk & Cierpiałkowska, 2016). Moreover, fatigue severely limits daily activities and restricts participation in individual and social roles (Blikman et al., 2013). Hence, it is considered to be a main predictor of quality of life (Concetta Incerti et al., 2015).

Up to 65% of MS patients have cognitive impairment (Brown, Colbeck, Fogarty, & Funk, 2016; Heesen et al., 2010; Khan & Amaty, 2017). Presence of cognitive impairments

in early stage of the illness seems to remain stable throughout the patient's lifetime (Chruzander et al., 2013). Therefore, it is considered a poor prognostic factor (Lanzillo et al., 2016). Patients with cognitive dysfunctions might lose their jobs, might not be engaged in social and vocational activities and might face problems in their daily tasks (Schwartz et al., 1999). In addition, the hypothesis that depression in MS is in part due to neurological consequences of the illness process is supported in the work of Holden and Isaac (2011). Accordingly, Siegert and Abernethy (2005); Holden and Isaac (2011); Bulloch et al. (2015) and many other studies believe that depression as a symptom of illness has a strong impact on MS patients' quality of life.

Therefore, patients with MS are faced with a set of psychological issues because of the nature of the illness. The literature is abundant with evidence of this kind. The range of psychological problems include lack of self-efficacy and motivation (Backus, 2016); limitation in activities of daily living (Khan & Amatya, 2017); decreased sense of self control and control over daily tasks, as well as lack of self-esteem; problems in family and marital relationships and feeling of loneliness (Holden & Isaac, 2011; Olsson et al., 2008); mood disturbances (Lanzillo et al., 2016); behavioral, environmental and employment problems (Concetta Incerti et al., 2015).

A mutual relationship can be found between mental health and physical health such that psychological well-being also has a critical impact on illness (Pompili et al., 2012). On the other hand, there is a physiological link between the nervous system and the immune system. For instance, as believed by Van Der Hiele, Spliethoff-Kamminga, Ruimschotel, Middelkoop, and Visser (2012), moderate chronic stressors in daily life may increase a person's vulnerability to MS inflammations. In addition, "stress" is generally considered as the main risk factor for mental health and plays a pivotal role in development, progression, relapse, and stability of MS (Nasiry Zarrin Ghabaee, Bagheri-Nesami, & Malekzadeh Shafaroudi, 2016).

Because MS mainly begins during early to middle adulthood (Pakniya et al., 2015), and it is most prevalent in middle life (Multiple Sclerosis International Federation, 2013), leading to serious physical and psychological disabilities, it is essential to make use of psychological interventions that would reduce the level of individual stresses and increase the sense of self-efficacy and self-esteem. Interventions of this kind may also help patients control their symptoms and reduce the probability of relapse.

Despite the fact that a wide range of studies have examined physical and psychological disorders as well as psychological problems of MS patients, few studies have considered specific issues and concerns of MS patients based on the patients' real life experiences; this is the main aim of the present research. Since we aim to explore issues faced by MS patients, the methodology is qualitative and phenomenological (la Cour & Hvidt, 2010). Hence the present study aims to offer an exploratory insight into MS patients' thoughts, experiences, and attitudes regarding weaknesses, disabilities, and other psychological experiences they may have in the process of the lived experience of their illness. In this study, we endeavored to explore patients' experience of MS within the context of phenomenology, with special attention to how these participants experienced and described problems, concerns, and worries.

## **Method**

We classify this study as a descriptive phenomenological qualitative approach, which focuses on the in-depth study of specific instances of a phenomenon (Gall, Borg, & Gall, 1996). We use Colaizzi's (1978) framework in the present study.

Concerning the suitable qualitative research approach for exploring the subject matter of the current study, it should be noted that the focus of the research topic is on understanding a phenomenon from the point of view of those who have experienced it (Smith & Osborne,

2015). “Lived experiences” is one of the constructs in phenomenological research (Vagle, 2018). Lived experiences described by participants are used to define the universal structures (i.e., essences) of the phenomenon (De Chesnay, 2014). The important thing is to describe the shared notion linked to a particular phenomenon by all participants in the study. To put it straight, this method involves dealing with a phenomenon - catching the MS illness in case of the current study. Next, we collect from the people who have experienced this phenomenon and a mixed description is provided from the common essence of their experiences of the phenomenon. This description encompasses both “what” they’ve experienced and “how” they’ve experienced it (Creswell, 2007).

We collected the data through in-depth interviews to conduct more detailed and accurate examination on experiences and perceptions of the participants. The authors transcribed data verbatim and analyzed using Colaizzi’s method (Colaizzi, 1978; Vagel, 2018). Eligible participants included all MS patients having brain plaques- with or without spinal plaques (as determined by their physician). We did not apply any limitation for inclusion of participants regarding their age, age of onset, illness duration, sex, and EDSS degree. Our exclusion criteria included presence of spinal cord plaques alone, history of psychotic disorders or hospitalization in a mental hospital, and other neurological disorders accompanied by MS illness.

### **Procedures in Participant Selection and Data Collection**

The study received ethical approval by the Department of Psychology of Shahid Beheshti University in Tehran. Furthermore, we informally took the informed consent about the aims of the study from the participant before data collection. Also, to enhance participant safety, we used the specific code for each one to maintain anonymity.

We recruited the participants in two ways: announcements in a number of neurologists’ offices and invitation letters in social networks for MS patients. We followed them by a phone call to assess patients’ interest in taking part in the study.

Within a two-month schedule, 42 patients agreed to participate. In the initial screening interview, 17 patients were excluded from the sample for the following reasons: seven patients for having only spinal plaques; four patients for having a co-morbid psychiatric disorder and six patients due to inability to attend interviews. A final sample of 25 patients with MS were selected for participation. Since a number of participants did not live in the Tehran area, the time of their interviews was set based on the time they could come to Tehran, whether for attending a medical appointment or any other reasons. The data saturation, as the criterion for sample size estimation (Saunders et al., 2018; Marshall, Cardon, Poddar, & Fontenot, 2013), had been reached after interviewing 12 participants, we continued the interviews with three additional participants to make sure saturation point had been reached. The level of data saturation was determined by the interviewer as well as an independent researcher in a process carried out in parallel with data collection. Finally, based on purposive sampling and after data saturation, we determined the sample size in this study as 15.

Accordingly, we analyzed the content of interviews with 15 MS patients in the present study.

Two/three 30-45 minutes weekly interviews were held for each participant based on the severity and variety of their problem, physiological ability, and mental readiness. The sessions included psychiatric, personal history, and in-depth interviews. Afterwards we transcribed, re-read, and analyzed the recorded interviews.

## Instruments

**In-depth interview.** We collected the data through an in-depth, semi-structured, face-to-face interview. “The in-depth interview is a qualitative research technique that involves conducting intensive individual interviews with a small number of respondents to explore their perspectives on a particular idea, program, or situation” (Boyce & Neale, 2006, p. 3). We followed the three phenomenological interview series (Bevan, 2014; Seidman, 2006):

- Contextualization (focused life history): we started the interview by focusing on the participants' life history, and then we searched how the participants have experienced the disease phenomenon in that context. For this purpose, the participants were encouraged to talk freely about their illness experience, difficulties, and problems they have faced since the time of diagnosis.
- Apprehending the phenomena: we began to focus on and explore the concrete details of the participants' lived experience from the disease phenomenon. The participants were asked some questions like: You mentioned that you...Could you please describe what you mean? Or Can you describe what you do when...
- Reflection on the Meaning: Finally, we focused on the participants understanding of their experience, and for clarifying their meaning of their lived experience of phenomenon we asked them to reflect on the meaning of their experience.

**Structured clinical interview.** As psychiatric disorders were assigned as exclusion criteria in this research, a semi structured clinical interview to assess and diagnose mental disorders based on diagnosis and statistical manual of mental disorder - fifth edition (DSM V) was also carried out for patients suspected to psychiatric disorders.

**Personal and family history interview.** This brief interview was conducted before the in-depth interview to better understand the context of the participant's family and personal life to deeper search in context which the disease has developed on. This interview was conducted with open-ended questions focusing on four domains: early childhood and family background, teenage years, adulthood, and self-evaluation overview.

## Data Analysis

Colaizzi's method was used for coding and analyzing the data, respectively. The Colaizzi method is a seven-step process. In the first phase, the recorded interviews of the participants are listened to repeatedly, and their statements are put down on paper word by word following the end of each interview and compilation of field notes. The transcripts are studied several times to grasp participants' feelings and experiences. In the second step, when all descriptions, provided by the interviewees of the topic, are studied, the significant information and statements, related to the phenomenon under discussion, are underlined to draw attention to the important lines. The third phase involves induction of the formulated concepts; that is, subsequent to highlighting the important statements in each interview, the researcher try to conclude a concept indicating the scene and basis of the individual's thought. Having extracted the codes, in the fourth step, the researcher starts studying the developed concepts carefully and makes classification through comparing the concepts. Subsequently, thematic categories are built upon the developed concepts. Next, in the fifth phase, the results are put together to come to a comprehensive description of the phenomenon under study and

make broader categorizes. During the sixth step, a comprehensive description (as clear and unambiguous as possible) is provided for the phenomenon. The final step is validation that is done through coming back to each sample and questioning on the founding.

Important lines relative to the phenomenon, under study, were highlighted in the text. Marginalia is suggested by Creswell (2007) in this stage to preserve the immediate ideas and perceptions. Therefore, the primary concepts were saved through making marginalia.

Then significant statements and phrases were made out and noted down on a separate sheet. Formulated meaning was derived from the aggregation of these significant statements. Specific codes were assigned to each one of formulated meanings (This is illustrated in Table 1) and related codes were classified into clusters that were put into corresponding themes and, finally, main themes and the sub-themes were determined.

Next, more themes were extracted from the formulated meanings, which were more qualitative and analytical.

Table 1. Sample of Data Analysis Process

Significant statements	Formulating meaning	Coding
Why did I catch the disease? Why not the others? I reached the conclusion that; I don't have no choice except satisfaction and surrender! Why I was born? What was the purpose of God from my creation?	Deal with existential questions and eventually trying to forget with passive surrender.	<b>Why me?</b> <b>Why I was born?</b> <b>What was the purpose of my creation?</b> <b>Despair and surrender and depression</b>
Whenever I'm too distracted ,as I don't have any one to talk to, I eat a lot of sleeping pills and fall asleep.	Time to distress, because sense of loneliness, escape of problem and try to ignore it, and sleep.	<b>Escape from problems</b> <b>Problem solving with sleep</b> <b>Loneliness</b>

To test the credibility of these analyses, data was sent to two Ph.D. students familiar with qualitative analysis methods to review and check the codes, themes, and sub- themes. Ultimately, the validity of the obtained themes was examined and approved by all participants.

## Results

Derived from qualitative analysis of interviews, our results indicate that the concerns, worries, and psychological issues of patients with MS can be divided up into six main concepts and 34 categories. The main concepts follow and are identified by numbers; associated categories, with excerpts are shown under each concept.

**Existential concerns.** Existential concerns refer to the issues which may arise in time of confrontation with givens of existence. Existential givens are certain and ultimate anxieties constituting an inevitable part of human existence in the world; the part that people are often trying to escape from. However, sometimes, as is the case with MS patients, avoiding or escaping from these "givens" may be difficult or even impossible. Hence, in this study, seven

separate sub-themes were identified. Most of these were concerned with confrontation with existential givens:

**Confrontation with ontological whys and questions.** From the beginning of the illness, all participants reported having to face up with questions such as “Why me?” “Why when I am still so young?” “Why was I ever born?,” “Why did I get sick?,” “What will happen to me at the end?” as well as other existential questions. Some of these questions were directed towards god or a deity as being responsible for their illness. Participants repeatedly asked God questions such as: “Why did you create me like you did?” and “Why did you do this to me?” The various strategies people used while seeking an answer to these sorts of questions can be categorized as follows: avoiding answering the questions, pondering on the questions, surrendering passively, conflict and aggression, self-blame and depression (self-reference), using sublimation mechanism for answering the questions, purposefulness and positive thinking and active surrender.

**Will and responsibility.** Two significant issues are suggested in this sub theme: first one is the issue of determinism and free will as far as MS is concerned (illness-induced factors, participant’s personality before the illness, life stressors) and the other one is participant’s responsibility as far as treatment is concerned. In general, people are of three different groups in this case while the majority of participants belong to the first group.

A. The participant views the illness and its treatment as totally deterministic. This group also expressed a low level of responsibility for treatment. For example, following are comments made by participant 1: “...after all, everything is deterministic, the illness...even taking drugs...recovery from the illness...if God wants, I will get well, there is no need for drugs and other stuff...if only one or two percent of life can be decided by your free will, it is ridiculous to plan for your future... whenever you intend to make God laugh, tell Him about your plans for the future...God says, make a plan, I will ruin it for you.”

B. The participant views getting ill as somehow deterministic but, thinks he / she has some control and they bear responsibility for treatment. As participant 8 described: “ You must withstand the illness and do it with all your might . . . I did not want to cry... it did not have anything to do with me but, I controlled it...in this illness, you know better what you are doing to yourself...you are able to take over the reign...it is hard but possible...you must be tough”

C. The participant considers both divine determinism and personal free will affecting the illness but, they think the major cause of the illness is associated with personal factors concerning themselves as well as their freewill. This group is also responsible for their improvement. For instance, as stated by participant 6: “I have only myself to blame for both catching the illness and staying disciplined to get well... I have never blamed God...I am so impressionable, Irritable, and blow a gasket quickly...I never give up easily... It is my fault getting sick”

**Give meaning to the illness and life.** Following confrontation with ontological questions, the participant begins to make the illness and life meaningful. This attempt manifests as either optimism or pessimism. The illness can provide the participants’ life with positive meanings by making their life purposeful, promoting their personality development, and empowering them to take advantage of their opportunities. Meanwhile the illness can also



insert negative meanings into the participants' life by putting them on the track of gradual death, bitter experience, disability and paralysis.

***Shift in purposefulness and orientation toward the course of life.*** According to the results, purposefulness of the subjects before becoming ill is effective in their orientation toward life in the aftermath of being diagnosed. Before the illness, participants could be categorized put into two groups, namely those having a purpose and those being aimless.

***Death as a boundary situation.*** What has been understood about death can be outlined under the following three headings: Contemplations surrounding death and life after death, Suicide and thoughts surrounding it, and Death Anxiety.

***Loneliness.*** The presence of a sense of loneliness is an undisputable issue in the participants which is characterized by pain and sadness.

***Love.*** This is described as having an emotional relationship with another individual (in the case of the present sample, the opposite sex). Here, the goal is to be in a peaceful and secure relationship rather than a romantic one. There are cases to be mentioned about the power of love as a lost key, able to heal the illness and increase the level of tolerance for pain inflicted by the illness, as expressed vividly by participant 12): "love can save you from despair...we married with love, but our sexual affairs are not too many! Although I am not able to meet her needs, our romantic relationship goes very well... without love, it is impossible for me to put up with the illness." Similar words were mentioned by participants 5 and 3.

***Crisis of facing up with the illness.*** Crisis occurs when several aspects of the participant's life may be transformed by the process of the illness. Additionally, how an individual may be able to face the crisis is of great significance. Crisis consists of three sub themes.

***First is confrontation with the illness.*** This involves how the participant is informed of his illness and what mood and mental reactions he makes in return. Regarding how the participants confront the illness, they are divided into three groups:

- A. Those who face up and become aware of the illness directly through an unplanned process by their doctor.
- B. Those who face up and become aware of the illness through an unplanned process by an unrelated person such as a friend or relative.
- C. Those who face up and become aware of the illness via a gradual process by immediate family members.

Generally, participants' mood reactions to the illness begin by not believing the story and is usually followed by astonishment and denial. They continue to deny the illness for a long time and continue to regard the diagnosis as incorrect. Within a maximum of a few days, their mood will turn to anger, deep sadness, and high emotional responses such as weeping, aggression, and even suicidal thoughts and actions. Aggression is a frequent response. Only those who confront the illness during a gradual process are likely to control their anger, and their emotional reactions are just limited to deep sadness, temporary social isolation, and lamentation. For example, as quoted by participant 8: "I became so sad and avoided talking to anybody for about two to three days. I preferred to be alone back then. My disabilities especially made me sick... but then, I told myself that I must be strong..."

***Rise of dysfunctional thoughts and beliefs in confronting the illness.*** A range of thoughts and beliefs are immediately activated after the illness is diagnosed. Generally, several kinds of beliefs were activated in participants and were as follows: Activated beliefs about the cause of illness and how it is related to God; activated beliefs about death and end of life and activated beliefs about MS itself.

**Suffering from the illness.** The patient views the illness as constant, chronic, irrefutable, and inevitable suffering. Factors causing the patients' suffering are categorized into nine groups.

**Disabling, unpredictable, inevitable, and uncontrollable symptoms** (fatigue as a symptom casting a shadow on the entire life), most important of which include: having difficulty in walking, standing up and, consequently, tumbling down, as well as experiencing gradual loss of abilities. As stated by participant 1: "little by little, the illness makes you believe that non-existence is better than existence" The illness convinces some participants to give up and just wait for death to come. Furthermore, the sudden onset and unpredictability of symptoms of the illness usually catch the patients off guard, leaving them in constant fear of new disabling signs and symptoms. While some participants are in grave pain due to the condition of illness, and fear the prospect of being plagued by the illness in the future, others feel that they must cope with their disability to shoulder the responsibility they have toward their children and spouse.

**Concerns over future.** Waiting for an unknown, imminent, and catastrophic future; fear of getting married, and the future of the relationship, and worries about prospects.

**Frustration in life.** The major factors contributing to participants' frustration in life include obstacles created by the illness so that achieving goals become difficult. These obstacles, when coupled with the early onset of the illness, would multiply the sense of frustration.

**Life difficulties and limitations.** Depending on the level of progress and the extent of disabilities experienced, the illness will impose limitations on the participants and may result in hardship and discomfort in life. Social limitations, disability that prevents taking part in preferred social activities, difficulty in moving around, and career limitations are among the major concerns of the participants.

**Illness as a stigma and people's judgment.** People's judgment is one of the reasons leading to self-imposed isolation from the community.

The illness stigma is what makes us extremely upset. It really hurts us... I accept the fact that I must go along with all these limitations but, it is what people usually cannot swallow. They think MS is a horrible illness. As soon as they hear that I have MS, they think it is a terrible disaster! And what a miserable person I am...this MS illness stigma (i.e., the image of a disabled, a miserable, and a wheelchair user is really offending). (Participant 5)

**Annoying clinical representation.** Appearance of symptoms of illness is considered as another suffering caused by the illness, whether it is a sign of illness such as walking or moving with difficulty or a side effect of taking drugs such as hair loss.

**Never ending restlessness.** This is another suffering inflicted in the aftermath of illness. Participants 15 and 13 refer to it as "always feeling bad," "which never lets go."

**Side effects of drugs.** Various drugs have various side effects. These side effects seem to occur in one way or another in most participants, as reported by participant 4: "I never inject drugs anymore, it is horrific. It gives me 48 hours of raging fever."

**Economic problems.** Despite the fact that participants in the present study belonged to different social classes, they all expressed worries and unhappiness about high costs of treatment in one way or another.

**Relationship.** This refers to the quality and nature of the individual's significant relationships following the diagnosis of MS and the effects it brings about on the individual.

This theme consists of seven sub themes, which are as follows.

**Parents and primary family.** This includes support received from the family as well as interfamily conflicts. The interfamily conflicts include conflicts between parents, disturbed relationship between parents and other members, and disturbed relationship between other family members.

**Marital relationship and sexual affairs.** The marital relationship is influenced by the illness at two different levels: affective and sexual. Following the diagnosis of MS, the marital relationship is affected differently; it may continue, break down, or even lead to remarriage of the unaffected spouse. The major issue reported in the aftermath of illness is related to sexual affairs, which may have harmful effects on the emotional relationship between couples. On the other hand, all single participants seem to worry about the issue of marriage. It is due to their sense of disability to make a family and continue their life naturally as well as to have an intimate relationship with a person as their spouse. Sexual problems as reported by some participants, include worry about the ability to have a healthy sexual relationship and meeting such demands by their spouse in their marital relationship.

**Children.** In this section, children's issues and childbearing arise as two different topics. In regard to those participants having children, the presence of children is seen as a motivation and stimulus for improvement. Meanwhile, fertility, transmitting the illness to children through genes, unpredictability of the process of illness as well as anxiety over the progression of illness during pregnancy are among the most important matters of concern for both single and married participants. As stated by participant 4,

I don't want to die, mostly because of my son, Pouriya; I want to improve because of Pouriya, I don't want to be depressed, my son does deserve a better parent; I think I would kill myself if Pouriya weren't by my side.

Participant 8 tried to block the effects that his illness may have on how his children think about him.

this thought keeps haunting me that my kids think their father would be crippled one day, I wouldn't let them learn anything about it. There are nights I can't sleep at all because of my poor condition, but in the morning, I sit at the table fresh and perky as always, not let my wife and children spot my health problems. There have been times I have gone tracking in the mountains with my son so as to show him I am fine, despite my bad condition. Even when he got tired, I have often given him a piggy back ride! If you ask my son, he believes I should take part in the World's Strongest Man contest.

**Friends, relatives, and colleague.** In most cases, the participants tried to hide their illness from others. It may be owing to their intense irritation at people's wrong judgments or other social outcomes of their illness such as losing their job. The subjects usually report that they lose contact with their old friends and try their best to find new friends under new circumstances.

**Peers** (other patients with MS). Some participants tried to make new contacts with other patients with MS after being diagnosed. Some found it positive and soothing to make new friends with the same problem while others were reluctant to make such a contact or once contact was made, their relationships deteriorated or broke down after a while. Participant 2 considers having friends with the same problem as a factor helping him to improve. Similarity participant 13 said:

We can understand each other better; other people can't understand what we talk about; when I laugh with other people, I think they don't experience the pain I've suffered, but when I laugh with someone who is like me, I think he is suffering from the same pain and is still laughing, then I begin to laugh heartily too. What am I supposed to see? To see what is going to happen to me within the next 30 minutes or 20 years!? What am I going to learn by hanging with a group of people sitting on a wheelchair or walking with the aid of a walker? Do you think I thank God because I'm not like them!? My dark days will also come soon, I've only had the illness for years, I should deal with it to the end of my life, maybe I am forced to use a walker tomorrow, nothing is certain.

**Self.** Most participants reported loneliness and took a plunge into their inner self as they avoided making any sort of relationship. Indeed, their avoidance was seemingly a sign of significant conflicts they were experiencing.

**Confrontation with spirituality and religion.** Varying levels of a new different spiritual and religious experience, from positive to negative, and from a basic superficial change to a deep broad one bringing the entire life under its effects, had been undergone by most participants (14 cases). This theme involved five sub themes, which are as follows.

**Definitions of spirituality and religion.** Definitions provided by participants for the concepts of spirituality and religion were very similar. They saw religion as the factor contributing to spirituality and a religious person as being spiritual.

**Performing spiritual and religious practices.** The level of spiritual and religious activities was different in subjects and depended on their religious beliefs and attitudes, type of relationship with an attitude towards God as well as their religious identity.

**The place of God in life.** Results indicate that there are three influential factors in spiritual and religious orientation of individuals. The kind of image participants have of God; the reasons they have for having a relationship with God; and the strategies for relationship with God. This relationship was divided into five main categories, namely the relationship accompanied with a sense of deep fear and conflict (with or without anger), the relationship accompanied with a sense of guilt (with or without anger), the relationship based on hope and seeking support, the relationship based on love and affection, and finally an attempt to pay less attention to and turning away from God.

Participant 1 said: "New experience from a new God, a God you can talk with, and has everything under his control! And I'm a puppet in his hands. His very presence, makes you more spiritual." Participant 15 also describes his feelings as:

I feel like a bee trapped in a beehive ! The bee thinks he's free to fly round but the truth is that he could make a short turn around himself in the hive , only able to make a wish; if God is not allowed, he could not even breathe in the hive; now I'm feeling like this, I can't do anything, but it doesn't mean that I don't want to, it means that the God doesn't want.

**Religious strategy.** Given the same image, the participants have about religion and spirituality, the religious attitude results in developing unique strategies to deal with the illness. These methods and strategies could be divided into two groups of positive and negative strategies based on the significance of God in the participant's life. The positive group relied on optimism and hope in strengthening spiritual power and the negative group relied on emotions like fear of divine retribution and feelings of guilt.

**Change in attitude toward religion.** This type of change occurred differently in various people and could be classified into two groups in general: taking a perspective centered on God

and monotheism or holding animosity toward religion and spirituality. Most participants could be grouped in the former as they tried to adopt a viewpoint that further developed their spiritual strength.

**Searching for tranquility.** Serenity is like a lost precious haven for the participants, looking after it following the end of the distressed periods resulted from the confrontation with the illness. The following groupings could be extracted from the content of the interviews:

**Pacifism.** Achieving tranquility is a goal for some, while a need and desire for the others. Achieving tranquility is considered as the ultimate goal for some participants as it encompasses other goals of life and mobilizes everything for its realization. It even makes people ignore other things in their life to only focus on and try to achieve tranquility. Tranquility is considered a need and desire for some participants. Albeit the fact that it is hard, and sometimes even impossible to achieve. Talking about his never-ending restlessness, participant 9 reported the following:

I am so confused and exhausted. I have no peace, no quietness. I cannot be pacified by anything. What used to be my favorite yesterday, only make me more frustrated today. I feel sick. Even when I am in good physical health, I feel sick...My father says your problem is due to the lack of peace and tranquility within yourself.

**Solutions to find peace.** The patients attempted to achieve tranquility via four main strategies: Finding tranquility through spirituality; deriving tranquility from entertainment; use of behavioral solutions such as superficial pleasure; deriving erive tranquility from believing that they can control their symptoms.

**Sources of peace.** In order to achieve tranquility, participants asked multiple sources for help, from God and their friends and family members, to psychologist and practitioner. Participants reported that they acknowledged their relationship with God and love of a faithful and devoted spouse as healing factors leading to tranquility.

## Discussion

Given the chronic, progressive, and degenerative nature of multiple sclerosis, from the early phases of the illness, patients are face a set of difficulties, concerns, and worries that burden them with significant pressure and stress. The results of the present study showed that these difficulties, concerns, and worries of the patients could be classified into seven main themes. Consistent with the work of Pakniya et al. (2015) on the effectiveness of cognitive-existential therapy on the quality of life of MS patients, also consistent with Nasiry Zarrin Ghabaee et al. (2016), the results of present paper confirm that the major mental concerns and distresses of MS patients are existential concerns and conflicts. An illness such as MS may be considered to be threatening not only to life but to the very meaning of existence itself. According to the analyses presented in this study, the primary concern of MS patients immediately after being diagnosed is confronting existence-related and ontological questions. These sorts of questions directly address the issues of existence and sources of existence. Olsson et al. (2008) briefly point to the presence of these questions among MS patients. Accordingly, they suggest that having ontological discussions as well as taking meaningful and purposeful attitudes toward life when trying to answer existential questions would help patients achieve self-authenticity in the course of the illness, try to resolve (albeit superficially at times) certain existential conflicts, plan for the future, and develop meaning in life which may lead patients towards self-integrity.

It seems that the all-important question of Determinism versus Free Will becomes a major concern for MS patients when trying to investigate the causes of their illness. In addition to this issue, the level of responsibility felt by the patient for his or her illness is determined by decisions and choices made when trying to respond to this question. Lingering in the crisis to decide how much responsibility the patient may have had towards the illness (referred to as *crisis of will* by Rollo May), the patient may suffer from the illness when he is burdened with grave responsibility of living with the illness, undergoing treatment, living in pain and, while struggling to make sense of his life in the time that he has at his disposal. It is under such circumstance that the patient may show wide variety of reactions and responses. As Rollo May has stated: “instead of engaging specific mechanisms in body, the illness casts a shadow on the whole self” (2007, p. 39). Indeed, the “self” plunges into confusion that strips it of the power of will and choice. The crisis of will in this group of patients, is the result of a conflict between existence and non-existence of power in the personal world. Rollo May described: “choosing yourself means choosing life, between life and death and, the one who does so will take responsibility of his life” (2009, pp. 195-196). It is after accepting the responsibility for treatment and living on with illness that one can create new meanings in new situations and stay faithful to them.

Our results show that the illness is far more assigned with negative meanings than positive ones. However, there are participants who find reasons to continue their life and to attempt to recover, which help them lead a purposeful life. Pakniya et al.’s (2015) findings also seem to reiterate this fact that the creation of meaning in life by these patients would be fairly effective in the improvement of their psychological welfare. So that such a person, as quoted by Frankl (2000, pp. 120-125), “is capable of not only deciding on how to live but how to die.” Adamson (1997) suggests that existential uncertainty is one of anxiety-provoking factors in patients with chronic illness. Kierkegaard (1813/1855, cited by Adamson, 1997) believes that death and its unpredictability is a place wherein the person is confronted with existential uncertainty. Consistent with this study’s findings, Adamson (1997) notes that existential uncertainty along with uncertainty and unpredictability of the illness, in patients plagued by chronic illness, would keep them more alert and more aware of the existential concerns such as death. Accordingly, they are exposed to higher levels of both overt and covert anxiety. In this regard, suicide and suicidal thoughts are observed almost in all participants, though it seldom leads to committing suicide. Pompili et al. (2012) also recognized that a chronic illness such as MS, will increase the risk of committing suicide. According to the findings of the present study, meaninglessness and absurdity of life as well as self-disintegration are two key factors that may give rise to suicidal thoughts and committing suicide. A study reported by Pakniya et al. (2015) also endorses the idea that existential isolation, that is, the fundamental loneliness in this world, is commonplace in suicidal MS patients.

The essence of loneliness of participants is made up of an array of interpersonal, intrapersonal, and existential loneliness; however, it is the experience of intrapersonal loneliness that is generally credited with the pain inflicted by loneliness. Participants usually fail to connect to those parts of “oneself” that are either unknown or unacceptable to them. This is caused by a disintegrated “self” that shows up in the form of annoying thoughts and, either rational or irrational, fears and worries. Running away from the loneliness they feel towards community may result in slipping into false love and attachment, and that may be one reason for why dysfunctional affective relationships are widely observed among this group. It is also suggested that in preparing the patient to confront the illness, the presence of social and family network and relationships, which have concerns for the patient’s illness, is very important. Social and family support can improve the patient’s ability to keep calm and self-confidence when MS is diagnosed. The patient’s capacity to cope with the illness and belief in him or herself may also improve. Consequently, the patient may accept the illness, accept the

responsibility for treatment, become more active in life and gain “self” integrity (Bulloch et al., 2015).

There are a wide variety of factors involved when considering the process of suffering as a result of illness. These factors which may be socio-cultural in nature and may affect the level at which suffering is inflicted as well as how it is prolonged (Adamson, 1997). To mention one of the social factors, we could refer to the strategies employed by medical staff and/or family related to how the patient be informed of the diagnosis and prepare to confront their illness. Patients are suffering from an immediate and unprepared confrontation with seriously disabling symptoms, which are uncontrollable and there is no clear way to treat them. Moreover, predicting the inevitably of forthcoming symptoms could be anxiety provoking. Olsson et al. (2008) recognize the unpredictability of later symptoms, dubbed as “unpredictably unknown body,” as one of the gravest concerns of all participants.

The prediction of a catastrophic feature along with a sense of inability to control the symptoms, fear of marriage and the future of relationships, and worry over job prospects, taken as a whole, add to the suffering of the illness. As confirmed by the present study, family and professional relationships are significant territories heavily influenced by the illness (Papuc & Stelmasiak, 2012). Additionally, the sense of inability to shoulder the responsibilities placed on the subject, such as family and children, education and profession, is taken into account as an important stressing factor (De Judicibus & McCabe, 2005; Cook et al., 2013). How people judge is another factor which may contribute to patients’ suffering, which could affect marital and other emotional relationships and inflict direct damage to the patients’ self-concept. Since, in the aftermath of the illness, the patient tends to hide the illness, (possibly because of cultural taboos and issues), the rise of clinical symptoms may cause difficulties for the patients when faced with negative evaluation and judgment from others. As a result of this fear of negative evaluation, MS patients may experience lower self-esteem and self-imposed avoidance of social situations and interactions, as found in the present study. In the present study, patients described themselves as being frustrated with life and wistfully longing for their dreams to come true. These sorts of longing are not caused by the distant impossible dreams but, as described by some participants, are due to disability to do simple, basic, and day-to-day household tasks like using a napkin and cleaning the home. As mentioned by Olsson et al. (2008) one of problems of these patients, and women in particular, is that they are dependent on others even for simple everyday tasks, which they are longing to do by themselves. As stressed by Backus (2016) and Nasiry Zarrin Ghabaee et al. (2016), the ability to do routine activities has a significant effect on participants’ self-concept. Indeed, some findings (e.g., Bakus, 2016) indicate that increase in self-concept pushes the subject to do more of the activities of this sort even with fatigue and disability. Backus (2016) believes that MS patients will feel healthier and more self-confident if they can manage to do daily activities.

At the same level of disability, the degree of impressionability of participants is related to their psychological capacity and structure as well as their “self” integrity before the illness. It is heavily influenced by family status and caretakers and the quality of their lives. At the same time, any shifts or rise and fall in the quality of life is influential in the behavior of patients (Asmahan, Alshubaili, Ohaeri, Awadalla, & Mabrouk, 2008; Giordano et al., 2016). Family disintegration and serious conflicts are widely observed among the families of participants. These results are confirmed by a collection of studies in which the role of family-induced stress factors are highlighted in developing serious difficulties and illnesses in children (Frankel, Umemura, Jacobvitz, & Hazen, 2015; Stover et al., 2016). As children need to be offered love and security by their parents, any conflict between them and damage to their relationship would lead to permanent nervous tensions with which the children have to be confronted throughout their life. Furthermore, experiencing a strained atmosphere between family members is effective in that it increases relapse of and the risk of attacks in MS patients.

Building on the results of the current study, it is revealed that the marital relationship is profoundly affected by MS. This should not be interpreted as suggesting that a healthy relationship may necessarily be forced into dire conflict and disarray, but rather it is suggested that the diagnosis of MS may result in the existing characteristics of the relationship becoming more salient. In other words, existing problems may be reiterated. However, in the case of very strong relationships, closeness between partners may occur as they rise to meet the challenge of MS. Popp, Ann, Robinson, Britner, and Blank (2014) and Messmer Uccelli et al. (2013) showed that unhealthy marital relationships before the illness will continue after the illness but, the illness rarely ruins healthy marital relationships. Additionally, the presence of love and affection in the marital relationship could bring meaning to the lives of these patients. Ivtzan, Lomas, Hefferon, & Worth (2015) also point out that in the case of chronic and disabling illness, embracing 'the dark side of life' (suffering, hardship, and challenges), may result in personal growth and development. In the present study, most participants believed that receiving emotional support from the family has a positive impact on their health improvement and life expectancy, A study by Hughes, Locock, and Ziebland (2013) confirms the results obtained from the present paper that emotional support the patients receive from their partner and children is so important that it could play an effective role in mitigating the symptoms of the illness, as well as boosting self-confidence and cultivating self-acceptance.

A similar argument can be put forward regarding sexual relationships as an effective factor in marital relations. As suggested by Sevène et al. (2009), in many cases involving patients suffering from chronic illnesses, couples report sexual dysfunction and mention this as the main factor contributing to the relationship's break up. Major causes of sexual problems in MS include psychosocial and cultural challenges such as low self-confidence, poor morale, difficulties in interpersonal skills and initiating and maintaining relationships (Prévinaire, Lecourt, Soler, & Denys, 2014). Consistent with Cordeau and Courtois's (2014) study, participants in the present study reports of dysfunction in sexual performance and desire, especially in female patients was very common. We believe that physiological effects of the illness and side effects of drugs may be the main reason for this. However, as confirmed by other research, (e.g., Cordeau & Courtois, 2014; Samios et al., 2015; Sevène et al., 2009) the authors of the present study believe that there may be a strong interactive effect between patients' problems with emotional and sexual relationships and social and cultural factors such as isolation and fear of negative evaluation. In other words, the MS patient's relationships are limited partly because of other people's judgments and social consequences of the illness. The patient would prefer to stay away from the crowd rather than to be challenged with new problems. Isolation from the others is in part interpreted as accepting loneliness. However, due to fear of loneliness and the inability to enjoy a rich inner world, the patient experiences anxiety. This interaction needs to be investigated by future researchers to establish both the mechanism through which social and cultural factors interact with physiological and psychological factors to create feelings of loneliness and anxiety.

Here, the only distinct relationship identified is the one with God. Most participants reported that they did in fact maintain a relationship with God, whether positive or negative. Though this relationship is sometimes strained and conflicting, participants in the present study seem to agree that the need to make such a relationship (i.e., the need to connect to a higher or ultimate source of power) is necessary. Results of the present study, which is in keeping with that of Nasiry Zarrin Ghabaee et al. (2016), indicate that the type of spiritual and religious relations, and the relationship with God in particular, is highly effective in improving the quality of life of MS patients. The present study confirms results obtained by Tofiqi, Azzadeh Forouzi, Tirgari, and Iranmanesh (2014) according to which the issues of spirituality, spiritual experience, and religious attitude are specifically highlighted by the participants in the aftermath of illness. The issues of religion, God and spirituality, and God's role in the



occurrence, process, and the fate of the illness are inevitably facing the patients in times of crisis. The results of the present study are also confirmed by results obtained by Michaelson et al. (2016), Zimmer et al. (2016), Rosmarin et al. (2013), that the place of God in participants' life and their faith in God are crucial when they confront illness and try to cope it. As suggested by Papuc and Stelmasiak (2012), though the effect of religion on the quality of life of MS patients has received little attention, those patients who invite spirituality into their lives and choose spiritual coping strategies, would enjoy life with a higher quality. Meanwhile, according to findings of Nowaczyk and Cierpiakowska (2016), having spiritual resources in particular could not only make up for the loss of other sources of support but also help these patients to be able to further exploit their potentials. Developing a spiritual relationship is considered as a haven to achieve tranquility, security and inner peace, which are viewed as major concerns of MS patients.

Finally, it could be asserted that all the above-mentioned categories are interconnected and interrelated, a constellation, as it was, affecting and being affected by one another. Meanwhile the search for meaning and the crises created by existential questions, along with possible changes made in the state of the "self" are regarded as the particularly significant factors in this constellation. All the mentioned factors affect the self-concept of participants directly. If the influence is positive, self-concept will be strengthened. Otherwise, the patient may suffer from a weakened self-concept. Similarly, we found that most participants suffered from a lack of "self" integrity. Likewise, participants tend to move towards the negative side of this spectrum (i.e., self-disintegration) rather than the positive side (i.e., self-integration).

Multiple Sclerosis is an auto-immune illness in which the body's immune system cannot recognize body cells from foreign substances. Results of the present study poses an important question: How do behavioral and psychological signs and symptoms of MS, mirror what happens at the cellular level? What is the mechanism through which damage at the cellular level may result in self disintegration? Accordingly, it is suggested that future studies should focus on psycho-neurological processes of MS.

Finally, based on the results of the present study, it seems that MS patients may benefit a great deal from suitable psychological interventions. It is suggested that these possible intervention programs should concentrate on concepts such as self-consistency and self-integration of patients. It may also be argued that symptom-oriented treatments are only capable of improving some problems these patients are facing in their everyday life. The present study suggests that "self-focused" intervention approaches could deliver higher stable efficiency.

## **Conclusion**

The present study attempted to investigate Iranian MS patients' worries and concern by analyzing the data obtained through in-depth interviews. We conclude that MS patients authentic worries are rooted in ontological issues related to existence, existential causes and anxieties. These worries contribute to a set of concerns across different aspects of life. The major concerns of these patients are over job prospects, education, and relationships with significant others as well as worrying over the unpredictability of the illness. The latter is of particular importance since it seems to influence the patient's life as a whole and resulting in low self-concept, causing self-disintegration and loss of meaning in life.

## **Practical Implications**

The results of the present study provide valuable information about how MS patients experience their illness and their main worries and concern. This is not only useful to patients

themselves but also to their families and carers as well as doctors, medical staff, psychologists, nurses and social workers working with MS patients. The results reiterate the need for better and more detailed insight into MS patients' needs and psychological problems. Psychotherapists in particular could try and formulate their approach on a more existential perspective in order to help MS patients live a fuller life and overcome some of the problems they face as result of living with this illness. The implications of our findings are also important since they highlight the need to concentrate on patients' families and significant others, as relationship with others was a major concern of the patients in our study. It is suggested that this could be done with three main aims in mind: (1) Empowering and educating families about how to manage the likely domestic conflicts to minimize the stress; (2) Managing crisis and stress experienced by those looking after the patient; and (3) Providing education about the illness, medical procedures, and interaction with the patient. Furthermore, as the patients, in the course of their lives, face new, unknown, and unpredictable symptoms that could affect their quality of life, it is suggested that MS patients should remain in controlled programs whereby they may be constantly monitored and followed up.

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