Coping with Disease in Multiple Sclerosis Patients: A Concept Analysis

Ali Dehghani

Abstract:
Background and Objective: Coping with disease can lead to disease recovery and improve quality of life in people living with multiple sclerosis; therefore, correct definition of this concept is essential. Different dimensions of coping have been emphasized in various studies. This study was aimed to define, clarify and analyzing its concept in people with multiple sclerosis.

Materials and Methods: In this study, analysis was conducted using the hybrid model in three phases. In the theoretical phase, literature on coping with MS was reviewed until 2016. In the field work phase, in-depth interviews were conducted with 11 people with MS. The conventional content analysis was used in two theoretical and field work phases using Graneheim and Lundman stages. Then, the results of two phases were combined in the final analysis phase.

Results and Discussion: The literature review in the theoretical phase revealed five features of coping: accepting the current situation, Self-regulation, Self-efficacy, Multi-dimensional, complex and dynamic nature and Maintenance of effect balance. In the field work phase, maintenance and development of human interactions were added to the features of the concept. Conclusion: Considering these characteristics is necessary in planning to improve coping and quality of life for people living with MS.

Keywords: Coping, Multiple Sclerosis, Concept analysis, Hybrid model

Introduction
Multiple sclerosis (MS) is a chronic progressive and debilitating disease of the CNS which affects motor and sensory functions. MS is one of the most common chronic neurological diseases in young adults, affecting about one in 1000 people. There are an estimated 1-1 million patients worldwide. The age of onset is early – middle adulthood (mostly 20 to 40 years), and the progress of the disease is unpredictable.

MS produces various degrees of neurological symptoms, cognitive problems, fatigue, and pain. There is currently no cure, and only symptomatic relief is available for people with the disorder. Patients must learn to live with uncertainty of the disease’s progression, symptoms, and psychosocial consequences. Activities of daily living are disrupted, including psychological-social dimensions, emotional balance, self-satisfaction, sense of competency, family functioning and self-efficacy and social interaction that need for coping with them.

People with MS need to cope with unpredictable deteriorating health, uncertain prognosis, changing social and intimate relationships and increasing support needs. In order to effectively manage the disease by patients, their perspective on coping used needs to be understood.

Coping as a concept provides a psychological construct that includes behavioral and cognitive events, permits a prescription for learning by the patient, promotion of disease, and helps to distinguish successful from unsuccessful patients. It appears that patients employ a wide variety of strategies for coping with their disease. Although coping has been seen as an important element in living with MS, little attention has been paid to it. As a result, no clear and precise definition of this phenomenon has been provided.

Despite the importance of this concept, there are multiple definitions of “coping” by nurses and health care providers; this shows that knowledge of coping for the health care providers is not well-developed. Also, one of the most important points that have been mentioned regarding coping with MS is lack of a satisfactory and clear definition of it.

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Hence, presenting a true definition for the concept can be determined in giving care to patients and the manner of caring. In addition to multiple definitions and overlap between the concepts of coping, adjustment, adaptation along with the textual variation in relation to these concepts, the need to explain and clarify concept of coping seems necessary. Coping with disease is a multi-dimensional, context-based concept and influenced by social and cultural factors as well as interpersonal and intrapersonal differences. On the other hand, expressing different dimension about coping in the texts causes ambiguity in the definition and understanding of this concept. Hence clarification of the concept can provide correct definition of concept of coping with disease proportional to the context of living with MS. Using concept analysis can lead to identity-giving and providing meaning to coping, creating transparency as well as increasing an understanding that can provide fundamental knowledge for nurses in helping to caring of MS patients. In addition to, updating the knowledge and clarifying in definition the concepts would be a key of evidence-based operation and can provide a basis for evidence-based care. To clarify and conceptualize the phenomenon of coping with disease by MS patients, we attempted to determine the definition, characteristics and features of coping with disease by MS patients:

1. How is coping defined in MS disease?
2. What are the features of coping with disease by MS patients?

In this study, the hybrid model was used for concept analysis of coping with MS.

**Methods**

In this study, the concept of coping was analyzed using the hybrid model in people living with MS. The hybrid model helps to clarify, identify, analyze and refine concepts in the preliminary phases of developing a theory. The method relies on concept development and is executed through qualitative explorations of a phenomenon. This model consists of three phases: theoretical, field work, and final analysis. In this method, a certain approach is adopted in which the theoretical and experimental methods are merged with each other. Then final development of the concept is attained through induction and comparison so that a form of reduction is formed at the end.

**Theoretical phase**

In this phase, a systematic review was conducted based on the guidelines of York University and Cochrane Collaboration. A protocol was set and implemented including review questions, inclusion and exclusion criteria, search strategy, study selection, data extraction, quality assessment, data synthesis, and plan for dissemination. The databases of PubMed, PROQUEST, OVID, SCOPUS, WEB OF SCIENCE, CINAHL, EBSCO, Med-lib, SID, Mag Iran, Iran doc, Iran Medex and Oxford Dictionary of Medical Terms were searched with a combination of keywords (Coping/Adjustment/Adaptation/Deal with/Manage/ measure/ tool/ scale/ questionnaire/ inventory/ instrument/ and Coping With Multiple Sclerosis or MS) both in Persian and English without time limit until the end of 2015.

Figure 1 shows the process of reviewing and selecting the texts in the theoretical phase. As the figure shows, first duplicated records were removed, then abstracts were assessed for concept-relatedness, and after that, full texts were reviewed for eligibility and relatedness in order to conform to the aim of study. In the initial searching, 1350 articles were obtained. The inclusion and exclusion criteria were applied, and the quality of the articles and texts was assessed. A total of 32 texts in English and Persian met the inclusion criteria and were analyzed. Finally, 19 original research articles, seven review articles, five theses, and a chapter of a book were included in the study. Inclusion criteria: articles and texts published both in English and Persian language were included; an access to the abstracts of studies with qualitative, quantitative, mixed method design was implemented, systematic and integrative review, and peer review of articles were carried out. Definition, properties, and measuring of the concept should be mentioned in the texts. Book reviews and texts in other languages were excluded from the review. We started our search about coping with MS within the literature with the following questions: What is the nature of coping with MS?

How has coping with MS been defined?

How is coping with MS conceptualized?

How is coping with disease measured?

The conventional content analysis method was used to analyze texts according to stages proposed by Graneheim and Lundman. The texts and articles were read line by line for several times to obtain a general understanding. Some parts of text were selected, and the initial codes were extracted. Then, similar codes were classified as sub-categories. The sub-category formed categories together. Figure 1 shows the process of reviewing and selecting the texts in the theoretical phase.
The Field work phase
At the fieldwork phase, in-depth and semi-structured interviews were conducted with 11 people with MS. Each interview lasted between 60 and 110 min. Participants were selected using purposive sampling. Data collection continued until reaching data saturation. Inclusion criteria were (a) having a definite diagnosis of MS, (b) having the desire to participate in the study, and (c) having the ability to express experiences. Further interviews were conducted with the participants, when necessary. All interviews were recorded. In the selection of participants, maximum diversity was considered in terms of age, gender, marital status, education level, disease experience, socio-economic condition and employment status. Location and time of the interviews were selected according to the participants’ preferences, so that one of the interviews was conducted in the researcher’s office in Nursing and Midwifery school (table 1).

Questions guiding the interview at this phase included the following: “What is the meaning of coping with disease?”, “What did you do when faced MS”?, “You think, what can help you for coping with MS”? “Express your experiences about coping with your disease?” “What problems have you had for coping with MS?”

Data Analysis
The data were analyzed using content analysis through conventional method and Graneheim and Lundman model. After each interview, transcriptions were read line by line and paragraph by paragraph for several times to obtain a general understanding. Then, the initial codes were extracted. In the next stage, sub-categories, categories and themes were formed.
Concept Analysis of Coping with Multiple Sclerosis

based on similar extracted codes. Categorization of the first interview began, and following interviews helped to complete primary category. An attempt was made to create the greatest homogeneity within categories and greatest heterogeneity between categories. The data were managed and organized using the MAXQDA software, Ver10.

To provide rigorous and reliable data according to Lincoln and Guba’s criteria16, the researcher spent a long time in the field searching for data, gathering and analyzing the data. Recommendations of associates and other specialized partners in this area were used to determine the categories. Coded interviews were returned to the participants to achieve agreement among the researchers and the participants. In the final analytic phase, the results of previous two phases were combined and confirmed.

Ethical considerations

The study was approved by the ethics committee of Jahrom and Tehran University of medical Science in Iran. Before the data collection, the researchers obtained an oral and written informed consent from the participants to ensure the confidentiality of the data, privacy and voluntary participation.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Gender</th>
<th>Marital Status</th>
<th>Education Level</th>
<th>Disease experience</th>
<th>Job</th>
</tr>
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<td>1</td>
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<td>Female</td>
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<td>PhD student</td>
<td>16</td>
<td>Instructor in university</td>
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<td>2</td>
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<td>Diploma</td>
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<td>Housewife</td>
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<tr>
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<tr>
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<td>11</td>
<td>24</td>
<td>Male</td>
<td>Single</td>
<td>Under diploma</td>
<td>4</td>
<td>Entrepreneur</td>
</tr>
</tbody>
</table>

Results

Phase 1: The Theoretical Phase

In the literature review for concept definition, coping was referred as a process, an attempt for role playing, an abstract concept, and an individual concept16. This concept was first defined by Lazarus,1960 as “Cognitive and behavioral efforts to manage, reduce or tolerate internal or external demands that threaten personal resources”17. According to the Dictionary of comprehensive psychology, coping was defined as using mental and behavioral methods to control the position of an event that is beyond the individual capabilities18.

A functional definition was presented for coping based on the literature review: coping with MS is a dynamic, complex and multi-dimensional concept and has many dimensions including maintenance of emotional balance, self-regulation, and self-efficacy and accepting of current situation (table 2).

In addition to the definition of concept in Table 2, five features of coping with MS appeared in literature review which includes the following: Maintenance of emotional balance: This feature indicates that coping with disease occurs in situations full of stressors which increase physical, mental and emotional burden on patients. In order to coping, patient makes attempt to manage emotional and mental distress and achieve emotional balance19, 20. Dynamic, complex and multi-dimensional nature: coping with disease in these patients is a dynamic, complex and multi-dimensional concept and process influenced by various factors including education, environment and environmental constraints, etc4, 8, 21. Accepting current situation: according to
the literature, acceptance of disease means that a person with MS accepts the disease with all difficulties, complications, and limitations due to constant existence of the disease\textsuperscript{1,22}. 

**Self-regulation**: another feature of coping with disease is continuous effort for maintaining independence along with having disease in different situations and moving towards self-regulation in life. 

**Self-efficacy**: in this feature of coping, patients show their ability and capacity to cope with disease. Patient with MS tries to cope with disease in different aspects through maintaining confidence and situation analyze be able and continue their normal life like other humans\textsuperscript{22,23}.

### Table 2. Definitions of coping observed in the theoretical phase

<table>
<thead>
<tr>
<th>Defining the concept of coping with MS</th>
<th>Measurement</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coping with disease is the process of controlling needs, which is assessed beyond individual sources, including practical and intra psychic attempts to control internal and external needs and conflict between them\textsuperscript{25}.</td>
<td>Ways of Coping Questionnaire (WCQ)</td>
<td>Ahadi et al., 2014</td>
</tr>
<tr>
<td>Coping with disease, is an abstract concept that is capable to stimulate a wide variety of individual perceptions and mental imaging, and it is different from person to person\textsuperscript{6}.</td>
<td>Literature review</td>
<td>Chinn and Kramer, 2011</td>
</tr>
<tr>
<td>Coping depends on personal experiences and includes specific techniques that people use in managing their disease\textsuperscript{13}.</td>
<td>Literature review</td>
<td>Seomun et al., 2006</td>
</tr>
<tr>
<td>Coping with MS is complex, multiply determined, and related to stress and coping factors\textsuperscript{21,26}.</td>
<td>paper-and-pencil measures</td>
<td>Van Der Wende, 2000 Bishop, 2012</td>
</tr>
<tr>
<td>Coping with disease was described as taking great personal effort, appropriate support from friends and family, and would have been made easier with assistance and information from health Professionals\textsuperscript{27}.</td>
<td>semi-structured Interview</td>
<td>Malcomson, 2008</td>
</tr>
<tr>
<td>Coping with disease was defined as the subset of self-regulation processes. Coping with MS points to strategies used to minimize the negative impact of life stressors on mental health\textsuperscript{28}.</td>
<td>Literature review and semi-structured Interview</td>
<td>Ona, 2007</td>
</tr>
<tr>
<td>Coping with MS was defined as the ability to foster a positive outlook on life, continuing to grow and develop in spite of MS\textsuperscript{23}.</td>
<td>Interview semi structure</td>
<td>Irvine et al., 2009</td>
</tr>
<tr>
<td>Coping was defined as a response aimed at diminishing physical, emotional, and psychological burden that is linked to stressful life events and daily hassles\textsuperscript{29}.</td>
<td>Literature review</td>
<td>Koehler, 2009</td>
</tr>
<tr>
<td>Coping with disease, strategies, or responses are the actual things that people think or do to deal with a particular problem that they encounter\textsuperscript{19}.</td>
<td>Literature review</td>
<td>Danovksy, 1994</td>
</tr>
<tr>
<td>Coping is the set of cognitive processes and behaviors that people use in response to stress in order to reduce or manage distressing emotional states\textsuperscript{30}.</td>
<td>COPE Scale</td>
<td>Rabinowitz and Arnett, 2009</td>
</tr>
</tbody>
</table>
Phase 2: The Fieldwork Phase

Features of the concept
Four features of the concept of coping with MS which were obtained at this phase include maintenance and development of human interactions, accepting current situation, self-regulation and self-efficacy.

Maintenance and development of human interactions
One of the features coping with MS is interaction with others. Thus patients cope with disease by maintaining and developing relationships with family and friends, creating new connections with other people and appropriate social interactions with peers. A participant said in this regard:
In Tehran and cities, I am friend with many MS patients. I always go to see them; we celebrate birthdays with each other and say that we always keep our communication open with each other (p6).

Another participant said:
I have maintained my relationships with other people like the past... The disease hasn’t affected my relationships with family and others (p2).

Accepting current situation
Accepting current situation is one of the most important features of coping with MS. The majority of participants expressed that MS is chronic and accompany them throughout life, therefore; they should accept it in order to deal with the situation. A participant in this regard, said:
As I know there is ... (MS) I have to cope with it. I say now: do not put stress and pressure on yourself. I’ve been ill for 16 years. When you know that you are ill, get ignore their, the same way I consoled myself. (p1).

Another participant said:
I’m happy with my condition. I have my job and also when students come to see me, I talk with them about my abilities... (p3).

Self-regulation
One of the features of coping with disease is self-regulation. Patients make attempt to achieve independence in personal life through searching knowledge about MS, adjusting activity and environmental conditions according to disease, focusing on individual empowerment and self-care. A participant in this regard, said:
I have no problem with MS. I go climbing. Now I have more time to get rest. For example, I used to work 8 hours a day. Now I work 6 hours a day, I do not let feel fatigue (p3).

Another participant said:
The research I did, my mind got open to the disease. I knew the disease better... studies were very helpful. (P1).

Phase III: Final analytic phase
The results of the field work phase confirmed the theoretical phase findings. Most categories obtained from texts were repeated in the field work phase. Data analysis in the theoretical and field work phases revealed six features of coping with disease including accepting current situation, Self-regulation, Self-efficacy, Multi-dimensional, complex and dynamic nature, maintenance of effect balance and maintenance and development of human interactions. These findings are presented in Table 3.
Table 3: Comparison of features of coping with MS

<table>
<thead>
<tr>
<th>Final analytic phase</th>
<th>Fieldwork phase</th>
<th>Theoretical phase</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accepting current situation</td>
<td>Accepting current situation</td>
<td>Accepting current situation</td>
</tr>
<tr>
<td>Self-regulation</td>
<td>Self-regulation</td>
<td>Self-regulation</td>
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<tr>
<td>Self-efficacy</td>
<td>Self-efficacy</td>
<td>Self-efficacy</td>
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<tr>
<td>Multi-dimensional, complex and dynamic nature</td>
<td>-</td>
<td>Multi-dimensional, complex and dynamic nature</td>
</tr>
<tr>
<td>Maintenance of effect balance</td>
<td>-</td>
<td>Maintenance of emotional balance</td>
</tr>
<tr>
<td>Maintenance and development of human interactions</td>
<td>Maintenance and development of human interactions</td>
<td>-</td>
</tr>
</tbody>
</table>

Discussion

In this study, concept of coping with MS was analyzed using the hybrid model. Qualitative data were obtained from Persian and Islamic context, as well as confirming the findings of the literature in other countries and some other aspects of the concept was explained. In the analysis, maintenance and development of human interactions feature was added to the five previous features, namely, accepting current situation, self-regulation, self-efficacy, multi-dimensional, complex and dynamic nature and maintenance of effect balance.

In both the theoretical and field work phase, the main feature of coping with MS is accepting current situation. This means that patients, who have accepted their disease, can have a more effective coping with their disease. So that coping with disease is equivalent with acceptance of disease to all the facts relating to it. In Pakenham’s study, one of the seven factors extracted from factor analysis of coping with MS was accepting disease and accepting existing situation. Participants of Dennison et al. study also believed that accepting constant presence of MS in lives is an effective feature of coping with disease. Another feature of coping with disease is self-regulation that was extracted jointly from both the theoretical and field work phases. So that patients attempt to cope through applying the most effective adaptive and management models, using knowledge search and sufficient information about disease to monitor and manage it, planning, trying to return to work and normal activities and maintain favorable living conditions. Steel et al. reported that patients who cope with their disease useda greaterproblem-solving methods and focusing on the management of psychological stress and less relied on emotion-based coping and fantastic approaches.

Other feature of coping with disease is self-efficacy so that people with MS try through maintaining confidence and analyzing the situation in order to cope with disease in different aspects and continue their normal life like other people. Many patients in the study Denison et al. emphasize on the necessity of choosing a positive view, maintaining confidence and the importance of finding realistic ways for coping with disease. Multi-dimensional, complex and dynamic nature is another feature of coping with disease. In the literature and texts frequently mentioned that coping with disease is a concept of dynamic, complex and multi-dimensional from individual, environment and affected by environmental constraints. So that concept of coping was influenced by multiple variables including education, individual, environment and environmental constraints. As well as other feature of coping with disease in this study is maintenance of effect balance. This feature in the literature indicates that coping with disease mainly occurs in stressful situations and full of life stressors which increase physical, mental and emotional burden in patients. Therefore, patients use cognitive and behavioral efforts for coping with disease and try to manage emotional and mental distress caused by the disease and achieve to emotional balance to manage internal and external requirements. Also coping with disease includes efforts to adjust to emotional distress associated with stressful situations.

Maintenance and development of human interactions is another feature of coping with disease in patients with MS. Participants in the literature mentioned that relationship to social network including family, friends, peers, employees and professional organizations is as one of the main features of coping with disease. Maintenance and development of personal and social human interactions means
developing communication with other people and avoiding isolation. Some studies have shown that interpersonal and social interactive relationships have positive impacts on knowledge, confidence, social support, clinical outcomes, behavior, decision-making, and self-care.\textsuperscript{36,37}

**Limitation**

Although this study helped to clarify the concept of coping with MS, it had some limitations as well. Access to all resources via electronic databases was not possible. Using a qualitative approach in the field work phase limited the generalizability of the findings.

**Conclusion**

According to the results, coping with MS means a dynamic, complex and multidimensional concept, with individual aspects and subjective and objective dimensions. This concept indicatesscognitive and behavioral activities that people with MS applied in their daily lives. Concrete effects of coping with MS include accepting current situation, self-regulation, and self-efficacy, maintenance of emotional balance and maintenance and development of human interactions.

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**Conflict of Interest**

None declared.

**Authors' contribution:**

Ali Dehghani: Data gathering and idea owner of this study, Study design, Data gathering, Analysis and interpretation of data, Writing and submitting manuscript. Editing and approval of final draft by an external editor named Dr. Maryam KeramatKar was conducted.

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