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Original Article

Concept analysis of coping with multiple sclerosis

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ABSTRACT

Objective: The concept of coping with disease appears frequently in the literature; however, there is no precise definition of coping. The aim of this study is to clarify coping concept, and to identify its attributes, antecedents, and consequences in patients with multiple sclerosis.

Methods: Rodgers' evolutionary method of concept analysis was used to clarify the concept of coping. A literature review was conducted with key terms 'multiple sclerosis', 'coping', 'adjustment', and 'deal with'. After searching databases, 1370 papers were found for the period 1995–2017. Finally, 55 articles and texts were selected for analysis. Data analysis was carried out using thematic analysis. An independent researcher checked the process to ensure credibility and reduce personal bias.

Results: Coping with multiple sclerosis is a multidimensional concept with three main attributes: maintenance of emotional balance, acceptance of the disease, and self-regulation. Social support, awareness toward the disease, attitude toward the disease, and religious-spiritual beliefs were found as antecedents. Health promotion, adherence to treatment regimen, independence in personal life and social relationships, and improvement of family relationships were found as consequences of these attributes.

Conclusion: These findings not only add to the body of knowledge in health science, but also serve as an important motivation for further theory development and research in this context. Nurses and health professions can also benefit from a deeper understanding of coping concept in providing and planning healthcare for these patients.

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1. Introduction

Multiple sclerosis (MS) is a chronic progressive and debilitating disease of the central nervous system (CNS) which affects motor and sensory functions [1]. It is one of the most common chronic neurological diseases in young adults, affecting about one in 1000 people. MS affects psychological-social dimensions, emotional balance, self-satisfaction, sense of competency and self-efficacy and social interactions in these patients [2]. Furthermore, coping with disease has particular importance in patients with MS, because the disease is unpredictable and has uncertain future. Especially MS is

more common in young people (20–40 years) [3]. The diagnosis of chronic diseases such as MS typically leads to a number of complex problems and emotional and practical difficulties, which result in changing life style. Hence, coping with disease can provide a promising avenue to improve quality of life in these patients [4].

Coping is a situation in which people respond to personal problems in life, crisis existence, or illness. Coping involves both behavioral and cognitive strategies that are used to adapt to difficult situations [5]. This concept was presented by Lazarus in the 1960s who defined coping as 'the cognitive and behavioral efforts made to master, tolerate, or reduce external and internal demands and conflicts among them' [6]. Lazarus and Folkman presented the transactional model in which coping responses are divided into emotion-focused and problem-focused strategies. The problem-focused coping is to actively alter stressful situation and is associated with better coping, while emotion-focused coping is directed

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at regulating response to a stressor [7] and is considered useful in coping with MS [8]. McCabe and McKern reported that all coping strategies are predictors of quality of life and adjustment to MS [9]; however, certain types of coping may lead to better coping [8]. Hence, patients evaluate the stressor (personal outcomes of MS to their lives) through the appraisal process and then select a coping approach that is most effective in reducing or removing stressors.

Coping is necessary in people with chronic disease to deal with disease problems and stressors. Coping with chronic disease has become an important area for research and intervention in health psychology because a large number of individuals suffer from such diseases [4]. Although the necessity of coping in these patients has been emphasized, a few studies have explored how people cope with chronic disease. In addition to, in various studies differently has been defined this concept that these matter need to explain and clarify further the concept for this chronic disease require [10].

There are various definitions of coping with MS in the literature, so that some studies consider the process of coping, and some mentioned coping is an abstract concept. Sometimes it is used to indicate a successful handling of a situation or crisis [5,10]. Although coping has been seen as an important element in chronic diseases such as MS, little research has been conducted in the area. As a result, clear and precise definition of this phenomenon has not been provided. For example, Chen and Tang mentioned that hundreds of studies have been conducted on coping. Unfortunately, the concept of coping is poorly defined, and there is ambiguity and lack of clarity about coping [11]. Seomun et al. reported that coping has clinical utility; however, it is clear that this concept has significant semantic limitations [12]. On the other hand, existing different dimensions about coping with MS in the texts results in ambiguity in the definition and appropriate understanding of this concept [4,13]. Therefore, clarification of the concept along with identifying its attributes, antecedents and consequences can provide correct recognition of the concept of coping with disease in the context of living with MS [3], using the concept analysis can also lead to transparency, identity-giving, and providing meaning to coping with MS. creating transparency and increasing understanding can provide fundamental knowledge for performance and care planning for diseases [10,12].

Rodgers method of evolutionary concept analysis was selected for the present concept analysis because of the emphasis on inductive inquiry and rigorous analysis compared with other methods. From the evolutionary perspective, the main emphasis is laid on heuristic approaches that facilitate the appropriate process for review and further exploration rather than answering the question 'what is the concept?' The evolutionary concept analysis method is based mainly on inductive approach and provides the basis for further research [14]. Rodgers also allows the concept to be viewed within a sociocultural and disciplinary context. Since coping varies based on cultural and social context, and individuals may have different definitions and perceptions in different situations, Rodgers' method could be suitable for analysis [14,15]. The aim of analysis in Rodgers' evolutionary method is to describe and explain the concept and to clarify its attributes, which can be used as the basis for further development of the concept [14]. Hence, the aim of this study is to clarify the concept of coping with MS; gain more understanding; recognize its attributes, antecedents, and consequences in the context of MS disease using Rodgers' evolutionary method.

2. Methods

In this study, Rodgers' evolutionary approach was used for concept analysis. In this approach, six preliminary activities are suggested for the study (Table 1). The six stages indicate activities

that must be conducted during the study, and the process should be considered sequential [14].

After identifying the concept, the most important step is determining the scope and range of literature on the study [14]. In this study, a systematic review was conducted based on York University Guidelines. 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 [16]. Scientific databases of PubMed, PROQUEST, OVID, SCOPUS, WEB OF SCIENCE, CINAHL, EBSCO, Medlib, SID, Mag Iran, Iran doc, and the Oxford Dictionary of Medical Terms were searched using the key terms 'Multiple Sclerosis', 'Coping', 'Adjustment', 'Adaptation', 'Deal with' and 'Coping With Multiple Sclerosis or MS'. Literature published from 1995 until September 2017 was searched for concept analysis, the following inclusion and exclusion criteria were considered for full literature review.

Inclusion criteria: texts 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, features, antecedents and consequences of the concept should be mentioned in the texts. Book reviews and texts in other languages were excluded.

In the initial search, 1370 articles were found. After removing duplicate articles, the figure reduced to 780 articles. Then abstracts of included articles were reviewed and reduced to 275 articles. In the final stage, 55 articles (45 original research article, 5 review articles, 2 dissertation and 3 books) were selected and fully reviewed. Then, an independent researcher checked the process to ensure credibility and reduce personal bias [15,17]. The quality of articles was assessed using the STROBE checklist [18] for quantitative studies and the COREQ checklist [19] for qualitative ones.

Data analysis was carried out using thematic analysis approach, with emphasis on the cultural and temporal context, consistent with Rodgers' evolutionary method [14]. Thus, articles were reviewed line by line and paragraph to paragraph several times to obtain a general understanding. Then, thematic analysis with iterative processes led to codes, sub - categories and categories that were classified into attributes, antecedents, and consequences of coping with MS. This analysis was reviewed by two researchers with experience of this model of concept analysis and familiar with Rodgers' evolutionary approach [14,15].

3. Results

The result of this study led to identification of definition, attributes, antecedents, and consequences of coping with MS (Table 2). In the present study, the concept of coping with MS is defined as a dynamic and multidimensional concept. Its main extracted attributes includes acceptance of the disease, maintaining emotional balance, and self-regulation. Also, social support, awareness toward the disease, attitude toward the disease, and religious-spiritual beliefs were identified as the antecedents of coping. Health promotion) physical, psychological, social and spiritual), adherence to treatment regimen, independence in personal life and social relationships, and improvement of family relationships were found as the consequences of these attributes.

3.1. Attributes

The attributes of coping with MS are described below.

3.1.1. Acceptance of the disease

In coping with MS, acceptance is considered a key variable.

Table 1
Evolutionary concept analysis activities.

- 1 Identify the concept of interest and associated expressions (including surrogate terms).
- 2 Identify and select an appropriate realm (setting and sample) for data collection.
- 3 Collect data relevant to identify
 - A The attributes of the concept; and
 - B The contextual basis of the concept, including interdisciplinary, sociocultural, and temporal (Antecedent and consequences) variations.
- 4 Analyze data regarding the above characteristics of the concept.
- 5 Identify an exemplar of the concept if appropriate.
- 6 Identify implications, hypotheses, and implications for further development of the concept [14].

Table 2
Antecedents, attributes and consequences of coping with multiple sclerosis.

Attributes	Antecedents	Consequences
Acceptance of the disease	Social support	Health promotion) Physical, Psychological, Social and Spiritual)
Maintaining emotional balance	Awareness toward the disease	Adherence to treatment regimen
Self – regulation	Attitude toward the disease	Independence in personal life and social relationships
	Religious - spiritual beliefs	Improvement of family relationships

When individuals accept the disease, it is assumed that they adjust to life goals towards more achievable goals through integrating with difficult life events [20,21]. Acceptance is described as 'a central concept in an accommodative coping strategy' and is indispensable in adjusting to life goals as a response to an unchangeable event [22]. Chronic diseases such as MS are seen as life events, which upset a person's emotional balance, and acceptance is crucial establishing a new balance. Also acceptance positively predicts physical functioning and mental well-being in cardiac patients [23], whereas helplessness has a negative influence [24].

Hwang et al. reported that accepting the diagnosis of MS and taking action to maintain health and positive outlook are essential for regaining a sense of well-being [25]. Positive acceptance of disease predicts physical activity and mental health of the individual; while, not accepting of disease has an adverse effect [23]. Studies found that patients who accept their disability and illness are more likely to be accepted by the community. These studies also confirm that such patients have a higher self-esteem and greater satisfaction with lives [22,26]. Perspective of participants in qualitative studies including Krouse et al. (2009) and Fournier et al. (2002), showed that acceptance of disease is the final product of coping and is considered as coping by many of participants [24,27].

3.1.2. Maintenance of emotional balance

In the literature, coping with disease is defined as maintenance of emotional balance [28–30]. This attribute in the literature indicates that coping with disease mainly manifested in stressful situations and overflowed from life stressors. This stressful causes increase physical, psychological and emotional burden on the patient [31]. Therefore, patient tries to use cognitive and behavioral efforts for managing the distress and acquired emotional balance [32]. Joachim et al. (2016) believes that coping is the process of controlling needs, which is assessed beyond individual sources, including practical and intra psychic attempts to emotional regulation, control internal and external needs and the conflict between them [33]. Ahadi et al. also mentioned coping with disease is process of needs control and emotional regulation [34]. According to Bianchi et al. study, coping may be defined as the result of a stress appraisal process with the purpose of managing psychological stress and balance maintenance in emotion [31].

3.1.3. Self – regulation

Self-regulation is another attribute of coping with MS that was repeatedly found in literature [27,30]. Self-regulation describes patient's efforts to regulate one's feelings and actions in the state of

disease. Overall, people with a higher sense of self-regulation over their lives adjust better to MS [35]. In other words, the content and skills of MS management are derived through the process of being self-regulated. The elements of self-regulation in this study include information seeking, planning, effort for symptoms management and etc. Many studies have emphasized on the ability of self-regulation as central in achieving desired outcomes [30,35]. Tolijamo et al. reported that using self-care and self-regulation behaviors in patients with chronic illness has great importance, and it is affect in comfort, functional ability and the process of their illness [36]. Also, Faircloth et al. found that searching information about the disease, self-regulation behaviors, and how to overcome psychological symptoms affect quality of life in these patients. Indeed, coping is a set of cognitive processes and behaviors that individuals use to respond to stress in order to reduce or manage emotional distressing situations that is known as a self-regulation behavior [37]. In the other words, coping should be considered as a subset of self-regulatory processes [32].

3.2. Antecedents

The next iterative process of the evolutionary conceptual analysis cycle is an examination of the antecedents and consequences of the concept [14]. The antecedents of coping with MS that are frequently reported in the literature include social support, awareness toward the disease, attitude toward the disease, and religious - spiritual beliefs.

Social support plays an important role in coping with chronic disease. A number of studies have shown social support to be related to better disease outcomes and psychological coping in a variety of disease [38,39]. Some studies have shown that social support has been related to better metabolic control in patients with diabetes, breast cancer, kidney failure, and heart disease [40] [41]. Social and family support has consistently appeared in the literature of rehabilitation and adjustment to disability [42] and has been identified a salient factor in coping with MS [43,44]. Wineman previously suggested that an individual's perception of uncertainty and social support may contribute to coping with MS, regardless of functional ability [45].

Supportive systems including family, spouse, friends, peer patients, staff and related professional organizations can reduce the adverse effects of chronic illness and help patients for better coping with disease [46]. Most participants in Hwang et al. study agreed that support from family and friends helped them adjust to the diagnosis, maintain their health, and participate in productive and

social activities [25]. The results of study by Krukakovova et al. (2008) showed that better emotional, psychological and social support from family and friends has a direct correlation with improvement of mental health and coping with MS. They confirmed that individuals with MS can help each other maintain their health by exchanging information for coping with the disease-related conditions [46]. While a survey of American black women with cancer, who did not receive adequate social support showed that they did not cope with disease [47]. according to some studies, social support from peers and professional organizations like MS society is an effective source of adapting to stressful experiences [39].

Another antecedents of coping with MS is having awareness and knowledge about MS. Acquiring knowledge and information about the disease and its therapeutic dimensions result in decreasing patient's fear gradually and better adaptation to conditions [48]. Langdon et al. found that awareness of patients and society about the disease and its problems is effective in coping with disease. The study also showed that using effective information resources by MS patients in relation to the nature and problems of the disease is effective in their coping with the disease [49].

Positive or negative attitude toward the disease was effective in coping with disease. Only those with a firm perception of 'personal Attitude' are able to maintain self-esteem [30]. Beliefs and attitudes that persons with MS have about the disease have been reported as having a significant role in coping, even when the effects of the severity of the disease are taken into account [50]. The results of Fraser et al. showed that patients with relapsing-remitting MS form have a more positive attitude towards the disease control and their duties than progressive forms of MS [51]. Irvine et al. argue that attitude that a person with MS has about their disease plays a significant role in coping with MS [44].

Many studies have emphasized on the positive role of religion, spirituality and the hope of God power in coping with disease [52–54]. The results of Fooladi et al. about chronic diseases showed that spiritual beliefs are not only effective in coping with disease, but also play an important role in patients' lifestyles [54]. Also, the results of the study by Ai et al. showed people who use religious coping in their daily lives, have less depression and anxiety and get faster recovery [55].

3.3. Consequences

Coping with MS was positively related to positive outcomes. The consequences of coping with MS that are frequently reported in the literature include health promotion, adherence to treatment regimen, independence in personal life and social relationships, improvement of family relationships.

Coping with MS is associated with a better health quality of life, both physical health related quality of life (PHQL) and mental health related quality of life (MHQL). So that, better coping with disease is associated with better perception of health [56]. The results of Hoppe et al. showed that coping is considered essential in improving quality of life, which is an important outcome in the care of patients with chronic kidney disease (CKD). Also, results of this research showed that a poor health related quality of life (HQL) significantly correlates with less coping and increased risks of mortality in end-stage CKD patients, irrespective of kidney function [22]. On the other hand, depression and low HQL in chronic diseases are related to the absence of appropriate coping behavior. Therefore, it is important to focus on adequate coping strategies in this population [35]. Sherwood et al. reported that training of coping skills improved quality of life in patients with Heart Failure [57,58]. Therefore, improving coping skills is emerging as an important aspect of clinical management of chronic diseases such

as MS that can reduce the disease burden and may improve clinical outcomes in this vulnerable population of patients [58].

Coping with MS led to improved adherence to treatment regimen, independence in personal life and social and family relationships. Effective coping with chronic disease require significant behavioral change such as improvement in social and family relationships. Avoiding and reducing presence in among family members and society in MS patients is such that they require long-term training courses [39]. On the other hand, involvement with disease at a young age and uncertainty about future of patients tend to be isolated and depressed. Therefore, using coping strategies can be achieved to importance outcomes and in this way, social and family relationships in these patients improved for a better quality of life [59].

Patients' adherence to treatment regimen is critical for achieving improved health outcomes, quality of life, and cost-effective health care [60]. The World Health Organization review of adherence behaviors noted that "increasing adherence affects health more than improvement in specific medical therapy". Non-adherence to treatment remains a challenge for the medical professions and chronic disease management [61]. Many studies showed coping with disease leads to improvement of personal life plans, self-esteem, and employment of patients [35,62]. However, lack of coping with disease over the long term leads to an accumulation of disabilities in the patient; therefore, patients increasingly rely on family, friends and rehabilitation professionals [30].

3.4. Surrogate terms

Surrogate terms are means of expressing concepts that differ from the expression that the researcher is focusing on (Rodgers, 2000a). During the analysis process, it was found that the concept of coping can be substituted with terms such as deal with [5,7] and dealing [5,63].

3.5. Related concepts

Related concepts bear some relationship to the concept being analyzed, but they do not have the same precise set of attributes (Rodgers 2000a). The following concepts related to coping were identified in this process: adaptation [25,27] and adjustment [44,64].

4. Discussion

The aim of the analysis was to investigate coping with MS with emphasis on identification of attributes, antecedent and consequences of concept. This analysis showed that coping with MS is a multi – dimension and dynamic concept. Rabinowitz (2009) reported that coping is a dynamic process that changes and develops over the course of a stressful transaction rather than a stable style [13]. Bishop et al. (2012) mentioned coping with MS is a multi-dimension concept and indicates individual's response to psychological, social, and functional changes [38]. This result indicates that coping with MS varies over time, and it depends on various factors such as individual, interpersonal, context, cultural agents, and etc. Therefore, coping with MS is different in patients and from person to person.

The result of this study led to discovery of attributes of coping with MS. This attributes can be used for care interventions in patients with MS. Some of identified attributes in this analysis matched closely to those identified by pakenham (2001), who undertook a similar investigation with patients affected by MS [28]. This demonstrates the need for research corroboration using further studies in this context. One of the main attributes of coping

with MS was acceptance of disease. Acceptance of MS emerged as the strongest predictor of coping with MS and distress [31]. Other researchers have also found that acceptance is inversely related to distress and positively related to positive outcomes. Also, they reported that acceptance was most strongly and consistently related to better adjustment [28,58]. Similarly, Bianchi et al. found acceptance of MS is predictive of better self-concept seven years later [31]. Arnett et al. reported that lack of acceptance of disease may put patients at risk of increased depressed mood [65]. Also, Pakenham (2006) reported that acceptance was positively related to life satisfaction and benefits in MS disease [66]. This finding shows that patients for coping with disease should accept their illness with all its strengths and weaknesses. After accepting the disease, they can cope with their illness.

Other attributes identified in this analysis including maintaining emotional balance and self – regulation. Few studies have addressed these attributes of coping in these patients. In some studies, there are other dimensions such as tolerance or adjustment to negative events and realities, preserving a reasonable emotional balance and etc. [63]. Results of the Pakenham's study (2006) indicate that personal health control was related to positive coping. Also, this study showed that personal health control and self-regulation was positively related to benefits about MS disease [66]. Also, Steel et al. expressed patients who cope with their disease are trying in life more rely on problem-solving strategies, psychological stress management and self – regulation in different dimensions of life [67]. These findings could be consistent with dimensions gained in the current study. These dimensions indicate that individuals are able to regulate their living conditions and environment independently. Therefore, MS patients manage psychological and emotional distress and achieve an emotional balance to coping with their disease.

Other prominent findings in this study was the discovery of antecedents and consequences of coping with MS that play an important role in education, healthcare planning, interventions, progress of treatment process, and etc. This review of the literature reveals many stresses and challenges encountered by MS patients. Therefore, in addition discovery attributes should be effective factors on coping with disease (antecedents) and also outcomes of coping identified until to recognition all aspects of disease, can to take an effective step in the recovery process of patients.

One of the main antecedents of coping with MS was social support. These supportive systems can be provided by the family, spouse, friends, peers, and health professionals and organizations that help patients in coping with disease. Lode et al. (2010) reported that social support is predictor of better quality of life [8]. Also, in many studies, relationships with others, family and friends, and in some cases communication with higher powers like God, mentioned a great strength in coping with disease [40,41]. Other antecedents include awareness toward the disease, attitude toward the disease, and religious - spiritual beliefs. On the other hand, coping with disease can lead to positive outcomes. These outcomes play important roles in improving quality of life in patients. One of the outcomes of coping with MS was health promotion in different dimensions (physical, psychological, social and spiritual). So that coping with disease regulates distress in MS patients and also improves health in MS patients. Thus, coping with MS leads to individual health control, expression of emotions and recovery in physical symptoms of disease. Other studies have also found coping with chronic disease is strongly related to positive outcomes such as health promotion and better quality of life [56,57]. Also, adherence to treatment regimen, independence in personal life and social relationships, and improvement of family relationships are the consequences of coping with MS.

Duo to the complex nature of coping with disease, it has

different definitions in the literature. The philosophical foundation of Rodgers' evolutionary method places emphasis on concept analysis as a basis for further inquiry and concept development rather than as an end point [15]. According to our findings, the following definition is suggested for coping with MS: coping with disease in MS patients is a dynamic and multi-dimensional concept with dimensions of maintaining emotional balance, acceptance of the disease and self-regulation. This concept has emerged in the context of social support, awareness toward the disease, attitude toward the disease, religious-spiritual beliefs so that coping with disease leads to positive outcomes including health promotion (Physical, Psychological, Social and Spiritual), adherence to treatment regimen, independence in personal life and social relationships and improve of family relationships in the patient.

This concept analysis was done only using literature review. The researcher hopes that this concept could be investigated and analyzed in the future from the viewpoints of caregivers, patients and their families using qualitative approaches.

5. Limitation

Although the concept of coping with MS was clarified in this study, it had some limitations. It was not possible to have access to all resources through database. Using texts in Farsi and English was another limitation of this study.

6. Conclusion

The findings of this study explored attributes, antecedents, and consequences of coping with multiple sclerosis and described coping as a complex, multi-dimensional, and dynamic concept. These findings not only add to the body of knowledge, but also serve as an important motivation for further theory development and research in this context. Therefore, awareness of these attributes, antecedents, and consequences of coping with disease can promote significance, using, and application of this concept in chronic diseases such as multiple sclerosis.

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Conflicts of interest

None declared.

Appendix A. Supplementary data

Supplementary data related to this article can be found at <https://doi.org/10.1016/j.ijnss.2018.04.009>.

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