



A study of stigma among Iranian family caregivers of patients with multiple sclerosis: A descriptive explorative qualitative study



Reza Masoudi ^a, Fereydoon Khayeri ^{b,c,*}, Leili Rabiei ^d, Kourosh Zarea ^e

^a Community-oriented Nursing and Midwifery Research Center, Shahrekord University of Medical Sciences, Shahrekord, Iran

^b Faculty of Nursing and Midwifery, Iran University of Medical Sciences, Tehran, Iran

^c Brain and Spinal Cord Injury Research Center, Neuroscience institute, Tehran University of Medical Sciences, Tehran, Iran

^d Department of Health Education and Promotion, School of Health, Shahrekord University of Medical Sciences, Shahrekord, Iran

^e Nursing Care Research Center in Chronic Diseases, Ahvaz Jundishapur University of Medical Sciences, Ahvaz, Iran

ARTICLE INFO

Article history:

Received 15 June 2015

Revised 25 May 2016

Accepted 19 November 2016

Available online xxxx

Keywords:

Family caregivers

Stigma

Multiple sclerosis

Qualitative study

Iran

ABSTRACT

Aim: This study was done to investigate the experiences of family caregivers of people with multiple sclerosis (MS) about stigmatization in Iranian health care context.

Background: Stigmatization has been observed obviously among patients with MS but few studies have been conducted on stigma among the family caregivers of these patients.

Methods: This qualitative study with thematic analysis was done to explore this issue. Fourteen family caregivers of patients with MS were selected by purposive sampling. The data were collected through in-depth and unstructured interviews.

Results: Four main subthemes emerged from the analysis of the transcripts: “feeling shame”, “fear of being ridiculed by others”, “ignored by family” and “concealing disease to be secure against the perceptions of disease”.

Conclusions: Healthcare professionals should be encouraged to inform caregivers about social engagement strategies and to train them on the management of stigma as an important factor for the reduction of their social problems.

© 2016 Elsevier Inc. All rights reserved.

1. Introduction

Multiple sclerosis (MS) is one of the most prevalent acute demyelinating inflammatory nervous system diseases which has involved many young adults. MS prevalence varies from 60 to 200 per 100,000 people in the United States (Lublin & Miller, 2008). Iran is considered a region of moderate prevalence of MS with 50,000 people affected (Saadatnia, Etemadifar, & Maghzi, 2007). The clinical progression of this disease may cause permanent debilitating, unclear and unpredictable complications which may lead to disorders in most dimensions of life, including emotional or behavioral functioning (Molina, Choi, Cella, & Rao, 2012). As MS progresses, the patients become functionally more and more dependent and unable to do their daily activities. Hence, they need to be cared for mostly by their families in the long term. Because the caring activities of family caregivers happen mainly in homes, most of these caregivers are ignored (Navab, Negarandeh, Peyrovi, & Navab, 2013; Masoudi, Sharifi Faradonbeh, Mobasheri, & Moghadasi, 2013). Due to the exhausting nature of MS and biological, social and psychological

demands of the MS patients, the caregivers may endure high levels of ambiguity and face many challenges) (Khayeri, Rabiei, Shamsalinia, & Masoudi, 2016; Masoudi, Abedi, Abedi, & Mohammadianejad, 2015).

Two main features of Iranian culture which are also flourished by social expectations are amity and strong family relationships. Most Iranians tend to keep warm and sincere relationships with their family and to care for a sick family member stringently. Nowadays, it is obvious that the emphasis on MS patients care is moving from patient-centered approaches to a combined patient- and caregiver-centered ones because these factors are essential to the long-term caring for MS patients (Benito-León et al., 2011). Consequently, nursing a sick family member is a highly worthwhile and admirable act, chiefly among the Shias, such as Iranians. In this study, any prejudice about a person can influence both the patients and their family members (Navab et al., 2013).

MS can be considered both a medical event, with clinical and personal features, and a social event, with a scope beyond the patient's limitations (Grytten & Måseide, 2006). In Grytten and Maseide study, because of the unpredictability and progressively worsening conditions of nervous system in MS patients, these conditions are much more obvious throughout caring process in MS patients than in patients with other neurological disorders (Grytten & Måseide, 2005).

Most of studies have emphasized the psychological effects of MS on the caregivers. The results show that nursing a person with MS can have

* Corresponding author.

E-mail addresses: masoodi@skums.ac.ir (R. Masoudi), khayeri.f@iums.ac.ir (F. Khayeri), Leila_Rabiei@yahoo.com (L. Rabiei), zare_k@ajums.ac.ir (K. Zarea).

some adverse effects on the mental health of the caregiver (Bogosian, Moss-Morris, Yardley, & Dennison, 2009).

Many improvements have been achieved in medical care to increase survival rate. However, family caregivers are more likely to offer stricter care to the patients. The prevalence of emotional problems, such as stigmatization, is higher among the main family caregivers than other family members. Indeed, MS patients' family caregivers experience various degrees of psychosocial burden and stigmatization (Abendroth, Lutz, & Young, 2012).

Stigmatization is defined as a procedure in which people detect the unhealthy persons by assigning stereotypes to them inappropriately. The studies on stigma have mainly emphasized patient cooperation methods and the convenience of care. Besides that, scientific knowledge about stigma has focused mainly on supporting patient and family and preventing discrimination (Grytten & Måseide, 2006).

Goffman (1963) considered stigma a determining factor, which was defined mainly as experiences of being treated disrespectfully in specific social interchanges. He found that stigmatized people are ignored and forejudged. These conditions were likely to transfer from the stigmatized person to his or her close relatives (Goffman, 1963).

In a study by Werner et al. that explored the subjective experiences of family stigma reported by the children of patients with Alzheimer's disease, family stigma was one of the disfavored features of nursing a family member with neurological malfunction. They mentioned that family stigma was first experienced in three forms—lay public stigma, stigma of caregivers and structural stigma (Werner, Goldstein, & Buchbinder, 2010).

Stigma is a detrimental phenomenon for family because it limits the available social support and results in the seclusion of the stigmatized person (Navab et al., 2013). Family stigma was coined to refer to the stigma experienced by the close family caregivers of a stigmatized person. Family stigma damages the identity of family members because they are discriminated despite having normal characteristics (Navab et al., 2013). According to Grytten and Måseide (2006), depending on the intensity of the disease, patients with MS experience various dimensions of social distance and ignorance. They reported certain experiences such as being rejected or, in opposite, being paid too much attention in social dealings (Grytten & Måseide, 2006).

In Iran, MS can aggravate the vicious circle of the illness and negative social reactions, and lead to social exclusion and discrimination of both patients and family caregivers. Certain characteristics of MS (e.g. imbalance, tremors and debilitating symptoms) may be visible to others, resulting in stigmatization in social interactions and emotional, cognitive and physical disabilities (Grytten & Måseide, 2005).

When stigma and MS occur concurrently, MS may result in weaker self-care outcomes. Theorists have expressed some terms and features to define stigma's effects, including internalized stigma and enacted stigma. Momentous societal misunderstanding is a significant factor in the studies conducted on the populations of patients with neurological diseases. MS may cause different degrees of weakness and result in differences in the recurrence of stigmatizing incidents due to neurological malfunctions (Navab et al., 2013).

Molina et al. believes that when the negative viewpoints of the public affect people with degraded conditions, internalized stigma occurs (Corrigan & Penn, 1999; Corrigan & Watson, 2002). They may therefore experience various detrimental consequences (Corrigan, Watson, & Barr, 2006). Self-differentiation, manifested as self-demotion, has many detrimental effects resulting in the reduction in healthcare services use and poor quality of life and health outcomes (Fung, Tsang, & Chan, 2010; Rüşch et al., 2009). Major examples of these negative consequences are low self-confidence, low self-esteem and poor self-efficacy, which have been associated with loss of life management opportunities (Molina et al., 2012).

Regarding the disadvantages of being ignored and enacted stigma, the family caregivers of patients with less visible symptoms are not willing to reveal their patients' conditions even in medical settings (Molina et al., 2012).

In addition, studies have less frequently investigated stigma among the family caregivers of patients with MS, and no study has yet investigated this issue in Iran. Ghanean, Nojomi, and Jacobsson (2011) studied the stigmatization of people with emotional problems in Iran and reported 72% of these people were ignored, and thus isolated from society because of the negative attitudes toward mental disorders (Ghanean et al., 2011; Zarea, Nikbakht-Nasrabadi, Abbaszadeh, & Mohammadpour, 2012). Because most studies have focused on the patients and have not considered family caregivers, it is necessary to explore the experiences of the caregivers of MS patients about stigmatization. Therefore, the aim of this study is to investigate the experiences of family caregivers of people with MS about stigmatization in Iran health care context.

2. Methods

The study was conducted according to a qualitative and descriptive explorative method to explore the perspectives of the family caregivers of people with MS about stigmatization in Iran. For this purpose, a thematic analysis approach was adopted.

2.1. Participants and enrollment

The study was conducted from February 2012 to March 2013 in Shahrekord, Iran. The participants were 14 family caregivers that were selected purposively. When there is little information about a specific subject, unstructured interview can be helpful and the most well recognized fit for qualitative research studies (Kazemi, Nasrabadi, Hasanpour, Hassankhani, & Mills, 2011).

2.2. Data collection

Data gathering techniques in this study were observation and in-depth, unstructured interview. The interviews were conducted in Persian, and started with the core question: "Please explain about caring for a patient with MS." They asked the respondent to express their life experiences by their own explanation. In the case of indefiniteness, more detailed questions such as "What do you mean by ...?", "Please give an example?" and "Would you please think over on your explanation?" were asked. All the interviews were conducted in a calm and private environment, such as neurology department, Shahrekord, MS Society, or a neurologist office. The interviews were digitally recorded with an MP3 player and their duration varied from 45 to 100 min depending on the mental and physical conditions of the participants and their tolerance. In order to gather the data precisely, in addition to the recording of the interviews, field-note taking was conducted.

2.3. Data analysis

The data were analyzed based on the topics to determine the standards within the transcripts (Kazemi et al., 2011). After the first interview, data collection and elaboration were done simultaneously. The interviews were translated and written in Persian language verbatim by first author and then were analyzed. By means of the data collection and constant comparative analysis, the researcher will be able to ask more detailed questions in the next phase (Birks & Mills, 2011; Strauss & Corbin, 2008). At first, the researcher read and compared the transcripts with the recorded interviews to ensure the correct transcription of the respondents' replies. Then, they encoded the transcripts separately. Next, emerging codes were compared with previous codes using constant comparative analysis to examine the similarities or differences (Strauss & Corbin, 2008). Finally, after conducting 23 interviews, the codes lists were merged into themes until and the themes were saturated.

Download English Version:

<https://daneshyari.com/en/article/5567423>

Download Persian Version:

<https://daneshyari.com/article/5567423>

[Daneshyari.com](https://daneshyari.com)