

# Impact of Ménière's Disease on Significant Others' Health and Lives

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## Abstract

**Background:** Ménière's disease (MD) is a chronic and, in part, intermittent illness that poses multiple challenges for both the physical and psychological well-being of patients, as well as on those around them. The patients face psychosocial consequences, which include disruptions to life goals, employment, income, relationships, leisure activities, and daily living activities that also influence their family members and friends. However, there is a limited understanding of the impact of MD on significant others (SOs).

**Purpose:** The current study was aimed at identifying how the SOs of patients with MD respond to different aspects of the impact of the disorder on health and life (i.e., psychological aspects, activities, participation, and positive aspects).

**Research Design:** The study employed a cross-sectional survey design.

**Study Sample:** The study sample was 186 SOs of patients with MD who were recruited through Finnish Ménière's Federation.

**Data Collection and Analysis:** Participants completed a 25-item structured questionnaire focusing on different aspects of the impact of the disorder on health and life, and also provided some demographic information. Data were analyzed using Kruskal–Wallis test, Pearson's correlation, and *K*-means cluster analysis techniques.

**Results:** Examination of response patterns suggests that the disorder had, on average, a marginal effect on SOs' psychological aspects, activities, and participation as the SOs generally focused on complaints. Interestingly, SOs reported some positive consequences as a result of their partners' condition. The results show a limited association between SOs' demographic variables and response patterns. The Pearson's correlation suggested a strong association between the subscales psychological aspects, activity limitations, and participation restrictions. Also, a weak negative correlation was observed among positive aspects and participation restrictions. The cluster analysis resulted in three clusters, namely, (1) "non-engaged," (2) "supportive," and (3) "concerned."

**Conclusions:** The current study results identify that the SOs' reaction to patients' condition varies and this may be from coping with victimization. Although the impact of MD on SOs is limited, some of the SOs may have more severe consequences and may require rehabilitation. The information gathered about SOs' coping and adjustment in this study can also help while developing management and/or rehabilitation plan for people with MD.

**Key Words:** coping, Ménière's disorder, rehabilitation, significant others, third party disability

**Abbreviations:** FMF = Finnish Ménière's Federation; ICF = International Classification of Functioning, Disability and Health; MD = Ménière's disease; SOs = Significant others

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## INTRODUCTION

The Center for Disease Control defines chronic illness as prolonged in duration, not resolving spontaneously, and rarely cured completely (Goodman et al, 2013). Ménière's disease (MD) is a chronic and, in part, intermittent illness that poses multiple challenges for both the physical and psychological well-being of patients, and also on those around them. The patients face psychosocial consequences including disruptions to life goals, employment, income, relationships, leisure activities, and daily living activities that also influence their family and friends (Stephens et al, 2010; Tyrrell et al, 2015). The empirical literature attests to elevated rates of depression and distress (Stephens, 1975), increased anxiety (Levo et al, 2010), low subjective well-being and quality of life (Söderman et al, 2002; Levo et al, 2012), and reduced social roles (Yardley et al, 2003; Pyykkö et al, 2015a). However, in most disease conditions, the analysis is focused on mood and psychological aspects and relationship difficulties of the patient, whereas the impact on significant others (SOs) is often neglected. Such effects of chronic conditions on SOs are considered as a third party disability (World Health Organization, 2001).

Managing a chronic illness affects not only ill individuals but also their partners and the relationships of these individuals as well (Acitelli and Badr, 2005; Bodenmann, 2005; Berg and Upchurch, 2007). Checton et al (2015) reviewed on how couples cope with the stresses associated with managing a chronic illness known variously as relationship-focused coping (Coyne et al, 1990), social coping (Lyons et al, 1998; Afifi et al, 2006), internal communication (Acitelli and Badr, 2005; Rohrbaugh et al, 2008), and dyadic coping (Berg and Upchurch, 2007). Yet couples may experience the impact of one partner's illness differently in their relationships (Checton et al, 2015) as numerous factors influence both patients' and partners' appraisals of managing chronic illness. Although the terms are often used interchangeably in the literature, Checton et al (2015) defined the term "dyadic coping" to refer to a variety of ways that couples potentially interact (e.g., uninvolved, support, collaboration, protective buffering, and active engagement) as they manage stressors. Social support (e.g., emotional, instrumental, and communicative) is one aspect of dyadic coping and is a salient feature of managing the day-to-day stresses associated with chronic illness (e.g., Goldsmith, 2004; 2009). Some researchers have also explored the quality of life of the SOs in these conditions. Ostlund et al (2010) reported that in relationships, mood and psychosocial responses were widely scattered from depression to improved strength of the mental health of the SOs. In traumatic brain injuries, Dawson et al (2006) reported that SOs increased their emotional coping significantly after the incident; therefore, they concluded that addressing pain,

depression, and coping in rehabilitation programs may have a positive impact on various outcomes of the patients. Despite this, there has been only limited number of studies focusing solely on impact of MD on the SOs (Stephens et al, 2012; Manchaiah et al, 2013; Pyykkö et al, 2015b).

In a previous study, we reported that SOs of individuals with MD had different views on the patient's condition (Stephens et al, 2012). The data were collected using two simple open-ended questions: (a) "Please make a list of the effects of the disease on YOUR life. List as many as you can" and (b) "Please make a list of any positive effects that the disease has had on YOUR life. List as many as you can." The responses were classified by using the World Health Organization—International Classification of Functioning, Disability and Health (ICF) (World Health Organization, 2001). The responses fell into three broad categories: described effects on the SOs (67%), described effects on the patient with MD (28%), and described positive experiences on SOs (5%). The SOs' responses were mainly concerned effects on their lives and lifestyle—participation restrictions (i.e., effects on personal and community life)—and on personal contextual factors (i.e., uncertainty of life). In contrast, they fail to list such effects of the patients with MD, focusing rather on the patients' symptoms, which suggest that the SOs may regard the patient's restrictions in MD as being impairments only. We observed that a part of the SOs may interpret the patient's situation as a voluntary relinquishment from activities, hobbies, and previous lifestyles. In the successive study, the responses of SOs to open questions were classified into different reactions and conditions (Pyykkö et al, 2015b). The most prevalent were those related to communication problems for the SOs themselves and hearing complaints for the patients. These problems led to restrictions for SOs and caused limitations in their lifestyles. In addition, responses related to psychosocial problems and dependence were also frequently reported. Of the psychosocial problems, the most commonly reported was "frustration" together with "feeling sorry for the patient" (Pyykkö et al, 2015b). Interestingly, SOs of patients with MD have also reported positive experiences as a result of their partners' condition (Manchaiah et al, 2013). The predominant positive experiences concerned improved relationships, acceptance and positive attitude, perspectives on MD, treatment-related benefits, and information and support received.

Differential illness experiences between patients and partners are worth exploring so as to develop effective strategies for supporting SOs, especially in terms of variables over which they have control (e.g., support perceptions, patterns, and practices) versus those they cannot control (i.e., the chronic illness) (Checton et al, 2015). The attitude of SOs is a key player in the rehabilitation process, and the SOs should know their

important role in the enablement. The patients may become dependent on such SOs, which will result in an even greater impact on the latter. We hypothesized that perceptions of partner support will positively influence perceptions of managing a chronic health condition (i.e., coping and adjustment). We believe that this understanding will help in developing strong support systems for patients with MD and for their SOs.

It is important to note that all the three previous studies used open-ended questions to explore the limitations, restrictions, and positive experiences of SOs of individuals with MD as a result of their partner's condition (Stephens et al, 2012; Manchaiah et al, 2013; Pyykkö et al, 2015b). Our studies indicate that only a limited number (i.e., 40–45%) of people with the disease and their SOs respond to open-ended questionnaires (Stephens et al, 2004), whereas a significantly higher percentage (i.e., more than 90%) of individuals respond to structured questionnaires (Stephens and Kerr, 2003). Hence, the current study was aimed at identifying how the SOs of patients with MD respond to different aspects of the impact of the disorder on their health and life (i.e., psychological aspects, activities, participation, and positive aspects) using a structured questionnaire.

## METHODS

The study involved a cross-sectional survey design and was conducted in collaboration with the Finnish Ménière's Federation (FMF). Under Finnish law, this type of survey study conducted with a patient organization does not require ethical approval; however, we complied with the ethical guidelines of our institutions and also of the funding agency.

### Data Collection and Participants

Members of the FMF who had taken part in our previous study (Stephens et al, 2010) and who had an e-mail address were contacted and encouraged to ask their SOs to respond to an Internet-based questionnaire. The questionnaire was administered using the Doodle ([www.doodle.com](http://www.doodle.com)), which is an online platform to create surveys and polls. All the questionnaires were issued with a detailed information sheet about the study. Participants had the option not to participate in the study. Most importantly, data were collected anonymously as the questionnaire did not ask for any personal details that identified the individual.

Completed questionnaires were received from 200 SOs although they were sent out to the 800 members of the FMF who had been approached in our previous study (Levo et al, 2012). As the questionnaire was anonymous, four reminders were sent to all participants. From the 200 replies, 14 were double replies and were excluded in the analysis, which resulted in 186 fully

completed responses from the SOs. Whereas this represents a crude response rate of only 24%, the previous study responses indicated that only a maximum of 62% was likely to have taken any action in terms of passing on the questionnaire to their SOs (Stephens et al, 2007). This results in a subject pool of 496 and a response rate of 38%. Eighty-two percent of the previous respondents were women, matching the gender balance of the FMF (Stephens et al, 2007). Of these, the mean age was 62.4 yr, and 52% were aged  $\geq 70$  yr. FMF data suggest that one-third of these were likely to be widows and living alone. This would reduce the potential subject pool to 327 and results in a possible response rate of 61.2%. As there is considerable uncertainty as to how many of the patients (among 800 FMF members) will have passed on the questionnaire to their SOs, we estimate the response rate to be within the range of 24–61%. It is not possible to calculate the precise response rate in this study because of the sampling method used (i.e., instead of contacting the SOs directly, the survey were sent to MD patients asking them to share with their SOs).

The median age of the current study sample ( $n = 186$ ) was 62.4 yr (range 26–86 yr). Of the 186 respondents, 101 respondents were men, and 85 were women; 160 of the respondents were spouses or partners of the patients, 20 were children, 2 were parents, and 4 were friends. The patients had a median duration of their MD of 16 yr (range 1–50 yr) as reported by their SOs.

### Questionnaire

The 25-item structured questionnaire (see Table 1) contained different aspects of the impact of the disorder on health and life (i.e., psychological aspects, activities, participation, and positive aspects). We call this a Ménière's Disease Impact Questionnaire. The questionnaire was shortened form of the ICF-based classification of impacts for the patients (Stephens et al, 2010; Pyykkö et al, 2015a) and from positive aspects (Stephens et al 2010). The ICF classification provided basic framework on the wide spectrum and complex character of the patient-perceived impacts of MD (Levo et al, 2012; Pyykkö et al, 2015a; Rasku et al, 2015). The questions were rated on a five-point Likert scale (i.e., 1 = always true; 2 = often true; 3 = sometimes true; 4 = rarely true; and 5 = never true). This instrument has been previously used to study the impact of MD on patients (Levo et al, 2013; Pyykkö et al, 2015a). In addition, we asked them to provide some demographic information including age, gender, relationship to the patient, and the duration of the patient's MD. The lead information in the questionnaire was worded as "We are keen to understand if your significant other's Ménière's disease interfere with your health and life. To help us understand this we request you to answer

**Table 1. Mean, Standard Deviation, and Percentage of Significant Others' Responses to a Structured Questionnaire**

SI No	Questionnaire Items	Mean	SD	% of Respondents				
				Always True	Often True	Sometimes True	Rarely True	Never True
<i>Psychological (stress related) aspects (Cronbach's alpha = 0.843)</i>								
1	Affects your sleep?	4.31	0.89	2.5	2.5	10	46	39
2	Makes you anxious or nervous?	4.09	0.81	0	3	21	41	35
3	Makes you feel tired or exhausted?	4.36	0.81	0.5	1.5	12.5	31.5	54
4	Makes you feel victimized by being dependent on your spouse's condition?	4.66	0.77	1.5	1.5	4	14.5	78.5
5	Makes you uncertain of the future?	4.15	0.99	2	4	18	29	47
<i>Activity limitation (Cronbach's alpha = 0.861)</i>								
6	Restricts your walking tours by reducing your mobility (e.g., spouse's poor balance etc.)?	4.18	0.92	1.5	3	15.5	35	45
7	Restricts your driving tours (because of spouse's nausea etc.)?	4.41	0.80	0	3	10	29	58
8	Affects your ability to do shopping?	4.43	0.79	0	3	10	27.5	59.5
9	Affects your work?	4.57	0.78	1.5	1	4.5	24	69
10	Interferes with your playing the sport you like?	4.61	0.78	0.5	1	7.5	15.5	75.5
11	Interferes with your hobbies?	4.54	0.79	1.5	0	7	23	67.5
12	Makes planning of activities difficult (feel uncertain planning activities)?	4.53	0.77	0.5	2	7.5	23	67
<i>Participation restrictions (Cronbach's alpha = 0.722)</i>								
13	Restricts your social life?	4.05	0.92	0	6.5	20	35	38.5
14	Affects your ability to watch the TV, listen to the radio, or communicate with others etc.?	3.78	1.18	4.5	9	26	23	37.5
15	Interferes with your relationships with friends and relatives?	4.56	0.72	1	0	7	25	67
16	Limits you going to the cinema, theater etc.?	4.41	0.87	1	2	10	24	63
17	Makes you avoid noisy places?	3.73	1.08	3	9	30	28	30
18	Hinders you eating what you would like to eat (salt free diet)?	4.54	0.71	0	1	9	24	66
<i>Positive aspects (Cronbach's alpha = 0.799)</i>								
19	Have you learned to live with your spouse's problems caused by the Ménière's disease?	1.71	0.89	50	35	11	2	2
20	Has Ménière's disease led you also to a healthy way of life?	3.06	1.17	7.5	25	33	19.5	15
21	Has Ménière's disease made you realize what is truly important in life?	2.56	1.15	19.5	32.5	28	12.5	7.5
22	Have you thought that things could be worse (there are many worse diseases)?	2.63	1.08	13	38.5	27.5	14.5	6.6
23	Has Ménière's disease taught you to think positively?	2.89	1.15	10	29	34.5	14.5	12
24	Has Ménière's disease brought you closer to your spouse?	2.72	1.23	20.5	20.5	35	13.5	10.5
25	Has the communication between you and your spouse improved?	3.00	1.24	12.5	23	30	19.5	15

Note: SD = standard deviation.

the following questions by indicating your answers in a five-point response scale." No other carrier phrase was used for each question, and the questionnaire was presented to participants as shown in Table 1.

### Data Analysis

In the first instance, the distribution of SOs responses was examined using the descriptive statistics (see Table 1).

Furthermore, the data were analyzed using various types of analysis, which included Kruskal–Wallis test, Pearson's correlation, and K-means cluster analysis. A significance level of 0.05 was used for all purposes.

The Kruskal–Wallis test was used to explore the relationship between the demographic variables and the SOs responses. Thereafter, we performed Pearson's correlation to understand the relationship between different subscales (see Table 2). Cronbach's alpha

was calculated for each subscale to represent the internal consistency. This was followed by the use of “K-means cluster” analysis (i.e., nearest neighbor analysis) to profile the attitude to cope with the patient (see Tables 3 and 4). The K-means cluster algorithm offers a cluster analysis of the variables and aims to identify relatively homogenous groups of cases and/or variables based on selected characteristics. One of the advantages of this method is that we do not have to calculate the distance measures between all pairs of participants (Mooi and Sarstedt, 2001). Initially, we investigated the optimal number of clusters by evaluating several options. Based on these analyses, we came up to use the three most common cluster centers in that all variables could be included. Basically, the algorithm calculates K-mean vectors around the space, which is densely populated with observations. Thereafter, the algorithm calculates distances between the K-mean vectors in the variables and classifies the distances of each variable vector. The K-means analysis included the original 25 dimensional vectors containing the variables detailed in Table 1. The scaling of the variables was identical. The  $x$  component of the new feature vector gives the number of ICF classified items. This procedure allows the use of conventional Euclidean distance metrics in comparison with the relational locations of individual feature vectors in the feature vector space. For distance calculations, the feature vector components  $x$  and  $y$  were divided by their respective maximum values to equalize their importance. This treatment converted the values of both  $x$  and  $y$  components into half open intervals. Final cluster means were then calculated as the average values of clustering variables for cases assigned to each cluster. Final cluster means do not contain classification centers. We used 11 iterations after which the algorithm stopped when the maximum change of cluster centers in two successive iterations was smaller than  $\epsilon$  times the minimum distance among the initial cluster centers. The algorithm resulted in the predetermined three-means “class labels” that include all feature vectors. The characteristics of the three classes are presented in Tables 3 and 4. An individual feature vector was classified as belonging to the “class”

whose mean value was closest to it. Finally, the probability of each binary vector component to have a value of one was calculated. This probability measure tells how common a particular component is among the class.

## RESULTS

### Distribution of SOs Responses

Table 1 provides the mean, standard deviation, and percentage responses of SOs' responses to a 25-item questionnaire. The responses of SOs suggest that the patients' situation resulted in some participation restrictions. For example, many reported a response of sometimes true for—makes you avoid noisy places and affects your ability to watch the TV, listen to the radio, or communicate with others. Interesting to note is that many of the SOs also identified positive aspects as a result of their partners' MD, for example, learned to live with your spouse's problems, realize what is important in life, made relationship stronger, and so on. Although, the disorder had, on average, a marginal effect on SOs' planned activities, work, hobbies, and feelings of guilt or feeling like a victim (see Table 1), it is important to note that some SOs reported psychological issues, activity limitations, and participation restrictions as a result of their partners' MD.

### The Effect of Gender, Duration of the Disorder, and Relationship with the Impact on SOs

We performed the Kruskal–Wallis test to explore the relationship between demographic variables and their association with the impact on SOs. In one of the variables, the impact could be explained by gender differences and duration of the disease. The positive item “healthy way of life” was associated with the partner's MD and was more prevalent among males when compared with females ( $\chi^2 = 9.9, p = 0.002$ ). The age of the patients had an impact on SOs' condition in that poor hearing impacts watching TV in the age group of 60–70 yr ( $\chi^2 = 13.34, p = 0.010$ ). Among the younger age groups (30–40 yr of age), it impacted SOs by “interfering

**Table 2. Pearson's Correlation Between Subscales of the Questionnaire**

	Psychological (Stress-Related) Aspects	Activity Limitations	Participation Restrictions	Positive Aspects
Psychological (stress related) aspects	1.00	—	—	—
Activity limitations	0.57**	1.00	—	—
Participation restrictions	0.48**	0.73**	1.00	—
Positive aspects	0.07	0.14	−0.23*	1.00

Note: Psychological (stress related) aspects = items 1–5; Activity limitations = items 6–12; Participation restrictions = items 13–18; and Positive aspects = items 19–25.

\* $p < 0.05$ ; \*\* $p < 0.001$ .

$r < 0.3$  is a weak correlation;  $r = 0.3$ – $0.7$  is a moderate correlation; and  $r > 0.7$  is a strong correlation.

**Table 3. Final Cluster Centers in K-Means Cluster Analysis**

Questionnaire Items	Cluster		
	1	2	3
Psychological (stress related) aspects			
Affects your sleep?	5	4	3
Makes you anxious or nervous?	4	4	3
Makes you feel tired or exhausted?	5	4	3
Makes you feel victimized by being dependent on your spouse's condition?	5	5	3
Makes you uncertain of the future?	5	4	3
Activity limitation			
Restricts your walking tours by reducing your mobility (e.g., spouse's poor balance etc.)?	4	4	3
Restricts your driving tours (because of spouse's nausea etc.)?	5	4	4
Affects your ability to do shopping?	5	4	3
Affects your work?	5	5	3
Interferes with your playing the sport you like?	5	5	3
Interferes with your hobbies?	5	5	3
Makes planning of activities difficult (feel uncertain planning activities)?	5	5	3
Participation restrictions			
Restricts your social life?	4	4	3
Affects your ability to watch the TV, listen to the radio, or communicate with others etc.?	4	4	3
Interferes with your relationships with friends and relatives?	5	5	3
Limits you going to the cinema, theater etc.?	5	4	3
Makes you avoid noisy places?	4	3	3
Hinders you eating what you would like to eat (salt free diet)?	5	4	4
Positive aspects			
Have you learned to live with your spouse's problems caused by the Ménière's disease?	2	2	2
Has Ménière's disease led you also to a healthy way of life?	4	3	3
Has Ménière's disease made you realize what is truly important in life?	3	2	2
Have you thought that things could be worse (there are many worse diseases)?	3	2	3
Has Ménière's disease taught you to think positively?	4	2	3
Has Ménière's disease brought you closer to your spouse?	4	2	3
Has the communication between you and your spouse improved?	4	2	3

with their job" ( $\chi^2 = 13.42, p = 0.009$ ) and in "planning for the future" ( $\chi^2 = 10.77, p = 0.021$ ). Interestingly enough, aging did not interfere with the improved communication or relationship. Duration of MD did not influence the condition of SOs.

### Interdependences Between Subscales

Table 2 shows the Pearson's correlation between different subscales. Psychological aspects had a moderate

statistically significant correlation with activity limitations (i.e.,  $r = 0.57$ ) and participation restrictions (i.e.,  $r = 0.48$ ). A strong statistically significant correlation (i.e.,  $r = 0.73$ ) was observed among activity limitations and participation restrictions. However, positive aspects were only related to participation restrictions with only weak but a statistically significant correlation. These results suggest a strong relationship between the subscales psychological aspects, activity limitations, and participation restrictions, whereas a

**Table 4. Classification of the Significant Others Based on Their Responses Using the K-Means Cluster Analysis**

Classified Impact Items and Scores	Clusters		
	1 Nonengaged SOs (N = 74)	2 Supportive SOs (N = 91)	3 Concerned SOs (N = 20)
Psychological (stress related) scores (maximum possible score 25)	24	21	15
Activity limitation scores (maximum possible score 35)	34	27	22
Participation restriction scores (maximum possible score 30)	27	24	22
Positive item scores (maximum possible score 35)	24	15	19

*Notes:* The numbers in table indicate the differences in the SOs' strategies to manage the patient's condition (i.e., MD) on their health and life. For the three items related to psychological aspects, activity limitation, and participation restriction, high scores indicate less concern about the impact of MD on SOs' health and life. However, for the positive items, a high score indicates great concern.

weak negative correlation (i.e.,  $r = -0.23$ ) was observed among positive aspects and participation restrictions.

### Modeling of Impact on SOs Using the Cluster Analysis

After examining the responses of SOs to each subscale, we performed a cluster analysis to determine the conditions that reflected the attitude of the SOs on their spouse's condition. Three cluster centers were defined (see Tables 3 and 4), and the  $K$ -means cluster centers for each question were identified. In this table, we calculated the mean cluster centers of each question and summed them up to describe the subscale cluster centers. Thus, the numbers in Table 4 indicate the differences in the SOs' strategies to manage the patient's condition in psychological, activity limitation, and participation restriction items. For these items, high scores indicate less concern. Also, the positive items were included. For these items, a high score indicates great concern (i.e., limited positive experiences). Finally, the three clusters were defined, and the impact scores were determined for each class (see Table 4). The results indicate that 74 SOs rarely or never experienced problems related to psychological aspects, had few limitation in activities and in participation, but did not adapt to living with the spouse's disease, and did not adapt to understanding what is important in life. This first cluster could be named as "Nonengaged SOs." The second cluster had 91 SOs and had more severe problems with psychological aspects, had moderate problems with activity limitations, severe problems with participation restrictions but experienced that the spouse's disorder had improved their relationship, and they had improved communication and a positive attitude. This cluster could be named as "Supportive SOs." The third cluster consisted of 20 SOs who experienced significant amount of problems related to psychological aspects in their spouse's disease by feeling victimized and uncertain about the future. They, however, considered that their activity limitation was relatively minor, whereas participation restriction was moderately affected. The SOs had problems in realizing what is important in life and did not experience a positive attitude or improved communication. This cluster could be named as "Concerned SOs." Here, the concern refers relates to SOs reaction on how their partners' condition interferes with their health and life.

## DISCUSSION

The current study was aimed at exploring the limitations experienced by SOs of individuals with MD in different aspects of health and life. In previous studies, we have used open-ended questions to study

the impact of MD on patients and their SOs (Stephens et al, 2007) and thereafter classifying their responses using the ICF classification (Stephens et al, 2012; Pyykkö et al, 2015b). The results of the previous qualitative study were used to develop a structured questionnaire (Levo et al, 2010). In this study, we used a structured questionnaire that had been used to study the impact of MD on the patients themselves (Levo et al, 2010).

In the current study, the questionnaire contained items in a broad spectrum but could be classified into four categories: the psychological (or stress related) aspects, activity limitations, participation restrictions, and positive aspects. Interestingly, the ICF does not include positive items in its classification, although some studies suggested that chronic conditions can result in some positive experiences for patients and their SOs (Manchaiah et al, 2015), and such aspects can be related to personal factors in the ICF classification. The items within each of the four subscales showed that they have a strong dependence with each other as confirmed with the high Cronbach's alpha value (i.e., internal consistency of the subscale). In addition, there is also a positive dependency between the subscales, which was confirmed by the Pearson's correlation (see Table 2). These findings suggest that the psychological aspects, activity limitations, and participation restrictions are all interrelated. However, positive aspects (e.g., personal factors) showed great independence among the items impacting the SOs by the patient's condition. Only participation restrictions were correlated with positive items, and this correlation was negative, that is, the more participation restriction the SOs experienced by the patient's conditions the less positive items they had developed. This calls for a biopsychosocial approach in the management of a chronic condition such as MD. The results also indicate that the SOs need to have instruments to help them develop better coping strategies to be supportive of their patient's condition. In addition, we have previously suggested a peer-support system to SOs that could be operated through the Internet and can prove an effective component of the patient's peer-support program (Rasku et al, 2015). It is noteworthy, however, that the disorder generally had only a marginal effect on SOs' health and life (see Table 1). Although, clearly many SOs had at least a few specific areas where they reported to have some difficulties as a result of their partner's condition.

Perceptions of a chronic illness as interfering in couples' lives may influence dyadic coping. Thus, in dyadic coping, the severity of disease may also affect the SOs. We have recently investigated this issue and shown that the general health-related quality of life in patients correlated with SOs responses in items relating to "mood" and "anxiety" (Pyykkö et al, unpublished data). Thus, the impact of disease causes emotional reactions in SOs. In therapeutic aspects, an improvement in coping

of complaint burden of patient can also lead to alleviation of SOs' emotional reactions.

### SOs Response Patterns

The *K*-means cluster analysis provided a more specific understanding of the problems experienced by SOs through identifying the patterns in the SOs' responses to the four subscales of the questionnaire. The three main patterns (i.e., "nonengaged," "supportive," and "concerned") show differences and similarities in the responses of SOs. The most common (used by 46.2% of the SOs) experienced little psychological stress because of their spouse's condition, did experience neither participation restriction nor activity limitation, and reported limited positive experiences. We named this attitude of SOs as "nonengaged." It can be questioned whether the condition can or will provide improved coping skills for the partners of patients with MD. The second strategy was used by 41.3% of the SOs and was characterized by psychological stress experienced as a result of the health condition of their partner, significant participation restriction, and also activity limitations. In addition, the SOs had great empathy for their spouses. This category of SOs is likely to help the patient through daily conversation, appreciation of the good days, helping the patients cope with their condition, and by providing support in their daily activities. This attitude is called "supportive," and such an approach is needed to empower the patient. The third category experienced prominent psychological stress due to the patient's condition, but had only moderate activity limitation, whereas the participation restrictions were relatively high. However, they did not think positively and had not learned to live with the spouse's condition. The increased worrying and shortage of positive thinking may cause problems in alleviating the patient's condition as well as interfere with the patient's ability to cope with the situation through lack of encouragement. We call this attitude as "concerned." This attitude in turn can victimize the SOs and, in the long term, be hazardous to the relationship. These findings highlight that some SOs seem to cope better than others. For example, the SOs in "nonengaged" and "supportive" clusters report fewer limitations when compared with SOs in "concerned" cluster. This may indicate the SOs in "nonengaged" and "supportive" clusters have better coping mechanism. These strengthen our previous study findings, which suggested that the attitudes of SOs of patients with MD could vary from coping to victimization (Pyykkö et al, 2015b).

### Role of Positive Attitude

The positive attitudes identified by the SOs of patients with MD seem to be quite important as that kind

of attitude in SOs may help motivate patients in developing coping strategies for the disease. For example, everyday conversations, routines, and shared activities with one's partner can assist patients' recovery from chronic illness (Goldsmith, 2009). As in the present study, couples may experience the impact of one partner's illness differently in their relationships as numerous factors influence both patients' and partners' appraisals of managing chronic illness (Checton et al, 2015). Differential illness experiences between patients and partners are worth exploring to develop effective strategies for supporting couples, especially in terms of the variables over which they have control (e.g., support perceptions, patterns, and practices) versus those they cannot control (i.e., the chronic illness). Berg and Upchurch (2007) proposed a developmental-contextual model as a framework for understanding how dyadic processes may vary across life spans and across different contexts that couples find themselves adapting to, especially in relation to the constraints of different illnesses. Checton et al (2015) defined the term "dyadic coping" to refer to a variety of ways in which couples potentially interact (e.g., uninvolvement, support, collaboration, protective buffering, and active engagement) as they manage stressors. These authors inspect "dyadic coping" with a model that views chronic illness as affecting both patients and partners, thereby requiring assessments of contextual factors, the illness itself, coping, and adjustment from the perspective of both individuals. For MD, such an analysis is needed through observing the impact on both persons; subsequently, final conclusions on the education needed to improve coping strategies can be made. Thus, we hypothesize that the better the perceived quality of partners' relationships the less likely they are to view a chronic illness as interfering in their lives. The model has been recently established as dyadic appraisal of chronic illness (Checton et al, 2014). In this model, the relational quality had a significant influence on patient support that correlated with better health condition management of the patient and the partner.

### Study Implications

As the SOs have significant influence on the patient's condition in everyday life, we believe that current study findings are important as this information can be used to educate the SOs to become more supportive of their spouses. One possibility is to teach the SOs to increase positive thinking (Manchaiah et al, 2015). However, more understanding is needed before such an approach can be initiated. In addition, the severity of the patient's health condition may influence the SOs' reaction and should be explored (Checton et al, 2014). From the exploratory analysis between responses and demographic variables, we have learned that duration of the disease



did not influence how positively and supportively the SOs respond to their partner's needs. The gender differences were minimal in assessing how SOs respond to their partner's condition. Neither age of the SOs explained their reactions, although elderly subjects were more prone to express items related to participation restriction and activity limitation. We would argue that involving the SOs in the audiological management is necessary, and in some cases, SOs may need rehabilitation to cope with the problems they have developed as a result of their partner's condition. Hence, developing peer-support programs for those with MD and their SOs may be necessary to improve adjustment and coping with the various consequences of a chronic condition such as MD. Although, the structured questionnaire used in this study can be used to understand the limitations and restrictions experienced by SOs of people with MD, it is important to note that it is not possible to categorize the SOs into three groups solely based on scores. Therefore, future studies with larger sample size and multicenter data should focus on developing normative values with cut-off scores.

## CONCLUSIONS

The current study was aimed at identifying how the SOs of patients with MD respond to different aspects of the impact of the disorder on health and life (i.e., psychological aspects, activity limitations, participation restrictions, and positive aspects). Examination of responses suggests that the disorder had, on average, marginal effect on the SOs' psychological aspects, activities, and participation. Interestingly, SOs reported some positive consequences as a result of their partner's condition. The results show limited association between SOs demographic variables and response patterns. Pearson's correlation suggested a strong association between the subscales psychological aspects, activity limitations, and participation restrictions, whereas a weak negative correlation was observed among positive aspects and participation restrictions. The cluster analysis resulted in three clusters, namely, (a) "nonengaged," (b) "supportive," and (c) "concerned." The current study results identify that the SOs' reaction to the patient's condition varies, and this may range from coping to victimization. Hence, the SOs of patients with MD may require rehabilitation in their own right. Moreover, the information gathered about SOs coping and adjustment in this study can also assist in the development of management and/or rehabilitation plans for people with MD.

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