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ORIGINAL COMMUNICATION

Religiosity and its relation to quality of life in primary caregivers of patients with multiple sclerosis: a case study in Greece

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Abstract The first objective of the current observational study was to assess the degree of religiosity in Greek Christian Orthodox primary caregivers of patients with multiple sclerosis (MS). The second objective was to evaluate the interrelations between religiosity and quality of life (QOL) and to identify the determinants of QOL, an endpoint of considerable importance in clinical research and practice. Twenty-two male and 13 female primary caregivers (mean age 47.3 ± 12.4 years) of an equal number of patients with MS, who consented to participate, completed the Systems of the Greek version of the Belief Inventory (SBI-15R) and the Greek validated version of EuroQOL (EQ-5D). The analysis revealed high scores on religiosity, especially among females. Caregivers scored in the religious beliefs and practices subscale of SBI-15R with a mean score of 22.8 ± 7.8 (range 0–30) and with 7.1 ± 4.8 (range 0–14) in the social support subscale. However, both of the SBI-15R domains were almost unrelated to the degree of overall QOL. There was only a reliable (but with little clinical value) association between the pain/discomfort domain of the EQ-5D with the SBI-15R beliefs and practices subscale ($r = -0.38$, $p = 0.03$). Although high levels of religiosity among Greek Christian Orthodox primary caregivers of MS patients were evident, this study did not demonstrate any beneficial effect of religious beliefs and practices on their QOL. Further prospective studies with a population with the same and/or diverse religious and cultural backgrounds are needed to better elucidate the complex association between religiosity and QOL in primary caregivers of MS patients.

Keywords Caregivers · Religiosity · Quality of life · Greece · Multiple sclerosis

Introduction

It is generally considered that patients with a severe or chronic disease are more prone to develop emotional distress and decreased quality of life (QOL). The same applies to primary caregivers who provide daily assistance to disabled patients. In particular, it has been maintained that caring for patients with a severe neurological disease can be rather demanding and burdensome for their primary caregivers, especially when they are caring for a patient with neuropsychological deficit [14].

Over the last years, several research studies have investigated the association between religiosity, spirituality, and health [22, 28]. Although the constructs of religiosity and spirituality may appear interchangeable to a certain degree of their origins, it seems that they are not identical. Religiosity, in its broadest sense, is a comprehensive term used to refer to the numerous aspects of religious activity, dedication and belief (religious doctrine), inspired by a specific religious faith [21]. Spirituality, on the other hand, is a broader concept, including any emotional, cognitive, and behavioral aspects of a person's quest for the Divine. Spiritual practices, including meditation,

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prayer, and contemplation, are intended to develop an individual's inner life [21].

In the aggregate, prior research has shown that religious and spiritual beliefs and practices are associated with better coping skills, and a lesser degree of anxiety and depression, thus providing comfort and support in a significant degree to both patients and their families [4]. Religious involvement, with regular prayer, seems to represent a general protective factor that promotes psychological health and improves QOL in patients with chronic diseases, including patients with cancer and coronary, pulmonary, or neurological diseases [4, 16, 26]. This interplay between religiosity, spirituality, and health is mediated through a variety of causal pathways [25]. It has also been previously been demonstrated that individuals with lower religious involvement are at greater risk of death compared to people more religiously involved, whereas religiosity and spirituality may also significantly reduce risk of death in healthy people [15, 21].

Thus far, a small number of studies have indirectly addressed the association of religiosity with the degree of the QOL in multiple sclerosis (MS) patients [4, 5, 29]. Nevertheless, the data provided on this issue are not sufficient enough to derive general conclusions about the relationship between religiosity and patients' attitudes towards the illness. This becomes more restricted taking inevitably into account each individual's religious and cultural background.

To date, in Greece, only two studies have been carried out to examine the effects of religiosity on Greek cancer patients. The research data have highlighted the significant role religiosity plays in improving the emotional status and QOL of cancer patients [1, 16]. Besides, only a few studies are found in the literature that have assessed the interplay between religiosity and overall QOL in patients with a severe neurological disease [4, 6, 29]. To our knowledge, even less is known about the effects of religiosity on the QOL of patients' caregivers with a severe neurological disease derived from any religious nomination.

In this regard, it is worth making a passing reference to the Greek religious doctrine. Greek society belongs to the body of Eastern Orthodox Church and the population has maintained a homogeneous religious orientation with the overwhelming majority of them defining themselves as Greek Orthodox. Available data from the European Social Survey (ESS) demonstrate that Greeks are more religiously involved, compared to other European populations of any nomination [7].

Considering the chronic, progressive, and disabling nature of MS, often being associated with emotional distress and decreased QOL in patients and their corresponding primary volunteer caregivers [19, 24], the first objective of the current observational study was to assess the degree of religiosity in Greek Christian Orthodox caregivers of patients with MS. The second objective was to evaluate the interrelations between religiosity and QOL, to identify the determinants of QOL.

Patients and methods

Male and female primary caregivers of a Christian Orthodox doctrine, aged 18 years or older, who were providing voluntarily (non-paid) caregiving to patients suffering from MS were asked to take part in the study. Patients and their corresponding caregivers were recruited from the MS Day Clinic, Department of Neurology of "Saint Andrew's" General Hospital of Patras, Greece. The sample of primary caregivers consisted of husbands or wives, parents, and other members of the family, i.e., brothers/sisters. Primary caregiving precluded that they had to live in the same home with the patient and take care of them, responding to the patients' overall needs. Caregivers with pre-existing major neurologic or psychiatric problems and those who were illiterate or had vision impairments that could affect their ability to read were excluded from the study sample. All eligible caregivers gave informed consent before study entry.

Individuals who consented to participate were administered the questionnaires in an office set aside especially for the purpose of the research by a researcher who offered assistance when needed, and checked the answers for omissions. Sociodemographic data were elicited from caregivers and disease-related information of patients with MS was obtained from our clinic charts.

Religiosity was assessed using the Greek validated version of the Systems of Belief Inventory (SBI-15R) [1, 16]. The SBI-15R consists of 15 items rated on a four-point Likert-type scale. Ten items measure religious and spiritual beliefs and practices (range 0–30), and five items measure the social support derived from a community sharing those beliefs (range 0–15). Higher scores indicate a higher level of religiosity/spirituality and social support [16].

The EuroQOL (EQ-5D), which is a European standardized instrument for measuring health outcomes and QOL in population health surveys, was used to examine the QOL of caregivers. The Greek validated version of the EQ-5D was used for the purposes of our study [10]. EQ-5D has demonstrated good validity and sensibility in a variety of clinical settings and populations, including oncology, neurological diseases, and mental disorders [18].

The basic EQ-5D instrument is composed of two principal parts. In the first, called "self-classifier" part, which includes five dimensions of health (i.e., mobility, self-care, usual activity, pain/discomfort, anxiety/depression), the responder is asked to score on a three-point scale from step

1 (no problems) to 3 (extreme problems). Step 2 indicates some moderate problems. The second part is comprised of the EQ-VAS, in which the research participants are asked to self-rate themselves on a thermometer vertical scale across a continuum of values ranging from 0 to 100. A zero (0) value means the worst imaginable health status and 100 the best imaginable health status. Scores from 0 to 40 indicate a severe health disorder due to evidence of serious somatic symptoms (pain) or symptoms of psychological distress (depression, anxiety). Scores from 50 to 70 are in keeping with moderate affectation of health status due to evidence of a moderate degree of somatic symptoms or psychological distress, whereas scores from 80 to 100 are consistent with no evidence of somatic symptoms or psychological distress [23].

Statistical analysis

Data were analyzed using SPSS for Windows (version 16.0; SPSS Inc., Chicago, IL). Descriptive statistics were generated for all variables. Because many of the variables had skewed distributions, Spearman rank correlation coefficients were calculated for possible relations among continuous measures, and the Kruskal–Wallis test was applied to compare means of continuous measures for two or more groups. All tests were two-tailed and statistical significance was set at $p < 0.05$.

Results

The diagnosis of MS for patients was based on the revised McDonald diagnostic criteria [20]. All patients suffered from SPMS and were treated with either natalizumab or immunosuppressive agents. At the time of the survey, patients had a mean score in the Kurtzke Expanded Disability Status Scale (EDSS) of 5.1 ± 0.7 (range 4–6). An EDSS score above 5 is supportive of impairment of ambulation [11]. Their disease duration from the time of first MS diagnosis ranged between 7 and 25 years (mean 15.5 ± 6.3 years).

Forty eligible caregivers of an equal number of patients with MS were initially approached and 35 (87.5%) of them consented to participate. In this observational, case control study, the sample consisted of 35 primary caregivers (22 males and 13 females with a mean age of 47.3 ± 12.4 years). The sociodemographic characteristics of the caregivers are presented in Table 1.

Table 1 Sociodemographic characteristics of primary caregivers ($n = 35$)

Characteristics	Values
Age (mean years ± SD)	47.3 ± 12.4
Gender	*n* (%)
Males	22 (62.9%)
Females	13 (37.1%)
Relation to patient	*n* (%)
Husband/wife	24 (68.6%)
Parent	4 (11.4%)
Brother/sister	5 (14.3%)
Other	2 (5.7%)
Education (years)	*n* (%)
6	6 (17.1%)
9	8 (22.9%)
12	10 (28.6%)
>12	11 (31.4%)
Employment	*n* (%)
No	21 (60.0%)
Yes	14 (40.0%)

Overall, caregivers scored relatively high on both subscales of the SBI-15R, mostly in the beliefs-and-practices subscale (Table 2). Of all sociodemographic characteristics of caregivers, only gender was found to be associated with religiosity. Female caregivers reported significantly higher levels of perceived social support ($p = 0.044$, Kruskal–Wallis) than their male counterparts. In contrast, females scored comparably with males in the SBI-15R religious beliefs-and-practices subscale ($p = 0.420$, Kruskal–Wallis).

EQ-5D scoring demonstrated that 11 (31.4%) caregivers experienced somatic problems (discomfort/pain) of moderate severity, while seven (20%) also had limited usual activity. Twenty-seven persons reported moderate and three extreme degree of anxiety/depression in the corresponding dimension of health of the EQ-5D. The mean values of caregivers in the EQ-VAS were 61.9 ± 13.8 (range 40–100). Ten caregivers rated their overall health status with a score of 50 or lower, seven with 50 and three with 40. The mean scores in EQ-5D domains are described in Table 2.

We then examined whether caregivers' QOL varied with the degree of religiosity and found that there was almost no evidence for a clear constellation of associations between scores in the EQ-5D domains and SBI-15R subscales (Table 3). Only one reliable association between the pain/discomfort domain of the EQ-5D with the SBI-15R beliefs-and-practices subscale ($r = -0.38$, $p = 0.03$) was disclosed.

Discussion

Religiosity is divided into three sub-constructs: intrinsic, extrinsic, and quest [12, 13]. The use of SBI-15R in the

Table 2 Scores in SBI-15R and EQ-5D

Parameters	Caregivers
SBI-15R subscales	
Beliefs-and-practices subscale (range 0–30)	22.8 ± 7.8 (range 0–30)
Social support subscale (range 0–15)	7.1 ± 4.8 (range 0–14)
EQ-5D domains (range 1–3)	
Mobility	1.0 ± 0.3
Self-care	1.0 ± 0.3
Usual activity	1.2 ± 0.4
Pain/discomfort	1.3 ± 0.5
Anxiety/depression	1.9 ± 0.7
EQ-VAS (range 0–100)	61.9 ± 13.8

Table 3 Correlates (Spearman's *r*) of QOL

	SBI-15R beliefs and practices (*r*/*p* value)	SBI-15R social support (*r*/*p* value)
EQ-5D subscales		
Mobility	−0.09/0.601	0.18/0.292
Self-care	−0.10/0.550	0.30/0.083
Usual activity	−0.29/0.190	0.20/0.250
Pain/discomfort	−0.38/0.030	0.05/0.780
Anxiety/depression	−0.10/0.570	−0.13/0.450
EQ-VAS	0.19/0.287	0.07/0.682

r = correlation coefficient

current observational study allowed us to assess both the intrinsic and extrinsic dimensions of religiosity. The intrinsic religiosity (the way one lives religion) was assessed using the religious beliefs-and-practices subscale of the SBI-15R, while the extrinsic religiosity (the way one uses religion) was examined with the use of a social-support subscale [16]. The quest orientation, which is related to the willingness to question complex ideas, is not included in SBI-15R and thus it was not examined in the current study. Overall, the SBI-15R was well accepted by the participants, thereby suggesting that it represented an easily administered and valid research tool of religiosity.

Our sample of Greek primary caregivers of MS patients scored high on both subscales of the SBI-1R5, underlying the significant role religion generally plays in Greek society. However, we cannot make any direct comparison on this specific issue against the results of other studies because, in our knowledge, there is a lack of relevant studies either in Greece or elsewhere assessing the degree of religiosity in caregivers of MS patients. Nevertheless, comparing our data with the results of another study focusing on cancer patients [1], we found out that our sample's mean scores on the beliefs-and-practices subscale (22.8) were close to those reported in Greek cancer patients (24.5). Furthermore, the rates of intrinsic religiosity in our study were also similar to those reported in other populations, i.e., religious nationalist Jews (23.0), whereas they were higher than those of Canadian (16.3) and Israeli lay people (6.0) [3, 16]. In line with earlier studies, we also found that female caregivers reported higher levels of extrinsic religiosity than males [1, 2]. Moreover, in our case, it should be stated that no other significant associations were emerged between religiosity and sociodemographic characteristics of our sample.

Various dimensions of religiosity may link in different ways to the improvement of health status and QOL. Taking into account the relatively high rates of religiosity in our sample, one could assume that the high religious orientation (particularly the intrinsic one) may exert beneficial effects on the QOL of Greek primary MS caregivers. Contrary to our expectations, the main aspect of our findings was that the overall QOL of our sample remained independent from both the religious beliefs and practices as well as the social support provided by the religious community. There was only evidence of one significant association, i.e., between the pain/discomfort domain of the EQ-5D with the SBI-15R beliefs-and-practices subscale, which, to our opinion, has little clinical value. Although high rates of religious resources were disclosed, the overall QOL of primary caregivers of MS patients was significantly altered, thoroughly indicating that the degree of their QOL appeared to be unrelated to both the subjective experience of religion, i.e., intrinsic religiosity and participation to a religious group, i.e., extrinsic religiosity.

The above-mentioned element of our findings is particularly interesting and rather surprising because our sample is coming from a Christian Orthodox setting and, as such, an attempt to rely on God in times of crisis or a period of continuous emotional distress would be expected as representing a very helpful resource. Our results might dispute the general idea advocating that religious coping may definitely have a beneficial effect on health status, QOL, and overall well-being [17, 21]. However, we should note that our findings are in agreement with those of other previous research studies, which demonstrated an insignificant relationship between religious/spiritual coping (active reliance on religion) and the degree of QOL in samples of cancer patients [27].

The differentiation from the majority of relevant results leads us to assume that available data are rather suggestive than conclusive and so merit further exploration, given the multidimensional nature of religiosity and the diverse effect of each of these dimensions on individuals' health. It seems that primary caregivers use overlapping but distinct coping patterns compared to patients. These coping efforts may not rely on religious faith and they may be possibly related to emotional adjustment in different ways. It also appears that the perceived high level of emotional burden from a disease, e.g., MS, with an unpredictable course and the resultant affectation of the QOL cannot be counterbalanced by the primary caregivers of MS patients, despite the high levels of their religious resources. Another theoretical aspect that could also hold responsibility is that of emotional contagion [8]. This suggests that primary caregivers mutually experience affective or emotional status, implying that when a patient manifests emotional distress and decreased QOL, the other spouse is likely to experience similar symptoms [8] in a degree that they cannot be easily over passed into turning to religiosity. The consequential perceived incapability of caregivers to provide a substantial assistance to the disabled patients with MS might also significantly contribute towards this effect.

Nevertheless, we should note that the cross-sectional study design we applied, as well as the small sample size with the resultant low statistical power, restricted us from being confident on the issue. In addition, our sample does not represent the general population of caregivers of MS patients in Greece and therefore further prospective and longitudinal studies with a larger sample of individuals should be carried out before any definitive conclusions can be drawn.

To summarize, high levels of religiosity were observed in our sample of primary caregivers of MS patients, especially in females. However, religious beliefs and practices together with the social support were unrelated to overall QOL. Our findings do not support the general view suggesting that integrating spiritual and religious resources into conventional clinical practice may ameliorate the level of medical care. At present, we can do no more than speculate at present until further empirical data become available. Further wider-scale studies from the same and diverse religious and cultural backgrounds are needed to better elucidate the dimensions of religiosity that might be beneficial to primary caregivers and to clarify the complex associations between religiosity and QOL.

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