Journal of the Neurological Sciences 337 (2014) 67–73

Contents lists available at ScienceDirect

Journal of the Neurological Sciences

journal homepage: www.elsevier.com/locate/jns

The coexistence of well- and ill-being in persons with multiple sclerosis, their caregivers and health professionals

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ARTICLE INFO

Article history:
Received 2 September 2013
Received in revised form 21 October 2013
Accepted 12 November 2013
Available online 19 November 2013

Keywords:
Multiple sclerosis
Quality of life
Depression
Well-being
Patients
Caregivers
Health professionals

ABSTRACT

Background: Studies on emotional distress and health-related quality of life (HRQOL) broadened the traditional bio-medical focus in MS research, but little attention was paid to general well-being indicators.
Objective: To investigate for the first time both ill-being and well-being dimensions in persons with MS (PwMSs), caregivers and health professionals, in relation to both health and life in general.
Methods: A multi-center study assessed participants' depression (Beck Depression Inventory-II), HRQOL (Short Form-36), psychological well-being (Psychological Well-Being Scales), optimal experience (Flow Questionnaire), life satisfaction (Satisfaction with Life Scale), hedonic balance (Positive Affect and Negative Affect Schedule). Demographic and clinical information was also gathered.
Results: Overall, 71 PwMSs, 71 caregivers and 26 professionals were enrolled ($N = 168$). Compared to healthy populations, PwMSs reported higher depression, lower HRQOL and lower general well-being; caregivers presented higher depression and lower general well-being; professionals reported the best ill- and well-being profiles. However, after controlling for demographic differences in age and education, hierarchical regressions highlighted that, though PwMSs reported higher depression and lower HRQOL than caregivers and professionals, their general well-being substantially leveled off.
Conclusions: Well-being coexists with ill-being. It can counterbalance the negative effects of disease or caregiving, and its measurement could complement and support medical intervention.

1. Introduction

Multiple sclerosis (MS) is a chronic progressive condition posing relevant psychological challenges to affected people and those who take care of them. Persons with MS (PwMSs) and their caregivers experience high levels of anxiety and depression, and reduced health-related quality of life (HRQOL) associated with factors like increasing physical disability, uncertain prognosis, and taxing treatments [1–3]. Also health professionals assisting chronic patients face stressful situations, which can reduce their HRQOL and facilitate burnout [4].

Although research on these topics has broadened the traditional bio-medical focus to include subjective evaluations of living conditions, the limitations of such approach are increasingly evident. First, in MS literature QOL is substantially related to health issues, while other relevant life domains are neglected [5]. Second, research and intervention primarily target physical and emotional symptoms, namely the negative aspects of illness. Such focus implicitly equates health with the absence or reduction of disease/infirmity, and not with a state of complete physical, mental and social well-being, as defined by the WHO. In this respect, psychologists recently called for a shift in attention from human shortcomings and deficits to personal resources and potentials, showing through empirical studies that well-being is not the opposite of ill-being; rather, it comprises unique dimensions [6,7].

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http://dx.doi.org/10.1016/j.jns.2013.11.018

Well-being studies refer to two conceptual approaches. The hedonic one focuses on emotions and operationalizes well-being as life satisfaction and prevalence of positive over negative affect (hedonic balance) [8]. The eudaimonic approach focuses on meaning-making and goal pursuit [9,10]. It comprises various constructs such as optimal experience or flow, identified by Csikszentmihalyi [11] as a positive, complex and gratifying experience of deep concentration and enjoyment, which can foster individual development through skill refinement and engagement in meaningful activities [12]. Another eudaimonic construct is psychological well-being, described by Ryff [13] as comprising self-acceptance, positive relations, environmental mastery, purpose in life, and personal growth.

Research has shown that conditions such as chronic disease or taking care of an ill person (as caregiver or health professional) are not necessarily perceived as stressful threats [10]. They can also be interpreted as challenges and opportunities for growth, thus not hampering well-being, especially its eudaimonic components such as meaning-making, interpersonal relations, and engagement in daily activities [14]. Accordingly, in the few studies targeting hedonic well-being in MS research, PwMSs were more dissatisfied with their lives than healthy individuals, whereas caregivers did not statistically differ from non-caregivers [15,16]. As for eudaimonic well-being, only one study was carried out: It showed that PwMSs and healthy controls reported similar levels of personal growth [17].

These preliminary findings suggest that an integrated well-being approach could provide useful information not only on impaired areas to be mended, but also on personal and social resources. These have been so far largely unexplored in MS research, and their implementation could counterbalance the negative effects of disease. To this purpose, we conducted an exploratory study among the three major characters of the MS care system: PwMSs, caregivers, and health professionals. Our aim was to analyze for the first time in MS research participants' perceived levels of ill-being and well-being, focusing on both health-related and general evaluations.

2. Methods

2.1. Participants and recruitment

This study included PwMSs, their caregivers and health professionals from 7 MS centers in Italy: three in the North, two in the Center, and two in the South. Each center recruited 10 PwMSs, 10 caregivers, and three professionals. PwMSs' inclusion criteria were: being of age, having a clinically-definite MS diagnosis (McDonald's revised criteria) for at least 3 years, having a caregiver. Exclusion criteria were neurological disorders other than MS, psychiatric disorders, severe physical impairment (EDSS ≥ 8), being in the active phase of disease, severe cognitive impairment in comprehension and logical abilities with at least one score at Token Test or Raven Matrices below the cut-off point (16th percentile; equivalent score 0–1) [18,19]. No specific criteria were set for caregivers and professionals.

Prior to the study, psychologists working in each center took part in a joint meeting in which they were briefed about the research protocol and common administration procedures. In each center, eligible PwMSs were identified by the psychologists based on the criteria described above, and were then contacted during check-ups or by phone. Upon participation agreement, PwMSs were asked to identify their primary caregiver and to inquire about his/her participation in the study. PwMSs' neuropsychological evaluation was then scheduled and performed by a psychologist. If no severe cognitive impairment was detected, the PwMSs and their caregivers were enrolled in the study. The professionals were contacted individually by the psychologists at their workplace. Written informed consent was obtained from all participants before inclusion. All local ethical committees approved the study protocol.

2.2. Measurements and procedure

Neurologists provided patients' clinical information including MS type, age of onset, disease duration, and current level of impairment/disability measured with Expanded Disability Status Scale (EDSS; ranging from 0 "normal examination" to 10 "death from MS") [20]. All participants reported on their age, gender, education, civil status, employment, and clinical conditions (e.g. disease other than MS).

All questionnaires were validated in Italian. To measure HRQOL we chose the Short Form-36 Health Survey (SF-36) [21,22] which could be administered to participants in the three groups. It comprises 36 items measuring eight dimensions: physical functioning ($\alpha = 0.96$), role limitation due to physical health problems ($\alpha = 0.87$), bodily pain ($\alpha = 0.89$), social functioning ($\alpha = 0.81$), mental health ($\alpha = 0.87$), role limitations because of emotional problems ($\alpha = 0.80$), vitality ($\alpha = 0.83$), and general health ($\alpha = 0.81$). Ratings were summed for each dimension and then transformed to have a common range from 0 (worst health) to 100 (best health).

The Beck Depression Inventory II (BDI-II) was used to appraise depressive symptoms [23,24]. It includes 21 items rated on 0–3 scales yielding a maximum summed score of 63 ($\alpha = 0.89$). Five levels were identified: normal scores (0–9), minimal depression (10–15), mild (16–19), moderate (20–29), and severe (30–63) [25].

Eudaimonic well-being was assessed through the 18-item version of the Psychological Well-being Scales (PWBS) [13,26] and the short form of Flow Questionnaire (FQ) [27]. PWBS taps with three items each the dimensions of psychological well-being: environmental mastery, autonomy, purpose in life, personal growth, self-acceptance, and positive relations. Ratings range from 1 (strongly disagree) to 6 (strongly agree). According to previous confirmatory factor analyses, items were aggregated into one factor ($\alpha = 0.74$) with scores ranging from 18 (low) to 108 (high) [28]. In FQ participants were asked to read three quotations describing optimal experience, to report whether they had such experience before and, if so, to list the associated activities. For this study, we focused on occurrence vs absence of optimal experience.

Concerning hedonic well-being, the Satisfaction with Life Scale (SWLS) [29,30] asked participants to report how much they agreed (from 1 "strongly disagree" to 7 "strongly agree") on five statements assessing their level of overall life satisfaction ($\alpha = 0.91$). The total score ranges from 5 (extreme dissatisfaction) to 35 (extreme satisfaction). Hedonic balance was evaluated with the Positive Affect and Negative Affect Schedule (PANAS) [31,32] in which 10 items measure positive affect (PA, $\alpha = 0.87$) and 10 measure negative affect (NA, $\alpha = 0.92$). Item scales range from 1 (very slightly or not at all) to 5 (extremely). Hedonic balance was calculated as the difference between PA and NA ratings.

Individual briefings were scheduled to present the questionnaires and to clear participants' doubts and questions. Option was given to complete the battery in situ or at home.

2.3. Data analysis

Data screening and analyses were performed with SAS 9.2. Descriptive statistics were expressed as means (SD) for normally-distributed variables and percentages for categorical variables. For non-normally-distributed variables, both means (SD) and medians (interquartile distance) were reported.

Between-group comparisons were conducted for demographic and clinical information: age, gender, education, employment, civil status and disease other than MS. ANOVA (GLM) with Scheffé post-hoc comparisons or χ^2 statistics were used according to variable type. Next, *t*-tests or χ^2 statistics were performed to compare ill-being, general and health-related well-being scores (measured with BDI-II, SWLS, PWBS, FQ, PANAS, SF-36) obtained for PwMSs, caregivers, and professionals vis-a-vis healthy populations. Finally, hierarchical regressions were