Health related quality of life in people with multiple sclerosis

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The aim of this study is to contribute to the understanding of the effect of the multiple sclerosis (MS) on health-related quality of life (HRQoL). MS is a chronic neurological disease with an unpredictable course, making it a very subjective and case specific disease. The emphasis in this thesis is put on psychological and social factors that have shown to play an important role on quality of life in various health conditions, but so far not in MS [1-8]. This chapter covers the theoretical background of the thesis, describes the aims and the theoretical model used for the study, presents the research questions and outlines the structure of this thesis.

1.1 Multiple sclerosis

Multiple sclerosis (MS) is the most common neurological disease with disabling consequences that occurs in young adults, more often affecting women than men [9]. It is a chronic disease characterised by diffuse changes in the white and grey matter, the breakdown of myelin and damage to axons within the central nervous system (CNS) [10]. Globally, the median estimated prevalence of MS was 30 patients per 100,000 people in the year 2008 and increased to 33 per 100,000 in 2013 with the highest prevalence in high income countries [9,11]. The prevalence of MS varies around the world with the highest prevalence being in Europe and North America (108 and 140 per 100,000 respectively) and with the lowest prevalence occurring in the Sub-Saharan Africa and East Asia (2.1 and 2.2 per 100,000). Latitude also seems to be a factor in prevalence of MS where proximity to equator correlates with lower risk of developing MS. The average onset of MS is 30 years and the duration of this disease can last for many decades. 85% of the new patients are diagnosed with relapsing-remitting MS which is characterized by acute attacks of worsening symptoms followed by a recovery phase. The duration of these attacks is individual and can last from days to months. In this type of MS, the disease does not worsen in the periods between the attacks. 80% of patients who are diagnosed with the relapsing-remitting type of MS later develop a secondary-progressive type of the disease. 10% of the patients are initially diagnosed with primary-progressive MS which is characterized by a gradual but steady progression of disability. Relapses and remissions are not present in this type. 5% of the patients are diagnosed with the progressive-relapsing type of MS which has a steady progression of disability and also acute attacks that may or may not be followed by recovery [9,12].
Some of the most prevalent symptoms of MS are sensory problems (occurring in 40% of the MS population), problems with movement and transportation (occurring in 39% of the MS population) and fatigue (occurring frequently, but the more severe form can be found in 30% of the MS population) [9]. These disabling symptoms pose multiple challenges for both physical and psychological well-being [13] and have a negative impact on a patient’s health related quality of life (HRQoL) [14], which is an area in need of more research focused on it [9]. Symptoms of MS and their effects are reflected in the disability that can be quantified using the Expanded Disability Status Scale (EDSS). It assesses various functional systems (pyramidal, cerebellar, brainstem, sensory, bowel and bladder, visual, cerebral and other) and assigns to patients a functional system score based on their disability [15,16].

The most widely used criteria for the diagnosis of MS are the McDonald criteria that underwent revisions since their implementation and now include magnetic resonance imaging (MRI), which demonstrates multiple areas of involvement and also involvement over time with the appearance of new enhancing lesions [17,18]. Advanced MRI and spectroscopy may allow clinicians to follow the pathological progression of the disease and to monitor the response to the treatment [19]. MS patients frequently suffer from depressive symptoms, which impact their HRQoL and can even lead to suicidal ideations [20]. Other psychological symptoms most often associated with multiple sclerosis include anxiety [21], cognitive impairment [22] and fatigue [23].

1.2 Health Related Quality of Life

The diagnosis of MS brings with it a serious risk of worsening patient’s HRQoL and previous research in this field supports this notion [24]. Domains of HRQoL affected by MS include the physical, mental and social domains. Most of the symptoms resulting from MS are responsible for the decreased quality of life in the physical domain like pain, sensory problems, fatigue, movement impairments and bowel and bladder issues [25]. The mental domain of quality of life is mostly impaired by various symptoms of depression, anxiety and fatigue [26]. Depression especially is a very prominent factor influencing quality of life and even when physical symptoms are not very limiting, in combination with depression, levels of HRQoL can be very low [27]. Depending on the phase in which the patient currently is, mental symptoms can have various forms. In the initial progression of the disease high levels of anxiety can lead to neurotic problems, which can get even higher during attacks. In remissions, depressive symptoms can take root because of the uncertain onset of the next attack. Cognitive impairment in any stage of MS can lead to low levels of self-worth and self-esteem [28]. MS can also affect the social
domain of HRQoL with negative impacts on work patterns which can lead to problems with co-workers or unemployment [29], it can cause psychosexual problems and consequently dyadic issues and problems in relationships [30] and social participation can be impaired as well, with patients unable to engage in social activities as much as their peers [31].

1.3 Coping self-efficacy
Coping is defined as the effort to manage a stressful situation and involves various cognitive and behavioural efforts to overcome external or internal demands which are appraised as either taxing or exceeding the person’s resources [32]. To manage a stressful situation, various coping strategies can be used. Problem-focused coping encompasses all strategies that try to actively eliminate threatening factors or actively try to diminish the impact of such factors [33]. Emotion-focused coping implements strategies such as searching for social support, understanding from other people and positive emotions from other people [34]. Coping focused on stopping unpleasant emotions and thoughts is, as the name of this type suggests, focused on avoiding unpleasant factors associated with stressful situation. Although avoidant tendencies were generally perceived as maladaptive, this type of coping can have a positive effect in situations when the individual does not have the resources to eliminate the problem directly or a solution is not possible [35]. Problem-focused and emotion-focused coping can easily occur simultaneously. Emotion-focused coping can even facilitate problem-focused coping by removing some of the distress that can hamper problem-focused efforts; similarly, problem-focused coping can render the threat less forbidding, thereby diminishing distress emotions [33].

Problem-focused coping was found to contribute positively to the health-related quality of life (HRQoL) of patients with various chronic conditions. The positive effect of coping can appear either in the mental health component of HRQoL only [36], or in both the mental and physical components [37]. Folkman and Lazarus state that men use more problem-focused coping than women at work and in situations requiring acceptance and requiring more information [38]. Increasing age is usually associated with a decline in the use of both problem-focused and emotion-focused coping strategies [39].

Self-efficacy is a construct describing some one’s personal belief about one’s ability to perform certain behaviour successfully with the expected outcome [40]. Research on self-efficacy in the MS context has mostly focused on aspects related to physical activity and exercise, such as beliefs about performing activities of daily living, autonomy issues, movement and work [41-44]. Other studies focused on the association between self-efficacy and fatigue and depression but the psychological
aspects of self-efficacy such as coping were not prominent in the research [45,46].

1.4 Type D personality and Self-esteem

MS negatively affects the patient’s HRQoL, and influences various psychological resources such as the concept of self and self-esteem and even plays a role in modification of personality through depression and anxiety, which are frequent symptoms of MS [47]. On the other hand, previous research also indicates that depression and anxiety are more important for HRQoL than personality [48,49]. Depression and depressive symptoms along with anxiety are closely intertwined with Type D personality which can be described as a personality where negative affectivity and social inhibition play a large role in daily activities. Focusing on the negative side of things coupled with inhibition of behaviour and emotional responses during social interaction can subsequently influence mental and social aspects of HRQoL [50]. Another deeply integrated personality variable is self-esteem which results from a personal self-view and is prone to change over time [51]. Self-esteem is easily modified by depressive symptoms [52], especially in a situation of chronic illness and can change one’s outlook on self-worth, self-efficacy and lead to low levels of mental HRQoL [53].

1.5 Social participation

The presence of a disease or disorder was until recently considered as satisfactory prerequisites for various decisions in the caretaking process of patients with chronic conditions. The main source of these decisions was the International Statistical Classification of Diseases and Related Health Problems (ICD-10), which classifies them. In 2002 the scientific approach and research operationalization underwent a significant shift by introducing the World Health Organization’s International Classification of Functioning, Disability and Health (ICF) (Figure 1.1).
This classification is complementary to the ICD-10 because where the ICD-10 classifies causes of death, the ICF classifies functioning and disability associated with health conditions. Key terms for the ICF model are impairment, activity and participation, where participation is the key construct that has been included to replace the term handicap [54].

Participation is defined by the ICF as involvement in life situations [54] and can be affected by impairments and activity limitations interacting with environmental and personal factors [55]. A subcategory of overall participation is social participation which is closely linked to self-esteem, life satisfaction and mental health status, making it a very important factor for Health Related Quality of Life (HRQoL) [56,57]. This makes the ICF a truly biopsychosocial model combining physical, psychological and social aspects of HRQoL all together and providing a more complete picture of health in all its facets. The social aspect of HRQoL, engagement with community activities, friendships and meaningful volunteer work are perceived as strategies for maintaining social participation, especially for people suffering from a chronic disease [58]. Social participation is also a subjective variable in which the same level of social participation may be satisfactory for one person, but it may be too low for another. The peer concept of comparison is thus an important factor to get an objective assessment of this variable.
1.6 Aim of the thesis and its research questions

This thesis aims to provide insights in the associations between physical and psychosocial factors and health related quality of life in patients with multiple sclerosis. It builds on previous studies describing psychosocial factors in health impaired populations [59-61] and also adds research questions to previous studies focusing on multiple sclerosis [62]. Because of its multidimensional nature both physical and psychological variables were studied in association with HRQoL. By associating sociodemographic variables, functional disability, disease duration, coping, social participation, fatigue, type D personality and self-esteem with HRQoL we tried to answer the following research questions (Figure 1.2).

**Research question 1**
Are different coping strategies associated with different levels of health related quality of life? (Chapter 3)

**Research question 2**
Is social participation associated with the physical and mental components of quality of life? (Chapter 4)

**Research question 3**
Do different coping strategies mediate the association between fatigue and health-related quality of life? (Chapter 5)
1.7 Outline of the thesis

This thesis is divided into eight chapters.

Chapter 1: “Introduction” provides the basic background about multiple sclerosis and focuses on the importance of psychological and social resources of patients with multiple sclerosis for their HRQoL. Furthermore, the theoretical model and five research questions are formulated.

Chapter 2: “Data sources” provides information about the design of the study. It describes the data collection and the study sample used in this thesis. It also provides a short description of the measures and analyses used.

Chapter 3: “Coping and its importance for Quality of Life in patients with multiple sclerosis” explores the association between three coping strategies and health-related quality of life in patients with MS.

Chapter 4: “Social participation and Health-Related Quality of Life in people with multiple sclerosis” describes social functioning of patients with MS and their social participation and its links with health-related quality of life.

Chapter 5: “Can coping make you less tired? The mediating effect of coping on the association between fatigue and Quality of Life in patients with multiple sclerosis” elaborates on the association between fatigue and health-related quality of life and how it can be mediated by coping.

Chapter 6: “Do coping strategies mediate the association between Type D personality and Quality of Life among patients with multiple sclerosis” analyses the association between Type D personality and health-related quality of life and how this it is mediated by different coping strategies.

Chapter 7: “Self-esteem, social participation and their association with Quality of Life in patients with multiple sclerosis” explores whether self-esteem encourages social participation and association of these two variables with health-related quality of life.

Chapter 8: “General discussion, implications and conclusions” presents and discusses the main findings of this thesis as well as its strengths and limitations and its implications for practice and further research.
References


