

# Suffering Dimensions in Adults with Chronic Diseases or Life-Threatening Illness

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## Introduction

Chronic diseases are an obstacle or constraint to the fulfilment of the patient's expectations and needs, which compromise the health transition process, often cause suffering and adaptation problems [1]. Suffering is personal and affects both younger and older people in different suffering experiences. The question "Why me?", "For what?" is intimately related to the individual's suffering experience. Literature also consistently associates the concept of suffering with sadness, fear, anguish, distress, pain, loss of control, self-identity or even meaning of life and is perceived as a threat to the person's integrity [2,3], according to peoples' accounts of their suffering. Health professionals play an important role as they are able to establish a close relationship with patients and their family and often become the sole witnesses to the patients' suffering. Suffering involves the person as a whole, thus be able to understand it means that all patient's dimensions must be addressed to relieve the suffering.

## Objective

The study aimed to assess the suffering in adults with chronic diseases or life-threatening illness.

It is based on the salutogenic idea [4] to rise the processes that allow people, living in situations with a difficult quality of life, to have notable health, by using/creating general resources of resistance (GRR) [5]. Antonovsky's (1988) enunciated some possible GRR, such as natural, physical/biochemical, emotional, interpersonal, socio-cultural, environmental, spiritual, from which emerge senses of comprehensibility, manageability and of meaningfulness [4,5]. Generalized resistance resources can, in themselves, supply to an individual, group or population's Sense Of Coherence (SOC).

## Methods

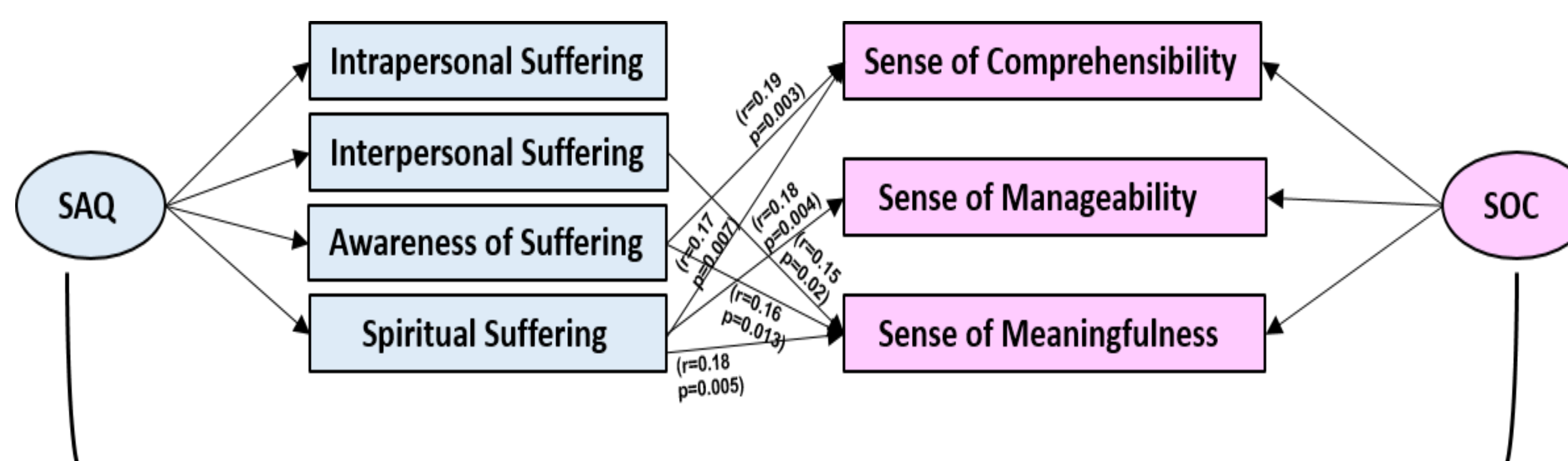
A methodological, cross-sectional correlational study was developed. This study was approved by the Ethics Committee of Abel Salazar Institute of Biomedical Sciences, University of Porto, Portugal (decision 060/2014). We selected the Association of Patients with Multiple Sclerosis and the Association of Patients with Fibromyalgia and Chronic Diseases, because it is an easy way to reach chronic disease patients. In order for the participant group to be more homogeneous, we decided to include people which have been diagnosed with: multiple sclerosis, invalidating arthritis and fibromyalgia. The Associations usually have patients diagnosed on an initial stage of the diseases or middle stage. As we wanted to also include people in advanced stages of their diseases, we chose to access a Palliative Care Unit. Participants in this study had to meet the following eligibility criteria: (1) have no cognitive impairment; (2) demonstrate effective oral communication skills and (3) be aged 18 or over; (4) not have a diagnosed cancer disease. The sample included 100 participants which were diagnosed with Multiple Sclerosis (MS); 51 participants with Fibromyalgia; 50 participants with Invalidating Arthritis and 50 participants on Palliative care (PC). Most of the 50 PC participants had been diagnosed with MS, followed by congestive heart failure, chronic obstructive pulmonary disease and amyotrophic lateral sclerosis. The final sample consisted of 251 people.

### Instruments

In addition to the sociodemographic assessment questionnaire for this specific purpose, the study also included the Suffering Assessment Questionnaire in Adults with Chronic Diseases or Life-Threatening Illness (SAQ) [6] and the translated and validated Portuguese version of Antonovsky's [7] Sense of Coherence Scale (SOC), as well as the translated and validated Portuguese version of O'Brien's [8] Spiritual Assessment Scale (SAS). The authors have authorised the use of the scales for this study.

## Results

The average age of the 251 participants was 50.78 with a standard deviation (SD) of 15.70 (minimum age of 21 and maximum of 89 years). Most of the sample (74.5%) consists of females. The average years of study with academic achievement was 10.42 (SD = 5.45), more or less evenly distributed across the different groups, aged from 4 to 26. Only one participant had no school education. 27.1% of the participants had over 13 years of school education. Only one participant had no school education. 27.1% of the participants had over 13 years of school education.



The SAQ global scale shows a 0.21 correlation with the SOC global scale, but with high statistical relevance (p=0.001), suggesting that the understanding and awareness of suffering may be interpreted as the individual's abilities to manage their internal resistance resources.

It was possible to verify a weak association of Awareness of Suffering (r=0.21; p=0.001) with SAS, as well Spiritual Suffering (r=0.30; p=0.0001) as a weak association with the Spiritual Contentment. These indicators may reveal that the greater the awareness of suffering and the perception that it may bring more challenges and knowledge to life experiences, the greater the spiritual peace felt by people. A weak association between Awareness of Suffering and Religious Practice (r=0.18; p=0.005) was found, that is, people who exhibit greater suffering are less likely to engage in religious practices. In addition, no association was found between SAQ dimensions and Personal Faith.

## Conclusion

From this study, we deduced that as the coherence sense gets stronger, the greatest is the person ability to understand, manage and give a significance to suffering (on its four dimensions: intrapersonal suffering; interpersonal suffering; awareness of suffering and spiritual suffering), meaning that, throughout a strong sense of coherence, the empowerment process aims the promotion of the person's health and has as its goal their development, the increase of its protective factors (the general resistance resources), which allows him to read the reality more easily, find resources and get involved in the resolution of its problems, which leads to the accountability of his health, of its family's health and all the community which he is part of.

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