

Employment of People with Multiple Sclerosis: A Systematic Approach and Comprehensive Questionnaire

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Introduction

Employment is an essential issue of participation in our society. This is even more so for people with a chronic illness such as multiple sclerosis (MS) and it is applicable on a micro-, meso- and macro level. Employment on the micro level, thus on level of the patient and his immediate environment, is related to self-realization, autonomy, structuring of time, social contacts and self-esteem. On the higher meso level, different organizations related to employment of persons with MS (PwMS), such as MS societies, MS centers, labor unions, ... are developing an increasing awareness of the importance of employment and its relevance for patients with MS. Ensuring the accompaniment and/or the pursue of employment can be perceived as a measure of quality of care. Employment is an important contemporary issue on the macro level, the level of the society: there is a growing conviction in Europe that everybody will have to work more and longer to maintain the current level of prosperity. Therefore a number of employment promoting policies have already been implemented to enhance the employment degree of vulnerable individuals such as people with chronic illnesses like MS.

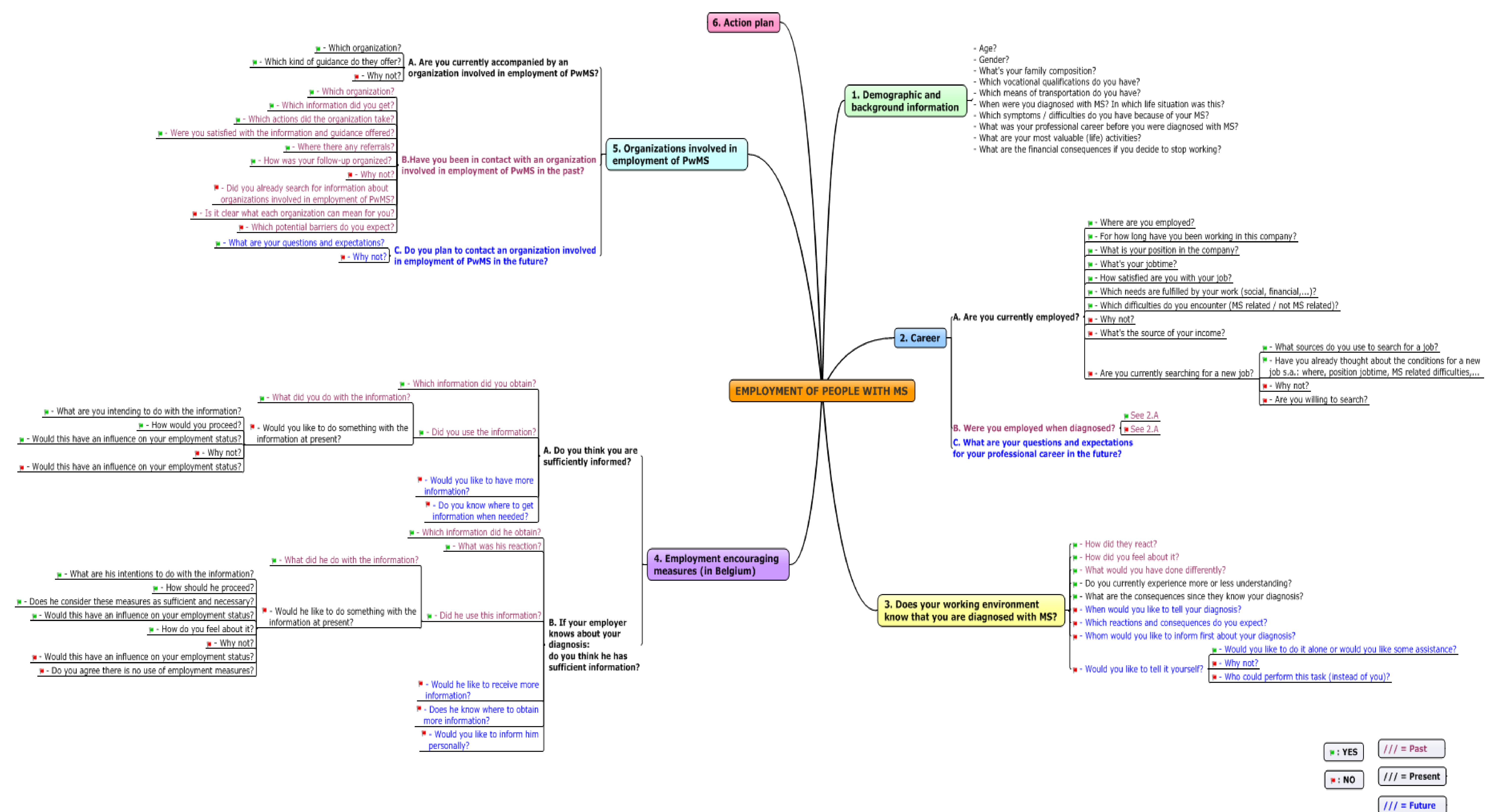
Objective

Our goal was to develop a systematic approach through a comprehensive questionnaire to determine the spectrum of employment related problems encountered by PwMS.

Methods

An initial survey was issued to 32 patients with MS involved in an early guidance program. This care program focuses on assessment and tailor made advices supplemented with hands-on interactions by experienced therapists, and is aimed at PwMS novice to rehabilitation in the National Multiple Sclerosis Center in Melsbroek (B). 26 of them accepted to participate: 14 patients were employed, 7 patients recently quit their job and 5 patients were looking for employment at that time. This survey inquired about the possibilities and obstacles that PwMS experience in the reality of their daily work or search for work. A systematic review of literature was conducted and relevant organizations were contacted for their insights on this topic. This led to the development of a systematic and comprehensive questionnaire.

The systematic and comprehensive questionnaire



A few relevant results

Knowledge of MS

70 % indicates that in the society there exists a lot of misconceptions about MS in general but also about employment of PwMS in particular. (macro level)

Organizations involved in employment of PwMS

60 % believes that too much non-specific information is offered through too many different channels. (meso level)

10 % received inconsistent opinions and advices regarding their employment from different organizations. (meso level)

50 % would appreciate more follow-up of their employment situation. (meso level)

Employment encouraging measurements

35 % is not informed about employment encouraging measurements for PwMS. (meso level)

20 % would like to receive more spontaneous information about their rights as a PwMS in the labor market. (micro level)

Work Environment

65 % experiences fatigue and concentration problems at work but avoids discussing this with their employer. (micro level)

60 % needs support to explain to their employer what MS is and which specific employment encouraging measurements could be applicable for their own situation. (micro level)

100 % wants to inform their employer personally about their diagnosis. (micro level)

Discussion

Each individual employment situation is influenced by several contextual factors. To establish and to chart all the different facets, a systematic tool was devised. This tool has taken the form of a questionnaire with a sequential structure and results in a multidisciplinary (MD, SW, NP, P, OT, VT,...) phased action plan, taking into account all actual and near-future employment needs of PwMS. As such, it composes an overview of the employment situation and also documents associated obstacles. Thus information and advice can be provided in a systematic and pro-active way, finally resulting in an informed decision-making and a concrete action plan by PwMS. If needed, PwMS can be referred to specialized organizations.

Conclusion

The encountered employment impediments detected in our survey are consistent with the results in the literature, however, to our knowledge, exact quantifications of obstacles in regard to employment of PwMS are not available.

We propose that our systematic and comprehensive questionnaire assesses and charts the needs of persons with a work disability (wanting to be) active on the regular labor market. However we also acknowledge that this questionnaire is meant as a guideline and that in-depth interviewing is necessary to explore the whole employment context.

Our initial survey was limited by the restricted number of participants. Future research is necessary to assess the effectiveness of this systematic and comprehensive questionnaire.

■ : YES /// = Past
■ : NO /// = Present
/// = Future