

Unmet Needs of People with Multiple Sclerosis: Findings for an Improvement of the Patient Journey in Portugal

Dimitrovová K^{1,2}, Ferro M¹, Navalhinhas M³, Mata S³, Margarido S³, Andrade S⁴

¹ MOAI Consulting, Lisbon, Portugal; ² Comprehensive Health Research Center, CHRC, NOVA University Lisbon, Lisbon, Portugal; ³ Portuguese MS Society (*Sociedade Portuguesa de Esclerose Múltipla*), Lisbon, Portugal; ⁴ Janssen-Cilag Farmacêutica, Lda, Oeiras, Portugal;

INTRODUCTION

Multiple Sclerosis (MS) is a chronic autoimmune disease that is estimated to affect around 6,585 people in Portugal (64 per 100,000 inhabitants), with the annual number of new diagnoses being 318.¹

Patient engagement is vital in MS, in order to optimize outcomes for patients, society and healthcare systems.² However, to ensure that people with MS are included in shared decision-making and disease management, their perception of key areas for improvement and unmet needs must be identified. The lack of evidence, in Portugal, on these topics motivated the conduct of this study.

OBJECTIVES

- To quantify MS patient satisfaction and main unmet needs during health care provision;
- To characterize the MS patient journey in Portugal, through patient-reported experiences and identification of main unmet needs;
- To propose areas of intervention to meet the identified needs.

METHODS

An exploratory sequential mixed-methods design was implemented. This method involves the integration of quantitative and qualitative results, to provide a more comprehensive understanding of the research topic. The recruitment of participants was made by the Portuguese MS Society.

Quantitative phase – questionnaire

The initial quantitative phase consisted of an online questionnaire (self-reported) targeting patients with MS. The questionnaire contained socio-demographic and clinical questions, as well as close-ended questions on patient satisfactions and unmet-needs.

Qualitative phase – focus groups

The quantitative phase consisted of five online focus groups meetings, with patients with MS, to complement the previously collected data. The focus group script focused on the patient's experiences and unmet needs alongside the patient journey, within five pre-defined steps: onset of symptoms, first appointment, diagnosis, treatment, and follow-up. Subsequently, patients were asked to suggest recommendations that could lead to improvements in their experience.

Descriptive data analysis of the data collected in the questionnaire was complemented with content analysis, and qualitative insights from the focus groups.

RESULTS

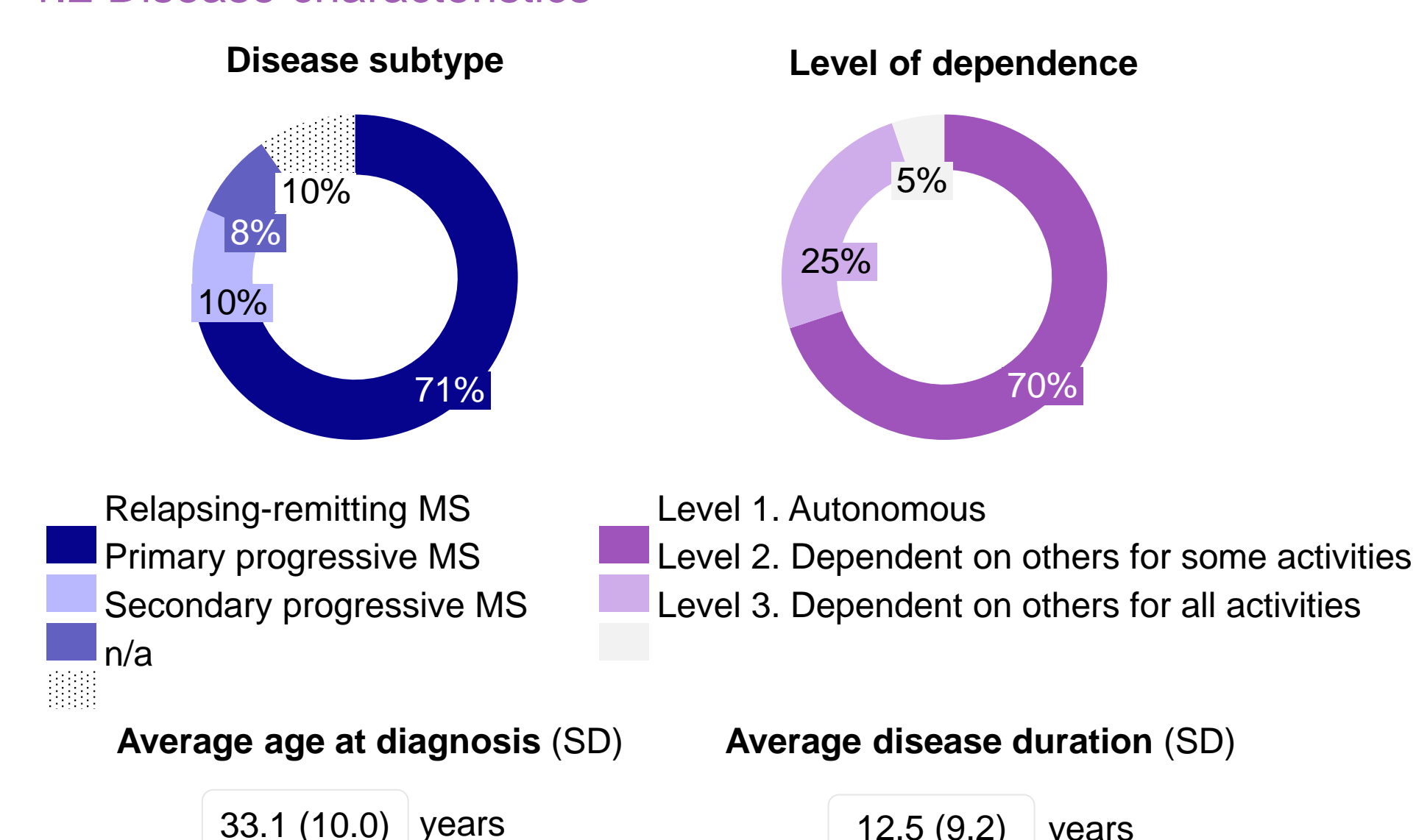
1. Quantitative phase

Between August 2021 to May 2022, 555 patients answered the questionnaire

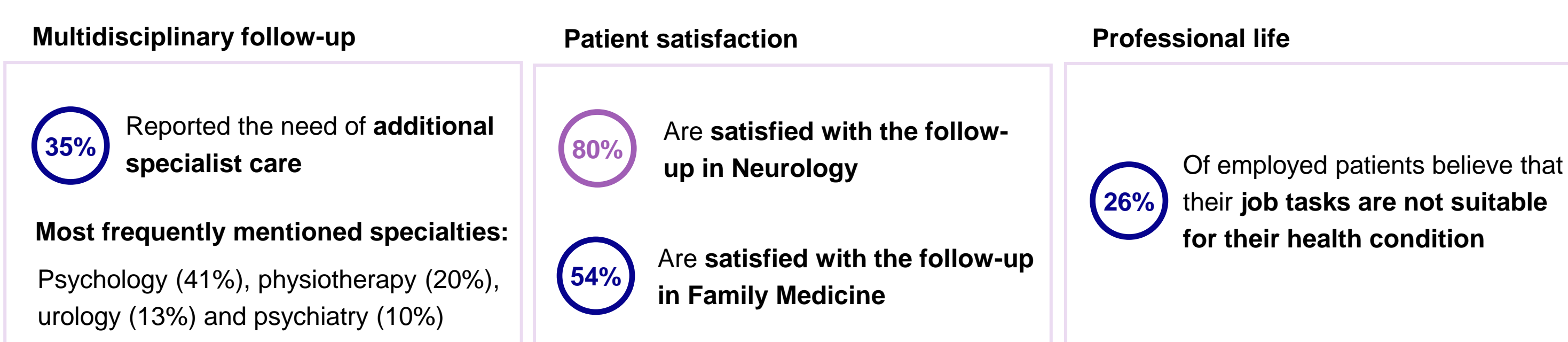
1.1 Patient characteristics

	N (%)
Sex	
Male	392 (71)
Female	163 (29)
Age group (years)	
1-30	49 (9)
31-60	460 (83)
> 60	46 (8)
Level of education³	
Basic	70 (13)
Intermediate	183 (33)
Advanced	302 (54)
Employment status	
Employed	311 (56)
Retired	156 (28)
Unemployed	57 (10)
Other	31 (6)

1.2 Disease characteristics



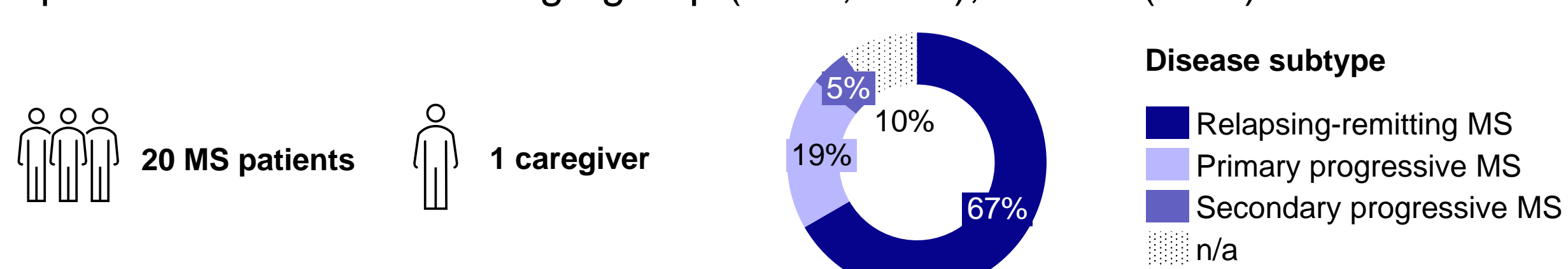
1.3 Patient unmet needs



2. Qualitative phase

2.1 Patient characteristics

During September 2022, 21 people participated in the online focus groups meetings. Most participants were in the 31-60 age group (n=17, 82%), and 12 (57%) were female.



2.2 Main identified unmet needs by patients with MS

Onset of symptoms

- Lack of patient awareness regarding MS symptoms and/or underestimation of these symptoms
- Lack of awareness of MS initial symptoms among healthcare professionals, which can make differential diagnosis more difficult
- Lack of support from family and friends, due to lack of awareness of MS symptoms, which can also contribute to their underestimation

First appointment

- Inadequate responses within the public sector, leading to a delay in the referral process to specialists

Diagnosis

- Delays in diagnostic which can enhance patient anxiety
- Limited time available for clinical consultations for providing all the necessary information
- Insufficient communication about the complexity of MS in a way that is understandable for the patient
- Failure in the provision of timely referrals for psychological support after diagnosis

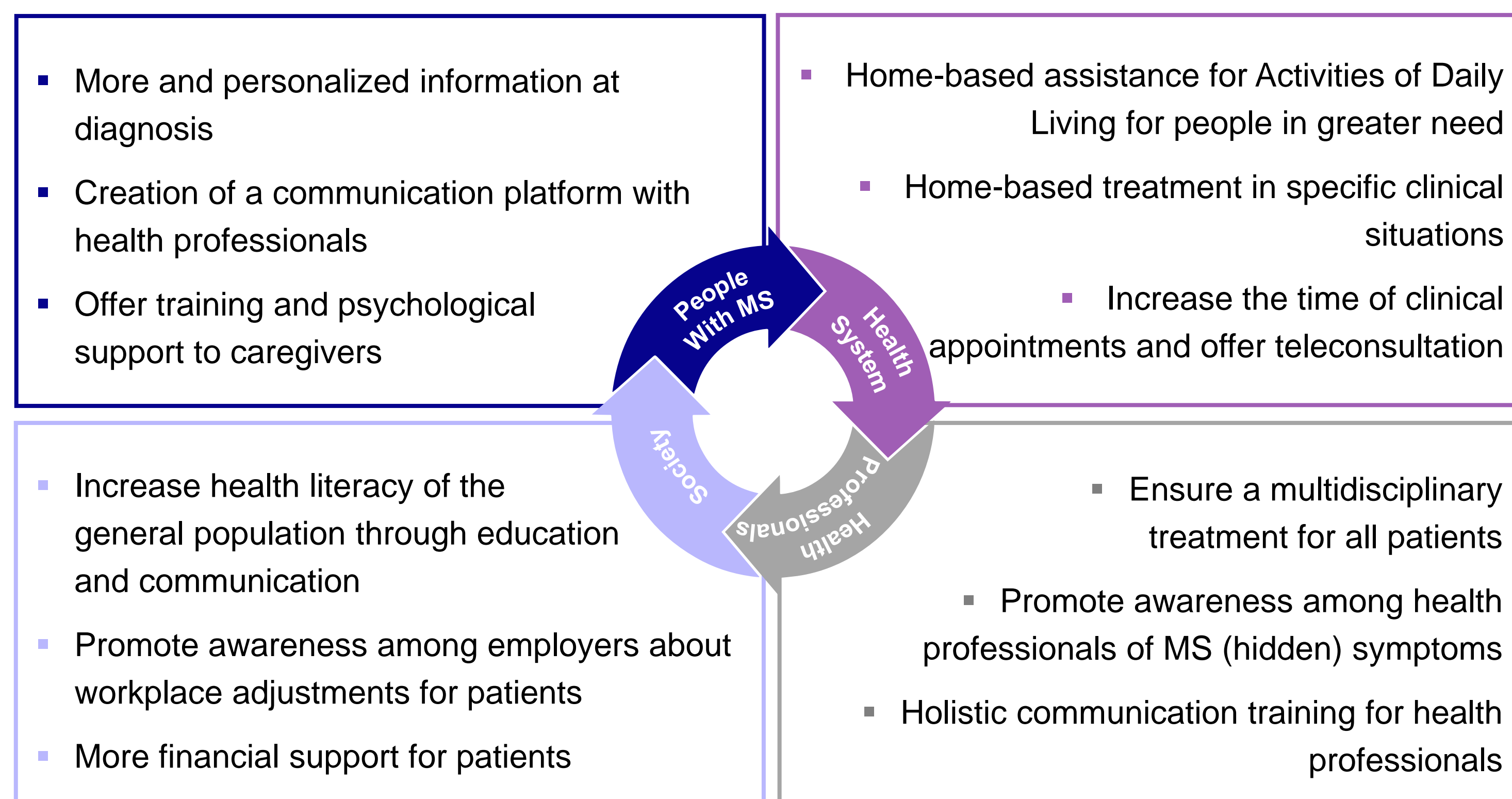
Treatment

- Insufficient information provided regarding the available therapies;
- Lack of inclusion in the treatment decision-making process
- Treatment inefficacy and/or occurrence of adverse events.

Follow-up

- Absence of a multidisciplinary team, including other medical specialists (e.g., psychiatry) and as well as psychologists, physiotherapists and nurses, specially in the rural areas
- Lack of support from social workers to inform patients about their rights and entitlement to social and financial support
- More efficient communication channels with healthcare professionals to answer questions in a timely manner
- Low frequency and limited time available in follow-up consultations in order to address patient priorities
- Lack of training for informal caregivers about MS as well as the support that should be provided to patients
- Insufficient psychological support for families (and informal caregivers)
- Lack of specific strategies for MS awareness in the workplace, and the implementation of work adjustments without discrimination
- Lack of MS awareness, as well as of patients' rights, within other organizations

2.3 Main recommendations proposed by patients with MS



Limitations

- The online methodology may have contributed to a selection bias, since patients from lower socio-economic levels have a lower probability of enrollment;
- The views of patients with higher dependency levels may also be underrepresented.

TAKE HOME MESSAGES

In Portugal, patients with MS face many challenges alongside their journey, especially during medical and social follow-up, which are fundamental throughout life;

This exploratory study can set the starting point for the development of future initiatives to address patients' unmet needs.