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Listening to the neurological teams for multiple sclerosis: the SMART project

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Objective of the research:

- to define the current Italian neurologists and nurses' professional quality of life caring for multiple sclerosis, in their clinical practice and within the working team;
- identify possible signals of distress and compassion fatigue.

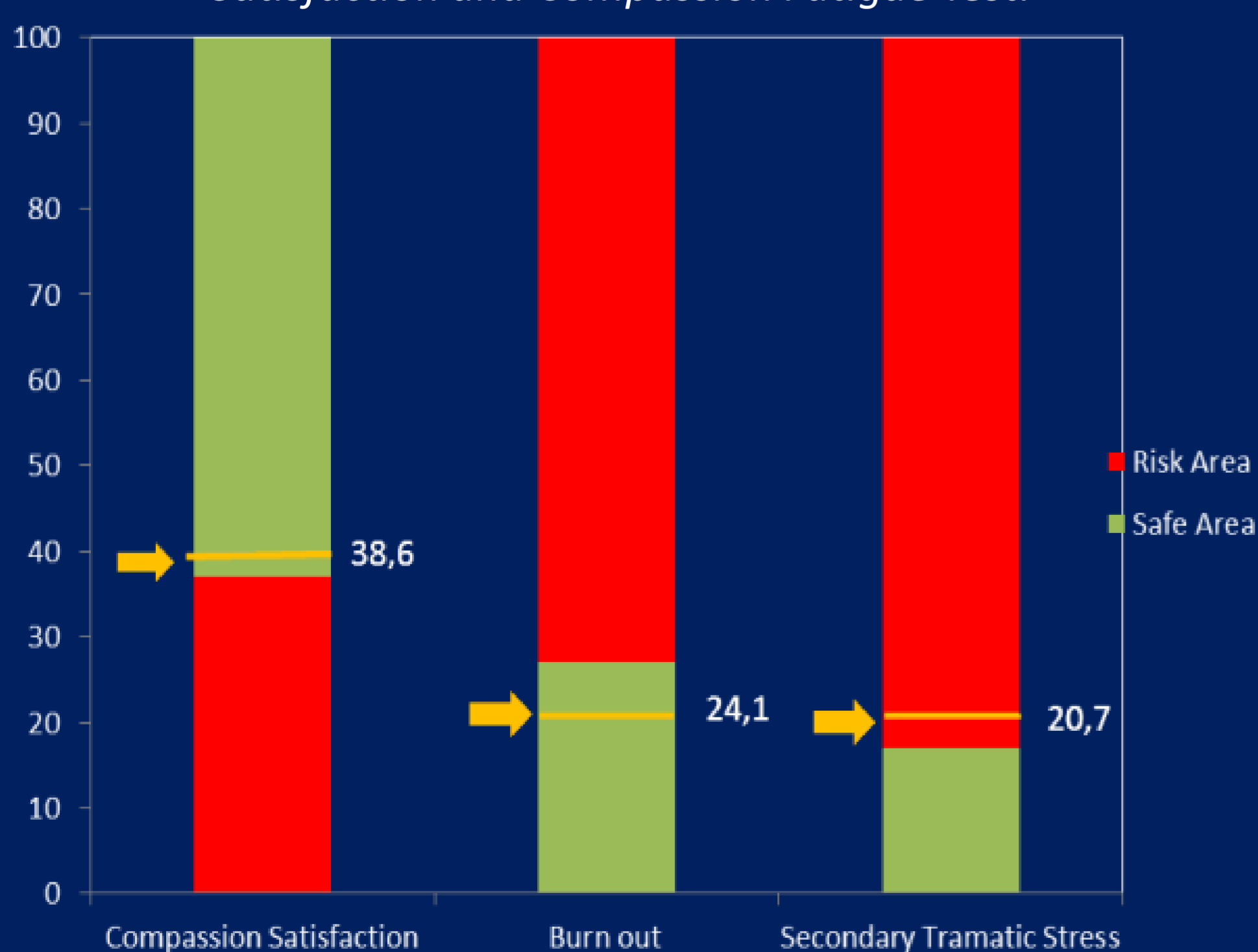
Methods: thirty Italian multiple sclerosis centres were involved in an online quali-quantitative survey on the organization of the cares, combined with the Satisfaction and Compassion Fatigue Test and two Narrative Medicine tools: a semi-structured plot for the professional biographies, and the parallel chart on the relationships of care.

- **The Satisfaction and Compassion Fatigue Test** evaluates the professional quality of life in relation to the work as helper. It incorporates three sections: Compassion Satisfaction, Burnout and Secondary Traumatic Stress¹.
- **Narrative Medicine** has been defined as "what is circumscribed between the physician and the patient, from the collection of information on events before the disease, to how it has been revealed, focusing on psychological, social and ontological implications."² Narrative-based medicine includes the person's experience in coping with distress and its integration with Evidence Based Medicine provides clinicians with fresh methods to fortify their clinical practice.

Results:

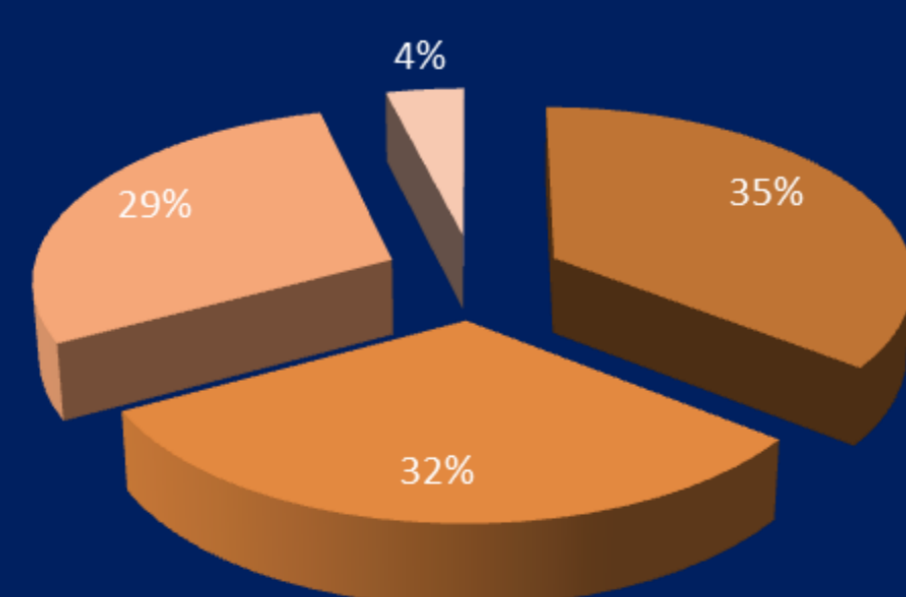
- **From the survey:** most of the health care providers were neurologists, 46 average years old, equally representative of the North and Centre-South Italy. An **increased number of patients** in the last three years was referred in 97% of the centres - mean 77 patients more/year - and 53% of the providers of care were part time dedicated to multiple sclerosis. The positive results in the Compassion Satisfaction (38.6) and the level of Burn Out (24.1) evaluated from the test, appeared threatened by the emerged **risk of Secondary Traumatic Stress** (20.7), enhanced by the intensive working paces and job precariousness, especially from young neurologists – *Graph 1*
- **From narratives:** the professional biographies confirm the results from the quantitative survey: "I am aware of the importance and appreciation of my job, but I am in conflict with administrative and devaluating decisions, worried about the increasing number of patients under my responsibility and the lack of human resources"; "My future is uncertain because of my precarious working condition. This anguishes me, since in the meanwhile my daughter was born". From the parallel charts, both the positive and negative long term relationships of care were depicted as influencing professional quality of life: "The patient didn't come anymore. I saw her again after some years, unfortunately in a progressive phase and on a wheelchair. She told me about many changes of centres of care and therapies. I felt failure for not having been able to build a relationship of care based on trust with her, contributing to this situation"; "For me, it is really satisfying hearing from my patient that when she comes for the therapy she feels cared and as in a family". The openness to their inner emotions and reflections in relating with patients – illness centred narratives - reveals the key role of this tool in reducing the not expressed considerations, which could represent possible sources of stress – *Graph 2*

Graph 1 - The results from the three sections of the Satisfaction and Compassion Fatigue Test.



- Compassion Satisfaction: safe area > 37, risk area < 37
- Burn out: safe area < 27, risk area > 27
- Secondary Traumatic Stress: safe area < 17, risk area > 17

Graph 2 - The Kleinman classification applied to parallel charts



- **Disease:** narratives focused on clinical elements
- **Disease/Illness:** narratives focused both on clinical elements and personal inner reflections and emotions
- **Illness:** narratives focused on personal inner reflections and emotions
- **Sickness:** narratives focused on the social perception of the disease.

Conclusion: a warranted stronger acknowledgment of the neurological teams and more satisfying relationships of care could be the key elements to reduce the risk of compassion fatigue. It is known that the empowerment of the narrative competences improves the professional quality of life preventing burn out³; in addition, Narrative Medicine could give new tools to cope and overcome the perceived limits of the clinical practice, by improving the relationships of care.

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