ORIGINAL ARTICLE

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

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Abstract

Objective Aim of the research was to define the quality of life of Italian neurologists and nurses' professional caring for multiple sclerosis, to understand their living the clinical practice and identify possible signals of compassion fatigue.

Material and methods One hundred five neurologists and nurses from 30 Italian multiple sclerosis centres were involved in an online quali-quantitative survey on the organization of care, combined with the Satisfaction and Compassion Fatigue Test and a collection of narratives. Descriptive statistics of the quantitative data were integrated with the results obtained by the narrative medicine methods of analysis.

Results Most of the practitioners were neurologists, 46 average years old, 69% women, 43% part time dedicated to multiple sclerosis. An increased number of patients in the last 3 years were referred in 29 centres. Differences were found between neurologists and nurses. Physicians showed higher risks of burnout, reporting intensive working paces, lack of medical personnel, and anxiety caused by the precarious employment conditions. Nurses appeared more satisfied, although the reference to the lack of spaces, and the cross professional roles risk of compassion fatigue. Both positive and negative relationships of care were depicted as influencing the professional quality of life.

Conclusion The interviewed neurological teams need to limit the risk of compassion fatigue, which appeared from the first years of the career. The prevalence of the risk among neurologists suggests more awareness among scientific societies and health care managers on the risk for this category, as first step to prevent it.

Keywords Burnout · Compassion fatigue · Narrative medicine

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Introduction

Medical practitioners are continuously exposed to the suffering and the distress of patients, and this painful reality can lead to compassion fatigue, burnout, and professional distress, and result in a low sense of accomplishment and severe emotional exhaustion [1]. In addition, career dissatisfaction, excessive workload (i.e. hours and patient volume), loss of autonomy, inadequate support staff, and increased administrative duties are associated with the high prevalence of burnout [2]. All these elements can have a negative effect on an individual's enjoyment of work and might result in poor patient care and satisfaction [3, 4].

Burnout (BO) has been described as a combination of emotional exhaustion, depersonalization, and personal accomplishment [5]. Compassion fatigue (CF) is a state of physical or psychological distress, consequent to an ongoing process in a demanding relationship with needy individuals [6, 7]. CF is composed of secondary traumatic stress (STS), secondary exposure to people who have experienced extremely or traumatically stressful events [8], and compassion satisfaction (CS), which determines the positive effects from the professional role of helper, resulting in work satisfaction and wellbeing [9].

In USA, burnout resulted more prevalent among physicians than the general workforce [10]. More, it has been showed that burnout prevalence, career dissatisfaction, and work–life imbalance are higher among neurologists than physicians in most other specialties [11]. The care for specific neurologic illnesses requires more hours of dedication and intellectual and emotional engagement [12], such as a sense of failure and frustration when the patient's illness progresses, facing uncertainty in clinical practice, or a desire to separate from and avoid patients to escape these feelings [13]. Repeated exposure to these emotions and experience of distress contributes to the high levels of stress doctors experience in their profession. No specific studies were carried out to investigate the possible risk of BO and CF in carers for multiple sclerosis (MS), although it is possible to consider this condition among the neurological illnesses requiring more health providers' engagement. MS is increasing in Italy and worldwide, both in its incidence and prevalence [14, 15]; it predominantly affects young adults of female sex (female to male ratio 2.5:1 or greater), although the disease may begin in children [16] and subjects over the age of 60 [17]. The improvements in therapy for MS increased the complexity of care, requiring the management of a long-term disability, with a considerable variability of patients experience along the pathway of care [18–20].

In such contexts of care, knowing better the health care providers' point of view is at the basis of a process to support their living the clinical practice. Together with validated tests and questionnaire, this activity can be carried out also through narrative medicine, which has been defined as the set of relationships between the health professional and the patient, starting from the collection of information on events before the disease, to how it has been diagnosed, focusing on psychological, social, and ontological implications for the patient [21, 22]. While evidence-based medicine (EBM) focuses on clinical processes and problem solving, narrative-based medicine (NBM) includes the person's experience in coping with distress [23]. The integration of EBM and NBM provides clinicians with fresh methods to fortify their clinical practice with narrative competences [24, 25]. The World Health Organization (WHO) recommends the use of narrative research to improve health care policies "at the level of the individual, the health professional, the health care organization, and the health care system" [26]. The narrative medicine tool for collecting health care providers' perspective is the "parallel chart", which allows physicians to represent also their emotional reactions to clinical practice [27, 28].

The "SMART Project—Listening to the Neurological Teams caring for Multiple Sclerosis" was designed and carried out by the Healthcare Area of Fondazione ISTUD, with the active support and participation of the Italian Society of Neurology and the Italian Multiple Sclerosis Study Group, with the aims to implement sessions of active listening for the neurologists and nurses composing the neurological teams for MS, to evaluate their experiencing the professional role and ordinary work, and identify possible signals of compassion fatigue.

Material and methods

From March to June 2018, 30 Italian MS centres were involved in an online quali-quantitative survey, disseminated through the website www.medicinanarrativa.eu/SMART. The materials and method of analysis were agreed upon by the Steering Committee of the project board. All the participants were informed of the research aim and submitted their narratives voluntarily. Written informed consent was gained in compliance with the current Italian data privacy law [29]. The MS centres were selected in order to obtain an equally representative scenario of the different geographical areas, Northern, Central, and Southern Italy, and dimensions, small, medium, and big centres of care, calculated on the basis of the officially declared number of patients cared for.

The survey included three sessions: (1) a section to collect information on the organization of the cares; (2) the Satisfaction and Compassion Fatigue Test; (3) the Narrative Medicine section, to collect health providers' narratives—Supplemental material 1. The first quali-quantitative section aimed to collect the respondents' main socio-demographic data, information on the organization of the work—numbers of patients, times, spaces, and team of care—and on their living the professional role, throughout the expression of metaphor and the Plutchik Wheel of Emotions; this model is

Table 1 Health providers' characteristics

Health providers' characteristics	N = 105		
Women % (n)	69 (72)		
Men % (n)	31 (33)		
Mean age	46 (min 28, max 71)		
Professional years	18 (min 1, max 46)		
Area of residence % (n)			
Northern Italy	49 (51)		
Central Italy	16 (17)		
Southern Italy	35 (37)		
Work setting % (n)			
Public hospital	48 (51)		
University public hospital	40 (42)		
Private hospital	9 (9)		
University private hospital	3 (3)		
Professional specialization % (n)			
Neurologist	73 (77)		
Nurse	27 (28)		
Neurologists professional role % (n)		Nurses professional role % (n)	
Head of department, responsible	25 (19)	Coordinator, case manager	11 (3)
Doctor	51 (39)	Nurse	86 (24)
Researcher, under training	17 (13)	Under training	0 (0)
Freelance	2 (2)	Freelance	0 (0)
Unspecified	5 (4)	Unspecified	3 (1)
Neurologists employment % (n)		Nurses employment % (n)	
Permanent contract	66 (51)	Permanent contract	100 (28)
Fixed-term contract	17 (13)	Fixed-term contract	0 (0)
Fellowship	9 (7)	Fellowship	0 (0)
Freelance	3 (2)	Freelance	0 (0)
Internship	1 (1)	Internship	0 (0)
Unspecified	4 (3)	Unspecified	0 (0)

based on the eight basic emotions—joy, trust, fear, surprise, sadness, anticipation, anger, and disgust—and the different degrees, named secondary emotions [30].The second section included the Satisfaction and Compassion Fatigue Test, which evaluates the professional quality of life in relation to the work as helper. It incorporates three elements of analysis: CS, BO, and STS. The test is composed of 30 items to be evaluated according to a score from 1 (never) to 5 (very often); specific steps have to be carried out, in order to obtain three scores, respectively related to CS, BO, and STS [31]. Finally, the third session of the survey was dedicated to the collection of the health providers' narratives; in particular, they were invited to follow a semi-structured plot on their professional biography, and to write two parallel charts related to two specific stories of care for MS.

Data and text analysis

Data and narratives were collected through the Survey Gizmo online survey platform (www.surveygizmo.com); at the end of the survey period, raw and anonymous data were downloaded as an Excel spreadsheet (Microsoft, Redmond, WA, USA). All data

Table 2 Numbers of people with MS*

Estimate average number of MS patients/year	2015	2016	2017	Average increase/year	% of MS patients
Number of MS patients referred at the centre	1182.65* (min 80, max 3000)	1269.27* (min 70, max 3500)	1337.71* (min 80, max 4000)	+ 77.4 (min 5, max 1000)	/
Number of MS patients visited by the singular respondent	397.30 (min 10, max 2000)	420.67 (min 15, max 2000)	444.54 (min 20, max 2000)	+ 23.6 (min 0, max 440)	33
Number of MS patients with EDSS > 8	31.61 (min 0, max 200)	33.44 (min 0, max 200)	44.70 (min 0, max 400)	+ 6.5 (min 0, max 100)	3
Number of MS patients with cognitive problems**	212.15 (min 0, max 1500)	239.3 (min 0, max 1500)	259.43 (min 2, max 1500)	+ 23.6 (min 0, max 600)	19

* The reported numbers are estimations based on the aggregated respondents' declarations, which in 23 out of 30 centres of care differed among members of the same care team. More, the table reports data from centres of care with different dimensions, revealing a wide range

** Deficits in complex attention, executive functioning, processing speed, and long-term memory

Table 3 MS care team composition

MS care team average composition	Care team	Multidisciplinary group	Consultant
Physicians	5.1 (min 1, max 23)	4.7 (min 0, max 22)	4.1 (min 0, max 15)
Nurses	3.6 (min 0, max 14)	2.1 (min 0, max 12)	0.3 (min 0, max 3)
Physiotherapists	2.6 (min 0, max 15)	2.1 (min 0, max 10)	1.5 (min 0, max 10)
Psychologists	1.6 (min 0, max 6)	1.3 (min 0, max 6)	0.8 (min 0, max 6)
Social workers	0.6 (min 0, max 2)	0.7 (min 0, max 2)	0.5 (min 0, max 2)
Volunteers	1.2 (min 0, max 5)	0.8 (min 0, max 2)	0.4 (min 0, max 4)
Average MS care team composition	14.7	11.7	7.6

were self-reported and submitted anonymously. No patient-sensitive data were reported.

Descriptive statistics of the quantitative data were integrated with the results obtained by the Satisfaction and Compassion Fatigue Test and the narrative medicine methods. Two researchers independently read and analysed the texts, according to frameworks for thematic content, and the following classifications:

1. Launer and Robinson classification: progressive/stable narratives. This model is based on the individual's ability to cope with a difficult, uncertain situation. Progressive narratives show coping strategies, whereas in stable narratives the person fails to control the situation [32].
2. Kleinman classification: disease/illness/sickness-centred stories. In this model, disease narratives focus on the clinical evolution of the condition, using a highly technical language, whereas illness narratives highlight the individual's emotional and relational experiences in an open and flowing narration. Sickness is the perception of the society with respect to a given condition [33].

Narratives were also clustered through the semantic evaluation software NVivo 10 (QSR International, Melbourne Australia) [34, 35].

Results

One hundred five health care providers participated to the survey, from 30 Italian MS centres of care. Most of them were neurologists, 46 average years old, 69% female, equally representative of Northern and Central-Southern Italy. Although stable working conditions prevailed, precarious contractual conditions were referred by young neurologists (Table 1).

During the 3-year period 2015–2017, an increased number of people with MS were referred in 29 out of 30 centres—average increase 77.4 per year. This higher number emerged also at individual level, since each provider of care visited an average of 23.6 more MS patient per year. Also, the number of cases with EDSS > 8 and cognitive problems increased (respectively average + 6.5 and + 23.6 per year), indicating an intensification of the complexity of care (Table 2).

Fifty-three percent of the providers of care were part time dedicated to MS, of whom 43% were represented by neurologists (58% of all the neurologists), who stated to care for other activities and diseases within the Neurology Departments. The organization of the work was mainly based on care teams composed by neurologists and nurses, and less frequently physiotherapists and psychologists, showing wide differences among the centres (Table 3).

Despite the general satisfaction for the working team (88%), 32% of respondents reported poor autonomy in the management of the times of care, and 59% not adequate times and spaces for sharing among colleagues. Furthermore, while the collaboration within the health care facilities were mainly evaluated as sufficient, the collaboration with providers of care on the territory, such as family doctors or specialists, were considered poor or lacking. Indeed, the development of local networks was the most common requirement (40%), followed by the need to increase the staff (33%); in particular, lack of neurologists and psychologists were underlined (Supplemental material 1, Sections C-D-E).

Thirty-eight percent of the respondents did not answer to the request to describe the own professional role through a metaphor. Among those who expressed it, the images used were representative of the general strong motivation and engagement in the relationships of care, but also of the perceived burden: the protective helper (33%); the guide and point of reference (18%); the requiring for help and support (18%) (Supplemental material 2).

From the Plutchik Wheel, the most common emotions felt by the respondents in the last current month—at the moment of the survey—were anticipation (28%) and trust (20%). However, differences were found between neurologists and nurses, ages and gender: trust prevailed among nurses (P value 0.01 to 0.05—significant), while physicians and the youngest health care professionals reported more sadness (P value < 0.001—very significant) and fear (P value 0.001 to 0.01—very significant); anticipation and fear were more frequent among women (respectively P value 0.01 to 0.05, and < 0.001), while men tended to respond less frequently to this specific question (P value < 0.001) (Fig. 1).

From the Satisfaction and Compassion Fatigue Test, the sufficient results of CS (38.6) and BO (24.1) appeared threatened by the emerging risk of STS (20.7). Again, differences
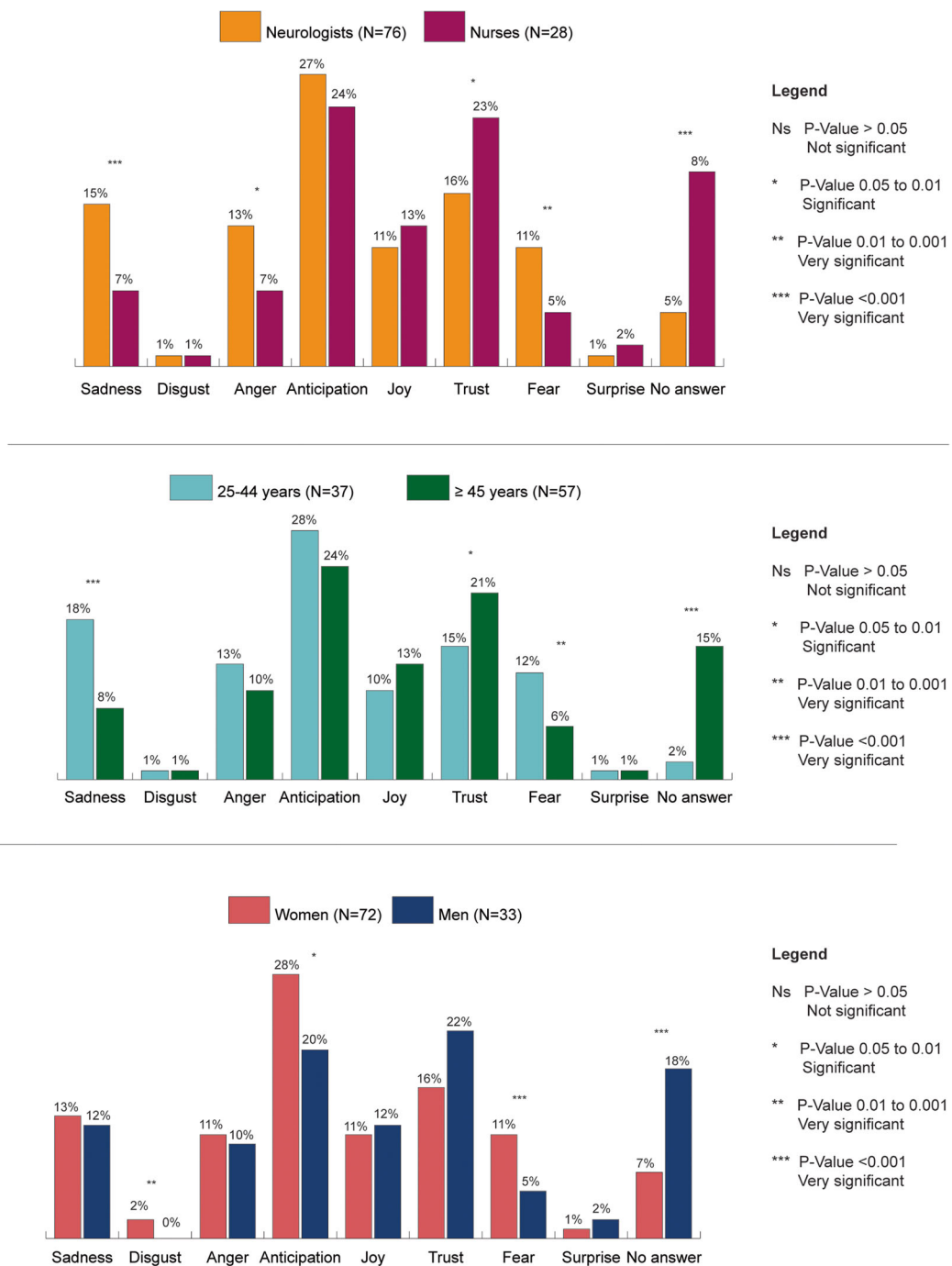
Fig. 1 Emotions

were found according to professional role and age, but only related to CS and BO: neurologists and the youngest health care professionals showed lower levels of CS (P value < 0.001) and higher risks of BO (respectively P value < 0.001, and 0.01 to 0.05), while STS resulted transversely high (P value > 0.05—not significant). No gender differences emerged (Figs. 2, 3, and 4).

Findings from narratives

Eighty-five percent of the involved providers of care wrote the own professional biography and two parallel charts each.

From the biographies, talking about the present, the ordinary burden—identified with the increased number of patients and the lack of time—prevailed among the health care

Fig. 2 Compassion satisfaction
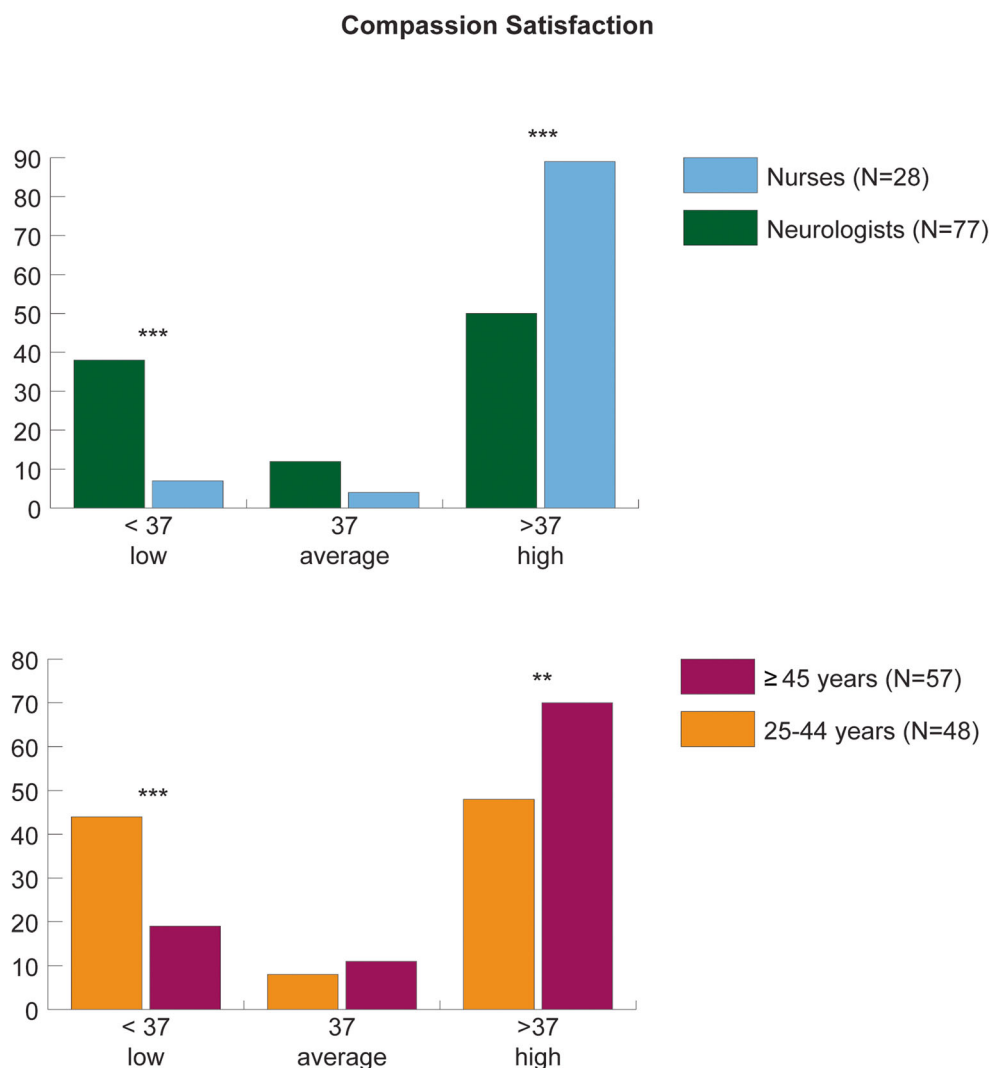
Compassion Satisfaction

Legend

Ns	P-Value > 0.05	Not significant
*	P-Value 0.05 to 0.01	Significant
**	P-Value 0.01 to 0.001	Very significant
***	P-Value <0.001	Very significant

professionals (22%), followed by elements of satisfaction (20%), awareness on the own professionalism (14%), and gratification from wider possibilities of care offered by therapeutic innovations (11%). Willing to continue and improve the career path and to pay attention to the patient (28%), trust toward new therapies (15%), but also the professional uncertainty and the precarious working conditions (11%) were the themes expressed about the future (Supplemental material 3).

From the analysis of the 170 parallel charts, 46% focused on cases with positive outcomes of cure, while the remaining part divided between uncertain and negative results (27%

each). The people with MS' average age told in the narratives was 30, and the most recurring element emerging in 58% of the narratives was their young age—22% of the parallel charts concerned minors. This issue was frequently underlined by the providers of care, particularly involved in the relationships of care with these patients. The quality of the relationships of care was the second more recurring element (49%), equally represented by relationships considered positive from the beginning of the pathway of care, lived with difficulty at the beginning, and then developed more positively, or remained difficult. Twenty-eight percent of the parallel charts focused

Fig. 3 Burnout
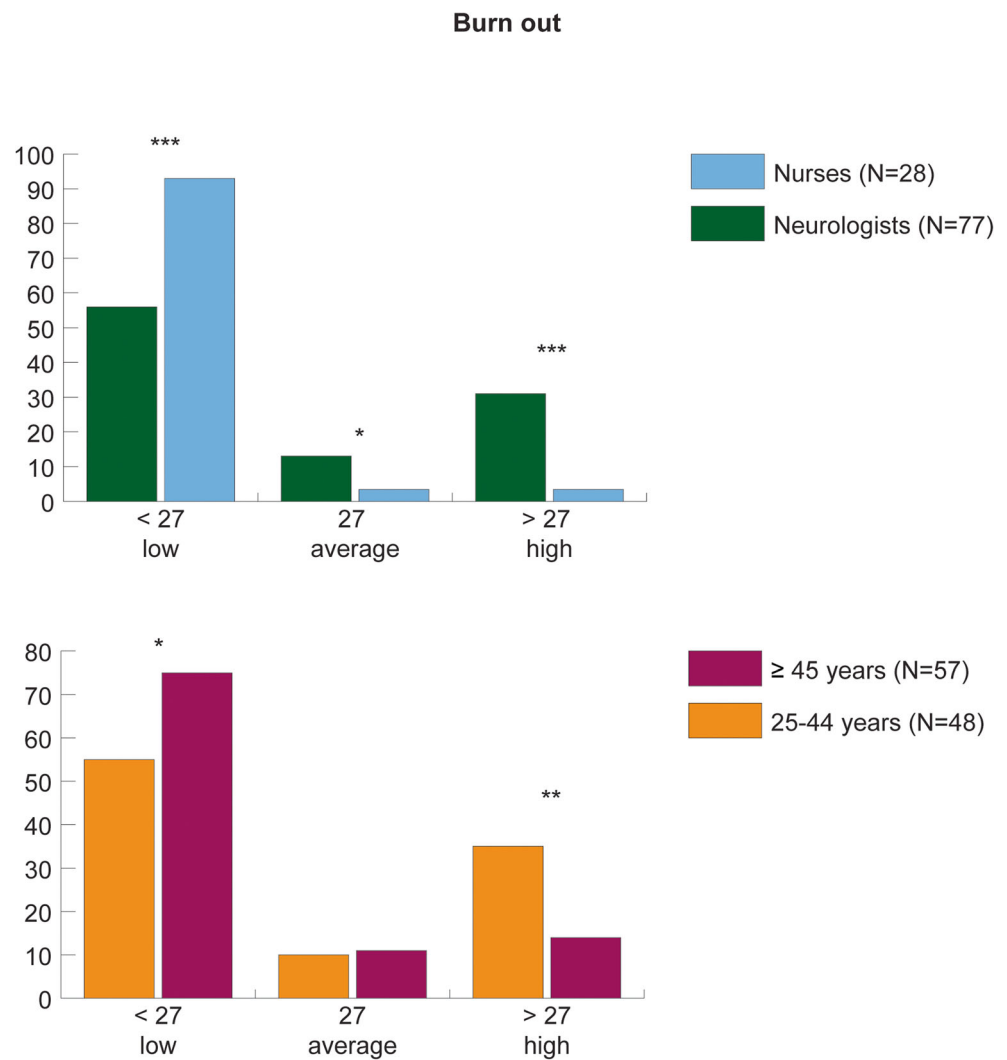
<div align="center">Burn out</div>

Legend

Ns	P-Value > 0.05	Not significant
*	P-Value 0.05 to 0.01	Significant
**	P-Value 0.01 to 0.001	Very significant
***	P-Value <0.001	Very significant

more on the care process, describing stories of therapeutic success or failure, equally represented. Finally, 12% of the narratives concerned pregnant patients (Supplemental material 4).

The language of the narratives

Referring to the Launer and Robinson classification, the narratives were mainly progressive (66%), for the presence of the following elements of coping, able to maintain a positive expectation for the future: the strong medical interest in the care for MS (21%), the awareness of the own professionalism (18%), the relationships of care (13%). However, the remaining 34% of narratives revealed to be stable, for the presence of elements deactivating the coping resources, such as the professional uncertainty (25%), the concern about future organizational set-up of the care (22%), and the workload (11%).

From the Kleinman classification, both the professional biographies and the parallel charts revealed the prevalence of a disease-centred language, rich of technical and clinical terms, and more focused on the care process content. Nevertheless, a difference between the two different tools was evident: while in the professional biographies the disease prevailed in 84% of the texts, in the parallel charts it decreased

Fig. 4 Compassion fatigue/
traumatic stress

Compassion Fatigue/Traumatic Stress
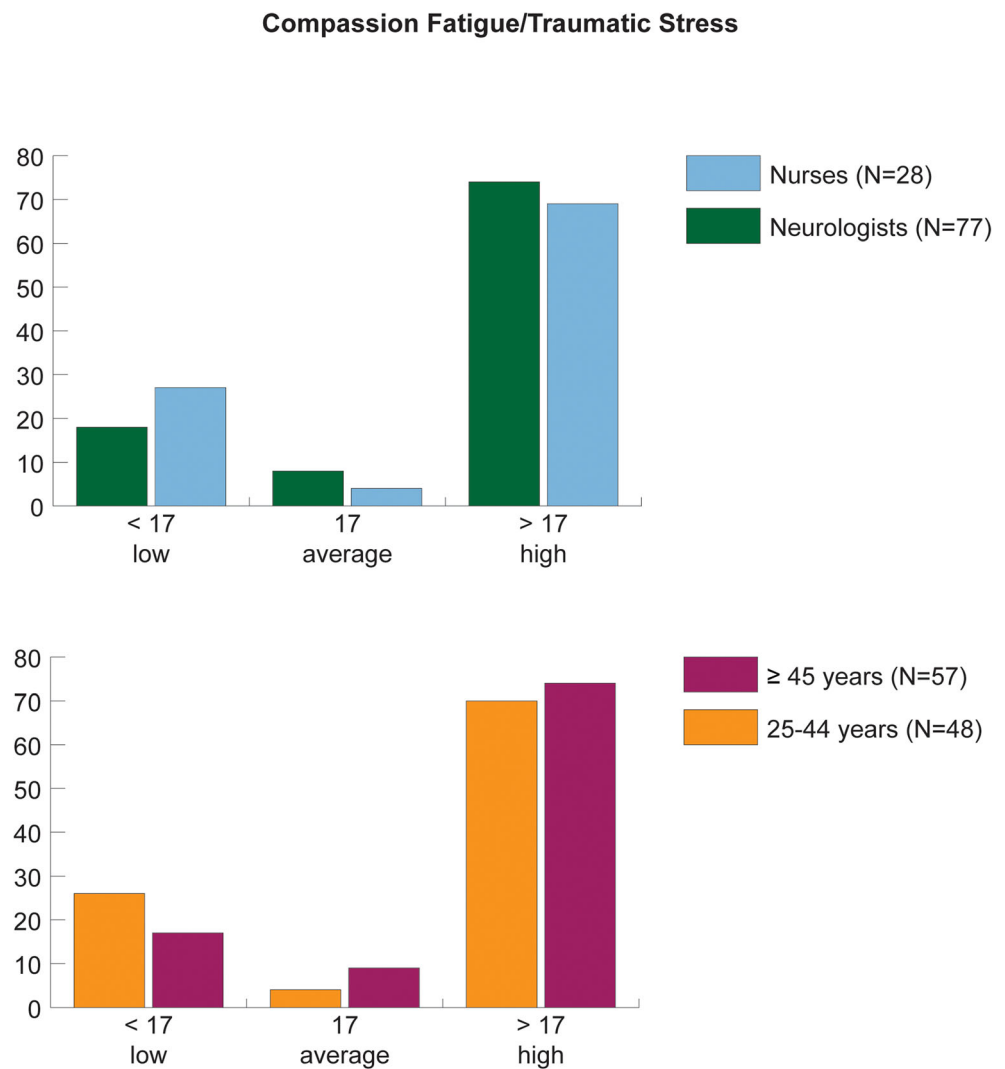
to 68%, revealing a wider space for the elements of illness, represented by contents on patients' inner, family and social lives, personal reflections, and emotions in the relationship with them. Elements of sickness were usually missing.

Discussion

The SMART project represented the first systematic activity of listening to the Italian neurological teams caring for MS. The first consideration is about the notable participation of the providers of care, who offered their time and energy for this unusual survey, not only through data, since 85% of them also shared their narratives and inner considerations.

The unveiled scenario of the wellbeing of these care teams was double. From one side, the consulted health care providers revealed a strong professional interest, motivation, and gratification, reinforced by the therapeutic innovations and the positive relationships of care; more, nowadays, MS facilities are considered as centres of excellence. On the other

hand, all this risks to be insufficient to support the paradox of the increasing burden and number of patients (average + 77 per year), and the decrease of the staff, times—58% of the neurologists was part time dedicated to MS—and also spaces. Finally, the lack of local networks increases the team's workload, for the impossibility to transfer some services of care on the territory. This situation can partially explain the not so positive result from the Satisfaction and Compassion Fatigue. Although the scores of CS and BO were "technically" positive, their values were close to the limit between positive and negative result, and the final section on the STS was clearly negative. More, analysing the details of these results, it is remarkable that neurologists revealed the lowest levels of CS and the highest risks of BO and STS. Integrating the test with the quantitative survey, they resulted the category with less time available and more precarious working conditions (all the fixed-term contracts were from neurologists).

The collected narratives not only confirmed this scenario, but gave further elements and perspectives to understand the providers of care' level of wellbeing. From the professional

biographies, the concern about the uncertain working conditions was underlined; this uncertainty was not only referred to the contractual situation, but it was enlarged to the worry about current and future tendencies of the organizational setting of care, more and more challenging and stressing. More, from the parallel charts, a new element to understand the negative result of STS was given: more than 50% of the narratives concerned the people with MS' young age; this element was often underlined by the health care providers, who revealed to be particularly engaged in these relationships of care. Many recurring expressions were referred to the possible mirroring with young patients and the strong personal involvement. This evidence suggests an implicit request to receive more support in facing this daily emotional burden, to which probably the carers were not trained and prepared, considering that the decrease in people with MS' age comes from the recent revision of diagnostic guidelines allowing for early diagnosis, together with the evolution of the incidence and prevalence of the disease. Furthermore, the collected narratives represented a precious tool to express and give space to considerations and emotions in relating with patients—illness centred narratives—which in the ordinary professional settings can be repressed, contributing to increase the levels of stress. Indeed, the positive effect of the narrative medicine approach on daily practice and professional quality of life, preventing burnout, has been shown [36–38].

The present survey showed the excellent qualities of health care providers, which need to be preserved, in order to face the increasing number of people with MS.

Compliance with ethical standards

Conflict of interest None.

Ethical approval None.

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