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Epileptologists telling their experiences caring for patients with epilepsy

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ABSTRACT

Objective: This research was focused on expert professionals in epilepsy care to understand their points of view on the care pathway and their living relationships with patients.**Methods:** Researchers prepared a semi-structured parallel chart and distributed it online among 21 Italian centres of care. Each health professional was prompted to write five narratives on cases of patients with epilepsy, subsequently analysed through narrative medicine methods. Next, a consensus meeting was held, to individualise an action plan based on the narratives.**Results:** Ninety-one parallel charts were collected from 25 epileptologists, who had a mean age of 50 years; their narratives concerned patients with a mean age of 37 years, with different types of epilepsy (53 % drug-resistant; 31 % unemployed). The limitations in the daily life of people with epilepsy (57 %), employment (42 %), caregiver burden (51 %), and the universal prevalence of fear were the primary topics that emerged. Attentive and reassuring care relationships were found to be the main element of coping (21 %). A new multi-factorial classification of epilepsies, integrating clinical with social and legal risk factors, was the main agreed action to face the issues identified.**Conclusions:** The narrative medicine approach supplied a broader scenario of living with epilepsy, including the family and social impact and possible effects on the choices for care pathways. The epileptologists showed a strong motivation to care for patients with epilepsy and deep involvement in the care relationships; the use of parallel chart demonstrated to be an effective tool to preserve their wellbeing.

1. Introduction

Epilepsy affects 70 million people worldwide, 90 % of whom are in developing regions [1]. In Italy and other European countries, seizure disorders are among the most widespread neurological diseases, which affect an estimated 500.000 people with more than 30.000 new diagnoses every year [2,3]. More than one factor makes epilepsy a complex disease: its definition is regularly reviewed based on the new seizure criteria and classifications [4,5]; there are still unknown causes [6], and several cognitive mechanisms remain undefined [7]; its course can change in response to treatment [8]; finally, because of drug-resistant epilepsy [9], more than one-third of patients do not achieve seizure control by current treatments [10].

Although up to 75 % of people with epilepsy can live a free-from-seizures life, if they are appropriately treated [11], approximately 50 % of patients experience stigmatisation and social exclusion, from school to employment [12–14], including the possibility of motherhood for women [15]. These difficulties may crucially impact people with epilepsy and their family members [16,17].

Therefore, care is not limited to biological and clinical issues since physicians must address and treat of the overall consequences of the stigma, which can affect the care pathway. In such a context, better knowledge of the health care providers' points of view could be the basis of fostering their clinical practice. This activity can be conducted through narrative medicine (NM), namely, the set of relationships between the health professional and the patient, starting from the collection of information on events before the disease to its appearance, focusing on the psychological, social, and ontological effects on the patient. NM can be applied in clinical practice, in the education of patients and health professionals, in communication, and as narrative research [18,19]. While evidence-based medicine (EBM) focuses on clinical processes and problem-solving, narrative-based medicine (NBM) includes the individual experience coping with distress. The integration reflects the difference between 'disease' and 'illness': the former means an objective alteration of the biological structure or functioning of the body; the latter refers to the human experience of living with a physical condition, including perceptions, feelings, and thoughts. Furthermore, narratives integrate the element of the 'sickness', namely, the social perception of

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¹ Full details available in [Appendix A](#).

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the disease [20]. The integration of these dimensions provides clinicians with new methods to fortify their clinical practice with narrative competencies [21,22]. World Health Organization (WHO) recommends the use of narrative research to improve healthcare policies [23].

The ERE project - Epileptologists tell Epilepsy - (in Italian, 'gli Epilettologi Raccontano l'Epilessia') was created by the Healthcare Area of ISTUD Foundation with the active support and participation of the ILAE Italian chapter of Lega Italiana Contro l'Epilessia (LICE). The project aimed to listen to professionals with expertise in epilepsy about their daily experience and care relationships, enabling them to test new tools from NM to improve their relational competencies.

2. Methods

The research was conducted from September 2018 to May 2019, included epileptologists from 21 Italian centres of care and was disseminated through the website www.medicinanarrativa.eu/ERE. The Steering Committee of the project board agreed on the materials and methods of analysis. The centres were selected to obtain an equally representative sample of the different geographical areas—Northern, Central, and Southern Italy.

The project was approved by the Ethics Committees of the Umberto I General Hospital of Rome and the Oasi Santa Maria SS Scientific Institute for Treatment and Research of Troina. All physicians voluntarily participated in the survey, and written informed consent was obtained in compliance with the current Italian privacy law [24].

Before being involved in the survey, all participants were trained on NM and informed of the aim of the research throughout a training webinar. 'Parallel chart' was the NM tool adopted for collecting health care providers' testimonies, which was conceived as a space where clinicians can record their impressions, with integration of technical and quantitative medical reports [25]. This tool allows expanding the physician's focus beyond clinical data to envision the person as a whole - including desires, interests, and life projects - and to express emotional reactions to clinical encounters [26]. For the specific purpose of the present survey, the parallel chart was designed through a semi-structured plot with short prompts to stimulate physicians to open themselves up along the whole chronology of the care pathway. The first section aimed to collect the main physician' and patient' sociodemographic data and characteristics of epilepsy (Fig. 1). Respondents were required to write five parallel charts each, referring to five experiences of epilepsy care that occurred within the timeframe of the survey; the selection of the cases was independent of the patient's type of epilepsy, the duration and outcome of the care pathway, and the perceived quality of the care relationship.

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

Two researchers independently read and analysed the texts according to frameworks for thematic content and the following classifications:

- Kleinman's classification: disease/illness/sickness-centred stories. Disease narratives focus on the clinical evolution of the condition, using highly technical language, whereas illness narratives highlight the individual's emotional and relational experiences. In sickness narratives, the social perception concerning a given condition prevails [27]. This classification allowed us to understand whether the parallel chart was helpful to use a different and less technical language.
- Bury's classification: contingent/moral/core narratives. The contingent form corresponds to the factual narrative, containing the analysis of causes, symptoms, and effects of a condition. Moral narratives refer to the personal social-cultural context or belief connected to the disease, introducing an evaluative dimension. The core forms reflect

the deeper personal meaning and feelings in the illness experience [28]. This model enabled us to identify the physicians' levels of involvement in the care relationships and the presence of any possible judgements towards their patients.

The coping strategies developed along the care relationships were analysed referring to Carver's model; in particular, the activating or deactivating coping factors were individuated [29].

Finally, narratives were clustered through the semantic evaluation software NVivo 10 (QSR International, Melbourne Australia) [30,31].

The analysis of the narratives was validated and integrated through a consensus meeting conducted with the Steering Committee of the project board and a selected group of 12 epileptologists involved in the survey. The participants were selected based on their geographical location, gender, and age to obtain a heterogeneous representative group; their number was limited to allow direct interaction among them. Consensus methods aimed to determine the extent to which experts agree about a given issue. The consensus meeting followed the nominal group technique methodology, consisting of an alternation between plenary sessions and working groups, the presence of one expert on the topic, and the supervision of a facilitator for each group. In the last plenary session, the proposals from each group were announced and further debated until consensus was reached [32].

3. Results

Twenty-five epileptologists from 21 Italian centres of care wrote 91 narratives. Sixty percent of them were male, with a mean age of 50 years, who were mostly neurologists working in university hospitals, and there was almost equally representation of North, Central, and South Italy (Table 1).

In the first session, health professionals were asked to describe their professional role through a metaphor. The most recurrent groups encoded the meaning of efficiency (20 %) - "A repairing technician"; "as a mechanic who intervenes when the car does not work anymore" - followed by the ordinary burdens (16 %) - "A table without a leg, but standing and bearing many things"; "A very old person, dragging a big bag on her shoulders" - the role of guidance (12 %) - "A wise and respected American Indian chief, a reference point for his tribe"; "The helmsman of a boat, in which sometimes the patient is part of the crew, sometimes is a passenger" - the images of strength, protective and rebellious career (8 % each). Sixteen percent of the respondents did not provide a metaphor.

Patients described in the narratives were almost equally divided by gender, exhibiting a mean age of 37 years, mostly single (53 %) and childless (69 %), with a diploma qualification in less than half (47 %). Thirty-seven percent of them were employed, mostly as office workers, whereas the remaining percentage did not work. Regarding the care pathway, the participants had been following therapies for almost 15 years, and structural epilepsy was the most frequent type of pathology (44 %). Fifty-three percent of the reported cases were drug-resistant (Table 2).

Three main topics emerged from the parallel charts: the patients' limited life, the caregivers' burdens, and the employment issue. The overall prevalence of fear, which was universal to all the narratives, represented a further element.

The limited quality of life with epilepsy was the most recurrent theme, independent of the type of epilepsy and the specific clinical situation. Fifty-seven percent of the parallel charts reported patients with limited everyday lives, basically within their own home, under the control of family members, full of sacrifices in their activities, free time, and social life; they tended to avoid people, as they lacked confidence and feared unknown places. According to health professionals, this attitude originated from feelings of fear and shame that were reported both from people affected by epilepsy since childhood, who were living with limitations from the beginning, and patients in which the illness occurred later and who experienced a sudden change from active life. Five percent of the narratives described non self-sufficient patients. However, along 18

Section A – Physician’ sociodemographic data and professional biography

Gender: F M

Age: _____

Professional specialization: _____

Work setting: Hospital University hospital Health Authority Free lance Other ,
please specify _____

Region of residence: _____

Professional years: _____

For what reason did you choose your specialization? _____

Indicate a metaphor to represent your professional role: _____

We invite you to provide a short professional biography: _____

Section B – Patient’ socio-demographic data

Gender: F M

Age: _____

Marital status: Single Married/Cohabiting Divorced/Separated Widowed

Children: Yes No

Education: _____

Occupation: _____

Years of the care pathway for epilepsy: _____

Causes of epilepsy: Structural Genetic Unknown Other causes please specify, _____

Drug-resistance: Yes No

Section C – The parallel chart

The first time I met the person with epilepsy

She/He appeared

She/He told me

She/He at home

Her/his activities

Her/his free time

The others for her/him were

The unusual places for her/him were

Therefore, I

During the communication of the care pathway, I think the person with epilepsy felt

I felt

I thought

And I did

Today, she/he tells me

She/He at home

Her/his activities

Her/his free time

The others for her/him are

The unusual places for her/him are

I think

I do

The epilepsy care

From this relationship of care, I am learning

Tomorrow, I would like for me

Tomorrow, I would like for her/him

How did you feel writing the parallel chart?

Fig. 1. The semi-structured parallel chart.

Table 1
Health provider' characteristics.

Health provider' characteristics	N = 25
Women %(N)	40(10)
Men %(N)	60(15)
Mean age(min-max)	50(28–69)
Professional years(min-max)	24(3–45)
Region of residence %(N)	
Northern Italy	36(9)
Central Italy	36(9)
Southern Italy	28(7)
Work setting %(N)	
University hospital	64(17)
Hospital	24(6)
Scientific Institute for Treatment and Research	12(3)
Professional specialization %(N)	
Neurologist	80(20)
Neurophysiologist	12(3)
Child neuropsychiatrist	8(2)

Table 2
Characteristics of the people with epilepsy described in the narratives.

Characteristics of the people with epilepsy described in the narratives	N = 91
Women %(N)	53(48)
Men %(N)	47(43)
Mean age(min-max)	37(8–70)
Marital status %(N)	
Single	53(51)
Married/Cohabiting	36(33)
Divorced	6(5)
Widowed	2(2)
With children	30(27)
No children	69(63)
Unspecified	1(1)
Qualification %(N)	
Secondary school - First level	25(23)
Secondary school - Second level	47(43)
Degree	17(15)
Unspecified	11(10)
Occupation %(N)	
Employed	37(34)
Unemployed	31(28)
Student	12(11)
Home maker	9(8)
Retired	5(4)
Unable to work	3(3)
Unspecified	3(3)
Care years (min-max)	14,7 (0–49)
Type of epilepsy(N)	
Structural	44(40)
Unknown causes	32(29)
Genetic	15(14)
Other causes	2(2)
Unspecified	7(6)
Drug-resistant epilepsy(N)	
Yes	53(48)
No	35(32)
Unspecified	12(11)

% of the care pathways, a more open patient attitude was underlined.

The perceived burdens of family members represented the second topic, emerging in 51 % of the narratives. Together with people with epilepsy, their parents, partner, or children were depicted as restricted to their domestic lives, with consequent social isolation, to monitor

constantly their loved ones. Again, the main reason explained by the physicians was the fear of possible seizures in unprotected settings, shame, and the tendency to avoid talking about the condition with other people. In 18.5 % of the parallel charts, the caregivers' emotional state was also described: concern, anxiety, and desperation emerged as the most recurring emotions. Furthermore, 14 % of the cases concerned difficult situations caused by epilepsy, such as patients' aggressive behaviours, and separations, or caregivers' loneliness.

The employment of people with epilepsy represented the third recurring element, which was addressed in 42 % of the parallel charts. Most of the narratives reported patients who quit searching for a job or felt forced to give up their working activity because of the disease, while 10 % denounced an abrupt job loss after a seizure episode in the workplace; these specific cases also showed the ethical dilemma of the physicians since they felt responsible for their professional declarations and suggestions.

Physicians perceived fear as a universal emotion that was felt both by people with epilepsy and their caregivers. Fear emerged from the first encounter—in 10 % of the first medical visits, it was depicted as combined with a declared mistrust towards the care pathway—to the current phase of the care pathway, and to the attitude towards the future. Fear was also considered an influential element of the choices of therapy in 15 % of the cases because of the resistance and uncertainty towards possible changes in drugs or surgical treatment (Fig. 2 and Appendix A in Supplementary material).

Through NM classifications, the parallel charts were revealed to be mainly focused on the emotional and relational experiences of epilepsy care but at the same time they were integrated with the clinical elements and care pathways. Following Kleinman's classification, more extensive space for the elements of illness was observed (42 %), which was represented by information on patients' and caregivers' inner, family, and social lives, personal reflections, and emotions in relationship with them. Elements of the disease were noticed in 36 % of the narratives in which clinical terms and contents on the care process appeared. Finally, sickness emerged in 22 % of the parallel charts which was more focused on the social consequences of epilepsy.

Referring to Bury's classification, integration between the contingent style (44 %) and personal and more in-depth considerations (32 %) was observed. Twenty-four percent of narratives were classified as 'moral', containing the physicians' values and judgements.

Furthermore, the main coping strategies developed along the care relationships were identified: the physician's welcome and listening to patients' doubts and fears, together with attentive and reassuring actions, were the main strategies to engage the person with epilepsy in a trustful and efficient care pathway (21 %), followed by the effectiveness of the treatment (17 %). In contrast, the ineffectiveness of therapies, or the progression of the disease (11 %), together with the prevalence of fear (9 %), were revealed to be the leading causes of not fruitful relationships and care pathways (Table 3).

After the parallel chart, physicians were invited to write their opinion about the NM experience, which was positively evaluated by 73 % of them, for the usefulness of writing and the possibility of expressing emotions and reflections. Conversely, 20 % of participants suffered from a lack of confidence with the tool, or from negative emotions lived again through the parallel chart. Seven percent of health professionals did not express any opinions.

Finally, during the consensus meeting, each of the three main topics that emerged from the narratives was discussed within a dedicated working group. To increase the quality of life with epilepsy, the following actions were agreed upon and detailed: new channels for the dissemination of correct information and indications addressed to people with epilepsy to clarify and to reassure about the real possibilities for their social and day-to-day life; training on basic life support epilepsy conducted within schools and other social settings; integration of the current clinical classifications of epilepsies with the gradation of corresponding risk levels to be validated at legal and social levels. Both

Topic	%(N)	Fragments from parallel charts
The limited life of people with epilepsy	57(52)	<i>“He needed to be continuously monitored, because of the seizures. Any activities were impossible”; “Her father did not allow her going out alone. She suffered for not being free to do anything in autonomy”; “Now she cannot drive anymore and doing anything alone. Her daughters are like custodians”; “She lived with her parents, although she had planned to live alone. She was terrified by the possibility to have new seizure episodes and felt her life like frozen”.</i>
Caregiver burdens	51(47)	<i>“The mother gave up her work to be able to take care of him. The parents do not leave him with anybody, not even the grandparents, since they are terrified by the seizures”; “Her partner is the one who is suffering more, she cannot sleep anymore during the night, waiting for another seizure episode”; “Furious fights often occur within the family. I had to manage his mother and sister, who were desperate for his aggressive behaviour”.</i>
Denied employment	42(38)	<i>“She gave up her job some years ago because of the seizures: at work, she felt inadequate and lived a strong sense of exclusion from the colleagues”; “then a seizure came when he was with the clients. The day after, his boss asked him to go away”.</i>
Prevalence of fear	100(91)	<i>“We proposed to her the option of the surgical treatment twice, but she was too much afraid of it”; “Again, as it has been happening for years, I proposed him to try a new drug for epilepsy, and he gently answered “NO”. He told me that now, 40 years old, he found a balance and he did not want to risk to lose it, since he knew that when a new treatment starts there is a risk of worsening, and he could not face anymore this situation from the psychological point of view”.</i>

Fig. 2. The main topic emerged from the parallel charts.

Table 3
The activating or deactivating elements of coping.

Activating elements of coping	%	Deactivating elements of coping	%
Actions of listening to and reassurance	21	Treatment ineffectiveness/ progression of the disease	11
Treatment efficacy	17	Prevalence of fear	9
Trust and optimism	13	Lack of trust and compliance	6
Care for the quality of life of the patient with epilepsy	9	Poor quality of life with epilepsy	4
Patient’s acceptance and awareness	3	Patient’s denial and lack of awareness	2
Psychological support	2	Lack of psychological support	2
		Cultural barriers	1

social and legal actions in support of caregivers were identified to be included in the national health care system, such as home care and disability measures; furthermore, the participants agreed on the opportunity to increase social and psychological support from the patient’s associations focused on families living with epilepsy. For the employment issue, the need to act was identified in two main phases: before

entering the labour market, through an orientation activity or opportunity training and employment inclusion; during working life, through the identification of specific solutions for accommodations to be applied in the workplace, allowing the person to maintain his/her job and professional role, and living with the possibility of seizures.

4. Discussion

The ERE project represented the first systematic activity of listening to Italian health professionals caring for patients with epilepsy. The participation of the care providers was notable: 91 collected narratives, which means that 87 % of them completed all five proposed parallel charts, revealing a strong dedication to the research.

The narratives supplied a broader perspective on life with epilepsy, in addition to the clinical perspective, including family, social, and working issues. The universal presence of fear, perceived by physicians in people with epilepsy from the first encounter and along the whole care pathway, confirmed the still-present effects of the stigma on this pathology [33]. Even when the clinical conditions were stable and seizures were controlled, life with epilepsy was depicted as limited and

confined within domestic and family borders. Physicians illustrated a sequence of denials and sacrifices: university, sporting activities, social life, travel experiences, and maternity.

The issue of employment was particularly remarked upon, confirming the interference of epilepsy on employability [34–36]. Considering the mean patient age - 37 years - the percentage of employment was low, compared with the remaining 63 % who were unemployed. Again, fear and the general attitude of sacrifice were considered by the physicians to be the main factors since most people quit searching for a job or the job itself after seizure events. Ten percent of the cases of unemployment involved forced removals from work, which were not described as being due to safety reasons but rather as a company's tendency to avoid possible problems. These were the most painful cases for the care providers which, through the illustrations of their patients' lives and ordinary issues, showed their ethical dilemma between guaranteeing the safety of patients and ensuring their own quality of life.

Similar to previous studies [37], the person with epilepsy's limited life appeared to be reflected on family members, who were often described in their roles as 'guardians' who were affected by or affecting the prevalence of anxiety and fear. Therefore, physicians described a life full of limitations and loneliness.

As a consequence of these results, the consensus meeting focused on physicians' needs to obtain standardized guidelines on the concrete answers to give to people with epilepsy. The emerged action plan represented a further confirmation of the physicians' willingness to take care of the patients, including their psychological wellbeing and social inclusion.

The research was not focused on people with epilepsy and their family members, which could represent a possible limitation. Nevertheless, this project was intended to represent precisely physicians' direct perspectives on living with epilepsy care. The parallel charts revealed motivated and involved health professionals who deeply knew their patients' lives and were not limited to clinical data but taking charge of all the effects of epilepsy. From their narratives, the needs and desires of patients and their emotional and psychological states along the care pathway appeared to be both considered and fostered. This finding resulted in being, on the one hand, the most crucial element to create trustful and efficient relationships of care and, consequently, to reach professional satisfaction; on the other hand, physicians' regular contact with emotions, such as fear and anxiety, could become a risk factor, leading to compassion fatigue and burnout. Recent studies have shown that burnout prevalence, career dissatisfaction, and work-life imbalance are higher among neurologists than physicians in most other specialties [38].

The decision to structure the parallel chart with a prompt may represent another limitation since the health professionals' spontaneous expressions can be reduced. The tool was chosen for methodological reasons, to be able to compare all the narratives and to foster the participants in their first approach to NM. The "white paper" approach is more recommended in the following steps after having taken confidence with the inner writing process. However, the collected narratives represented a precious space to express considerations and emotions that can be repressed in ordinary professional settings, contributing to increasing the levels of stress. The prevalence of illness-centred narratives revealed the physicians' welcoming of this possibility of expression as confirmed by 73 % of them at the end of the writing process. In this context of care, NM can play an important role. Reportedly, daily practice of the narrative approach has a positive effect, and narrative competencies improve professional quality of life thus preventing burnout [39,40].

5. Conclusion

The NM approach emerged as crucial for health professionals to integrate clinical care into patients' emotional, family, and social elements in a structured way. Moreover, through narratives, the epileptologists could express and share their points of view and their professional roles, which is at the basis of a real process of improving their wellbeing and, ultimately, epilepsy care.

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Appendix A

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Appendix B. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:<https://doi.org/10.1016/j.seizure.2020.12.012>.

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