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## Is it worth it, or possible, to measure what matters to patients with epilepsy and their caregivers?

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## ABSTRACT

**Objective:** The objective of this study was to collect perspectives, ideas, and values of people affected by epilepsy and their carer to include them in new research in this area.

**Design:** This is a semiquantitative study analyzing needs, emotions, and medical issues emerging from focus groups with patients and carers divided in three severity levels of disease.

**Participants:** The participants were 25 patients and 36 carers attending outpatients' service of tertiary epilepsy center in Umbria, Italy.

**Results:** Assistance was the need expressed by more than 40% of the participants followed by experience-sharing, knowledge, control, clarity, and security. The only significant effect in logistic regression analysis after adjusting for severity was the patients' expressed need for "experience-sharing" more than their carers (OR 7.29, 95%CI: 1.76–30.18).

Hope was the emotion expressed by more than 50% of the participants, followed by anger, fear, and resignation. After adjusting for severity, carers were more likely to express anger, in comparison with patients (OR 17.23, 95%CI: 3.55–83.74;  $P < 0.001$ ). The patients were 6.88 times more likely (95%CI 1.84–25.75;  $P = 0.004$ ) to express "resignation" than their carers.

The most frequent medical issues were related to: "medications", "frequency of crises", "work impact", "quality of life", "psychomedical integration of care", and "development of new drugs". After adjusting for severity in a logistic regression analysis, patients were more likely to express concerns for the frequency of crises than carers (OR 3.57, 95%CI: 1.16–11.04;  $P = 0.027$ ).

**Conclusions:** Patients' and carers' priorities, based on intense personal insight, represent a starting point to work for shared outcome measures in clinical trials and shared agenda in research, including research of strong evidence in complex intervention as service models for people with epilepsy.

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### 1. Introduction

A sensible research agenda must consider the needs of patients and caregivers, alongside those of clinicians, researchers, decision makers, and even the pharmaceutical industry so that each stakeholder is aware of the others' needs [1]. Academic institutions have generally left the choice of topics and methodologies to their professional and scientific committees, often ignoring nonprofessionals when making these decisions. Patients' preferences should be included in the choice

of topics and in the design of clinical trials, especially regarding the selection of outcome measures, the most relevant and important part of research for the end users of treatments and care [2].

Seizure frequency, in epilepsy research, is often the primary outcome in clinical intervention trials; however, it may not be the best predictor of patients' daily life skills, and it cannot be assumed that good psychosocial outcomes will be associated with the attainment of a seizure-free state. It may be necessary to go beyond seizure counts in the assessment of the disease and beyond the simple appearances of symptoms. Similarly, the obsessive research for a new drug may not be the exclusive aspiration of a patient. It could be useful to look for further and innumerable aspects that undermine the life of the ill individuals and their carer [3].

The aim of this work was to elicit perspectives, ideas, and values from people with epilepsy and their carers in order to offer clinicians

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and researchers new indications, suggestions, and hints able to reshape the future of treatment and care in a joint effort.

## 2. Materials and methods

### 2.1. Inclusion criteria

Adult patients affected by epilepsy, attending the outpatient service of the Neurophysiopathology Department, Santa Maria Misericordia Hospital, Perugia, Italy, and carers were invited to participate in this study. Patients had to be over 18 years of age, able to give informed consent, and have a clinical diagnosis of epilepsy. Caregivers, including all the people involved in the care of the patient: family members, friends, significant others, and personal home caretakers, had to be over 18 years of age and able to give informed consent.

### 2.2. Exclusion criteria

Participants who were unable to provide informed consent or were affected by learning difficulties and medium to severe mental challenges were excluded.

### 2.3. Methodology

Patients and carers were recruited by phone using the patients' lists from the outpatient epilepsy clinic. During recruitment, 15 phone call invitations were made by a researcher with the aim of having 6 to 8 participants in each group Fig. 1.

During each phone call, the researcher informed the potential participant of the aim, methodology, and practical aspects of the study. During the conversation, an evaluation of the patient was made. Participants who agreed to take part in the study were divided into different groups based on the severity of his/her disease and were classified, using the different grades of the Modified Rankin Scale 0–2, 3, 4–5, into three different groups: mild, moderate, and severe. This scale is a simple, easy-to-administer tool, and can be given over the phone by both experts and nonmedical study personnel. It is used to measure functional outcome in a broad population of patients with neurological diseases [4–6]. Patients in the mild group are those who are self-sufficient, with a good pharmacological control of their seizures, and no loss of personal or social abilities. Moderate patients often require the assistance of a caretaker in order to accomplish some of their personal and social activities. Severe patients depend almost completely on a caregiver for every need. Once each participant with epilepsy was

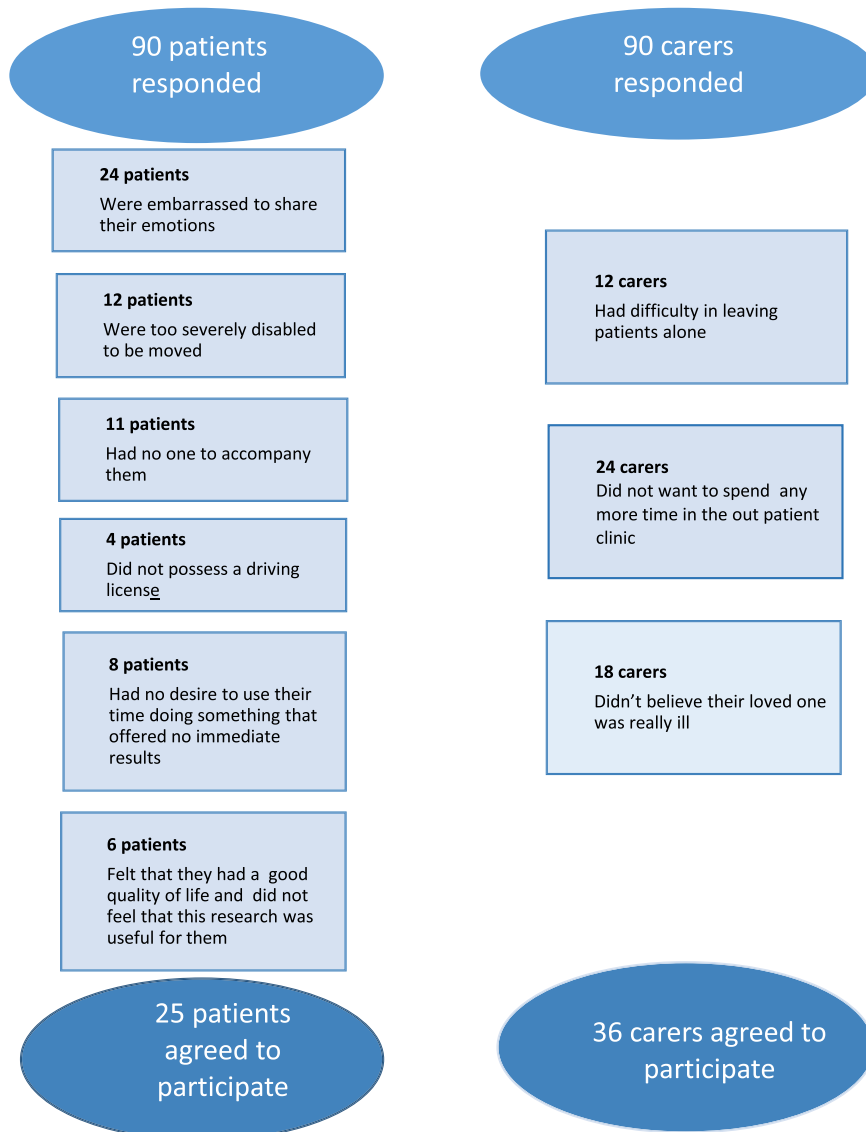


Fig. 1. Flow chart patients' and carers' responses.

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