



# Support values through the eyes of the patient An exploratory study into long-term support of persons with refractory epilepsy

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## ABSTRACT

A significant group of persons affected by refractory epilepsy require a wide range of long-term support from professionals as well as informal support givers. To enhance person-centeredness, it is important to know which patient values are associated with long-term support.

An Internet survey produced a total of 1176 statements from 289 persons with epilepsy for analysis. Statements were expressed in the respondent's own words and were related to positive experiences (704) as well as possible areas of improvement (472) regarding the support received in the past six months. Thematic summaries of the survey results were presented to four focus groups of persons with epilepsy and proxies with a request to formulate the most important patient values which should be observed in long-term support. In iterative sessions with a panel of epilepsy experts, a framework of twelve value domains was formulated, organized in four major value clusters.

An example of how these value domains can be operationalized for use in practice is next presented as a checklist to help evaluate the support patients with long-term support needs actually receive. Correspondingly, two sets of reflective questions were formulated for informal and professional support givers for the purpose of evaluating and improving person-centeredness in their support practices.

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## 1. Introduction

In the Netherlands, about 120,000 individuals have been diagnosed with epilepsy. After appropriate diagnosis and treatment, the majority of these subjects are well-controlled by medication, and their outlook is good [1]. There are, however, about 36,000 cases, which are socially affected by refractory epilepsy and in need of long-term support in order to enhance their functioning and quality of life [2,3]. Kalsbeek and Plateel did carry out a Dutch study about quality criteria from the patient's perspective in medical diagnosis and early treatment of epilepsy [2], but it is still not clear what patients perceive as being important in long-term care and support situations that extend beyond early diagnosis and treatment.

Literature on this topic is scarce. To ascertain patients' views on how epilepsy healthcare services should be organized, Elwyn et al. [4] held focus group interviews, but the number of patients was low – 19 individuals in 5 groups – and persons with learning disability were excluded. Miller et al. [5] studied the needs of persons with epilepsy but focused exclusively on the elderly and on self-management. Wagner et al. [6] undertook surveys to investigate patient needs with a special

interest in support by community partners. In the extensive review by Mahendran et al. [7] on unmet healthcare needs in patients with epilepsy, the most recent paper on this subject was published in 2001.

We, therefore, undertook an exploratory study to ascertain patients' views on support values.

We use “support” as a collective term for ‘resources and strategies that aim to promote the development, education, interests, and personal well-being of a person and enhance individual functioning’ [8,9]. Supports to enhance individual functioning may stem from professional (for example: neurologists, nurses, social workers, psychologists, teachers, and coaches) as well as from informal (such as parents, partners, children, relatives, colleagues, and volunteers) resources. Further, there are multiple forms and functions of supports ranging from monitoring, coaching, instructing, offering personal assistance, facilitation, or the use of technical aids. In the present study, the concept of “value” is defined as a person's subjective appreciation and esteem with respect to support received; it is not used to monitor healthcare outcome relative to costs as, for example, defined by Michael Porter [10].

The present study was initiated and sponsored by two Dutch advocacy associations: the Dutch Epilepsy Association<sup>1</sup> and the Family and

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<sup>1</sup> Epilepsievereniging Nederland (EVN), <http://www.epilepsievereniging.nl>.

Parents Association for Intensive Support in Epilepsy.<sup>2</sup> The project was supported by the care departments of SEIN and Kempenhaeghe, two Dutch tertiary referral centers for epilepsy. The purpose of the project was to explore support values from the person's perspective to validate future actions such as:

- promoting a person-centered focus in the work of neurologists, nurses, direct support staff, psychologists, and social workers in the field of long-term epilepsy support;
- empowering persons with epilepsy as well as their advocacy groups by raising awareness of legitimate expectations with respect to support; and
- facilitating development of quality-of-care instruments such as assessment scales, checklists, or guidelines.

The research questions to be answered in this study were as follows:

1. What do persons with epilepsy, who are receiving long-term support, report about what they consider to be “good” and what they consider to be “areas of improvement” in the support received in the past 6 months?
2. On the basis of the answer to research question 1: what do focus groups of persons with epilepsy and their proxies formulate as a framework of values to be observed when delivering person-centered support in long-term epilepsy?
3. How can answers to research questions 1 and 2 be converted into reflective questions for patients, informal support givers, and professional support givers in practice?

A qualitative research path was followed to reach an interpretative understanding of experiences of persons with epilepsy regarding long-term support (Ritchie et al. [11]). A central feature of the procedure was to establish a dialogue between the researchers and persons with epilepsy who are involved in receiving or offering long-term support. This dialogue was started with a survey submitted to the membership of the initiators and continued in iterative sessions with focus groups of those concerned and a discussion panel of stakeholders to arrive at consensus on a framework of values [12,13].

This research was approved by the boards of both participating patient organizations: the Epilepsy Association and the Family and Parents Association for Intensive Support in Epilepsy. All participants were informed about the purpose of the research project and were completely free to complete the questionnaire. Questionnaires were submitted anonymously.

## 2. Method

The first research question was addressed by a survey aimed at sampling personal experiences of good practice support as well as aspects of support that require improvement from the perspective of the person with epilepsy. The second question was addressed through focus groups; they reflected on the results of the survey and were invited to reach consensus on important characteristics of “good support”. A discussion panel of experts acted as a sounding board to comment on the outcomes of both the survey and the focus group studies to enhance consensus on the final value framework. This panel consisted of two neurologists and five self-advocates, as well as a psychologist and a social worker, both of whom were working in residential services for persons with epilepsy. The third question was answered using an iterative consensus procedure carried out with the discussion panel, resulting in a checklist of reflective questions for patients, informal support givers, and professionals to enhance person-centered practices.

The Internet survey was conducted among members of the Dutch Epilepsy Association and of the Family and Parents Association for Intensive

Support in Epilepsy. An invitation to take the survey was posted on their websites as well as those of the epilepsy centers and also distributed to the e-mail addresses of members of the Dutch Epilepsy Association. Following this approach, the potential (maximum) number of respondents which could be reached was 2100. The questionnaire used was edited in two formats: (1) for the person with epilepsy and (2) for a member of the social network of a person with epilepsy who acted as proxy. The latter concerned persons with epilepsy, who even with help, were unable to complete the questionnaire (e.g., young children, persons with intellectual disability or other severe communication impairment).

Samples of “good support” as well as of “areas of improvement” were collected using two open questions. These questions addressed support in general (1. ‘What do you appreciate about the support as currently received?’ – 2. ‘In what way could your present support be improved?’). The same two open questions were asked with respect to each of a number of specific quality-of-care domains that were presented to the respondents (Table 1, domains 11–18). This was done to broaden the respondent's scope of perception and to avoid too narrow a perspective, which could result in reporting only about a particular or recent experience of the respondent.

In order to organize the resulting experiences, a content analysis was performed on all answers to the first question of what was seen as “good” support and next on all answers to the second questions of what was experienced as “areas of improvement”. Therefore, every answer was coded according to the “quality of support domains” (Table 1), developed by the Dutch association of service providers in disability care [15]. After organizing the answers to the open questions, they were used as input for drafting brief thematic descriptions for each support category. These descriptions focused on identifying specific valued topics that were present in either “good support” or “area of improvement” statements. These topics were presented as vignettes to the focus groups. Vignettes contained the most frequently reported subjects in each support domain.

Four focus groups were held, each lasting 2 h, to discuss the vignettes and to identify and formulate key values with respect to the quality of long-term support. Members of the focus groups were persons who indicated in the survey that they were willing to participate in such groups. They were further selected to represent the following persons:

- adults (>18) with epilepsy (n = 6);
- parents of children (<18) with epilepsy but no intellectual disability (n = 6);
- parents of children (<18) with epilepsy and intellectual disability (n = 4); and
- proxies of adults (>18) with epilepsy and intellectual disability (n = 5).

The output from the focus groups was then integrated by the first author to construct a draft framework of values in long-term support and to formulate a set of reflective questions to operationalize the values. This process was evaluated and commented on in four iterations by the discussion panel of experts that approved the final edition of the framework and reflective questions. The resulting set of questions is an exemplary translation of value framework that can be used, for example, in educational settings or team evaluation in service settings to raise awareness about person-centered support.

## 3. Results

### 3.1. Subjects

A total of 289 persons completed the Internet survey: 114 persons with epilepsy and 175 proxy respondents (parents, siblings, significant others), equivalent to 14% of those invited to participate. Respondent characteristics are shown in Table 2.

<sup>2</sup> Stichting Zorgintensief & Epilepsie (ZIE), <http://stichtingzie.nl>.

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