Coping strategies in adults with a diagnosis of refractory epilepsy: Development, antecedents, and consequences.

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Primary Objectives: To formulate answers to the following questions:Three main study objectives will be examined in the present project.1. What are the employed coping strategies in patients with refractory epilepsy and how do these develop over...

Ethical review	Approved WMO
Status	Recruitment stopped
Health condition type	Neurological disorders NEC
Study type	Observational non invasive

Summary

ID

NL-OMON43395

Source
ToetsingOnline

Brief title
Coping in adults with refractory epilepsy.

Condition

- Neurological disorders NEC

Synonym
convulsion, epilepsy, seizures

Research involving
Human

Sponsors and support

Primary sponsor: Universiteit van Tilburg

Source(s) of monetary or material Support: Ministerie van OC&W

Intervention

Keyword: coping, psychosocial functioning, refractory epilepsy

Outcome measures

Primary outcome

The primary study parameter of the study is coping strategies and hypothesized antecedents (i.e., executive functioning, illness identity and perceptions, and personality) and consequences (i.e., quality of life and seizure frequency/severity).

Secondary outcome

Secondary study parameters of the study are demographic and clinical variables: gender, age (date of birth), level of education, employment status, ethnic background, marital status, age of onset of the epilepsy, type of epilepsy, medication use, epilepsy surgery (yes/no), psychogenic non-epileptic seizures (PNES) (yes/no).

Study description

Background summary

Refractory epilepsy means that epileptic seizures remain uncontrolled despite adequate treatment with at least two antiepileptic drugs (Kwan et al., 2010). The unpredictable course of refractory epilepsy is an important factor in coping with this illness. There are different types of coping strategies, which means that everyone copes with having epilepsy in a different way. Various studies have shown that patients with epilepsy often employ an avoidant coping style, which may have a negative impact on different aspects of psychosocial functioning. Hence, coping strategies will function as the primary variable of interest in the present project.

First, we will examine which coping strategies adults with epilepsy commonly use in dealing with their illness and how these coping strategies develop over time. Coping is defined as the use of cognitive and behavioral strategies for dealing with pressures, demands, and emotions involved in stressful situations (Lazarus & Folkman 1984). Hence, coping is typically viewed as a multidimensional construct. A particularly important distinction can be made between engagement coping (aimed at active problem solving and dealing with stressors and related emotions) and disengagement coping (aimed at avoiding or withdrawing from problems and escaping feelings of distress) (Carver & Connor-Smith, 2010). In the current project, core exemplars of these two strategies (i.e., problem solving and avoidance) will be assessed, in addition to social support seeking which is generally viewed as part of engagement coping (Carver & Connor-Smith, 2010; Seiffge-Krenke, Aunola,& Nurmi, 2009). Previous research has focused mainly on cross-sectional snapshots of coping and has not examined the development of coping in patients with refractory epilepsy using multi-wave longitudinal data.

Second, we will examine how these coping strategies are related to, and potentially influence, quality of life and seizure frequency and severity in our patients. Although coping strategies are not universally beneficial or detrimental (Wrosch et al., 2003), prior research in community samples have typically found that problem solving and social support seeking predict better physical and psychological health, whereas avoidance predicts poorer outcomes (Compas et al., 2001). In individuals with epilepsy, the employed coping style has been shown to be an important predictor of patients* psychological wellbeing (Kemp, Morley, & Anderson, 1999), quality of life (Westerhuis, Zijlmans, Fischer, van Andel, & Leijten, 2011), and perceived seizure severity (Oosterhuis, 1999). By using multi-wave longitudinal data, we can investigate whether coping, quality of life, and seizure frequency/severity co-develop over time. Furthermore, we can examine the directionality of effects and identify reciprocal associations among the different study variables. For instance, one might hypothesize that the use of avoidant coping strategies may lead to a higher seizure frequency over time. However, a higher seizure frequency may also lead to a further increase in avoidant coping, thereby inducing a negative vicious cycle.

Third, we will examine how antecedent factors (i.e., executive functioning, illness identity and perceptions, and personality) relate to, and potentially influence, these coping strategies. With regard to executive functioning, the neuropsychological literature suggests a connection between coping and executive functioning. To effectively cope with stressful events (planning), it is necessary to remember previous confrontations with similar stressors (working memory), and at the same time to evaluate coping alternatives and adapt cognitive and behavioral responses to the situation (cognitive flexibility). A study with patients who have had a stroke shows that deficits in executive functioning (especially working memory) are associated with an increase in avoidant coping style (Kegel, Dux, and Macko, 2014). Another study in adolescents with treatment resistant depression shows that some aspects of executive functioning (inhibition and cognitive flexibility) affect the relationship between coping and depressive symptoms (Morris, Evans, Rao, & Garber, 2015). Decreased active and increased avoidant coping are associated with a higher number of depressive symptoms. It appears that higher scores on both inhibition and cognitive flexibility lead to fewer depressive symptoms through more active and less avoidant coping. In addition, it has been found that there is a low correlation between subjective executive functioning, as measured with the BRIEF-A, and objective executive functioning, as measured with cognitive tasks. Hence, in order to examine executive functioning thoroughly, both the BRIEF-A and the cognitive tasks are deemed necessary.

Another potentially important factor that could explain why certain patients experience difficulties, whereas others successfully manage their illness, is patients* illness identity. The concept of illness identity captures the degree to which the illness is integrated into patients* identity (Luyckx, Rassart, & Weets, 2015). This is the first study to date to look at this issue in the epilepsy population. Recently, four illness identity dimensions have been proposed in the literature: engulfment (patients completely define themselves in terms of their illness, which invades all domains of life), rejection (the illness is viewed as a threat or as being unacceptable to the self), acceptance (patients accept their illness as part of their identity, besides other social roles and identity assets), and enrichment (the illness results in positive life changes, benefits one*s identity, and enables one to grow as a person). In other chronic illness populations (e.g., patients with type 1 diabetes), important associations with depressive symptoms, quality of life, and treatment adherence were uncovered (Oris et al., manuscript in revision). Relatedly, previous research has demonstrated the importance of patients* illness perceptions in how they cope with their illness. For instance, a study by Goldstein, Holland, Soteriou, and Mellers (2005) in adults with epilepsy showed that patients with negative illness perceptions more often used an avoidant coping style in dealing with stressors. In contrast, patients feeling more in control of their illness reported a more active coping style.

Finally, personality has been proven to be an important factor in how patients cope with their illness (Rassart, Luyckx, Klimstra, Moons, & Weets, 2014). In the current study, we focus on the Big five personality traits: extraversion (engaging in social behaviors and experiencing positive emotions), agreeableness (showing empathy and engaging in prosocial behavior), conscientiousness (organizational and motivational aspects of behavior and taking responsibility), emotional stability (the tendency to be emotionally stable and managing negative emotions), and openness to experience (the way people seek and deal with new information) (Caspi, Roberts, and Shiner, 2005). Previous research, for instance, has shown that patients low in extraversion and emotional stability are more prone to depression after epilepsy surgery (Wilson, Wrench, McIntosh, Bladin, and Berkovic, 2010). However, research looking at the role of personality in this specific population is scarce.

In sum, we want to gain more insight into the coping strategies of adults with epilepsy, their associations with quality of life and seizure severity/frequency, and potential antecedent factors (i.e., executive functioning, illness identity and perceptions, and personality functioning).

Study objective

Primary Objectives: To formulate answers to the following questions:

Three main study objectives will be examined in the present project.
1. What are the employed coping strategies in patients with refractory epilepsy and how do these develop over time?
2. How do these coping strategies relate to, and potentially predict, quality of life and seizure frequency/severity in these patients (consequences of coping)? Can coping predict these outcomes over time after controlling for the effects of demographical and clinical variables (e.g., gender, age, type of epilepsy, medication use)?
3. How do executive functioning, illness identity and perceptions, and personality functioning relate to, and potentially predict, these coping strategies over time (antecedents of coping)? Can these factors predict coping strategies after controlling for the effects of specific life-events?

Study design

Our study is an observational longitudinal research with three time points (once a year for the duration of two years, that is, at baseline, baseline + one year, and baseline + two years) in which patients between the ages of 18-40 with refractory epilepsy complete the following questionnaires:
- Coping strategy: Shortened Coping Strategy Indicator (CSI)
- Illness identity: Illness Identity Resolution Scale (IIRS)
- Personality: Big Five Inventory (BFI-25)
- Subjective executive functioning: Behavior Rating Inventory of Executive Function (BRIEF-A)
- Quality of life: Shortened Quality of Life in Epilepsy (QOLIE-31)
- Illness perceptions: Brief Illness Perception Questionnaire (BIPQ)
- Severity and frequency of the seizures: Liverpool Seizure Severity Scale (LSSS)
- Life-events: one open and one impact question

The following demographic and clinical variables will also be measured:
- Gender
- Age (date of birth)
- Level of education
- Employment status
- Ethnic background
- Marital status

- Age of onset of the epilepsy
- Type of epilepsy
- Medication use
- Epilepsy surgery (yes/no)
- Psychogenic non-epileptic seizures (PNES) (yes/no)

An at random selected subgroup will be invited at three different time points (once a year for the duration of two years) to measure objective executive functioning. The executive tasks are:
- Cognitive flexibility and inhibition: D-Kefs Color Word Interference Test
- Working memory: WAIS-IV-NL Number sequences
- Planning: D-Kefs Tower Test
- Attention and information processing speed: WAIS-IV-NL Digit Symbol Substitution Test

Study burden and risks

The time required for completing the questionnaires per time point (3, once a year) is expected to be 60 minutes. A subgroup will be invited at three different time points (once a year) to measure objective executive functioning. The time expected to complete the executive tasks is 45 minutes. These executive tasks will be conducted at the Hans Berger Clinic, which means that some patients will need to travel. Patients could experience participation and the time required to participate as a burden. In addition, certain questions, for example about depressive symptoms, may cause some discomfort to some participants. Although our past experience with such questionnaires indicates that feelings of discomfort are very limited. The opportunity to contact the principal investigators (dr. Ruth Mark and drs. Ludo Verdyck) and independent expert (prof. dr. Marrie Bekker) is given in case certain questions evoke negative emotions or if the person has trouble handling them.

There are a number of steps taken to protect the subjects. The informed consent will be provided to the participants along with the questionnaires and the documents must be returned to the researchers in a sealed envelope. We will explicitly ask the participants for permission to view their electronic medical record and use certain data from it (e.g. type of epilepsy). Confidentiality of the data is ensured in several ways:

(1) All analyses will be carried out on a group level and not on an individual level.
(2) All documents (questionnaires and informed consents) will be provided with meaningless numbers that allow us to link the questionnaires over time and to link the informed consents to the questionnaires. These numbers will be used for entering and organizing the data. The numbers and the associated list of participants are kept separately in a secure document to which only the involved researchers from the University of Tilburg, Kempenhaeghe-HBK and KULeuven have access.

(3) The informed consents and contact details of the participants will be saved seperately from the dataset and questionnaires.
(4) Individual data obtained from the aforementioned questionnaires will not be passed to doctors and clinicians. This study, therefore, is independent from the possible clinical follow-up for patients, which means that patients are not in a dependent position in relation to the researchers of this project.
(5) Contact details of the principal investigator (dr. Ruth Mark and drs. Ludo Verdyck) and independent expert (prof. dr. Marrie Bekker) are given for any questions or remarks.

Contacts

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Trial sites

Listed location countries

Netherlands

Eligibility criteria

Age
Adults (18-64 years)
Elderly (65 years and older)

Inclusion criteria

Patients with a diagnosis of refractory epilepsy in the age range of 18-40 years with a sufficient knowledge of the Dutch language, no other chronic illness, and an estimated IQ above 70.

Exclusion criteria

Exclusion criteria include mental retardation or cognitive delays which makes patients incapable of filling out the questionnaires, presence of another chronic illness, insufficient knowledge of the Dutch language, no available contact information, no written consent.

Study design

Design

Study type: Observational non invasive

Masking:	Open (masking not used)
Control:	Uncontrolled
Primary purpose:	Diagnostic

Recruitment

NL

Recruitment status:	Recruitment stopped
Start date (anticipated):	29-09-2016
Enrollment:	300
Type:	Actual

Ethics review

Approved WMO

Date:	18-04-2016
Application type:	First submission
Review commission:	METC Brabant (Tilburg)

Approved WMO

Date:	08-12-2016
Application type:	Amendment
Review commission:	METC Brabant (Tilburg)

Study registrations

Followed up by the following (possibly more current) registration

No registrations found.

Other (possibly less up-to-date) registrations in this register

No registrations found.

In other registers

Register	ID
CCMO	NL55583.028.15