



## Failed transition to independence in young adults with epilepsy: The role of loneliness



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### ABSTRACT

**Purpose:** Many young adults with epilepsy are still living with their parents ('failed transition to independence') despite reaching the adult age. This study evaluated patient-related variables and measures of loneliness correlated to 'failed transition to independence' in adults, 25–30 years of age, with (childhood-onset) epilepsy.

**Methods:** Patients with (childhood-onset) epilepsy and 25–30 years of age were recruited from Epilepsy Center Kempenhaeghe. Inclusion criteria were: diagnosis of (childhood-onset) epilepsy, and an (estimated) IQ > 70. Patients were sent one questionnaire and informed consent was obtained from all participants. Questions included the patient's level of functioning and satisfaction on three transitional domains (medical status, educational/vocational status, independence/separation from their parents), satisfaction with their friendships, and the validated De Jong-Gierveld Loneliness Scale. 'Transition to independence' was defined and categorized in a continuum with scores ranging from 0 ('Failed transition') to 4 for all patients. A Bivariate Correlation analysis was used to compute correlations between patient characteristics and failed transition to independence.

**Results:** 59 patients were included in the analysis, of which 19 (32.2%) had a failed transition to independence. A statistically significant correlation was found between transition to independence and the social loneliness scale ( $p = 0.047$ ) and the total loneliness scale ( $p = 0.04$ ), and for the patients self-reported satisfaction with their independence/separation from parents ( $p = 0.01$ ) and friendships ( $p = 0.04$ ).

**Conclusions:** Adults with epilepsy with a failed transition to independence experience loneliness and are not satisfied with their current developmental and social situation.

### 1. Introduction

Chronic (childhood-onset) epilepsy continuing into adulthood can have major consequences for normal development on several domains. Epilepsy, comorbid conditions and the side-effects of antiepileptic drugs can affect the psychosocial outcome of children with epilepsy as they grow into adulthood [1]. For example, Kobau et al. [2], Espinola-Nadurille et al. [3] and Suurmeijer et al. [4] found that patients with epilepsy were less satisfied with their social life and experienced more loneliness compared to controls. Sillanpää et al. [5] and Sillanpää and Cross [1] found that adults with childhood-onset epilepsy had a lower educational status, a lower social participation, were less likely to be married, and had more problems in participating in daily activities

compared to healthy adults. Chin et al. [6] showed that patients with epilepsy (without cognitive disabilities or comorbid conditions) had more problems with social interactions and maintaining relationships compared to controls. Even after 35 years of follow-up, a significant poor social outcome was still found in patients with benign childhood-onset epilepsy [7].

It is hypothesized that the above mentioned psychosocial problems have their onset during adolescence and early adulthood in which friendships, social networks, and independence have to be developed [8]. Furthermore, during adolescence, patients with continuing seizures have to transfer from paediatric to adult care. Epilepsy transition clinics have been developed to cope with this shift in health care, and to stimulate psychosocial transition; i.e. aid adolescents with epilepsy to

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become independent [9–13]. In our multidisciplinary Epilepsy Transition Clinic for adolescents and young adults with epilepsy (15 to 25 years of age), multidisciplinary advice is provided for specific medical and psychosocial transitional problems, such as future perspectives in employment and housing [10,13]. The goal of this multidisciplinary transition clinic is not only to ease the transition to adult care, but also to stimulate independence among adolescents and young adults with epilepsy. In this multidisciplinary transition clinic we noticed that many young adults with epilepsy were still living at home with their parents and were not motivated at all to start living independently. These young adults seemed to fail transitioning to independence, a problem also noticed in the adult outpatients clinic. When pediatric patients with epilepsy remain dependent on the care of their parents into adulthood, they gradually tend to lose the initiative of self-care, and develop a passive coping style for problem solving later in life, the so called ‘learned helplessness’ [14].

For this study, we were interested in adults, 25–30 years of age, with (childhood-onset) epilepsy. Except for demographic and epilepsy-related characteristics, we were especially interested in the social participation and feelings of loneliness among participants. Loneliness is defined as the discrepancy between the relationships a person has in terms of intimacy and interpersonal affection, and the relationships a person wants. Loneliness can be further subdivided into social loneliness, defined as missing a broad social network, and emotional loneliness, defined as missing an intimate relationship [15]. As these definitions suggest, people with many friends can still experience loneliness when their friendships do not meet their social or emotional needs.

The age limit of 25–30 years of age was not strictly evidence based, but chosen with the idea that patients had just been through an important phase in life and had either successfully developed independence or failed the transition to independence. Similar to the situation in a pediatric population, it is known that in older patients who have become passive in problem solving, the situation can finally become chronic. Leading to acceptance of the situation and its negative consequences, instead of taking action [16].

This study evaluated epilepsy-related characteristics and measures of loneliness correlated to ‘failed transition to independence’ in adults aged 25–30 years with (childhood-onset) epilepsy.

## 2. Methods

### 2.1. Inclusion and exclusion criteria

All patients in this study were recruited from Epilepsy Center Kempenhaeghe (The Netherlands), a specialized tertiary referral center for patients with epilepsy. Patients with (childhood-onset) epilepsy with regular appointments at our outpatient clinic, currently or in the past, were invited to participate in this study. All patients were 25 to 30 years of age. Patients who had their full scale intelligence quotient tested in the past, and were diagnosed with intellectual disabilities (Full Scale Intelligence Quotient < 70) were not invited to participate. Patients were excluded from this study if they had ever visited our multidisciplinary Kempenhaeghe Epilepsy Transition Clinic for adolescents with epilepsy, because a transition intervention might have influenced the psychosocial outcomes we were interested in. After data collection, patients who had only completed primary school as their highest level of education, in combination with dependency on financial governmental support, were excluded from data analysis, because of a high probability of an intelligence quotient below 70.

### 2.2. Study design

One questionnaire was sent to all patients who met the inclusion criteria. Questionnaires were sent by mail, not by email. No telephone interviews took place. The questionnaire contained questions regarding the patient’s current medical, educational/vocational status and

independence. Specifically, items evaluated were: date of diagnosis of epilepsy, seizure frequency, number and type of antiepileptic drugs (AEDs), current and past treatment options (AEDs, vagus nerve stimulator, ketogenic diet, epilepsy surgery), the health care provider who facilitated regular appointments for epilepsy care (e.g., epileptologist, neurologist, or general practitioner) and the number of visits per year, hospital admittance due to epileptic seizures, highest completed education level, current education or employment, financial income, financial guardianship, relationships, housing, level of independence by self-reported completing household tasks, medication intake and making appointments with health care workers, satisfaction with friendships, and experience of emotional and social loneliness by the validated De Jong-Gierveld loneliness scale (See AppendixA) [15]. The De Jong-Gierveld loneliness scale consists of eleven questions, however, the word ‘loneliness’ is not mentioned in this questionnaire to avoid measurement bias. Five questions refer to social loneliness, and six questions refer to emotional loneliness. Negative answers (‘no’/‘more-or-less’) to questions regarding social loneliness (questions 1, 4, 7, 8, 11) and positive answers (‘yes’/‘more-or-less’) to items regarding emotional loneliness (questions 2, 3, 5, 6, 9, 10) were counted and determined the social loneliness score or emotional loneliness score, respectively. Missing answers were referred to as the ‘missing social loneliness score’ or ‘missing emotional loneliness score’. The total loneliness score is the sum of the social and the emotional loneliness score, and is only valid if the ‘missing’ scores were zero. Further, the loneliness score was also categorized as ‘not lonely’ (score 0 to 2), ‘moderate lonely’ (score 3 to 8), ‘severe lonely’ (score 9 or 10), ‘very severe lonely’ (score 11) [15]. We also asked patients to report their own satisfaction within three transitional domains; medical status, educational/vocational status, independence/separation from parents. We used these transitional domains before in our previous study [10], for the current study the satisfaction with friendships was added to the list. Self-reported satisfaction within the four above mentioned transitional domains was converted into a score of -2 (not satisfied at all); -1 (not satisfied) or 0 (satisfied).

‘Transition to independence’ was defined according to the patient’s age when he/she first started living independently from their parents, and categorized with scores ranging from 0 to 4 for all patients. Adult patients still living at home with their parents received the minimum score of 0, whereas patients living independent from their parents were scored from 1 to 4, according to their age at the time of leaving the parental home. Table 1 provides a complete overview of the categorization of ‘(failed) transition to independence’. Data of all patients who gave written informed consent and fully completed the questionnaire were entered in an IBM SPSS database.

### 2.3. Statistical analysis

All statistical analyses were performed by IBM SPSS Version 21. We used descriptive statistics to compute percentages (%) and frequencies (*n*) of categorical variables. Means are presented with median, standard deviation (SD) and range.

**Table 1**  
Definitions of ‘failed transition to independence’.

	Definition	Number of patients ( <i>n</i> )
Score 0	Failed transition: adults still living at home with their parents.	19 (32.2%)
Score 1	Start living independently > 25-30 years of age.	13 (22.0%)
Score 2	Start living independently 21-25 years of age.	13 (22.0%)
Score 3	Start living independently 18-21 years of age.	9 (15.3%)
Score 4	Start living independently < 18yrs of age.	0
Unknown	Data not reported	5 (8.5%)

**Table 2**  
Demographic and psychosocial patient characteristics.

	Median	SD	Range	
Gender				
Men	23 (39%)			
Women	36 (61%)			
Autism spectrum disorder	8 (13.6%)			
Mean age (years)	28.2	28.2	1.25	25.7 - 30.4
Mean Full Scale Intelligence Quotient (FSIQ)	94.5	91.0	15.5	77 - 126
Living arrangements				
At home with parents	19 (32.2)			
Supported accommodation	2 (3.4%)			
Independently, with support	2 (3.4%)			
Independently, without support	6 (10.2%)			
Living together (relationship)				
Employment	42 (71.2)			
Financial income				
Job/salary	41 (69.5)			
Governmental support	16 (27.1)			
Parents	2 (3.4%)			
Self-reported independence in:				
Household chores	57 (96.6)			
Medication intake	49 (83.1)			
Making medical appointments	52 (88.1)			
Over all	55 (93.2)			
Transportation				
Driving license, driving allowed	23 (39.0)			
Driving license, driving not allowed	5 (8.5%)			
Public transport	13 (22.0)			
Transport organized for people with disabilities	3 (5.1%)			
Bicycle/scooter	6 (10.2%)			
Parental transport	9 (15.3%)			
Patient's own satisfaction with:				
Medical domain	-0.56	0	0.70	-2 to 0
Educational/occupational status	-0.76	-1	0.82	-2 to 0
Independence/separation	-0.46	0	0.65	-2 to 0
Friendships/social skills	-0.46	0	0.65	-2 to 0

Data are presented as number (*n*, %). Means are presented with median, standard deviation (SD) and range.

We used a Bivariate Correlation analyses to determine patient characteristics and loneliness scores correlated to a failed transition to independence. All analysis were one-tailed. The nonparametric data was reported with the Spearman's rho Correlation Coefficient (*r*). A *p*-value < 0.05 was defined as statistically significant.

#### 2.4. Ethics

This study was approved by the Medical Ethics Committee of Kempenhaeghe. Patients could participate voluntarily. Written informed consent was obtained from all participants.

### 3. Results

#### 3.1. Patient characteristics

One hundred and eighty-five patients were invited to participate in this study. Finally, 59 patients (31.9%) met our inclusion criteria, fully completed the questionnaire and gave written informed consent.

The patient characteristics are shown in Table 2. Twenty-three men (39.0%) and 36 women (61.0%) participated in this study. The mean age was 28.2 years (median = 28.2, SD = 1.25). The mean full scale intelligence quotient (tested in 17 patients) was 94.5 (median = 91.0, SD = 15.5). Eight patients (13.6%) had been formally diagnosed with autism spectrum disorder by a clinical neuropsychologist or psychiatrist. Nineteen patients (32.2%) were still living at home with their parents, whereas two patients (3.4%) were living in a supported

**Table 3**  
Epilepsy-related patient characteristics.

	Median	SD	Range	
Mean age at diagnosis of epilepsy (years)	8.97	9.37	5.14	0.0 - 19.0
Mean duration of epilepsy (years)	19.2	19.2	5.15	8.86 - 27.3
Type of epilepsy				
Localization-related epilepsy				
Idiopathic	7 (11.9%)			
Symptomatic	15 (25.4)			
Cryptogenic	26 (44.1)			
Generalized epilepsy				
Idiopathic	9 (15.3%)			
Symptomatic	1 (1.7%)			
Not yet classified	1 (1.7%)			
Under follow-up for epilepsy at:				
Neurologist Epilepsy Center	48 (81.4)			
Kempenhaeghe	5 (%)			
External neurologist	6 (10.2%)			
Seizure free, medical follow-up not indicated				
Mean number of visits per year	1.47	1.00	0.96	0 - 4
Hospital admittance last 12 months due to epilepsy	7 (11.9%)			
Number of AEDs				
0	7 (11.9%)			
1	20 (33.9)			
2	22 (37.3)			
3	7 (11.9%)			
4	3 (5.1%)			
Self-reported AED adherence				
Yes	36 (61.0)			
Forget AEDs sometimes	17 (28.8)			
No current AED treatment	6 (10.2%)			
Other treatment option				
Vagal Nerve Stimulator	6 (10.2%)			
Epileptic Surgery	3 (5.1%)			
Ketogenic Diet	0			
Seizure frequency				
Daily	3 (5.1%)			
Weekly	9 (15.3%)			
Monthly	7 (11.9%)			
Yearly	10 (16.9)			
Seizure-free > 1 year	30 (50.8)			
Seizure-free				
Mean number of days	1337	444	1789	0 - 7305
Mean number of years	3.66	1.22	4.90	0 - 20

Data are presented as number (*n*, %). Means are presented with median, standard deviation (SD) and range.

accommodation and 38 patients (64.4%) were living independently (either with or without additional support) or together with a partner.

Participants had a mean age at diagnosis of epilepsy of almost nine years (median = 9.37, SD = 5.14), with a mean duration of epilepsy of 19.2 years (median = 19.2, SD = 5.15). Cryptogenic localization-related epilepsy was the most common type of epilepsy (*n* = 26, 44.1%), followed by symptomatic localization-related epilepsy (*n* = 15, 25.4%), and idiopathic generalized epilepsy in nine patients (15.3%). Thirty patients (50.8%) were seizure-free over one year, and the mean number of seizure-free years was 3.66 (median = 1.22, SD = 4.90, range 0–20).

Six patients (10.2%) reported that they did not necessarily need to visit a health care worker regularly because of seizure-freedom, whereas 53 patients (89.8%) still had regular appointments with health care workers with a mean number of 1.47 visits per year (median = 1.00, SD 0.96, range 0–4). Seven patients (11.9%) had been admitted to a hospital in the previous year due to epilepsy. A full overview of the epilepsy-related characteristics is shown in Table 3.

Loneliness scores and information about friendships are provided in Table 4. Thirty-nine patients (66.1%) had a relationship. Fifty-two patients (88.1%) reported that they were satisfied with the number of friendships. The mean self-reported emotional loneliness score was 1.27

**Table 4**  
Loneliness scores and social patient characteristics.

		Median	SD	Range
Friends with diagnosis epilepsy	13 (25.0)			
In a relationship	39 (66.1)			
Satisfied with number of friendships	47 (79.7)			
Asking friends for:				
Help in general	33 (55.9)			
Going out	46 (78.0)			
Discussing personal problems	46 (78.0)			
Mean emotional loneliness score	1.47	0	2.17	0-6
Mean social loneliness score	1.19	1	1.43	0-5
Mean total loneliness score	2.66	1	3.37	0-11
Loneliness scale				
No loneliness (0-2)	37 (62.7%)			
Moderate loneliness (3-8)	16 (27.1)			
Severe loneliness (9-10)	5 (8.5%)			
Very severe loneliness (11)	1 (1.7%)			

Data are presented as number (*n*, %). Means are presented with median, standard deviation (SD) and range.

(median = 0, SD = 2.17), the mean social loneliness score was 1.19 (median = 1, SD = 1.43), and the mean total loneliness score was 2.66 (median = 1, SD = 3.37). When categorized, 37 patients (62.7%) reported not being lonely at all, 16 patients (27.1%) reported moderate loneliness, five patients (8.5%) experienced severe loneliness, and one patient (1.7%) reported the maximum loneliness score of 11 points. We also compared the average loneliness score for the patients with successful transition versus the patients with failed transition using a cut-off score of -1. The results of the independent *t*-test showed that the group with failed transition (*n* = 37), defined with the cut-off value of -1 have a statistically significant higher loneliness-score (3.9 versus 1.6; *p* = 0.006).

### 3.2. Correlations

A statistically significant correlation was found between ‘transition to independence’ and the social loneliness scale ( $r = -0.230$ ,  $p = 0.047$ ) and the total loneliness scale ( $r = -0.249$ ,  $p = 0.04$ ). This means, the lower transition to independence was scored, the higher the social loneliness score and the total loneliness score, thus the more loneliness was experienced. The emotional loneliness score was not significantly correlated to a transition to independence.

A statistically significant correlation was also found for the patients self-reported satisfaction with their independence/separation from parents ( $r = 0.289$ ,  $p = 0.01$ ) and friendships ( $r = 0.218$ ,  $p = 0.04$ ), meaning the lower the transition to independence was scored, the less patients were satisfied with their own independence/separation and friendships.

## 4. Discussion

With this study we found that social loneliness and a higher overall score on the validated De Jong-Gierveld loneliness scale were correlated with failed transition to independence. The results also showed that patients with failed transition were not satisfied with their friendships and with the situation of still living at home with their parents.

The outcomes of this study reflect a troublesome situation in adults with epilepsy who have a failed transition to independence. In the first place, social problems, e.g., feelings of loneliness and lack of support/friendships are a frequent, but often under-recognized condition in patients with epilepsy. In this study 22 out of 59 patients (37.3%) reported feeling lonely to some extent, and six patients (10.2%) were (very) severe lonely. Unfortunately, comparative numbers for this specific age group cannot be found in the Dutch population. In our study we did not include a matched control group, limiting the

possibility to establish that loneliness is more prevalent in patients with childhood onset epilepsy. However, in a recent meta-analysis on loneliness in children and adolescents with chronic physical conditions an effect was found suggesting that children with a chronic disease suffer more loneliness than their peers without chronic disease.<sup>25</sup>

This was especially the case in children with visual and hearing problems, but also for children with neurological conditions.

Patients with a failed transition reported feeling lonely both socially and in general. Furthermore, they were not satisfied at all with their friendships. This outcome indicates that the number of friendships (the social network) and the quality of friendships (reflected by the experiencing of feelings of loneliness) did not fulfill their needs. Remarkably, emotional loneliness was not correlated to transition to independence. This might reflect that patients still living at home either experience emotional support from their parents, or that they feel ashamed to admit to emotional loneliness. The latter explanation is most likely, as patients also reported not being satisfied with the situation of living at home with their parents.

Second, based on prior observations in our multidisciplinary Epilepsy Transition Clinic and in our adult outpatient clinic, we had the clinical impression that adults with a failed transition to independence/separation accepted the situation of still living at home with their parents as being beneficial. However, this study indicated the exact opposite, namely that adult patients with epilepsy who still live at home with their parents were not satisfied at all with the situation, both developmentally and socially.

Several studies found reduced social skills and social competences among patients with epilepsy compared to a control group [17–21]. Reduced skills and competences in developing friendships and social networks, and experiencing feelings of loneliness can hypothetically be caused by the family environment, as parental overprotection of children with epilepsy may lead to decreased social activities and social interactions [17,18,20–22]. Subsequently, adult patients with epilepsy lack sufficient social skills and social competences to develop friendships, and experience feelings of loneliness because the friendships they have do not fulfill their needs [22]. Another reasonable explanation is that patients with epilepsy experience problems in participating in social activities such as leisure activities or getting out with friends [2]. Kobau et al. [2] described that over 25 percent of adults with epilepsy experience difficulties in participating in social activities, and that 13.9% of the patients with epilepsy are unable to get out. This is almost twice the number found in adults without epilepsy. Causes for avoidance of social participation, and thus social isolation, may for example include fear of having seizures in public places, difficulties in obtaining and maintaining a suitable job and job-related social interaction with peers, or stigma [2,3,22]. Another third substantial problem to participate in social activities is transportation to get to places (e.g., restrictions in driving). Kobau et al. [2] described that patients with epilepsy are unable to use any type of transportation three and a half times more often than adults without epilepsy. Facilitating transportation options can possibly provide improvement.

Although risk factors for failed transition or loneliness were not analyzed in this study, we hypothesize that these are primarily due to factors found in the family environment of patients with epilepsy (e.g., parental overprotection or an unsupportive family environment) and with persistent patient characteristics (e.g., lack of social competences). The persistent patient characteristic can be a low intelligence level, a higher comorbid anxiety or depressive disorder or an underlying social anxiety disorder [10,17,18,21]. Our previous study analyzing risk factors for poor psychosocial outcome in adolescents and young adults with epilepsy showed that an unsupportive family environment is associated with an adverse future outcome. In accordance with the study of Kokkonen et al. [17] we found no evidence that epilepsy (in terms of seizure frequency or age at onset of epilepsy) was primarily correlated with failed transition to independence, however, it should be noted that in our study population 30 patients (50.8%) had seizure-freedom over

one year (range 0–20 years). Furthermore, we found no statistical difference between patients with successful and unsuccessful transition to independence based on the type of epilepsy.

Preventive measures and interventions for loneliness, such as training of social competences, can be challenging. First, loneliness can be difficult to notice, as many people feel ashamed of admitting being socially isolated [16]. This might be reflected by the results of this study; 22 patients (37.3%) reported positive scores on the De Jong-Gierveld loneliness scale, but 79.7% ( $n = 47$ ) of the patients reported ‘yes’ to the question: ‘Are you satisfied with the number of friendships?’ that was included in our questionnaire. This might indicate that patients feel ashamed of reporting not having friends, or that these friendships did not fulfill their needs. Second, evidence is still conflicting, as some studies suggest that self-help groups or the improvement of social skills increase social networks, as others conclude that interventions were not successful in a population of social isolated people with multiple problems, because the interventions lacked attention for specific conditions and circumstances [22,23]. Nevertheless, the first step is to evaluate the social participation and social network, and feelings of loneliness during a consultation with a health care worker [3].

Clinically, we advise health care workers (e.g., paediatricians, health care workers staffing an epilepsy transition clinic, epileptologists) to pay attention to loneliness in adolescents and young adults with epilepsy who fail to separate from their parents. It is also advisable to evaluate social participation and social networks of young adults with epilepsy, with the idea in mind that patients might feel ashamed admitting loneliness. Since evidence of interventions to improve the social network is conflicting, we suggest to improve the separation and independence from parents, as leaving a chronically poor functioning family seems the first step in improving the social skills and reducing feelings of loneliness [18,21]. The effectiveness of epilepsy specific social support groups must be further evaluated.

#### 4.1. Strengths and limitations

To the best of our knowledge, this is the first study indicating a correlation between young adults with epilepsy with a failed transition to independence and the satisfaction with their social network. The results of this study are useful for health care workers who notice that adolescents and young adults tend to fail transition to independence.

This study also has some limitations. The overall small sample size limits the interpretation of the results of this study. A study by Richards

et al. [24] showed that response rates in population-based studies are generally low. Second, the use of questionnaires limited the characteristics (e.g., family environment) explored in this study, and the answers can be subject to recall or response bias.

Third, as it was impossible to conduct a non-responder analysis, selection bias cannot be completely ruled out. Since our hospital is a tertiary referral epilepsy center, we were unable to collect a valid group of matched control patients without epilepsy.

The patients were not selected by type of epilepsy or seizure frequency. Therefore this study population still may be representative for patients in chronic care of a tertiary referral center. Unfortunately, the group was too small to detect subgroup differences.

In our study we did not include a matched control group, limiting the possibility to establish that loneliness is more prevalent in patients with childhood onset epilepsy. However, in a recent meta-analysis on loneliness in children and adolescents with chronic physical conditions an effect was found suggesting that children with a chronic disease suffer more loneliness than their peers without chronic disease. This was especially the case in children with visual and hearing problems, but also for children with neurological conditions [25].

Last, this study showed correlations between patient characteristics and transition to independence, but predictors for failed transition to independence could not be identified.

## 5. Conclusions

Failed transition to independence is correlated with social loneliness and with a higher overall score on the De Jong-Gierveld loneliness scale. Patients reported that they were not satisfied with their independence/separation and friendships, reflecting a troublesome chronic situation. We found no evidence that epilepsy was primarily correlated with a failed transition to independence.

## Conflict of interest

None.

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## Appendix A

Appendix: *The De Jong-Gierveld loneliness scale* [15].

Question: Please indicate for each of the 11 statements, the extent to which they apply to your situation, the way you feel now. Please, circle the appropriate answer.

1	There is always someone I can talk to about my day-to-day problems.	Yes/more-or-less/no
2	I miss having a really close friend.	Yes/more-or-less/no
3	I experience a general sense of emptiness.	Yes/more-or-less/no
4	There are plenty of people I can lean on when I have problems.	Yes/more-or-less/no
5	I miss the pleasure of the company of others.	Yes/more-or-less/no
6	I find my circle of friends and acquaintances too limited.	Yes/more-or-less/no
7	There are many people I can trust completely.	Yes/more-or-less/no
8	There are enough people I feel close to.	Yes/more-or-less/no
9	I miss having people around me.	Yes/more-or-less/no
10	I often feel rejected.	Yes/more-or-less/no
11	I can call on my friends whenever I need them.	Yes/more-or-less/no

## References

[1] Sillanpaa M, Helen Cross J. The psychosocial impact of epilepsy in childhood.

Epilepsy Behav. 2009;15(Suppl. 1):S5–10. <https://doi.org/10.1016/j.yebeh.2009.03.007>.

[2] Kobau R, Luncheon C, Zack MM, Shegog R, Price PH. Satisfaction with life domains in people with epilepsy. Epilepsy Behav. 2012;25:546–51. <https://doi.org/10.1016/>

- j.yebeh.2012.09.013.
- [3] Espinola-Nadurille M, Crail-Melendez D, Sanchez-Guzman MA. Stigma experience of people with epilepsy in Mexico and views of health care providers. *Epilepsy Behav.* 2014;32:162–9. <https://doi.org/10.1016/j.yebeh.2013.12.007>.
- [4] Suurmeijer TP, Reuvekamp MF, Aldenkamp BP. Social functioning, psychological functioning, and quality of life in epilepsy. *Epilepsia* 2001;42:1160–8.
- [5] Sillanpaa M, Haataja L, Shinnar S. Perceived impact of childhood-onset epilepsy on quality of life as an adult. *Epilepsia* 2004;45:971–7.
- [6] Chin RF, Cumberland PM, Pujar SS, Peckham C, Ross EM, Scott RC. Outcomes of childhood epilepsy at age 33 years: a population-based birth-cohort study. *Epilepsia* 2011;52:1513–21. <https://doi.org/10.1111/j.1528-1167.2011.03170.x>.
- [7] Jalava M, Sillanpaa M, Camfield C, Camfield P. Social adjustment and competence 35 years after onset of childhood epilepsy: a prospective controlled study. *Epilepsia* 1997;38:708–15.
- [8] Camfield P, Camfield C, Pohlmann-Eden B. Transition from pediatric to adult epilepsy care: a difficult process marked by medical and social crisis. *Epilepsy Curr.* 2012;12:13–21. <https://doi.org/10.5698/1535-7511-12.4s.13>.
- [9] Appleton RE, Chadwick D, Sweeney A. Managing the teenager with epilepsy: paediatric to adult care. *Seizure* 1997;6:27–30.
- [10] Geerlings RP, Aldenkamp AP, Gottmer-Welschen LM, de With PH, Zinger S, van Staa AL, et al. Developing from child to adult: risk factors for poor psychosocial outcome in adolescents and young adults with epilepsy. *Epilepsy Behav.* 2015;51:182–90. <https://doi.org/10.1016/j.yebeh.2015.07.035>.
- [11] Iyer A, Appleton R. Transitional services for adolescents with epilepsy in the U.K.: A survey. *Seizure* 2013;22:433–7. <https://doi.org/10.1016/j.seizure.2013.02.014>.
- [12] Jurasek L, Ray L, Quigley D. Development and implementation of an adolescent epilepsy transition clinic. *J. Neurosci. Nurs.* 2010;42:181–9.
- [13] Geerlings RP, Aldenkamp AP, Gottmer-Welschen LM, de With PH, Zinger S, van Staa AL, et al. Evaluation of a multidisciplinary epilepsy transition clinic for adolescents. *Eur. J. Paediatr. Neurol.* 2016;20:385–92.
- [14] Seligman ME. Learned helplessness. *Annu. Rev. Med.* 1972;23:407–12.
- [15] de Jong Gierveld J, van Tilburg T. [A shortened scale for overall, emotional and social loneliness]. *Tijdschr. Gerontol. Geriatr.* 2008;39:4–15.
- [16] Machiels JEM. Sociaal isolement bij ouderen: een typologie als richtlijn voor effectieve interventies. [Social isolation among older people: a typology as guide for effective interventions]. *J. Soc. Intervention: Theory Practice* 2011;20:40–61.
- [17] Kokkonen J, Kokkonen ER, Saukkonen AL, Pennanen P. Psychosocial outcome of young adults with epilepsy in childhood. *J. Neurol. Neurosurg. Psychiatr.* 1997;62:265–8.
- [18] Koponen A, Seppala U, Eriksson K, Nieminen P, Uutela A, Sillanpää M, et al. Social functioning and psychological well-being of 347 young adults with epilepsy only—population-based, controlled study from Finland. *Epilepsia* 2007;48:907–12.
- [19] Hamiwka LD, Hamiwka LA, Sherman EM, Wirrell E. Social skills in children with epilepsy: how do they compare to healthy and chronic disease controls? *Epilepsy Behav.* 2011;21:238–41. <https://doi.org/10.1016/j.yebeh.2011.03.033>.
- [20] Jakovljevic V, Martinovic Z. Social competence of children and adolescents with epilepsy. *Seizure* 2006;15:528–32.
- [21] Tse E, Hamiwka L, Sherman EM, Wirrell E. Social skills problems in children with epilepsy: prevalence, nature and predictors. *Epilepsy Behav.* 2007;11:499–505.
- [22] McCagh J, Fisk JE, Baker GA. Epilepsy, psychosocial and cognitive functioning. *Epilepsy Res.* 2009;86:1–14. <https://doi.org/10.1016/j.eplepsyres.2009.04.007>.
- [23] Machiels JEM. Vrijwillige inzet bij sociaal geïsoleerden met multiproblematiek: mogelijkheden, voorwaarden en rollen. [Volunteering to social isolated people with multiple problems: possibilities, conditions and roles]. *J. Soc. Intervention: Theory Practice* 2013;22:5–23.
- [24] Richards J, Wiese C, Katon W, Rockhill C, McCarty C, Grossman D, et al. Surveying adolescents enrolled in a regional health care delivery organization: mail and phone follow-up—what works at what cost? *J Am Board Fam Med* 2010;23:534–41.
- [25] Maes M, Van den Noortgate W, Fustolo-Gunnink S, Rassart J, Luyckx K, Goossens L. Loneliness in children and adolescents with chronic physical conditions: a meta-analysis. *J. Ped. Psychol.* 2017;42(6):622–35.