

# Cross-cultural translation of the INSPIRIT-R for Brazil and its applicability among epilepsy patients

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## ABSTRACT

**Objective:** To describe the cross-cultural adaptation of the INSPIRIT-R instrument for evaluation of religious and spiritual experiences into a Brazilian Portuguese version and its applicability among epileptic patients. **Method:** After the translation and back-translation phases, a multidisciplinary committee compared the back-translation with the original text in order to evaluate its content, comprehensibility, conceptual equivalence, cultural and contextual adjustment for Brazilian population. Lastly, the final version was tested on 50 long-term followed-up outpatients with a confirmed diagnosis of epilepsy in Florianópolis, SC, Brazil. **Results:** The patients' mean age was 33.7 years (18-55) and 26 (52%) were women. They had attended school for a mean of 8.0 years (3-17) years. Most of them (80%) were Catholics and 82% had a confirmed diagnosis of temporal lobe epilepsy. In the final Portuguese version, questions 3, 7C and 7E required slight modifications, along with the layout of question 7. **Conclusion:** The Brazilian Portuguese version of the INSPIRIT-R instrument was easily understood by most of the patients, after minimal modifications.

**Key words:** translation, INSPIRIT-R, spirituality, religion, temporal lobe epilepsy.

## Adaptação transcultural do instrumento INSPIRIT-R no Brasil e aspectos de sua aplicação em pacientes com epilepsia

## RESUMO

**Objetivo:** Realizar a adaptação transcultural do instrumento INSPIRIT-R para avaliação de religiosidade e espiritualidade em pacientes com epilepsia no Brasil. **Método:** Após as fases de tradução e retrotradução do instrumento, uma equipe multidisciplinar julgou as versões obtidas quanto à clareza, compreensibilidade, manutenção do conceito original e sua adequação de sentido para a população brasileira. Foram testados 50 pacientes do ambulatório de epilepsia em Florianópolis, SC, Brasil. **Resultados:** A média de idade foi de 33,7 anos (18-55) e a média de escolaridade foi de 8,0 anos (3-17). As mulheres representaram 52%. Os católicos perfizeram 80% e 82% dos pacientes e apresentavam epilepsia do lobo temporal como diagnóstico sindrômico. Na versão final em português, as questões 3, 7C e 7E sofreram modificações, assim como a forma de apresentação da questão 7. **Conclusão:** A versão em português do INSPIRIT-R foi facilmente compreendida, sendo mínimas as modificações realizadas no processo de adaptação cultural deste instrumento.

**Palavras-chave:** tradução, INSPIRIT-R, espiritualidade, religião, epilepsia do lobo temporal.

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Temporal lobe epilepsy (TLE) is the most common form of focal epilepsy among adults, accounting for at least 40% of all cases. The seizures in this syn-

drome may be characterized by sensory phenomena such as conscious experiential auras of religious or spiritual content<sup>1,2</sup>. The types of experience and their

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content vary among patients and depend on their religious / spiritual / cultural and personal backgrounds<sup>3,4</sup>. These symptoms may precede complex partial seizures or progress to secondarily generalized seizures, and may also occur after a seizure, as postictal psychosis<sup>3-10</sup>. In addition, many of these patients exhibit interictal behavior characterized by hyperreligiosity, tendency to write copiously (hypergraphia) and lack of sexual interest (loss of libido and impotence), featuring the Gastaut-Geschwind syndrome<sup>7,8</sup>.

Religiosity and spirituality are considered important allies of people who suffer and/or are diseased<sup>11</sup>. Currently, there is a growing consensus about the importance and weight that these factors have on quality of life of ill people in general<sup>12</sup>. Several scales have been developed and validated in attempts to measure and evaluate the importance of religiosity and spirituality in such individuals' lives, such as: Functional Assessment of Chronic Illness Therapy Spiritual Well-being Scale (FACIT-Sp-12)<sup>12</sup>; Self-Reporting Questionnaire (SRQ-20)<sup>11</sup>; Range of Spiritual-Religious Coping (SRC), which was the first to be used in Brazil<sup>13</sup>; WHO Spiritual, Religious and Personal Beliefs (WHOSRPB) and the WHOQOL 100 Scale<sup>14</sup>; Hood's Mysticism Scale<sup>7</sup>; Neurobehavioral Inventory (NBI)<sup>15</sup>; and the Index of Core Spiritual Experiences (INSPIRIT, Copyright 1991, 1996, 2000)<sup>16</sup>. Among the instruments mentioned, only the SRC<sup>13</sup>, WHO-SRPB<sup>14</sup> and NBI<sup>15</sup> have been adapted for Brazil. The first of these assesses solely how people use faith to cope with stress, the second examines personal beliefs and how they affect quality of life, while the third evaluates several characteristics of personality nonspecifically, including spirituality. The INSPIRIT-Revised instrument (INSPIRIT-R)<sup>16</sup> has not been validated for the Brazilian population yet. Hence, for this population, there is currently a lack of an instrument to assess religious and spiritual experiences and their correlation with individuals' ability to cope with disease. Therefore, the objective of the present work was to accomplish cultural adaptation of INSPIRIT-R for assessment of religiosity/spirituality among patients with epilepsy in Brazil.

## METHOD

This study was conducted in accordance with the Declaration of Helsinki and was only started after approval by the Ethics Committees for Human Research of the Federal University of Santa Catarina (UFSC) and of Governor Celso Ramos Hospital (HGCR). Informed consent was obtained from all participants before their inclusion in this protocol.

In accordance with previously published guidelines<sup>17,18</sup>, the process of cross-cultural adaptation of the INSPIRIT-R included the following five steps: [1] trans-

lation; [2] back-translation; [3] review by an expert committee to ensure semantic, idiomatic, experiential and conceptual equivalence; [4] testing of the pre-final version; and [5] further testing of the adapted version and adaptation of the scores, under direct supervision by the developers of this questionnaire.

## The instrument

The development of INSPIRIT-R<sup>16</sup> was based on the observation that patients with religious experiences were more satisfied, had a better sensation of a meaningful life and better clinical outcomes than did patients who did not report such experiences. Kass et al.<sup>16</sup> also found that the majority of these patients presented a distinct event that led them towards a personal conviction of God's existence and towards the perception of a close relationship with God.

The questionnaire contains seven items<sup>16</sup>. The seventh consists of a list of 12 types of religious experiences, and the patient is asked whether some of these experiences occurred and convinced him that God exists. Questions 3, 5 and 7 identify whether there were experiences that led the individual to believe in the existence of God, while questions 1, 2, 4, 6, identify behaviors and attitudes in people who have the perception of a close relationship with God. For each item of the questionnaire, which all have the same weight, the patient has to choose within a score from 1 to 4.

A signed document was obtained directly from the author, who granted his authorization for the process of cross-cultural adaptation of the questionnaire to Brazilian Portuguese. The author also sent guidelines concerning how to calculate the total score of the instrument, with regard to its revised version (INSPIRIT-R).

## Translation and instrument evaluation

Two native Brazilian bilingual individuals with perfect knowledge of English, who knew the purpose of this study, carried out the translation of the original instrument into Portuguese, thus creating two versions of INSPIRIT-R. These two versions were sent to two independent native English-speaking translators with full knowledge of both languages, who were residents in Brazil, did not know the purpose of the study and had no access to the original instrument, for back-translation. A multidisciplinary team consisting of 16 individuals - five physicians (three neurologists, one psychiatrist and one endocrinologist), four undergraduate medical students, one neuropsychologist and two undergraduate psychology students, one physiotherapist, one nurse, one speech therapist and one biologist - made up the review committee. This group compared the back-translated version with the original in English, analyzed the discrep-

ancies between them, evaluated the clarity and comprehensibility of the questions, and assessed the cross-cultural equivalence with the source version of each item, in relation to the Brazilian population. Following this consensus meeting, a final version of the INSPIRIT-R instrument was obtained.

### Data collection

For the testing phase, 50 consecutive patients who had been followed up for at least two years at the epilepsy outpatient clinic of the State of Santa Catarina Epilepsy Center (CEPESC), at HGCR, in Florianópolis, SC, Brazil, were selected to participate in the study between January and June 2009. We excluded patients younger than 18 years, patients who refused to participate in the study, illiterate individuals and patients with intellectual, psychiatric or emotional comorbidities that would prevent them from understanding and answering the questionnaire appropriately. All patients had a definite diagnosis of epilepsy based on seizure history and semiology, in accordance with the Commission on Classification and Terminology of ILAE (Commission, 1989)<sup>19</sup>.

All the questionnaires were administered in face-to-face interviews to check the comprehensibility of the measurements. After each answer that the patient gave, the examiner asked: [1] Can you explain in your own words what you understood from that question? and [2] Were there any words in that question that you did not understand? If so, do you have any suggestion for making this question easier to understand?

### Statistical analysis

The data gathered were analyzed to ensure that the Brazilian Portuguese version of the instrument demonstrated the properties required for valid application. The total scores were calculated in accordance with the instructions sent by the original author. All the data were stored and analyzed using Microsoft Office Excel 2007 and SPSS for Windows 15.0. The association between the INSPIRIT-R scores and the clinical and demographic variables were assessed by means of Student's "t" test and p values <0.05 were considered significant.

### RESULTS

The final Brazilian Portuguese version of INSPIRIT-R was completed by 50 subjects, and the average time taken to answer the questionnaire was 20 minutes. The sociodemographic variables are listed in Table 1.

Regarding religion, apart from the Roman Catholic Church, the other religions cited were: Evangelical Adventist (2%), Evangelical Universal Kingdom of God (4%), Evangelical Assembly of God (4%), Foursquare Gospel (4%), Jehovah's Witnesses (2%) and Protestant (2%).

**Table 1.** Patients' sociodemographic variables.

Variables	Patients N=50 (%)
Gender	
Female	26 (52)
Male	24 (48)
Age	
Mean (SD)	33.7 (10.53)
Race	
White	40 (80)
Others	10 (20)
Schooling	
Mean years (SD)	8.0 (3.59)
Religion	
Catholic	40 (80)
Others	10 (20)

SD: standard deviation.

**Table 2.** Relationship between number of questions about which doubts were expressed and patients' schooling levels.

Questions about which doubts were expressed	Patients N=50 (%)	Mean schooling (SD)
None	20 (40)	8.4 (3.36)
1 question	14 (28)	8.3 (4.25)
2 questions	12 (24)	7.1 (3.43)
3 questions	3 (6)	7.6 (3.51)
4 questions	1 (2)	8.0 (0)

SD: standard deviation.

Among all the patients, 70% were practitioners. Only one patient reported having no religion.

Table 2 shows the relationship between the number of questions about which each patient expressed doubts and their average schooling level. The average educational level of patients who did not understand more than one question (7.6 years±3.75) was not different from the average educational level of those with a maximum of one question about which they were in doubt (8.0 years±0.21), with p=0.29 (Student's t test).

Some questions required complementary information for clarification. These questions were modified in accordance with suggestions from the patients.

The clinical characteristics of the patients who were interviewed and their relation with the INSPIRIT-R total score are listed in Tables 3 and 4.

In addition to the drugs mentioned in the table, the other antiepileptic drugs (AEDs) used by patients were clonazepam (5), divalproex sodium (1), phenytoin (7), lamotrigine (2) and oxcarbazepine (1). The mean daily doses of these drugs were, respectively, 3 mg, 450 mg,

**Table 3.** Patients' clinical characteristics.

Variable	Patients N=50 (%)
Age of onset of epilepsy (years)	
Mean (SD)	15.9 (11.58)
Duration of disease (years)	
Mean (SD)	17.8 (12.99)
Epileptic syndrome	
Temporal lobe epilepsy	41 (82)
Idiopathic generalized epilepsy	7 (14)
Frontal lobe epilepsy	1 (2)
Uncertain	1 (2)
Antiepileptic drug	
Carbamazepine	29 (58)
Phenobarbital	13 (26)
Clobazam	10 (20)
Sodium valproate	8 (16)
Others	16 (32)
Mean AED* dose (mg) (SD)	
Carbamazepine	1134.4 (502.33)
Phenobarbital	203.8 (103)
Clobazam	28.0 (17.51)
Sodium valproate	1125.0 (654.65)
Others	–

\*Antiepileptic drug; SD: standard deviation.

314 mg, 300 mg and 600 mg. Twenty-two patients were taking more than one type of AED, whereas only one patient was not using any type of medication.

According to the scoring methodology provided by the author, the mean score obtained by our patients was 3.2 (SD=0.49). Nineteen patients (38%) had scores higher than 3.5. The average score among the female patients

was 3.48 while among the males, it was 3.25 (p=0.36). The mean score among the patients with focal TLE was 3.32, and among those with idiopathic generalized epilepsy (IGE), it was 3.10 (p=0.047).

## DISCUSSION

The Brazilian Portuguese version of INSPIRIT-R was culturally validated among a sample of 50 outpatients with two epilepsy syndromes (TLE and IGE). The results indicated that the Portuguese version of the INSPIRIT-R questionnaire only required minor modifications and was easily understood. No more than 20 minutes were required to complete it.

Although 60% of the patients had doubts about at least one question, only 32% reported doubts about two or more. This latter group had a mean educational level that was lower than the former, but the difference was not statistically significant. In two questions (Questions 3 and 7E), we used the technique of adding explanations to the sentences in the questionnaire, while keeping the original meaning of the terms and increasing the clarity of what was asked. Question 7C required replacement of part of the sentence by a broader term, thus facilitating the understanding of the issue without, however, modifying the original concept.

Regarding religion, 80% were Roman Catholics and 12% were Evangelicals. According to the IBGE Census of 2000<sup>20</sup>, 73.6% of the Brazilian population is Roman Catholic, with Evangelical religion (15.4%) placed second.

The TLE syndrome was the most prevalent type among our patients (82%). Data in the literature indicate that among the focal epilepsies, TLE is the most common form, accounting for 40% of the cases<sup>1,2</sup>. Fur-

**Table 4.** Clinical variables and their relationship with INSPIRIT-R total score.

Variable	N=50 (%)	Score (SD)	p value*
Gender			0.36
Female	26 (52)	3.48 (0.40)	
Male	24 (48)	3.25 (0.58)	
Syndrome			0.047 <sup>†</sup>
Temporal lobe epilepsy	41 (82)	3.32 (0.47)	
Idiopathic generalized epilepsy	7 (14)	3.10 (0.45)	
Age			0.51
≤30 years	24 (48)	3.20 (0.59)	
≥31 years	26 (52)	3.30 (0.40)	
Educational level			0.36
≤8 years	27 (54)	3.31 (0.42)	
≥ 9 years	23 (46)	3.18 (0.58)	
Duration of disease			0.22
≤15 years	24 (48)	3.16 (0.51)	
≥16 years	26 (52)	3.34 (0.48)	

\*Student's t test; SD: standard deviation; <sup>†</sup>Statistically significant.



thermore, the higher prevalence of this syndrome in the study can also be explained by the fact that CEPESC is a tertiary unit that attends difficult-to-control epilepsy patients. TLE is frequently associated with resistance to drug treatment, and hippocampal sclerosis is the main etiology, found in 50-70% of patients<sup>21,22</sup>.

The mean score from the questionnaire was 3.2 (SD= 0.49), while Kass et al.<sup>16</sup> found 2.8 (SD=0.83). In this study 38% of the patients achieved a score greater than 3.5, while Kass et al.<sup>16</sup> encountered 26%. A score greater than 3.5, according to this author, indicates strong occurrence of spiritual / religious experiences. Kass et al.<sup>16</sup> also found a statistically significant difference between the females' and males' scores, with  $p<0.04$ , whereas this relationship was not confirmed in our study sample ( $p=0.36$ ).

Patients with TLE had a higher score than did patients with IGE. This finding agrees with most studies linking religiosity / spirituality with TLE<sup>3-10,23-25</sup>. Trimble and Freeman<sup>7</sup> applied the INSPIRIT instrument in its modified form to compare religious experiences among patients with epilepsy who were religious with the religious experiences among patients with epilepsy who were not religious, and with a third group of non-epileptic churchgoers. They concluded that religious patients with epilepsy had more religious experiences than did non-epileptic religious churchgoers, in various situations expressed in the questionnaire, for instance, as an experience of a miracle ( $p<0.001$ ), a near-death experience or life after death ( $p<0.001$ ) or an experience with an important spiritual figure ( $p<0.05$ ).

The majority of studies have reported a positive association between religiosity and TLE<sup>3-10,23-25</sup>. In 1970, Dewhurst and Beard<sup>4</sup> provided the concept that the temporal lobe is the cerebral region related to religious, cognitive and emotional experiences. While Devinsky<sup>10</sup> reported that there was a lack of studies concerning religious experiences and neurological disorders, other authors correlated religious experiences with anatomical and functional lesions located in the central nervous system. Wuerfel et al.<sup>8</sup> concluded that the right hippocampal volume was negatively correlated with religiosity among patients with refractory epilepsy. Lin et al.<sup>23</sup> described a complex hand automatism which they called 'sign of the cross', in four patients with unilateral right mesial TLE. The limbic system has often been suggested as the critical site for religious experiences. Moreover, it may be located predominantly in the temporal regions of the right hemisphere. Landtblom<sup>24</sup> described a patient with hypoplasia of the left hippocampus who presented religious auras. Ogata<sup>3</sup> described three cases of patients with TLE and postictal psychosis who had religious experiences during the ictal events as well as hyperreligi-

osity between seizures. The incidence of religious experiences during post-ictal psychosis was found to be 27.3%. Devinsky and Lai<sup>25</sup> noted that 0.4 to 3% of focal epilepsies were associated with ictal religious experiences, but a higher frequency was found when patients were directly questioned about it. Hyperreligiosity, as well as exacerbated religious / spiritual experiences in our patients may be related not only to the neural substrate and personality characteristics of TLE, but also to the general religious convictions of Brazilians.

In conclusion, there was a lack of an instrument capable of quantitatively measuring the level of religiosity and spirituality among individuals in Brazil. INSPIRIT-R may have utility in studies evaluating the weight of these elements in the quality of life of Brazilian people, whether diseased or not. Associations between different epileptic syndromes and the religious / spiritual experiences of Brazilian patients deserve further investigation.

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