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ORIGINAL PAPER

Measuring Spiritual Well-Being in Brazilian Adolescents with Chronic Illness Using the FACIT-Sp-12: Age Adaptation of the Self-Report Version, Development of the Parental-Report Version, and Validation

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Abstract

Spiritual well-being is a major issue in health care, but instruments for measuring this construct in adolescents are lacking. This study adapted the 12-item Functional Assessment of Chronic Illness Therapy-Spiritual Well-being Scale (FACIT-Sp-12) for use with Brazilian adolescents with chronic diseases and developed a parental observer-rated version, using an expert panel, back-translation, and cognitive interviews with 72 participants. The psychometric properties of both versions were verified with two- and three-factor models by testing with 212 participants. The self- and parental-reported versions showed face validity, content validity, and acceptable levels of internal consistency for the overall scale and the two-factor model. The convergent validity was satisfactory for most items in both two- and three-factor models, but there was a lack of discrimination in the three-factor model using multitrait–multimethod analysis. This study presents the first instrument to assess the spiritual well-being of adolescents from their point of view and to allow their parents to serve as evaluators. However, we recommend further psychometric testing of the self- and parental-report scales to assess spiritual well-being in adolescents with chronic diseases in Brazil.

Keywords Validation studies · Psychometrics · Adolescents · Parents · Proxy · Spirituality · Spiritual well-being

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Introduction

Spiritual well-being has become a major issue in health care as it is increasingly clear that it has an important impact on health outcomes (VanderWeele et al. 2017). However, the number of reliable and valid quantitative instruments for the assessment of spiritual well-being, or spirituality in general, and particularly in Portuguese (Lucchetti et al. 2013), is still limited for use in clinical practice (Draper 2012). Instruments that transcend beliefs and consider spirituality as a universal experience are important because they can assist people of various religions, or secular people, by taking their spiritual practice into consideration (de Meezenbroek et al. 2012).

The 12-item Functional Assessment of Chronic Illness Therapy-Spiritual Well-being Scale (FACIT-Sp-12) is a brief, self-reported instrument that measures spiritual well-being in adults (Peterman et al. 2002) by examining spirituality widely and not based on specific religious beliefs and practices (Whitford and Olver 2012). Since its inception, several studies have used FACIT-Sp-12 with individuals with chronic and/or life-threatening diseases, and it is available in at least 27 languages (Bredle et al. 2011). The psychometric properties of the Portuguese version of FACIT-Sp-12 were evaluated in adults, both in Portugal, with cancer patients (Pereira and Santos 2011), and in Brazil, with psychiatric patients (Lucchetti et al. 2013). Overall, these studies have demonstrated the importance of assessing spirituality and spiritual well-being in adult patients with chronic diseases.

Research indicates that spirituality influences adolescents dealing with chronic conditions (Damsma Bakker et al. 2018; Reynolds et al. Madan-Swain 2014), but few measures of religiosity and spirituality exist for use in this age group (Cotton et al. 2010). Although some studies have used FACIT-Sp-12 to assess spiritual well-being in adolescents (Cotton et al. 2012; Cotton et al. 2009a, b, 2010), the psychometric properties of the instrument in this population have not been evaluated. Due to the complexity of the scale's construct, this instrument cannot be assumed to be invariant to the development of adolescents. For instance, spiritual expression varies with age (Fowler 1981), because the cognitive and emotional development of adolescents may influence the expression of their spirituality (Cotton et al. 2010). Additionally, there are no instruments for assessing spiritual well-being in Portuguese validated for use with adolescents in Brazil. Furthermore, although subjects are the main source of assessment of their own spiritual well-being, when they are unavailable to answer the self-reported scales as the result of age, cognitive impairment, or disease progression, a parental observer report is an alternative (Rajmil, López et al. 2013). Yet, there is a lack of parental-report instruments that assess the spiritual well-being of adolescents. Hence, the objectives of this study were: a) to adapt the FACIT-Sp-12 scale for use with Brazilian adolescents with chronic diseases and to verify its psychometric properties; and b) to develop and test the psychometric properties of the FACIT-Sp-12 parental observer-rated version that complements the self-report scale for adolescents.

Method

This study received ethical approval from the ethics committee of the university and all the hospitals where data collection occurred. Written consent for participation was obtained from committee participants, parents or caregivers, as well as assent from the adolescents prior to study start.

The FACIT-Sp-12 Spiritual Well-Being Scale

FACIT-Sp-12 was developed based on the experience of cancer patients, psychotherapists, and hospital chaplains who described aspects of spirituality and/or faith that contributed to improving quality of life (Peterman et al. 2002). The responses to the items refer to a seven-day recall period and are presented on a five-point Likert scale ranging from 0 to 4, where 0 = not at all and 4 = very much. The initial study on the factorial structure supported two domains: Meaning/Peace consisting of eight items and Faith consisting of four items (Peterman et al. 2002). However, recent studies have demonstrated the three-factor model as a better fit than the two-factor model: Meaning (items 2, 3, 5, and 8), Peace (items 1, 4, 6, and 7), and Faith (items 9, 10, 11, and 12) (Canada et al. 2008; Murphy et al. 2010; Peterman et al. 2014). Items 4 and 8 must be recoded. The scores are summed to generate a total score that ranges from 0 to 48; the highest scores represent the highest levels of spiritual well-being (Bredle et al. 2011).

Participants

A total of 36 dyads of adolescents and one of their parents or caregivers ($n = 72$), recruited from the University Hospital of the Medical School of Ribeirão Preto (University of São Paulo, Brazil), participated in the semantic validation during the FACIT-Sp-12 process for age adaptation (Phase I). For the psychometric assessment (Phase II), 106 dyads of adolescents and one of their parents or caregivers ($n = 212$), who agreed to participate, were recruited at the University Hospital of the Medical School of Ribeirão Preto and Children and Young Adult's Cancer Hospital by convenience. Sociodemographic and religious data were collected in both phases.

Adolescents aged 12–17 years were included in the study if they had a diagnosis of chronic disease (cancer, type 1 diabetes mellitus, or cystic fibrosis) and were in regular outpatient or inpatient clinical follow-up. Parents or caregivers accompanying the adolescent in these follow-up appointments, living in the same household with the adolescent or parents who were involved in the care of their adolescent, but did not live in the same household, regardless of blood relationship, were also invited to participate in the study. Adolescents and parents or caregivers who were illiterate or had been reported to have intellectual disabilities in medical records or by health professionals were excluded.

Adaptation Process for Adolescents: Self-Report and Parental-Report Versions (Phase I)

When the instrument is developed for adults, and there is interest in its use in the pediatric population, it is necessary to verify the adequacy of terms, response format, and construct for the adaptation of the instrument (DISABKIDS 2004; Furr and Bacharach 2014). Some adolescents may not have reached the developmental level to respond to instruments that were developed for adults (Cotton et al. 2010). Therefore, this study was based on several studies with regard to the proposed adaptation of the FACIT-Sp-12 adult self-report for adolescents and the development of its parental proxy-report version (DISABKIDS 2004; Ferrer et al. 1996; Guillemin et al. 1993; Wartberg et al. 2016). Seven steps were taken, as illustrated in Fig. 1.

The FACIT-Sp-12 for adolescents originates from the scale translated into Portuguese by the FACIT group, which was validated for Brazilian adults (Lucchetti et al. 2013). Initially, no modifications were made to the FACIT-Sp-12 preliminary version for adolescents (self-report) (Step 1). The parental-report version (observer report) was developed from the FACIT-Sp-12 self-report version for adolescents, similar to Wartberg et al. (2016). There was no change in the scale content, only grammatical changes in the items and instructions with the aim of being answered by parents or caregivers from the adolescent's perspective. Therefore, the preliminary versions for adolescents and parents and/or caregivers have the same items, for example: (1) "I feel peaceful"/"My adolescent feels peaceful"; (2) "I have a reason for living"/"My adolescent feels that he/she has a reason for living."

Purposive sampling was used to recruit five professionals to serve on the expert committee with the objective of adapting the language in the items to respondents (adolescents and parents and/or caregivers) and to evaluate whether the instrument includes items that represent an adequate sample of the construct-relevant content for Brazilian adolescents (Step 2). They assessed the relevance and clarity of each item of the instrument considering semantic, idiomatic, conceptual, and cultural equivalence with the original instrument (Guillemin et al. 1993) as well as their suitability for respondents. They were asked to score each item on a three-point scale indicating whether the item was 1—not relevant; 2—unable to assess relevance without item revision, and 3—relevant and clear. Although pastoral counselors are highly qualified individuals for spiritual care, the expert committee was comprised of researchers and pediatric nurses who possessed a good command of the English language, knowledge, and experience in the area of spirituality, and experience in adolescent care and methodologies of adaptation of measurement instruments. The knowledge and experience were demonstrated through scientific publications and more than 18 years of experience in providing spiritual care to adolescents. The committee's suggestions were analyzed, and the research team calculated the content validity index (CVI) for each item and the entire instrument for quantification of content validity. Thus, suggestions were implemented when the number of items judged relevant and clear divided by the numbers of content experts had a CVI value of less than 0.80; CVI of 0.80 or higher for all items indicates content validity (Lynn 1986). The work of the expert committee was done before back-translation (Ferrer et al. 1996).

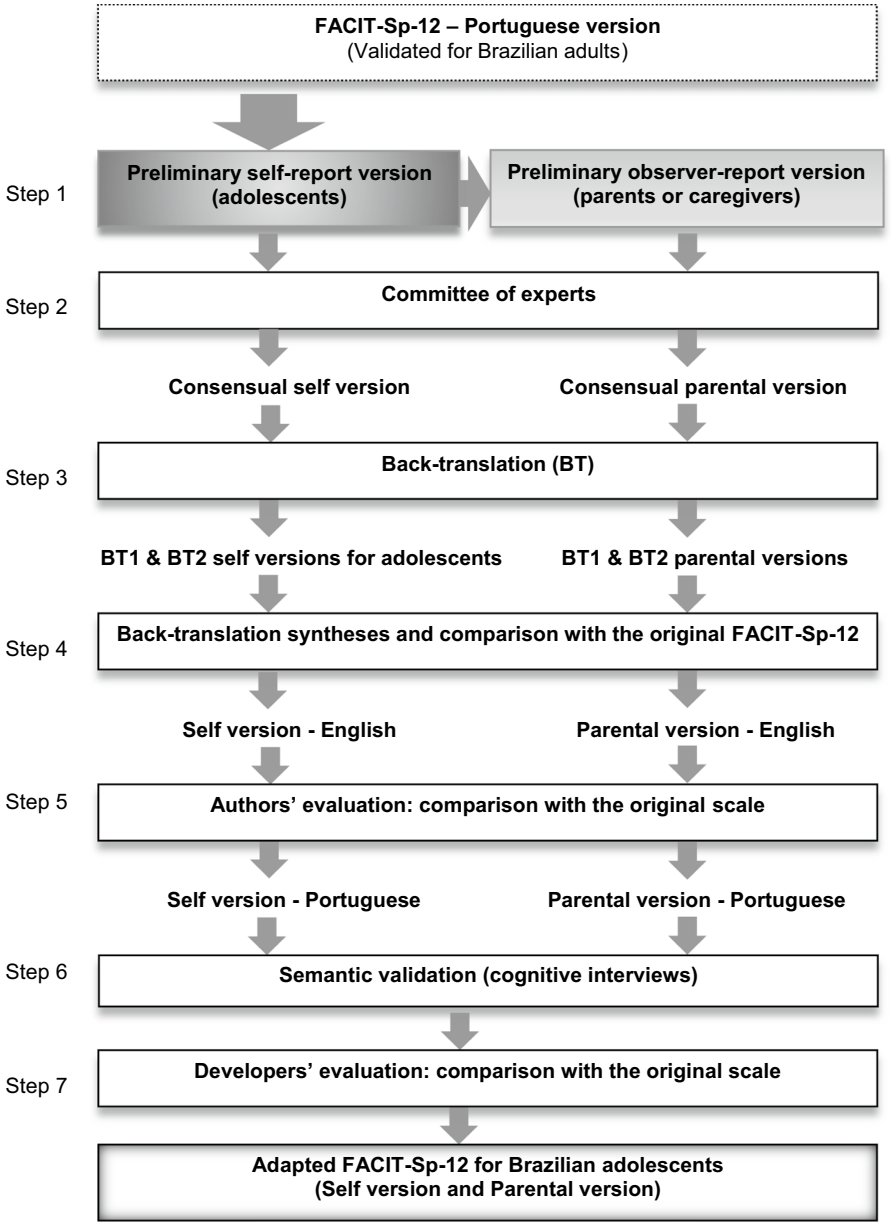

Fig. 1 Fluxogram of the adaptation to adolescents of the FACIT-Sp-12 self-report version and development of the parental-report version

The FACIT-Sp-12 consensus versions for adolescents and parental were translated into English by two independent translators who produced two back-translations of each version in parallel. The translators were bilingual, were unaware of

the scale's concepts, and were not professionals in the health area (Step 3). The synthesis of these translations was generated by consensus between translators and researchers by comparing the back-translation versions with the original FACIT-Sp-12 (Step 4). The English self- and parental-reported versions were sent to the FACIT authors for verification of equivalence with the original scale (Step 5).

Adolescents with chronic diseases and parents or caregivers answered the two scale versions, respectively; cognitive interviews were subsequently conducted focusing on the relevance, difficulty, comprehension, and adequacy of items in the scale (Step 6). Semantic validation tools elaborated by the European DISABKIDS group (DISABKIDS 2004) and adapted in Brazil by the Brazilian DISABKIDS group (DISABKIDS 2018) were used. Items were divided into subset A (items 1–6) and subset B (items 7–12) for specific evaluation. Each subset was answered by 18 adolescents with different chronic diseases (cancer, type 1 diabetes mellitus, or cystic fibrosis) who were grouped by age from 12 to 14 years and 15 to 17 years, resulting in 36 adolescents and 36 parents or caregivers. The total of this sample is the result of the distribution of six adolescents per subset and per disease. Their parents or caregivers also belonged to each respective group.

The final FACIT-Sp-12 self- and parental-report versions in Portuguese and adapted for Brazilian adolescents were examined and approved by the original FACIT-Sp-12 developers who verified equivalence with the original scale, and the scale in Portuguese validated for adults (Step 7).

Psychometric Assessment (Phase II)

The adolescents with chronic diseases and their parents or caregivers ($n = 106$ dyads) were purposely recruited for the psychometric evaluation of the self-reported and parental-reported versions. The purposive sampling intended to maintain a balanced distribution of adolescents considering gender and age for each chronic condition. For this purpose, the minimum sample number recommended is 50 (Terwee et al. 2007). Participants individually and concomitantly completed the final versions of the FACIT-Sp-12 self- and parental-report scales adapted for adolescents. Respondents of the parental-report version were instructed to respond from the adolescent's perspective instead of their own (Lobchuk and Vorauer 2003).

Statistical Analyses

The demographic and clinical characteristics of the sample are presented through descriptive analysis. The statistical analyses considered the original two-factor model (Meaning/Peace and Faith) and the three-factor model as suggested by the FACIT-Sp-12 authors (Peterman et al. 2014). Floor and ceiling effects were considered if more than 15% of respondents chose the lowest or highest possible score (Terwee et al. 2007). The scale's internal consistency was assessed using Cronbach's alpha values; α_{Cronbach} values > 0.70 were considered satisfactory (Terwee et al. 2007). The intraclass correlation coefficient (ICC) was used to assess concordance between the adolescent and parental scales. An ICC lower

than 0.40 was considered weak; 0.41 to 0.59, moderate; 0.60 to 0.75, good or substantial; and higher than 0.75, very good (Mcdowell 2006).

The multitrait–multimethod analysis (MTMM) assessed convergent and discriminant validity. Convergent validity is comprised of the correlation between an item and the dimension it belongs to, and values higher than 0.40 are considered satisfactory (Fayers and Machin 2007). Discriminant validity is supported whenever a correlation between an item and its hypothesis dimensions is higher than its correlation with the other dimension. Correlations very close to 1.0 (fitness close to 100%) are indicative of the instrument's discriminant validity (Fayers and Machin 2007).

The validity of known groups was assessed by comparing the scores with those of pre-defined groups; the Mann–Whitney test was used when two groups were compared, and the Kruskal–Wallis and post hoc tests were used to compare significant differences among multiple groups (Daniel 1990). The groups were "Religious practice" (yes or no) and "Diagnosis" (type 1 diabetes mellitus, cystic fibrosis, and cancer).

The descriptive data and basic statistical analyses were performed using the Statistical Package for the Social Sciences (SPSS), version 24.0 (IBM Corporation, USA). The Multitrait Analysis Program (MAP) (Hays and Hayashi 1990) was used to evaluate convergent and discriminant validity. The significance level was set at 0.05.

Results

Adaptation of the FACIT-Sp-12 Self- and Parental-Report Versions and Evaluation of Face and Content Validity (Phase I)

Committee of Experts

The expert committee suggested modifications to five items, both in the self-report version of the FACIT-SP-12 for adolescents and in the FACIT-Sp-12 observer-report version for parent/caregivers. These items had CVI less than 0.80 and underwent a second round of reviews after modifications, obtaining CVI of 0.80 or higher for all items that indicated content validity. In the FACIT-Sp-12 for adolescents, "produtiva" (productive) in item Sp3 was replaced with "proveitosa" (fruitful), "Custa-me" (I have trouble) was replaced with "Eu tenho dificuldade" (I have difficulty) in item Sp4, and the word "propósito" (purpose) was changed to "objetivo" (objective) in items Sp5 and Sp8. Word order in items Sp10 and Sp12 was reformulated. In the FACIT-Sp-12 adapted for parents or caregivers, the term "meu/minha adolescente" (my adolescent) was replaced with "meu/minha filho/a" (my child) in all items of the parental-report version because the latter is more commonly used by parents and caregivers. The basis for the suggested changes in this version of FACIT-Sp-12 was to make it easier for respondents to provide responses based on the parental perspective about their children and to make it similar to the self-report version.

Semantic Validation

The age, gender, and clinical condition of adolescents followed a balanced distribution. The majority of respondents of the FACIT-Sp-12 parental-report version were mothers, and all had coexisted with the adolescent for at least 10 years. Table 1 describes the educational level, religious practice, and importance of spirituality for the participants in Phase I.

In general, the adolescents evaluated the scale as good and considered it relevant and comprehensive. Overall, of 36 adolescents, 63.9% considered the scale good, and 58.3% said that the items were very important for their situation. There was no difficulty for the majority (80.6%) to choose among the five-point Likert response options; most of the adolescents (83.3%) did not want to change anything on the scale or add (91.7%) anything to it.

Similarly, all parents considered the adapted FACIT-Sp-12 parental-report version of the scale good; 75.7% considered the items easy to understand; and 97.3% thought the items were important for their adolescent's situation. The majority did not want to change (98.2%) or add (94.6%) anything to the scale, and 78.4% wanted to answer all questions. Thirty out of 36 (83.3%) parents/caregivers had no difficulty in distinguishing the five-point Likert response options. In general, parents and caregivers evaluated the scale well, considering it relevant and easy to answer. Parents or caregivers considered themselves capable of assessing their adolescent's spiritual well-being and were motivated to respond to the scale.

In establishing the comprehension and the assessment of the items through the cognitive interview, adolescents and parents or caregivers did not mention issues that were not covered by the items and neither a need to omit any item. They reported understanding the items and the Meaning, Peace, and Faith dimensions of the FACIT-Sp-12 determining the content validity of both instruments (Table 2). Most adolescents interpreted the items in an intended way, correctly grasping the meaning of the items. Only item 4, "Tenho dificuldade em sentir paz de espírito" (I have difficulty feeling peace of mind), was modified as a result of this phase in the study, because adolescents found it difficult to understand the expression "paz de espírito" (peace of mind) due to the term "espírito" that also means soul or disembodied spirit of a deceased person in the Brazilian culture. Thus, they suggested "paz interior" (inner peace) to replace it. Parents demonstrated understanding of all items. Item Sp4 was also changed in the parental-report version to make the scale equivalent to the self-report version.

We analyzed the participants' responses in this qualitative phase (Table 2) and grouped these as a way of evaluating the meaning of each dimension (Meaning, Peace and Faith) of the FACIT-Sp-12. The comprehension of the questions' concepts showed particular and closely related aspects among dimensions. The Meaning dimension was defined by adolescents and parents or caregivers as a sense of purpose or objective in life leading the adolescent to have a reason to be alive, going on treatment, living fruitfully, and being happy. They reported finding meaning through their relationships with family, friends and God, and a strong desire to study, work, or be healed. The Peace dimension was defined as a feeling of well-being, comfort, and tranquility with self and the situation of treatment and illness.

Table 1 Characteristics of the participants (adolescents and parents/caregivers) for the semantic validation (Phase I; $n=36$ dyads) and for the validation process (Phase II; $n=106$ dyads). Brazil, 2016–2017

Characteristics	Phase I *n* (%)	Phase II *n* (%)
Adolescents		
Age range (in years)		
12–14	18 (50.0)	58 (54.7)
15–17	18 (50.0)	48 (45.3)
Gender		
Male	17 (42.5)	64 (60.4)
Female	19 (52.8)	42 (39.6)
Chronic disease		
Type 1 diabetes mellitus	12 (33.3)	50 (47.2)
Cancer	12 (33.3)	31 (29.2)
Cystic fibrosis	12 (33.3)	25 (23.6)
Level of education		
Middle school	0 (0)	59 (55.7)
High school	18 (50.0)	47 (44.3)
Religious practice		
Yes	23 (63.9)	59 (55.7)
No	13 (36.1)	47 (44.3)
Importance of spirituality		
Very important	18 (50.0)	52 (49.2)
Somewhat important	16 (44.4)	43 (40.6)
Not very important	2 (5.6)	7 (6.6)
Not at all important	0 (0)	4 (3.8)
Parents/caregivers		
Age range (in years)		
<40	9 (25.9)	50 (47.2)
40–49	18 (50.9)	34 (32.1)
≥ 50	8 (23.2)	22 (20.7)
Relationship with the adolescent		
Mother	25 (69.4)	75 (70.8)
Father	5 (13.9)	14 (13.2)
Other	6 (16.7)	17 (16.0)
Time of home-living with the adolescent (in years)		
<10	4 (11.4)	9 (8.5)
10–17	31 (88.6)	97 (91.5)
Level of education		
Middle school	14 (38.9)	47 (44.3)
High school	9 (25.0)	43 (40.6)
University	6 (16.7)	16 (15.1)
Religious practice		
Yes	20 (55.6)	79 (74.5)
No	16 (44.4)	27 (25.5)
Importance of spirituality		

Table 1 (continued)

Characteristics	Phase I *n* (%)	Phase II *n* (%)
Very important	29 (80.6)	90 (84.9)
Somewhat important	6 (16.7)	14 (13.2)
Not very important	1 (2.8)	2 (1.9)
Not at all important	0 (0)	0 (0)

They reported family, God, religious community, and self as the sources of peace. The Faith dimension was defined as a belief in someone or something that is a source of peace and strength to continue living, enjoy well-being and comfort and having the confidence that things will be okay. God, religious community, and self were the sources of faith.

Psychometric Assessment (Phase II)

Sample Characteristics

In total, nine adolescents and their parents or caregivers declined to participate in the study because they were indisposed due to the symptoms of the disease. Two cases were excluded because they were illiterate or had intellectual disabilities. There were no missing data in any of the phases of this study. The final sample included 106 dyads of adolescents and one of their parents or caregivers who agreed to participate. The adolescents were at different ages and presented different chronic conditions; most parents were mothers. More than half of the participants practiced a religion and considered spirituality very important (see Phase II in Table 1 for further details). Adolescents needed an average of 2.7 min (SD 1.65) and their parents or caregivers needed an average of 4.0 min (SD 1.97) to respond to the scale.

Item Analysis and Reliability

The characteristics of score distribution for the self- and parental-report versions are given in Table 3. No floor and ceiling effects were observed in the response scores. A significant and moderate correlation was observed between responses in the overall scale and the "Faith" dimension, from adolescents and their parental observers (overall ICC = 0.46; "Faith" ICC = 0.46). The "Meaning" and "Peace" dimensions or "Meaning/Peace" dimension showed a significant and weak correlation ("Meaning" ICC = 0.29; "Peace" ICC = 0.36; "Meaning/Peace" ICC = 0.39).

The internal consistency was satisfactory in the self-reported and parental-reported total scale versions (self total $\alpha_{\text{Cronbach}} = 0.84$; parental total $\alpha_{\text{Cronbach}} = 0.86$) and in both "Faith" and "Meaning/Peace" dimensions of the two-factor model in the self and parental-report versions (Table 4). In the three-factor model, the "Meaning" and "Peace" dimensions had Cronbach's alpha values lower than 0.70 in the self and parental-report versions.

Table 2 Meanings ascribed by adolescents and by their parents or caregivers to the items of the adapted FACIT-Sp-12 during the cognitive interview ($N=72$). Brazil, 2017

Self-report version		Description (n)[a]			Examples of the discourse excerpts/meanings of the adolescents (A)
Dimensions	Items	Correct	Incorrect	Absent[b]	
Meaning	Sp2	17	0	1	"Even going on treatment, I have a reason to be living. My family and God are my main reasons" (A7, 13yo)
	Sp3	17	0	0	"I try to enjoy life. I have a good family, friends, and that makes my life fruitful and happy" (A12, 16yo)
	Sp5	18	0	0	"Even with everything that is happening, I will always have a goal to move forward, a dream to pursue like to study and work" (A20, 15yo)
	Sp8	14	0	4	"There is no sense in what I do, in what I am. When you want to give up everything and treatment" (A32, 15yo)
Peace	Sp1	16	0	2	"Feeling at peace with myself, nothing is disturbing me to live. I feel good with myself and comfortable with my situation" (A38, 15yo)
	Sp4	12	6	0	"I have peace within me. I am not worried about the situation I am living in" (A36, 15yo)
	Sp6	14	2	2	"Finding tranquility within you. You do not need someone to bring you comfort; you can do it for yourself" (A16, 12yo)
	Sp7	15	0	3	"Even though I have this disease, I feel at peace with myself" (A19, 15yo)
Faith	Sp9	14	0	4	"It is when I find peace and strength in what I believe. I like my belief, it comforts me. I feel good with my belief" (A11, 12yo)
	Sp10	15	0	3	"One should not lose faith to fight or achieve some goal. I pray, go to prayer groups, and feel renewed" (A40, 14yo)
	Sp11	14	0	4	"The disease greatly increased my faith, I began to pray more. Then I saw that everything God did had a purpose" (A24, 17yo)
	Sp12	15	0	3	"Even if I need a transplant, I know I can have it, and it will work out. It is confidence that things will be okay" (A40, 14yo)

Table 2 (continued)

Parental-report version		Description (n)[a]			Examples of the discourse excerpts/meanings of the Parents or Caregivers
Dimensions	Items	Correct	Incorrect	Absent[b]	
Meaning	Sp2	18	0	0	"Despite the difficult illness, she wants to continue treatment in order to live. Because she has a reason to live" (Mother33)
	Sp3	18	0	0	"Despite the illness, she makes the most of the time available to school, friendship, and leisure" (Father18)
	Sp5	18	0	0	"My son has a goal in life, he wants to live despite the severity of the disease" (Mother36)
	Sp8	17	0	1	"If there is no sense in her life, she will get worse during treatment. Strength to live, this is the sense of life" (Mother2)
Peace	Sp1	18	0	0	"My daughter feels at peace with herself, happy. She feels tranquility" (Mother7).
	Sp4	18	0	0	"Because he does not completely accept the disease, he is exposed to feeling embarrassed, and this takes some of his peace away" (Mother9)
	Sp6	18	0	0	"It is the person feeling good, loved, relieved, with tranquility within" (Mother35)
	Sp7	18	0	0	"Harmony is feeling good with the people you live and with yourself" (Father28)
Faith	Sp9	18	0	0	"When she is depressed, she goes in search of her faith. Hard as it is, she feels better." (Grandmother32)
	Sp10	17	0	1	"Because of his faith, he was not shaken by the illness. He finds strength in what he believes" (Mother14)
	Sp11	18	0	0	"The disease brought her closer to faith, especially in helping her to believe in healing. She asks God for healing" (Father39)
	Sp12	17	0	1	"Regardless of what happens, he gives me strength and confidence that everything will be fine because he told me that everything will work out" (Mother41)

[a]Items from Sp1 to Sp6 were evaluated by a group of 18 adolescents and 18 parents or caregivers; items from Sp7 to Sp12 were evaluated by another group of 18 adolescents and 18 parents or caregivers, totaling 72 participants in this phase

[b]Does not know how to explain or has difficulties in using synonyms

Table 3 Assessment of the floor and ceiling effect and concordance between self- and parental-report versions in the Phase II. Brazil, 2017

FACIT-Sp-12	Mean	Median	SD	Min (%)	Max (%)	Self–parental concordance intraclass correlation
Self-report version (adolescents)						
Meaning	12.3	13.0	2.9	3 (1.9%)	16 (13.2%)	0.29 (95% CI = 0.10–0.45); p = 0.001
Peace	11.2	11.0	2.9	1 (0.9%)	16 (6.6%)	0.36 (95% CI = 0.19–0.52); p < 0.001
Meaning/peace	23.6	24.0	5.2	4 (0.9%)	32 (2.8%)	0.39 (95% CI = 0.22–0.54) p < 0.001
Faith	10.3	11.0	3.5	2 (2.8%)	16 (7.5%)	0.46 (95% CI = 0.29–0.60); p < 0.001
Overall scale	33.8	34.0	7.6	11 (0.9%)	48 (0.9%)	0.46 (95% CI = 0.30–0.60); p < 0.001
Observer-report version (parents)						
Meaning	12.4	12.0	2.6	5 (0.9%)	16 (12.3%)	–
Peace	10.8	11.0	2.9	3 (0.9%)	16 (4.7%)	–
Meaning/peace	23.2	23.0	5.0	12 (1.9%)	32 (3.8%)	
Faith	10.1	11.0	4.2	1 (3.8%)	16 (9.4%)	–
Overall scale	33.3	33.5	8.1	13 (0.9%)	48 (1.9%)	–

Table 4 FACIT-Sp-12 reliability assessment and convergent validity assessment by multitrait–multimethod analysis of the item correlations and their corresponding dimensions, according to the two-factor and the three-factor models. Brazil, 2017

Adolescent-report version	Three-factor model			Two-factor model[b]
	Meaning ($\alpha_{Cronbach}=0.68$)	Peace ($\alpha_{Cronbach}=0.66$)	Faith ($\alpha_{Cronbach}=0.75$)	Meaning/peace ($\alpha_{Cronbach}=0.80$)
Sp2	0.47[a]	0.45	0.32	0.50[a]
Sp3	0.33[a]	0.47	0.31	0.46[a]
Sp5	0.52[a]	0.47	0.41	0.55[a]
Sp8	0.45[a]	0.47	0.34	0.52[a]
Sp1	0.57	0.54[a]	0.45	0.62[a]
Sp4	0.38	0.37[a]	0.43	0.42[a]
Sp6	0.44	0.52[a]	0.32	0.52[a]
Sp7	0.55	0.58[a]	0.40	0.62[a]
Sp9	0.38	0.42	0.69[a]	0.44
Sp10	0.52	0.49	0.72[a]	0.55
Sp11	0.38	0.47	0.70[a]	0.48
Sp12	0.30	0.36	0.44[a]	0.36
Total Cronbach's α	0.84			0.84
Parental-report version	Three-factor model			Two-factor model[b]
	Meaning ($\alpha_{Cronbach}=0.64$)	Peace ($\alpha_{Cronbach}=0.69$)	Faith ($\alpha_{Cronbach}=0.87$)	Meaning/peace ($\alpha_{Cronbach}=0.80$)
Sp2	0.56[a]	0.50	0.52	0.57[a]
Sp3	0.53[a]	0.50	0.27	0.56[a]
Sp5	0.48[a]	0.50	0.47	0.54[a]
Sp8	0.37[a]	0.58	0.31	0.54[a]
Sp1	0.59	0.52[a]	0.37	0.61[a]
Sp4	0.50	0.39[a]	0.18	0.49[a]
Sp6	0.50	0.51[a]	0.43	0.54[a]
Sp7	0.57	0.69[a]	0.43	0.66[a]
Sp9	0.45	0.36	0.81[a]	0.43
Sp10	0.50	0.43	0.87[a]	0.50
Sp11	0.42	0.32	0.78[a]	0.39
Sp12	0.51	0.52	0.62[a]	0.55
Total Cronbach's α	0.86			0.86

[a]Item-scale correlations for hypothesized scales, corrected for item overlap

[b]Faith is the same in both models and is not repeated here

Validity

When testing the validity of known groups for the self-reported version of the scale, adolescents practicing a religion scored higher than non-practicing adolescents in the "Faith" dimension (respectively, 12 vs. 9. $U=853.0$; $p=0.001$) and in the

total scale for spiritual well-being (total scores, respectively, 35 vs. 32, $U=1007$, $p=0.016$). Likewise, in the parental-reported version, parents practicing a religion attributed higher scores for adolescents, in the Faith dimension (respectively, 12 vs. 8, $U=566.0$; $p<0.0001$) and in the total scale (total scores, respectively, 35 vs. 31, $U=737$, $p=0.017$), than parents who do not practice a religion.

Both self- and parental-reported versions significantly differed between adolescents diagnosed with diabetes, cystic fibrosis, and cancer (self: total scores, respectively, 32.5 vs. 33 vs. 38, $\chi^2(2)=7.524$, $p=.023$; parental: total scores, respectively, 31 vs. 34 vs. 36, $\chi^2(2)=6.393$, $p=0.041$). Moreover, in the "Faith" dimension, these groups significantly differed in both the self- (respectively, 9 vs. 11 vs. 12, $\chi^2(2)=12.450$, $p=.002$) and parental-reported scales (respectively, 9 vs. 9 vs. 12; $\chi^2(2)=13.506$, $p=0.001$). Adolescents with cancer had higher spiritual well-being levels than adolescents with diabetes in both the self- (mean rank: diabetes 46.02 vs. cystic fibrosis 53.86 vs. cancer 65.27) and parental-reported scales (mean rank: diabetes 47.00 vs. cystic fibrosis 52.06 vs. cancer 64.07). Likewise, adolescents with cancer showed more faith than adolescents with diabetes (mean rank: diabetes mellitus 42.86 vs. cystic fibrosis 58.44 vs. cancer 66.68), and parents of adolescents with cancer attributed more faith to adolescents than parents of adolescents with other conditions (mean rank: diabetes mellitus 45.45 vs. cystic fibrosis 48.50 vs. cancer 70.52), according to the multiple comparison testing.

Table 4 shows the Pearson's linear correlation values between items and their dimensions obtained with the MTMM analysis. The FACIT-Sp-12 self- and parental-reported versions, for both the two-factor and three-factor models, indicated satisfactory convergent validity, with the majority of the items showing linear correlation with their dimensions postulated greater than 0.40.

There was an indication of lack of discrimination between "Meaning" and "Peace" in both self- and parental-reported versions, presenting 75.0% and 50.0% fit values for the self-reported version and 37.5% and 62.5% for the parental-reported version, respectively (Table 5). However, for the two-factor model "Meaning/Peace" showed 87.5% fit value in both self- and parental-reported versions, representing better discrimination than "Meaning" and "Faith." The discriminant validity in the "Faith" dimension was greater than 75.0% in both versions and models.

Discussion

This study adapted the self-report version of the FACIT-Sp-12 for use with adolescents in Brazil, also developing a parental-reported version for scoring by parents or caregivers. The adaptation process of this scale for adolescents and their parents or caregivers showed satisfactory psychometric properties, and the items were sufficiently understandable and relevant to respondents.

The language in the items in the FACIT-Sp-12 scale was adapted to meet the developmental and contextual levels of adolescents, in order to prevent a potential influence of different understandings of the meanings expressed in the items on the performance of respondents (Kristjansson et al. 2003). We followed suggestions provided by a committee of experts and then tested their suitability with cognitive

Table 5 Fit values for the discriminant validity, according to multitrait–multimethod analysis for the FACIT-Sp-12 self- and parental-reported versions. Brazil, 2017

	Three-factor model (n items/%)			Two-factor model (*n* items/%)	
	Meaning	Peace	Faith	Meaning/peace	Faith
Adolescent-report version					
− 2	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
− 1	2 (25.0%)	4 (50.0%)	1 (12.5%)	1 (12.5%)	1 (25.0%)
1	6 (75.0%)	3 (37.5%)	2 (25.0%)	2 (25.0%)	1 (25.0%)
2	0 (0%)	1 (12.5%)	5 (62.5%)	5 (62.5%)	2 (50.0%)
Adjustment 1 + 2	6 (75.0%)	4 (50.0%)	7 (87.5%)	7 (87.5%)	3 (75.0%)
Parental-report version					
− 2	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
− 1	5 (62.5%)	3 (37.5%)	1 (12.5%)	1 (12.5%)	1 (25.0%)
1	3 (37.5%)	4 (50.0%)	1 (12.5%)	3 (37.5%)	0 (0%)
2	0 (0%)	1 (12.5%)	6 (75.0%)	4 (50.0%)	3 (75.0%)
Adjustment 1 + 2	3 (37.5%)	5 (62.5%)	7 (87.5%)	7 (87.5%)	3 (75.0%)

− 2: correlation between item and dimension to which it belongs is significantly lower than its correlation with the dimension to which it does not belong. − 1: correlation between item and dimension to which it belongs is lower than its correlation with the dimension to which it does not belong. 1: correlation between item and dimension to which it belongs is significantly higher than its correlation with the dimension to which it does not belong. 2: correlation between item and dimension to which it belongs is higher than its correlation with the dimension to which it does not belong

interviews conducted with a sample of adolescents, parents, and caregivers, similar to Wiklander et al. (2013). Other studies have used different methods to conduct this process, such as: (1) changes in the scale implemented only by the researchers (Qualter et al. 2015); (2) use of a committee of experts (Amado et al. 2014; Greenfield et al. 2013); and (3) changes based on cognitive interviews with the target population (Juniper et al. 2005). Generally, these studies have achieved reliability and satisfactory validity in the measurements adapted for adolescents. However, in our study, the knowledge of the experts in both the language of the target population and the topic of spirituality, as well as cognitive interviews with adolescents and parents/caregivers allowed us to select the terminology used by the target group, resulting in changes to a number of terms in the scale. We believe that using both the expert committee and cognitive interview (in addition to back-translation) was key to preventing bias and preserving the face and content validity of the original version in the scales adapted or developed in this work.

As a result of the process of adaptation to age, no items were withdrawn or added, and there was no change in the format of responses or sum of the total scores of the original scale. Moreover, terms like "productive life," "purpose," "peace of mind," and other words were modified by their synonyms. The adolescent's difficulties in understanding items were not related to the levels of emotional development, faith development, and abstract thinking required to respond to items on spiritual well-being, including reflecting on their own emotional state (e.g., peace of mind or harmony). Some difficulty in understanding items, especially in the younger ones, may

be related to age of vocabulary acquisition and schooling (Cameirão and Vicente 2010), or the ordered continuum of responses of Likert-type scales that can be misunderstood and cause uncertainty in people with little formal education (Flaskerud 2012).

The results of the convergent validity were satisfactory for the majority of the items on the self- and parental-reported versions for both two- and three-factor models. This demonstrates that the items measure the construct that they are supposed to measure. For discriminant validity using measures from the MTMM analysis, the three-factor model (Meaning, Peace, and Faith) showed a low level of discrimination between the dimensions "Meaning" and "Peace" in this sample of Brazilian adolescents, consistent with the two-factor model (Meaning/Peace and Faith) employed in the original scale (Peterman et al. 2002). Indeed, the use of FACIT-Sp-12 in the Portuguese adult population presented two dimensions and satisfactory internal consistency (the factorial structure of the Brazilian version validated with adults was not evaluated) (Lucchetti et al. 2013; Pereira and Santos 2011). Nonetheless, this result contrasts with conclusions of other studies that demonstrated that FACIT-Sp-12 is more informative and fits significantly better with the three-factor model (Canada et al. 2008; Murphy et al. 2010; Peterman et al. 2014). Thus, it remains unclear whether the subscales of Meaning and Peace constitute distinct factors (Peterman et al. 2014).

The discriminant construct validity cast some doubt on the two- or three-factor model in the FACIT-Sp-12 for Brazilian adolescents. Differences in the conceptualization and operationalization of concepts might exist between cultures (Sidani et al. 2010), and theses affected the way adolescents and parents respond to or interpret the items on the scale. Although the understanding of the items by adolescents and parents through the cognitive interview reflected aspects of the construct, a factorial analysis is required to verify the dimensionality reflected in the items of the FACIT-Sp-12 self- and parental-reported versions that assess the spiritual well-being of Brazilian adolescents.

Internal consistency reliability values of the FACIT-Sp-12 self- and parental-reported versions adapted in this study were similar, in the two-factor model and in the overall scale, to the original study with the English language version of the instrument (Peterman et al. 2002) and to studies with adults in Portugal (Pereira and Santos 2011). However, in the three-factor model, Cronbach's alpha values in the "Meaning" and "Peace" dimensions were below 0.7 in both self (0.68, 0.66, respectively) and parental-report versions (0.64, 0.69, respectively). These Cronbach's alpha values may reflect a low interrelatedness of items in these subscales; however, the alpha should be confirmed in a future study with a larger sample.

The "Faith" and spiritual well-being total scores showed a difference between practicing and not practicing religion in the self- and parental-reported versions. These results support the discriminant property of the instrument, which expects higher levels of spiritual well-being in individuals expressing religious preferences than in those without religious preferences (Ando et al. 2015; Martoni et al. 2017). Peterman et al. (2002) observed that the Faith subscale has a "moderate to strong association with religion," suggesting that this dimension overlaps with or is reinforced by religion. Different results were found in the Japanese population with

no difference between people who have religious faith/religious feelings and those who do not (Noguchi et al. 2004). These results support the view that spirituality is not identical to religious feeling and suggest that cultural and religious differences between Japanese and Brazilian populations exert an influence on spirituality (Noguchi et al. 2004).

In our results, the scores of the "Faith" dimension and the total scores of self- and parental-reported versions significantly differ between different diagnoses in adolescents. Besides that, in the parental scale, adolescents with cancer had higher scores than adolescents with other conditions, while in the self-report version adolescents with cancer had higher spiritual well-being levels than adolescents with diabetes mellitus. This shows that the instrument is sensitive to differences, and similar results found by Peterman et al. (2002) showed differences in the spiritual well-being scores between different clinical conditions. Differential findings on the spiritual well-being levels of adolescents with cancer, diabetes, and cystic fibrosis show that the experience of the disease influences the spiritual well-being as a result of worse or better adaptation to the condition, or when the condition confronts adolescent with more suffering, hospitalization, and imminent death (Damsma Bakker et al. 2018).

Although the relationship with the family is a spiritual need of the adolescent (Zeighamy and Sadeghi 2016), and some aspects of an adolescent's religion and world view come from their parents (Cotton et al. 2010; Hexem et al. 2011), the degree of concordance between adolescent and parent reports was moderate in the spiritual well-being and the "Faith" dimension, and weak in the "Meaning" and "Peace" dimensions or "Meaning/Peace" dimension. The low level of agreement in the "Meaning" dimension may result from the existential meaning of spirituality attributed to this dimension, which is personal and related to the individual's world view, coherence, and purpose of life built from experiences throughout life (Lethborg et al. 2006), whereas "Peace" is an affective dimension of spirituality strongly associated with mental health (Canada et al. 2008). "Faith" had a higher level of agreement because it is a dimension observable by the parents, being considered a measure of religious well-being, and is strongly related to organizational and private religiosity (Edmondson et al. 2008).

This study presents the first instruments to evaluate the spiritual well-being of adolescents from their own point of view and to allow their parents and/or caregivers to serve as proxy evaluators when the adolescents are unavailable to respond. Despite the subjective aspect of spirituality, evaluating the spiritual well-being of adolescents with chronic illness from a parental observer perspective is important given the role of parents in decisions about adolescent health needs and use of health services (Rajmil et al. 2013). Moreover, this study is an example of a sequential approach to parental instrument development and to age adaptation, in which a measure for adults was then adapted and validated for adolescents and parents/caregivers. However, the study had some limitations. First, those who happened to accompany the adolescent were mostly mothers. The limited variability of caregivers may limit generalizability. The sample was relatively small, and we, therefore, recommend that future studies utilize larger sample sizes for proper evaluation of internal consistency at the subscale level and factor analysis for establishing

construct validation. The sample should also reflect balanced age and chronic condition of the adolescents where possible. Despite these limitations, the findings of this study support the utility of a dyadic parent-adolescent approach to spiritual well-being assessment and showed strong initial evidence of good psychometric properties, giving impetus for further validation work, especially construct validity.

Conclusion

The FACIT-Sp-12 items were adapted for Brazilian adolescents with chronic disease and included a parental observer-report version. The self- and parental-reported versions showed face, content, and convergent validity and acceptable levels of internal consistency for the overall scale and the two-factor model. Differences in the conceptualization and operationalization of the construct in a culture might reflect in the presence and nature of factors. The Brazilian culture had an influence on the discrimination between the dimensions of the FACIT-Sp-12 by adolescents and parents alluding to the role that culture might have on the generalizability of the adapted scale. Our results suggest the psychometric structure of the two factors for the FACIT-Sp-12 self- and parental-reported versions in Brazil. However, additional studies with larger samples of adolescents and parents are required to confirm the equivalence and validity of the FACIT-Sp-12 adolescent self-report and parental-report version adaptation. Future studies should test the factorial structure of the scales because it is still unknown whether the dimensions are measured similar to the adult's scale. The validation of the measure for use with adolescents should be further explored in relation to factorial structure invariance across age groups and respondents.

The availability of self- and parental-report scales to assess spiritual well-being in adolescents with chronic disease in Brazil will be useful for obtaining further details on spiritual well-being in this group, supporting health professionals and researchers in planning and evaluating interventions that promote increased levels of spiritual well-being.

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Compliance with Ethical Standards

Conflict of interest The authors declare that they have no conflict of interest.

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