Development, Validation, and Internal Consistency of the Positive Psychology-Based Acceptance of Illness Scale (PAIS): A Culturally-Appropriate Japanese Measure

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Abstract
Acceptance of illness has been shown to improve the well-being of individuals suffering from chronic illnesses. We developed a new acceptance of illness scale, “Positive Psychology-Based Acceptance of Illness Scale: PAIS,” for HTLV-1 associated myelopathy (HAM) patients, one of the intractable neurological diseases with a chronic course. The validity and internal consistency of this PAIS were examined in 260 HAM patients in Japan. Exploratory factor analysis extracted four factors with 21 items: “Loving myself as I am”; “Experiencing the grace of illness”; “Feeling a loving connection with others”; and “Developing as a mature person”. Cronbach’s $\alpha$ was .83 to .88, except for Factor 4 which was slightly low at 0.64, and internal consistency was confirmed. A significant correlation was found between the PAIS and the index of convergent validity. The study’s findings are an important step toward a more comprehensive concept of acceptance of illness.

Keywords
positive psychology, acceptance of illness, spirituality, scale development, culturally-appropriate scale

Introduction
The number of patients suffering from chronic illnesses has been rapidly increasing in Japan. In 1996, approximately 11 million people suffered from some of the most common chronic illnesses (such as hypertension, diabetes, and stroke). However, this increased by 26% to approximately 14 million people by 2014 (Ministry of Health, Labour and Welfare, Japan, 2014). Japan has an ageing population, with the 65 years or older cohort increasing approximately three-fold in the past four decades (Ministry of Internal Affairs and Communications, Japan, 2019). Thus moving forward, we estimate only more Japanese people will be affected with chronic illness. The impact of chronic illness on individuals is multifaceted. For an individual diagnosed and living with a chronic illness, their physical and mental health, their level of dependency on others, their self-perception, and their quality of life (QOL) can be affected (Goodman et al., 2013; Megari, 2013). Evidence from literature has shown that when patients with chronic illnesses are able to accept their condition, there are positive physical and psychological benefits (Bień et al., 2015; Jankowska-Polańska, Kasprzyk et al., 2016; Kurpas et al., 2013), reduced negative emotions (Jankowska-Polańska, Blicharska et al., 2016; Kostyla et al., 2013; Lewko et al., 2012), and healthier emotional management (Jankowska-Polańska, Kasprzyk et al., 2016; Nowicki et al., 2015).

Human T-cell leukemia virus type 1 (HTLV-1) associated myelopathy (HAM) is a rare intractable neurological disorder with a chronic course found in 0.25% of the individuals infected with HTLV-1 (HAM Medical Manual Second Edition Formulation Committee, 2016). The HTLV-1 infection usually results in chronic illness which causes inflammation of the spinal cord, with lower body dysfunctions, and the main symptoms of abnormal gait (100%), challenges in bladder control (93%), and loss of sensation in the lower limbs (56%) (HAM Medical Manual Second Edition Formulation Committee, 2016). The condition exacerbates over the course of the illness, thereby becoming a lifelong...
chronic illness. HAM patients experience intense emotional, physical and economic impacts on their daily lives, due to the nature of the symptoms, long process for confirmatory diagnosis, poor understanding from loved ones, and low social recognition of the illness (Health Science Council of Ministry of Health, Labour and Welfare, Japan, 2013.). Since HAM does not completely remit and is a disease that gradually worsens, it is considered a difficult disease to accept, resulting in low QOL and depression (Gavão-Castro et al., 2012). However, HAM does not affect cognitive function (Japan Intractable Diseases Information Center, n.d). Therefore, given HAM patients are able to understand and respond to questionnaires, they are suitable as participants in the study of acceptance of illness.

The mechanism of the acceptance of illness is not yet fully understood. Therefore, other processes, such as the “acceptance of disability” (Harrison et al., 2004), or the “five stages of grief,” describing the concepts of loss and mourning, could be applied to people’s experience of diagnosis and living chronic illness (Kübler-Ross & Kessler, 2014). In the “five stages of grief”: denial, anger, depression, bargaining, and ultimately acceptance, could be a similar process of what a HAM patient works through to finally accept their new situation in life.

In the past three decades, the majority of the studies examining acceptance of illness among individuals with chronic illness have been conducted in Western countries using Felton et al.’s (1984) Acceptance of Illness Scale (AIS) (Felton et al., 1984). This self-reported scale aims to measure the degree of illness acceptance regardless of the type of chronic illness the individual is experiencing. The AIS approaches the acceptance of illness concept from an illness-related social adjustment perspective (Johnston et al., 1995). In the AIS, items describe negative psychological states associated with lack of illness acceptance; therefore, the scale effectively measures the patients’ level of adjustment to aspects of their daily lives without experiencing negative feelings toward their illness and themselves. In its current form, the AIS has been shown to have moderate validity and reliability.

Positive psychology researchers have begun to consider the broader meaning of illness acceptance. “Acceptance” is not solely defined in terms of illness-related social adjustment, but also encompasses patients’ personal growth through overcoming the challenges of the illness (Kabat-Zinn, 1990; Spaniol & Gagne, 1997; Twohig et al., 2005). Martin Seligman and Mihaly Csikszentmihalyi’s revolutionary publication, “Positive Psychology—An Introduction” (Seligman & Csikszentmihalyi, 2000), has rapidly developed the positive psychology movement. As the Chairman of American Psychological Association at the time, Seligman described psychology as having mainly concentrated on “repairing damage within a disease model of human function” (Seligman & Csikszentmihalyi, 2000, p. 5) and “neglects the fulfilled individual and the thriving community” (Seligman & Csikszentmihalyi, 2000, p. 5).

Apart from the Peace, Equanimity, and Acceptance in the Cancer Experience (PEACE) questionnaire (Mack et al., 2008), which used a positive psychology approach to focus on peacefulness outcomes for advanced cancer patients, the majority of the scales, including AIS, that measure the degree of illness acceptance, are not based on positive psychology (Felton et al., 1984; Mack et al., 2008; Schmitt et al., 2014; Stuifbergen, 2008). Rather, conventional psychology used in these scales emphasize negative symptoms and emotions such as depression and anxiety, and on their resolution. However, it does not necessarily follow that if one has few negative perceptions, the degree of positive acceptance is high; this point has not been fully discussed in the literature (Ackerman, 2020).

For this research, we decided to incorporate the notion of positive psychology. As positive psychology is based on the idea that positive emotions and beliefs (e.g., love, gratitude, and faith) could greatly impact an individual’s mind and body, and emotional and physical symptoms (Chakhssi et al., 2018), the idea of “acceptance of illness” in this study is toward a “positive psychological state when fully accepting illness” rather than advancing acceptance of illness by resolving negative psychological states. In doing so, we hypothesized that the acceptance of illness would be enhanced. Considerations in support of this idea are: First, spirituality is an important concept in positive psychology. (Barton & Miller, 2015; Plante, 2012; Schnitker et al., 2017; Wong et al., 2007); Second, spirituality and acceptance have been often discussed as a related concept (Hayes et al., 2004). For example, sexual self-acceptance and spirituality (Gall et al., 2007; Helminiaik, 1989), death acceptance and spirituality (Cicirelli, 2011), and acceptance and commitment therapy (ACT) and spirituality (Kaplaner, 2019); Third, some researchers have examined the association between acceptance of illness and spirituality. For example, Nabolsi and Carson (2011) suggested that patients’ faith may facilitate their acceptance of illness. A patient’s faith may also play a core role in their decision making regarding their own health, and in accepting self-responsibility for their future health and well-being (Nabolsi & Carson, 2011). A connection to something bigger than ourselves can be a critical aspect of the process of acceptance of illness, but has not yet been properly addressed. The ultimate acceptance of a challenging circumstance in an individual’s life transcends the situation which is an expression of spirituality (Manning, 2012). We hypothesized acceptance of illness is, at some level, connected to this sense of life purpose, because acceptance and spirituality have be considered as a related concept. Therefore, we incorporate evidence identified in new fields such as positive psychology to create a more comprehensive and balanced acceptance of illness scale.

In Western countries, spirituality-related scales have been developed with a Christian influence which tend to include expressions or terms, such as “love myself and/or feel loved by others,” “forgiveness,” and “the relationship with one’s
God" (Ellison, 1983; Paloutzian & Ellison, 1982) but these expressions are not familiarly used in the daily lives of Japanese people. In Japan, although many religious elements, including the concept of God(s), are integrated in Japanese culture, few follow a particular religion (Ishii, 2008; Nishi, 2009) or hold a monotheistic assumption that God is ultimately the One to sustain everything a human needs (e.g., by the grace of God, the love of God). Rather, an important concept exclusive to Japan is the expression *Ikasareteiru* (sustained by all) (Kyota et al., 2010; Nabeshima, 2015). *Ikasareteiru* is a spiritual concept that expresses the connection of everything in and around us physically or spiritually, emphasizes increasing humility and focuses on community connection and gratitude. In other words, the concept of *Ikasareteiru* expresses the idea that all humans are supported by everyone and everything around them to assist them to live their life to the fullest.

We hypothesized that the expression of illness acceptance differs across cultures; therefore, to enhance the scales for this study, cultural and linguistic reference must be appropriate to Japanese people.

The purpose of this study was to develop a new acceptance of illness scale “the Positive Psychology-Based Acceptance of Illness Scale (PAIS)” in HAM patients, which is one of the intractable neurological diseases with a chronic course. This new PAIS scale aimed to reflect positive psychology concepts which are also appropriate for the Japanese population, by first exploring this scale in a specific patient population. In addition, this study aimed to examine the validity and internal consistency of the PAIS in Japanese HAM patients.

**Method**

**Participants**

The participants were human T-cell leukemia virus type 1 (HTLV-1) associated myelopathy HAM patients registered on a nationwide HAM patient registry kept by Coler-Reilly et al. (2016) in Japan, who had already given their consent for medical research. All participants were native Japanese speakers.

**Development of the PAIS Instrument**

We developed the new PAIS instrument in several steps: (1) extracting the main constructs based on a literature review, (2) validating the construct and items through expert panel consultation, (3) constructing scale items and pilot testing, and (4) developing the final version of the PAIS.

**Conducting a literature review and extracting the main constructs.** For a review of the literature, the keyword “acceptance of illness” was searched on MEDLINE, PsycINFO/PsychARTICLES, CINAHL, CINii, Igakuchuouzasshi (Japanese), MedicalOnline (Japanese), in May 2015. Our search returned with 104 peer-reviewed articles. After scanning the titles for relevancy, 46 articles were identified as relevant. Subsequently, the abstracts were scanned, and 40 articles deemed to be relevant to our topic of interest were identified. The grey literature was also reviewed using the same keywords and two relevant videos and eight reference books were found. Based on the literature, three main psychological constructs related to acceptance of illness in patients with chronic illnesses were extracted: (1) Seeing and acknowledging themselves as they are (Kabat-Zinn, 1990; Spaniol & Gagne, 1997); (2) No difference in overall self-esteem before and after experiencing the illness (Spaniol & Gagne, 1997; Ueda, 1980). Self-esteem may be defined by a different set of inner characteristics and values of the individuals (Donnellan et al., 2011). However, the overarching assumption of self-esteem is that the level of self-esteem may decrease after diagnosis for some chronic illnesses; after a period of coping with the illness, individuals will have had the chance to overcome their challenges. Eventually, they may discover an inner strength to cope. Then, their level of self-esteem will increase to pre-illness level, but the nature of the self-esteem may be different before and after they contract the illness. The nature of self-esteem may change from self-esteem that focuses more on the outer-self to one that focuses more on the inner-self (Ueda, 1980). Finally, (3) having positive feelings about themselves (Mack et al., 2008; Spaniol & Gagne, 1997).

A total of eight professionals, consisting of four medical professionals with extensive experience in psychiatry, psychology or internal medicine, and four researchers on social medicine, scale development, and HAM, who had access to the HAM database and understood the HAM patients’ clinical and psychological situation, formed the expert panel for this study. Based on the literature review, the principal investigator and the expert panel came to a consensus on the constructs over three to four brainstorming sessions. The initial pool of approximately 50 items was generated based on these constructs.

**Expert panel consultation and validation.** We also interviewed HAM patients, a medical doctor, and a nurse who specialized in HAM treatment, prior to consulting with an expert panel to attain consensus for our topic and to guide the scale development process. The specialist medical doctor and nurse were included to obtain a comprehensive picture of the process of acceptance of illness from HAM patients. As different perspectives of the scale development process were needed to enhance our construct and items, the principal investigator had two consultation (pre and post scale development) with the expert panel. The consultations included the constructs how to express the concepts of love, forgiveness, God(s), and Japanese religious expressions in the PAIS, including the Japanese spiritual concept *Ikasareteiru* (sustained by all). In addition, we reduced the number of items and improved the clarity of specific items (e.g., adding the word “virus” to item 16 as the cause of HAM).
Construction of scale items and pilot testing. Based on the expert panel consultation, we reduced the number of items to 21 and constructs to two: I. Emotions involved in accepting my illness: Seeing and acknowledging myself as I am. II. Self-cognitions involved in accepting my illness: Positive self-cognition. In this step, the second construct became a combination of the initial constructs 1 and 3 extracted from the literature review and expert consultation sessions. Pilot testing of the draft scale was conducted in July 2015 on five Japanese male and female HAM patients; all patients had experienced the illness for over 20 years. Based on the findings from the pilot testing, although no items were removed, some scale items were revised for additional clarity. Feedback from participants in the pilot testing included difficulty in understanding the meaning of “forgive” in items 8 and 16; several participants mentally substituted “accept” for “forgive” when answering these items. Thus, to facilitate clarity for end-users, in the final version of the PAIS, for items 8 and 16, “forgive” was changed to “accept.” The pilot study also revealed “love myself and/or feel loved by others,” was understood by all participants without difficulty.

Development of the final version of the PAIS. Based on the pilot testing, two items were revised to better reflect the participants’ understanding. In the final version of the PAIS, item 8 was revised to “I accept myself as ill,” and item 16 was revised to “I accept the circumstances that caused me to be ill, the person I caught the illness from, and/or the cause of the illness.” For each of the 21 items in the PAIS, participants were asked to choose from a four-point Likert scale: 1 = Strongly disagree; 2 = Somewhat disagree; 3 = Somewhat agree; and 4 = Strongly agree.

Data Collection I—Data From Questionnaire

Questionnaire design. The questionnaire consisted of four parts: (1) PAIS, (2) a Japanese version of the Acceptance of Illness Scale (JAIS), (3) an anxiety and depression scale, and (4) Spirituality-related information. Given HAM patients are an under researched population, we had concerns they may be unfamiliar with psychometric tests. To discourage participants from selecting a middle score as the easiest choice, an additional instruction was inserted at the top of the questionnaire to reassure them:

We will ask patients about your illness and feelings about the illness. Please circle a number from 1 to 4 that best represents how you are feeling in the past seven days. Please do not overthink too much, and give your most instinctive response. There are no right or wrong answers to any of the questions.

The questionnaires, sans PAIS, was as follows:

JAIS. To our knowledge, at the time of our study, there is no validated acceptance of illness scale in Japanese. Thus, to assess the convergent validity of the PAIS, we translated the AIS into Japanese, and developed a Japanese version of the Acceptance of Illness Scale (JAIS). Development of the JAIS followed the method recommended by the World Health Organization (World Health Organization, n.d.). In accordance with the Translation Process of the COSMIN Study Design checklist for Patient-reported outcome measurement instruments (version July 2019; Mokkink et al., 2019), the JAIS falls under “very good” in all items. The JAIS consisted of eight items divided into different types of restrictions imposed by the illness, lack of self-dependency, perception of dependency on other people, and decreased self-esteem. The responses for these items were on a 5-point Likert-scale ranging from 1 (strongly disagree) to 5 (strongly agree). The level of acceptance ranged from an overall possible score from 8 to 40, with a higher total point indicating a greater degree of illness acceptance.

Anxiety and depression scale. To analyze the correlation between the PAIS and anxiety/depression, we used the Japanese version of the Hospital Anxiety and Depression Scale (HADS) (Kugaya et al., 1998; Zigmond & Snaith, 1983). The HADS is a 14-item self-assessment scale to measure psychological distress using two factors: anxiety and depression. Each item is scored on a four-point Likert-scale ranging from 0 (strongly disagree) to 3 (strongly agree). The anxiety and depression total score ranged from 0 to 42, with a higher total point indicating a higher level of anxiety and depression. The HADS uses the odd-numbered items to indicate anxiety subscales, and the even-numbered items indicate depression subscales. In addition, items 1, 3, 5, 6, 8, 10, 11, 13 are reversely scored. This Japanese version of HADS had well-accepted reliability and validity (Kugaya et al., 1998; Zigmond & Snaith, 1983).

Spirituality-related information. Participants were asked if they: (1) followed a religion; and (2) had a type of faith and/or spiritual beliefs (this question was asked of participants who answered “No” to question (1) “Do you follow a religion?”).

Questionnaire dissemination. The questionnaires were mailed between August 2015 and October 2015 to 412 HAM patients who had no other concomitant illness or complications. Participants who met all our selection criteria were included in our study: (1) participants who answered the questionnaire by themselves; (2) questionnaire and HAM patient registry data were able to be linked and were anonymized; and (3) participants had completed all the items in the PAIS.

Data Collection II—Data From HAM Patient Registry

In addition to the questionnaire data, we extracted existing data from a Japanese HAM patient registry maintained by
Yamano and colleagues on July 28 2015 for eligible participants. Variables extracted were in three domains: (1) demographics (gender, age, and marital status); (2) HAM-related medical conditions (length of time since HAM diagnosis, degree of motor disabilities according to Osame’s Motor Disability Score (OMDS), type of HAM [in terms of disease progression]); and (3) QOL (according to the Short Form 36 Health Survey [SF-36v2 Standard Japanese], interview-administered) (Fukuhara et al., 1998; iHope International, n.d.).

Data Analysis

We initially conducted a descriptive analysis of the patient characteristics including details of their illness and their PAIS scores. To test the factor structure of the PAIS, we did exploratory factor analysis (EFA) using the maximum likelihood method with promax rotation—a commonly used approach in developing psychometric scales (Angel et al., 2020; Cordova et al., 2017). The number of factors was determined using a scree plot and the eigenvalues greater than one criterion.

We set a standard to choose items where the factor loading was 0.3 or more (Angel et al., 2020). To evaluate each item, we calculated Cronbach’s Alpha if Item Deleted in the Item-Total Statistics. Cronbach’s Alpha results determined our decision on whether to retain or remove the item(s) in PAIS. For the EFA, IBM Statistical Package for the Social Sciences (SPSS) version 24 was used. Based on the result of the EFA, a series of maximum-likelihood estimation of Confirmatory Factor Analysis (CFA) were conducted using R version 4.0.3 (R Core Team, 2020; Rosseel, 2012). We obtained Cronbach’s alpha for internal consistency of the PAIS: First we calculated it in the total 21 items. Then, calculated it within each factor. To test the convergent validity of the PAIS, we used the JAIS, QOL (SF-36v2 Standard Japanese) and anxiety and depression scale (HADS). Spearman’s rank correlation coefficient was calculated between the PAIS and JAIS total scores, SF-36v2 score and HADS score. All analyses were performed at 5% level of significance using IBM SPSS statistics version 24, except for CFA.

Results

Patient Characteristics

From the questionnaire we sent to 412 Patients, 330 patients responded (response rate = 80.1%). Of the respondents, 260 patients (78.8%) met our selection criteria and were used to develop and validate our scale. Table 1 summarizes the participants’ demographic characteristics. Among the 260 participants, there were 67 men (25.8%) and 184 women (70.8%), with 9 (3.5%) individuals not specifying their sex. The mean age was 61.7 years (SD = 10.5), and the age ranged from 23 to 87 years. Among the 260 participants, 68 (26.2%) were single, unmarried, divorced or widowed, and 161 patients were married (61.9%). The mean duration of illness 1 (defined as years from onset to the time of this study) was 16.9 years (SD = 10.7) and ranged from 1 to 50 years. The mean duration of illness 2 (defined as years since diagnosis to the time of this study) was 9.9 years (SD = 7.7) and ranged from 0 to 32 years. According to the OMDS, the average severity of motor impairment was 5.7 (SD = 2.2) from the score possibilities: from grade 0 (no abnormality) to 13 (no mobility on the entire lower limbs including toes). As for types of HAM, 189 patients (72.7%) experienced the slow progressive type, and 41 patients (15.8%) experienced the rapid progressive type. For Spirituality-related information, 52 participants (20.0%) followed a religion, 115 participants (44.2%) did not follow any religion, but had a type of faith and/or spiritual beliefs, while 61 participants (23.5%) neither followed any religion nor had a type of faith and/or spiritual beliefs.

Content Validity of PAIS

We demonstrated content validity through a series of steps. First, we conducted a review of the literature, interviews with HAM patients and HAM medical staff, and consulted with the expert panel to reach consensus. Based on these findings, we eventually refined the constructs from the initial three extracted from the literature to two constructs following further inputs from HAM patients and medical staff, as well as a consensus reached with the expert panel. We revised the wording of our items to improve clarity and readability, as well as reduced the number of items from 50 to 21.

Factor Analysis of PAIS

We used the two constructs and 21 items to conduct the EFA. Based on EFA, four factors were ultimately extracted. In the CFA, a four-factor model was assumed, and the results of fit were CFI = 0.851, GFI = 0.828 and RMSEA = 0.09, which were adopted as the final model. The final version of the PAIS, consisting of four factors with a total of 21 items, is shown in Table 2. Factor 1 has the largest number of items, 9 out of 21 (42.9%). The factor loading of item 10 was low (0.297). In the Item-Total Statistics, items deleting item 10 did not improve Cronbach’s Alpha both in total items and within each factor when we calculated Cronbach’s Alpha if Item Deleted. Therefore, all items were retained.

The initial construct I (Emotions involved in accepting my illness: Seeing and acknowledging myself as I am) was divided into three factors (Factor 1, 3 and 4). The four final factors of the PAIS were: Factor 1—“Loving myself as I am” with nine items. Factor 2—“Experiencing the grace of illness” with five items. Factor 3—“Feeling a loving connection with others” with three items. Factor 4—“Developing as a mature person” with four items.
Table 1. Participant Demographic Characteristics, Spirituality-Related Characteristics, Quality of Life (QOL), Depression, and Anxiety (N=260).

| Demographics | N | % or Mean (SD) |
|---------------|---|----------------|
| Gender | | |
| Men | 67 | 25.8% |
| Women | 184 | 70.8% |
| Missing | 9 | 3.5% |
| Age | | |
| | 230 | 61.7 (SD 10.5) |
| Missing | 30 | 11.5% |
| Marital Status | | |
| Unmarried/Divorced/Bereaved | 68 | 26.2% |
| Married | 161 | 61.9% |
| Missing | 31 | 11.9% |
| HAM-Related Medical Conditions | | |
| Length of time since HAM diagnosis | 230 | 9.9 (SD 7.7) |
| Missing | 30 | 11.5% |
| Osame’s motor disability score | 230 | 5.7 (SD 2.2) |
| Missing | 30 | 11.5% |
| Type of HAM | | |
| (in terms of disease progression) | | |
| Slow | 189 | 72.7% |
| Rapid | 41 | 15.8% |
| Missing | 30 | 11.5% |
| Spirituality-Related Information | | |
| Follows a religion | | |
| Yes | 52 | 20.0% |
| No, but has a type of faith and/or spiritual beliefsa | 115 | 44.2% |
| No, and does not have a type of faith and/or spiritual beliefsa | 61 | 23.5% |
| Missing | 32 | 12.3% |
| QOLb | | |
| Valid Response | 221 | 85.0% |
| Missing | 39 | 15.0% |
| Physical Functioning (PF) | | |
| | 5.6 (SD 19.3) |
| Role-Physical (RP) | | |
| | 41.6 (SD 15.7) |
| Bodily Pain (BP) | | |
| | 43.1 (SD 12.1) |
| General Health (GH) | | |
| | 39.3 (SD 9.9) |
| Vitality (VT) | | |
| | 42.8 (SD 10.5) |
| Social Functioning (SF) | | |
| | 46.1 (SD 12.4) |
| Role-Emotional (RE) | | |
| | 47.7 (SD 12.0) |
| Mental Health (MH) | | |
| | 46.6 (SD 10.3) |

| Depression and Anxietyc | | |
|-------------------------|---|----------------|
| Anxiety | | |
| Total | 6.7 (SD 4.2) |
| Normal (0–7 points) | 150 | 57.7% |
| Borderline abnormal (8–10 points) | 47 | 18.1% |
| Abnormal (11–21 points) | 49 | 18.8% |
| Missing | 14 | 5.4% |
| Depression | | |
| Total | 7.5 (SD 4.5) |
| Normal (0–7 points) | 141 | 54.2% |
| Borderline abnormal (8–10 points) | 48 | 18.5% |
| Abnormal (11–21 points) | 67 | 25.8% |
| Missing | 4 | 1.5% |

Note. HAM=HTLV-1 associated myelopathy; SD=standard deviation.

aThis question, “Do you have a type of faith and/or spiritual beliefs?” was directed to participants who responded “No” to the question “Do you follow a religion?”
bMeasured using the Short Form Health Survey 36 (version 2).
cMeasured using the Hospital Anxiety and Depression Scale (HADS).

Factor 1. “Loving myself as I am” refers to self-perception of accepting oneself in all respects, regardless of the individual’s challenging health condition. The nine items are described as: determining whether the individual perceived himself/herself in a positive, hopeful, and peaceful manner with a feeling of protection from something greater than himself/herself (Table 2).
### Table 2. Exploratory Factor Analysis (Maximum Likelihood Method, Promax Rotation) and Internal Consistency of the PAIS.

| Factor | Scale item | Loading |
|--------|------------|---------|
| 1      | Loving myself as I am: 9 items ($\alpha = .88$) |  |
| 6      | I love myself | 0.878   |
| 12     | I take good care of myself | 0.859   |
| 21     | I feel hopeful for my future | 0.704   |
| 11     | My future will be fine even with the illness | 0.676   |
| 8      | I accept* myself as ill | 0.667   |
| 3      | I am living happily even though I experience some difficulties from the illness | 0.580   |
| 5      | I take better care of myself and am kinder to myself since I became ill | 0.482   |
| 2      | My heart is calm and filled with peace when I think about my illness | 0.469   |
| 10     | I feel protected by something bigger than myself (e.g., god/s, ancestors, nature, the universe, heaven, saints) | 0.297   |
| 2      | Experiencing the grace of illness: 5 items ($\alpha = .83$) |  |
| 20     | I became ill so that I could use my experience to help others | 0.931   |
| 7      | I think that my illness has important meanings for me | 0.685   |
| 14     | I obtained something important that I really wanted; something I wouldn’t have obtained if I hadn’t become ill | 0.481   |
| 17     | I truly think that being ill was “supposed” to happen and I am okay with it | 0.413   |
| 9      | I feel like I have started a new life by becoming ill | 0.355   |
| 3      | Feeling a loving connection with others: 3 items ($\alpha = .84$) |  |
| 13     | I feel loved by people around me | 0.847   |
| 18     | I feel people around me take good care of me | 0.756   |
| 4      | I feel a bond with people around me | 0.391   |
| 4      | Developing as a mature person: 4 items ($\alpha = .64$) |  |
| 15     | I feel I am living not only by my own efforts but that I am being sustained by everything around me | 0.591   |
| 1      | I appreciate things more since being ill | 0.500   |
| 19     | Since I became ill, I feel more compassion for others who are suffering | 0.465   |
| 16     | I accept* the circumstances that caused me to be ill, the person I feel is responsible for my illness*, and/or the cause of the illness | 0.337   |

Note. PAIS = Positive Psychology-Based Acceptance of Illness Scale; $\alpha = \text{Cronbach's } \alpha$ constant. PAIS (total score): $\alpha = .92$. The following instruction was added at the beginning of the PAIS: “We will ask you about your illness, and feelings about the illness. Please circle a number from 1 to 4 that best represents how you are feeling this week. Please do not think too much, and give your initial response. There are no right or wrong answers to any of the questions.”

*In the pilot study, “forgive” (in Japanese) was used here. However, the pilot study participants (Japanese HAM patients) reported that it was difficult for them to understand the meaning of “forgive” in items 8 and 16. When they responded to these items, they mentally substituted “accept” for “forgive.” Thus, in the final version of the PAIS, “forgive” was changed to “accept” in items 8 and 16.

*The person from whom the participant caught the illness, or who caused the person to experience stress that induced the illness.

**Factor 2.** “Experiencing the grace of illness,” refers to the individual’s self-perception of the benefits and meaning in his/her life after experiencing the illness. The five items are described as determining whether the individual perceived the illness as a form of grace that eventually facilitated his/her personal growth. Ultimately, this may assist him/her in seeing the higher purpose of the illness, including using his/her experience to help others (Table 2).

**Factor 3.** “Feeling a loving connection with others,” refers to the self-perception of being connected with others. The three items are described as determining whether the individual perceived himself/herself as being loved and cared for by those around him/her (Table 2).

**Factor 4.** “Developing as a mature person,” refers to the perception of the individual in his/her self-growth and the ability to surrender control of his/her life to something greater than himself/herself, reflecting the concepts of humility, gratitude, compassion, and forgiveness. These emotions could be considered to be a form of personal grace, “sacred emotions.” The capability of feeling these emotions is one of the characteristics of a mature person, as is the capacity to accept his/her own life, hence Factor 4’s name (Erikson, 1994; Fowler, 1995). The four items are described as determining whether the individual perceived himself/herself as having more gratitude and compassion toward life, as well as being connected to everything physical and non-physical, and everyone around him/her (as per the Japanese concept Ikasareteiru as described in the introduction) (Table 2).

**Internal Consistency of the PAIS**

Cronbach’s alpha for the PAIS total scores was 0.92, and 0.88 for Factor 1, 0.83 for Factor 2, 0.84 for Factor 3, and 0.64 for Factor 4 (Table 2). We tested whether item reduction would
result in better Cronbach’s alpha and found that 21 items in the four factors still gave the best Cronbach’s alpha. Thus, all items were retained, even those with lower loadings.

**Convergent Validity**

The mean scores of the PAIS were: Factor 1 (possible score of 9–36) was 23.8 (SD=5.8), Factor 2 (possible score of 5–20) was 11.3 (SD=3.5), Factor 3 (possible score of 3–12) was 8.9 (SD=2.0) and Factor 4 (possible score of 4–16) was 12.2 (SD=2.3) (Table 3).

The JAIS mean total score (possible score of 8–40) was 21.6 (SD=7.3) (Table 3). Cronbach’s alpha for the JAIS was 0.86, which is comparable to the Cronbach’s alpha for the AIS (0.81%–0.83%, Johnston et al., 1995). Therefore, we concluded that the JAIS was suitable to test the convergent validity of the PAIS. A statistically significant positive correlation (ρ=0.497, p<.001) was found between the JAIS and PAIS scores (Table 3). The JAIS scores showed a statistically significant positive correlation with all four of the PAIS Factor 1-4 scores: PAIS Factor 1 (ρ=0.497, p<0.001); PAIS Factor 2 (ρ=0.319, p<.001); PAIS Factor 3 (ρ=0.340, p<.001); and PAIS Factor 4 (ρ=0.174, p<.05).

Correlations between the PAIS total scores and QOL (SF-36v2) demonstrated that participants with a greater degree of illness acceptance showed significantly better general health (GH) (ρ=0.153, p<.05), higher vitality (VT) (ρ=0.275, p<.01), and better mental health (MH) (ρ=0.227, p<.01) (Table 4). However, there were no correlations between the PAIS total scores and other SF-36v2 domains (i.e., physical functioning (PF), role physical (RP), bodily pain (BP), social functioning (SF), and role emotional (RE)) (Table 4). HADS scores showed a statistically significant negative correlation with the PAIS total scores and anxiety/depression. Therefore, participants with a greater degree of illness acceptance experienced less anxiety/depression. Spearman’s rank correlation coefficient for anxiety was −.403 (p<.001), and −0.572 (p<.001) for depression.

**Discussion**

In this research, we adopted the concept of positive psychology to develop a novel scale. The validity and the internal consistency of the PAIS were confirmed in HAM, one of the neurological disorders that has a chronic course and does not completely remit.

In accordance with the COSMIN Study Design checklist for Patient-reported outcome measurement instruments (version July 2019; Mokkink et al., 2019), the PAIS falls under “very good” or “adequate” for all items, except for item No.4 in the category of “General recommendation for the design of a study on measurement properties.” Item No. 4 states, “The origin of the construct should be clear: provided a theory, conceptual framework (i.e., reflective or formative model) or disease model used or clear rationale to define the construct to be measured.” Our answer was “Origin of the construct not clear,” because the mechanism of illness acceptance is not yet fully established, particularly in positive psychology. However, acceptance of illness has been researched in conventional psychology (Ćwiek et al., 2017; Wiśnicka et al., 2021), and acceptance has been researched in positive psychology (Helminiak, 1989; Kaplaner, 2019). Therefore, we decided that the study design is good.

**Factor Structure of the PAIS**

The EFA showed the four-factor structure in PAIS. Even though item 10, an item with low factor loading, was deleted, the internal consistency did not improve. Item 10 was an important item in PAIS, because it was related to acceptance and spirituality, so we decided to retain all 21 question items. The CFA index did not show a strongly adequate fit compared to previous studies (Cordova et al., 2017). However, this index showed a moderately adequate fit, and this index showed better fit than the index of the two-factor model. For the above reasons, we considered the four-factor structure to be valid.

Factor 1 has the largest number of items, 9 out of 21 (42.9%). Therefore, Factor 1 may be the core of acceptance of illness as measured by PAIS.

Of the two constructs initially envisioned, the item of construct I “Emotions involved in accepting my illness: Seeing and acknowledging myself as I am” is Factor 1 “Loving myself as I am,” Factor 3 “Feeling a loving connection with others” and Factor 4 “Developing as a mature person.” Eight of the nine items in Factor 1 consisted of items in Construct I. Four of the five items in Construct II “Self-cognitions involved in accepting my illness: Positive self-cognition” constituted Factor 2 “Experiencing the grace of illness.” In contrast, from Construct I, item 17 “I truly think that being ill was ‘supposed’ to happen and I am okay with it” was moved to Factor 2, which is mainly Construct II. Item 17 was originally created as an item in Construct I as a question expressing the state of mind where the illness has led to the patient falling into dismay. However, because cognitive understanding was required to understand the content of the question, it may have been classified into Factor 2, which mainly consists of cognitive items of Construct II. Also, from Construct II, item 10 “I feel protected by something bigger than myself (e.g., gods, ancestors, nature, the universe, heaven, saints)” was classified into Factor 1 which mainly includes items from Construct I. As a result of the examination, item 10 is classified as Factor 1 suggestive that when you love yourself as you are, you may also feel that you are protected by something larger than yourself. The factor loading of item 10 was low (0.297); a possible interpretation being that only 20% of the subjects answered they had a religion (Table 1).

**Internal Consistency of the PAIS**

The internal consistency of the PAIS was demonstrated by the high Cronbach’s alphas of the PAIS total score and all PAIS factors, except Factor 4. We hypothesize that the
|                   | N  | Mean | SD  | PAIS  (total score) | PAIS (Factor 1) Loving myself as I am | PAIS (Factor 2) Experiencing the grace of illness | PAIS (Factor 3) Feeling a loving connection with others | PAIS (Factor 4) Developing as a mature person |
|-------------------|----|------|-----|---------------------|---------------------------------------|--------------------------------------------------|----------------------------------------------------|---------------------------------------------|
| JAIS 8 items [8–40] | 245| 21.6 | 7.3 | **1.00**            | **.997***                              | .912***                                          | **.607***                                          |                                             |
| PAIS (total score) 21 items [21–84] | 260| 56.1 | 11.5| **.497***            | **1.00**                              | **.637***                                        | .912***                                            | **1.00**                                    |
| PAIS (Factor 1) Loving myself as I am 9 items [9–36] | 260| 23.8 | 5.8 | **.637***            | **.912***                              | **.319***                                        | .809***                                            | .607***                                     |
| PAIS (Factor 2) Experiencing the grace of illness 5 items [5–20] | 260| 11.3 | 3.5 | **.319***            | **.809***                              | **.607***                                        | .364***                                            |                                             |
| PAIS (Factor 3) Feeling a loving connection with others 3 items [3–12] | 260| 8.9  | 2.0 | **.340***            | **.666***                              | **.604***                                        | .364***                                            | **1.00**                                    |
| PAIS (Factor 4) Developing as a mature person 4 items [4–16] | 260| 12.2 | 2.3 | **.174***            | **.755***                              | **.566***                                        | .601***                                            | **.464***                                   |

**Note.** JAIS = Japanese version of the acceptance of illness scale; PAIS = positive psychology-based acceptance of illness scale; SD: standard deviation.

*Correlation Coefficients*<sup>a</sup>

*<sup>a</sup>*Spearman’s rank correlation coefficient.

<sup>b</sup>[number] indicates score range: Four-point Likert scale ranging from “Strongly agree” to “Strongly disagree.”

<sup>c</sup>p < .05.  **p < .01.  ***p < .001.
lower Cronbach’s alpha coefficient for Factor 4 was attributed to the lowest factor loading (0.337) in item 16, “I accept the circumstances that caused me to be ill, the person I feel is responsible for my illness, and/or the cause of the illness.” This suggests that patients may not be able to comprehend the notion of forgiveness toward himself/herself, others, or the challenging circumstance. However, removing this item did not improve Cronbach’s alpha, therefore, it was retained.

In general, we found that some of the terms discussed in the process of scale development, such as “love” (items 6 and 13), were acceptable to Japanese participants given their high loadings. However, other terms, such as “forgive” (substituted with “accept” in the final version of items 8 and 16) and “the relationship between Japanese people and something bigger like god(s)” (item 10), had lower loadings which suggested that these may be harder concepts to comprehend for Japanese participants. Finally, the Japanese spiritual concept of Ikasareteiru (item 15) had moderate loading, suggesting it can be understood by some of the participants. As item reduction did not improve Cronbach’s alpha, we retained all 21 PAIS items even when the item loading was lower than usually accepted.

**Convergent Validity of the PAIS**

For the last step of the and validation of the PAIS, we examined the correlation between the PAIS and other measures show development in previous studies to be related to illness acceptance.

The statistically significant positive correlation between the JAIS and PAIS scores indicates that the two scales had some shared aspects of illness acceptance, including a focus on how patients can accept situations caused by their illness without experiencing negative feelings, but may measure different aspects of illness acceptance, as was intended with the development of the PAIS, while the JAIS may not be measuring the aspects of personal maturity as part of the illness acceptance. The statistically significant positive correlation between the JAIS and PAIS Factor 1 scores may be due to both the JAIS and PAIS focus on how patients can accept situations caused by their illness without experiencing negative feelings. However, the relatively weaker but still statistically significant positive correlation between the JAIS and PAIS Factor 4 scores may indicate that the JAIS may not be measuring the aspects of personal maturity as part of the illness acceptance that the PAIS Factor 4 measures.

Previous research has shown that patients who have a higher degree of illness acceptance, as measured by the AIS, have better QOL (Bien et al., 2015; Jankowska-Polańska, Blicharska et al., 2016; Kurpas et al., 2013; Lewko et al., 2007, 2012). The positive association found here between the PAIS total score and specific aspects of QOL supports these previous findings.

The negative association between the PAIS total score and anxiety/depression was also consistent with previous research (Lewko et al., 2012). These findings suggest the PAIS is able to measure acceptance of illness just as AIS could.

Based on these findings, we conclude that the PAIS has demonstrated convergent validity.

### Table 4. Association Between PAIS Scores and Quality of Life (QOL), Depression, and Anxiety.

| QOL** | PAIS (total score) 21 items [21–84]** | N | Correlation Coefficient | p-Value |
|---|---|---|---|---|
| Physical Functioning (PF) | 221 | 0.019 | .782 |
| Role-Physical (RP) | 221 | 0.071 | .294 |
| Bodily Pain (BP) | 221 | 0.042 | .537 |
| General Health (GH) | 221 | 0.153** | <.05 |
| Vitality (VT) | 221 | 0.275*** | <.001 |
| Social Functioning (SF) | 221 | 0.042 | .530 |
| Role-Emotional (RE) | 221 | 0.048 | .479 |
| Mental Health (MH) | 221 | 0.227*** | <.001 |
| Depression and anxiety** | 256 | -0.572*** | <.001 |
| Anxiety | 246 | -0.403*** | <.001 |

Note.

PAIS = positive psychology-based acceptance of illness scale.

*[number] indicates point range: Four-point Likert scale ranging from “Strongly agree” to “Strongly disagree.”

**Spearman’s rank correlation coefficient.

*Measured using the Short Form Health Survey 36 (version 2).

*Measured using the Hospital Anxiety and Depression Scale (HADS).

*p < .05. **p < .01. ***p < .001.
PAIS can Promote Acceptance of Illness for Health Professionals

The PAIS can inform recommendations by healthcare providers. For example, if an individual has a low score for Factor 1, healthcare providers can recommend mindfulness-related programs such as Acceptance and Commitment Therapy (ACT) and Mindfulness-Based Stress Reduction (MBSR) therapy or other relevant development that can encourage acceptance of oneself. If an individual has a lower score for Factor 2, healthcare providers can recommend interventions such as psychological approaches (e.g., engaging in individual or group psychotherapy, such as cognitive behavioral therapy) that may be able to change the patient’s perception of their illness, or learn from the experience of other patients who have already realized the benefits of their illnesses. If the score on Factor 3 is low, for example, due to insufficient support for the patient, the healthcare providers may suggest approaches to increase the support. These approaches could involve discussing the treatment plan with patients’ loved ones, as well as other interventions to enhance the psychological support for the patient. Finally, if the score of Factor 4 is low, we can encourage patients to learn about concepts such as humility, appreciation, compassion, and forgiveness via different methods depending on the patient’s preference, such as through books, lectures, workshops and other media.

Limitations and Future Direction

In this study, participants were limited to HAM patients. Additionally, participants had voluntarily registered themselves on a Japanese HAM patient registry; participants’ willingness to join the registry suggests that they may have had a higher degree of illness acceptance prior to entering the study. Therefore, the results may not be entirely representative of the whole population of Japanese HAM patients. A second limitation was the restricted number of reliability considerations. We did not conduct a test-retest of the PAIS because we wanted to reduce the burden to HAM patients. In the future, it will be necessary to examine reliability using the test-retest method.

Japanese patients were used as participants to develop and validate the PAIS employing the following assumption: The mechanism for acceptance of illness is universal; however, we hypothesize the way that acceptance of illness is described or perceived may be different according to culture. Therefore, we believe the PAIS, which offers a broader measure of illness acceptance, can be further refined for various illnesses or populations by employing a multicultural survey to identify critical cultural differences in the understanding of acceptance of illness. In addition, examining PAIS-related factors in another population of refractory neurological disorders with a chronic course may provide a better picture of acceptance of illness. We hope that in the future, after further refinement, the PAIS can be used not only in research but also in the medical, welfare, and nursing care settings as a simple evaluation tool to guide healthcare professionals to offer better care through targeted interventions.

Clinical Implications of PAIS

This study marks an important step toward a more comprehensive understanding of acceptance of illness. The convergent validity and internal consistency were confirmed in PAIS among HAM patients thus, a positive psychological state and spirituality may be involved in the mechanism of illness acceptance. The four PAIS factors, “Loving myself as I am,” “Experiencing the grace of illness,” “Feeling a loving connection with others,” and “Developing as a mature person,” may also be part of the mechanism of acceptance of illness. Furthermore, these findings may well depict the psychological state of illness acceptance in patients with intractable neurological disorders with a chronic course, similar to HAM.

Conclusions

In this study, we developed a new disease acceptance scale “PAIS” that incorporates the idea of positive psychology. When the PAIS was verified in Japanese patients with HAM, which is one of the chronic and intractable neurological diseases, validity and internal consistency were confirmed. Factor analysis confirmed the four-factor structure of the PAIS; the four extracted factors were: “Loving myself as I am”; “Experiencing the grace of illness”; “Feeling a loving connection with others”; and “Developing as a mature person.”

This study not only generated a novel scale in this research field, but also marked an important step toward the comprehensive notion of acceptance of illness.

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Ethics Approval and Consent to Participate

The present study received ethics approval by the Ethics Committee of St. Marianna University School of Medicine (examination number 2044). As all registered participants had already agreed to participate in any research that the registry offered, no consent forms were needed for this study.

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