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Using cognitive interviews to improve a Psychological-Social-Spiritual Healing Instrument: Voices of Aging African Americans with Serious Illness

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Abstract

Aim—The purpose of this study was to contribute to content validity, by providing input into the linguistic and pragmatic validities, of a 53 item Psychological-Social-Spiritual Healing instrument.

Background—Discovery of cultural values and beliefs from African American elders' experiences of illness provides insight for development of more culturally sensitive instruments.

Methods—Through an exploratory descriptive design, this study used cognitive interviewing methods to examine linguistic and pragmatic validity of the Psychological-Social-Spiritual Healing instrument, from the perspectives of aging seriously ill AAs. Participants were recruited from urban Jackson, MS from community settings from October 2014 to January 2015. With a purposefully chosen sample of seriously ill African Americans elders (N=15), and using the method of cognitive interviewing, responses related to cultural relevance, clarity and meaning of the 53 items of the instrument were collected. This in-depth query of items was accomplished through the use of both verbal probing and think aloud methods of cognitive interviewing.

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Results—Thirty-seven items were retained. Eight items were revised. Eight items were deleted.

Conclusions—From the expert input of seriously ill African American elders, a systematic decision-making process of item retention, revision or deletion led to the development of a more culturally sensitive Psychological-Social-Spiritual Healing instrument.

Keywords

Psychological-Social-Spiritual healing; Instrument Development; African American; Cognitive Interviewing Methodology

Introduction

Culture influences health behaviors and the meaning of illness (Leininger & McFarland, 2002; Andrews & Boyle, 2008; Purnell & Paulanka, 2008). Research looking at cross-cultural differences in seriously ill aging African American (AA) populations is limited in scope, quantity and location (Cohen, 2008; Evans & Ume, 2012; Johnstone & Kanitsaki, 2009). Although some is known about barriers to adequate palliative care (PC) for AA elders with serious illness, the cultural aspects of psychological-social-spiritual (PSS) healing have been sparsely studied (Cohen, 2008; Evans & Ume, 2012; Johnstone & Kanitsaki, 2009). Furthermore, there is no widely utilized or validated quantitative measure of PSS healing. Therefore, there is a need for a valid and culturally sensitive instrument that seeks to measure the multidimensional concepts of PSS healing. With a valid measurement of these concepts, PC practitioners would be able to compare more effectively the outcomes of their interventions for patients with serious illness.

Through a cognitive interviewing approach, the purpose of this study was to contribute to content validity of a Psychological-Social-Spiritual Healing instrument by providing input into the linguistic and pragmatic validities of individual items within the instrument (Kvale, 1995; Maxwell, 1992). Through a culturally focused framework, the validation process examines and provides the arguments for increasing the culturally applicability of the items on the PSS Healing instrument. These steps provide input on cultural relevance, clarity, and appropriate wording of items (Knafl et al., 2007) from purposefully chosen population-aging seriously ill African Americans. This process provides a culturally focused refinement of the items based on the input from aging seriously ill African Americans. Through this cultural lens, a systematic and informed decision-making process for measure refinement will contribute to the content validity of the PSS Healing instrument (Maxwell, 1992).

Conceptual Framework

Within palliative care (PC), providers focus on seriously ill AA elder's needs, goals and preferences. These are shaped through culturally bound values and beliefs centered on AA elders' psychological, social, spiritual and physiological experiences—the framework of patient-centered PC. Through a culturally focused and patient centered palliative care framework, PC incorporates AA elder's cultural beliefs and values of PSS Healing (Leininger & McFarland; Andrews & Boyle, Purnell & Paulanka; National Consensus Project for Quality Palliative Care). Defined in many disciplines, healing is a subjective and

multidimensional concept (Denz-Penhey & Murdoch, 2008; Koithan et al., 2007; Kuhn, 1988; Mount & Kearney, 2003, Sajja & Pulchaski, 2017, Skeath et al., 2013). Healing, in this study, was defined as generating a “life transforming positive subjective change” or what has been described as PSS Healing phenomenon occurring when one experiences a serious illness (Skeath et al., p. 1).

When suffering is present, there is a decreased ability for patients to experience healing opportunities, a healing which is more than the biological cure of one’s medical diagnosis (Kearney, 2000, Lichenstein, Berger & Cheng, 2017). Some patients have shown PSS healing even when faced with physical progression of their serious illness (Skeath et al., Coats et al. 2015). The inability to provide physical healing or “cure” of all patients with serious illnesses creates a enhanced need to explore the other non- physiological dimensions so provision of PC can contribute to one’s PSS healing (Coats, 2017, Li et. al, 2017). For measurement of non-physiological dimensions, there is a need for a valid and culturally sensitive instrument that seeks to measure the multidimensional concepts of PSS healing. With a valid and reliable instrument to measure these concepts, PC practitioners would be able to measure the effectiveness of interventions for PSS healing for patients with serious illness.

Description of Instrument

The National Institute of Health (NIH) Pain and Palliative Care Services (PPCS) Psychological Social Spiritual Healing Instrument, at the time of this study, included a total of 53 items divided into three domains—spirituality, illness and religious. The spiritual items focused on contentment, connection, and purpose. The illness items concentrated on appreciation of life, connection, and life priorities. The religious items centered on beliefs, values and religious practices. These initial items were developed by a group at the PPCS at the NIH Clinical Center who were investigating the “nature of both substantial relief from suffering and personal positive change...defined as healing” (Young et al. 2014, p. 2) The 53 items were based on the results of two qualitative studies. One study used a sample of cancer patients (Skeath et al). The second study used a sample of cardiac rehab patients (Nadarajah et al., 2013). Neither study used a population of aging seriously ill AAs.

The specific aim in the current study was to examine the NIH Clinical Center’s PSS Healing instrument by assessing seriously ill AA elders’ understandings and interpretations of each individual item on the PSS Healing instrument. The expected outcome was to produce summary item analyses of each item on the NIH PSS Healing measure based on the input of the aging seriously ill AAs. The results of initial scale validation through exploratory factor analysis techniques for the instruments development are reported elsewhere. (Sloan et al., 2017).

Cognitive Interviewing Approach

At all phases of instrument development, the content and semantic forms of the items within an instrument require input from diverse populations and multiple contexts. With a culturally based framework, instruments can evolve into more valid and culturally sensitive

instruments when based on expert input from a variety of ethnic groups. One way to collect this expert input is from cognitive interviewing methodology.

Cognitive interviewing within diverse samples provides knowledge on the cultural applicability of individual items, contributing to culturally focused refinement of items within an instrument. This process contributes to content validity by providing input into the linguistic and pragmatic validities of the individual items of an instrument (Kvale, 1995, Maxwell, 1992). Linguistic or “communicative validity” reflects “testing the validity of knowledge through argumentation of the participants in a discourse” (Kvale, 1995, p. 30). Besides communication, pragmatic validity encompasses both “action” and “ethics” (Kvale, 1995, p. 32). Here, the action is the new knowledge constructed from the discourse between researcher(s) and participant(s) with new knowledge being developed together. The ethical portion of pragmatic validity then utilizes the new knowledge for action (Kvale, 1995, Maxwell, 1992). In the cognitive interviewing approach, participants’ answers to verbal probes and reflections on each individual item of an instrument are the mechanism that contributes to linguistic and pragmatic validities (Knafl et al.).

The overall purpose of cognitive interview methodology in instrument development is to evaluate participants’ understanding and interpretation of items within an instrument. The use of cognitive interviewing approaches for instrument development has shown to be a valuable research tool (Knafl et al.). Some literature even supports cognitive interviewing in instrument development as a fundamental part of the process (Drennan, 2003; Fowler, 1995; Knafl et al.). In addition, when developing new instruments, scientists advocate that appraisal of such tools should be performed in diverse samples (Barroso & Sandewloski, 2001). This form of preliminary appraisal gives more validity to the cultural sensitivity and specificity of instruments to close the “gaps between meaning and measurement” (Barroso & Sandelowski, 2001, p. 502).

Methods

Design and Methodology

Through an exploratory descriptive design, this study used cognitive interviewing methods to examine content validity of the Psychological-Social-Spiritual Healing instrument, from the perspectives of aging seriously ill AAs. The overall content validity was examined by evaluating the linguistic and pragmatic validity of each item on the instrument. This in-depth query of items can be accomplished through the use of both verbal probing and think aloud methods of cognitive interviewing.

The verbal probing approach can be used to elicit the participant’s meaning of the items but also to identify the participant’s interpretation of items and to depict any ambiguity of the wording used in each item. (Knafl et al.). Each participant was asked to give his or her interpretation of each item on the instrument. Through the think aloud approach; the participants’ views of how they would answer the item can be elicited (Knafl et al.).

Through this step, researchers obtain informative knowledge on the appropriateness of each of the items based on each individual’s response to each item. In this study, this was

completed to gain the cultural perspective of aging, seriously ill African Americans. When inconsistencies, incomprehensiveness or inappropriateness are found in the analysis of participant interpretations of the items, the items can be modified or deleted by the research team (Knafl et al., p. 229).

Recruitment and Sample

A purposive sample of fifteen seriously ill AA elders was recruited. After the University of Arizona institutional review board approved the study, participants were recruited from urban Jackson, MS, and the surrounding metro area in community settings from October 2014 to January 2015. All participants self reported as AA with one or more of the following serious illnesses: cancer (n=6); stroke (n=5); heart disease (n=1), limited here as heart failure); and/or diabetes (n= 4). These diseases were chosen based on the top four leading causes of death in African Americans (Center for Disease Control, 2013). All participants were English speaking. The mean length of illness was 14 years (range 3 month to 34 years). The mean age was 67 (range was 60–80 years). The educational preparation ranged from completion of 5th grade to completion of Master's degree. All participants reported a religious affiliation which included the following: Baptist (n=10); Independent Baptist (n=1); Presbyterian (n=1); Holiness (n=1); Temple Church (n=1); and Non-denominational (n=1).

Procedures

Each interview took place in each participant's home. No participants who volunteered were excluded. The first author was solely responsible for screening and obtaining consent from all participants. Fifteen participants voluntarily enrolled and completed a one time audio-recorded interview. The participants had the opportunity to decline at the screening meetings, as well as before, during, and after the interview had been collected. No participants declined to participate once screening occurred.

Data Collection

Since the items on the instrument were the unit of analysis, the PSS Healing instrument was the interview guide. For each audio recorded interview, the first author read aloud the first item on the measure, and the participants were queried as to what meaning(s) each item had to them, what problems, if any, they had in determining what the item was supposed to mean, and/or what concerns, if any, the participants had about the wording of items (Knafl et al.). This was done through a verbal probing approach (Knafl et al.). The verbal probes used were: Was that statement easy or hard to understand? Was that statement clear or unclear? Were there any words that were offensive? What does that statement mean to you? Next, using the think aloud approach, the participant's responses to the items were collected. The collection of data using both approaches requires an increased amount of participant time, leading to possible participant burden. However, during the interview process, it was natural for the participants to provide their personalized answer (think aloud) to each item as they answered the verbal probes.

This process was repeated with all 53 items. Researcher observations of non-verbal data were also recorded on field notes after the completion of each interview. The pauses from

the participants when either answering the verbal probes or thinking aloud were included in the transcribed data matrix. After all 53 items were queried, demographic information was collected which included: age, time since diagnosis, education level, marital status, retirement status, insurance status, and religious affiliation.

Data Management

Prior to transcription, a data matrix (Miles & Huberman, 2014) for each of the three sections of the instrument (spirituality, illness and religion) was created in Microsoft Excel. The answers to all the verbal probes were entered into the matrix directly from the audio-recorded interviews. Then verbatim responses from the participants' think aloud comments were entered into the comment section of this data matrix. The purpose of transcribing the verbatim comments was to help facilitate the decision making process of which items to retain, revise or delete.

Data Analysis: Results and Decision Making

Retention of Items

Each individual item on the PSS Healing instrument was the unit of analysis. From a first level data matrix, an item-by-item review was conducted on every individual item (N=53). Items that were "comprehensible and consistently interpreted by each and every participant" were retained (Knafl et al, p. 228). Of the 53 items, there were 20 items to which all participants answered "no" to the probes, "Was this item unclear?" and "Was this item hard to understand?" and "Is there anything offensive in this sentence?". There were twenty items that were removed from this level of the data matrix. At this first item level matrix, 20 items (clear, easy to understand and no offensive language) were retained without any modifications.

Revisions or Deletion of Items

Next, a second level matrix was constructed that included the remaining 33 of the 53 items. This matrix facilitated a systematic decision making process about retention, revision, or deletion of the remaining items. The purpose of this second level item data summary allowed the research team to evaluate each participant's interpretations of the 33 items and answers to the verbal probes. For the data analysis, the research team consisted of five experienced researchers, three with qualitative expertise and two with psychological, social and spiritual healing content expertise.

Once this second level matrix was completed, both the 33-item data matrix and the de-identified demographic data was shared with the research team. The second level data matrix included the transcribed verbatim participants' comments and the "yes" and/or "no" answers to the probes (unclear, hard to understand, or offensive).

Using these summaries for each item, the research team then met to discuss each of the 33 remaining items. During this meeting, the team discussed which items to revise or delete. The research team reviewed all items that any participant had answered "yes" to "unclear, hard to understand or offensive." Once consensus was obtained among the research team,

the following decisions were made. From this second level data analysis, additional items were retained based on consensus of the research team. At this point of the data analysis, 14 of 19 of the spirituality items met these criteria and were retained. For illness items, 10 of 18 met these criteria and were retained. For religious items, 13 of 16 met these criteria and were retained. The remainder of the findings will discuss the decisions that were made by the research on those items that were deleted or revised.

Deletion of Items

Overall, a total of 8 of the 53 items were deleted after discussion by the research team. For the spirituality domain, 3 items were deleted. For the item “my connection with others gives me meaning,” 3 participants found this statement hard to understand, 4 found item unclear, and 1 participant found the statement offensive. The following list reflects some of the participant’s verbatim quotes.

- Meaning comes from myself and a higher power
- No way, spirit filled Christianity gives me meaning
- I don’t depend on others to have meaning
- I can have meaning without connecting with others

For the item “I gain awareness from self-reflection,” 4 participants found this statement hard to understand, eight found this item unclear, and 1 participant found it offensive. The following list reflects some of the participant’s verbatim quotes.

- I want to be Holy like he [God] is Holy, and not on mine.
- Awareness of what?
- You can talk about your growth but to say you gain awareness?

For the item “I don’t feel comfortable when I am not in control of my situation,” 2 participants found this statement hard to understand, 11 found it unclear, and 3 found the statement offensive. The following is a list of some of the participant’s verbatim quotes pertaining to this item.

- It depends on situation
- I know I am not in control of my life, God is
- I have to be dependent on God and not on myself
- Sometimes you have to let go, and let God

For the illness domain, 3 items were deleted. For the item “Living in the moment makes life easier,” 3 participants found this statement hard to understand, 8 found it unclear, and none found the statement offensive. The following is a list of some of the participant’s verbatim quotes pertaining to this item.

- What moment?... this means too much
- I am trying to understand living in the moment
- I don’t know what this means

For the item “Living in the moment gives me joy,” 3 participants found this statement hard to understand, 5 found it unclear, and none found the statement offensive. The following is a list of some of the participant’s verbatim quotes pertaining to this item.

- Not sure what living in the moment is
- It depends on the moment
- Living in the moment could lead to trouble
- Living in the moment you might make a mistake

For the item “Connection (with myself, others, nature, a higher power, etc.) helps me deal with stress,” no participant found this statement hard to understand, but 3 found it unclear, and none found the statement offensive. The following is a list of some of the participant’s verbatim quotes pertaining to this item.

- My relationship with my Father God allows me to deal with stress
- Believe in God, less stress.
- Not others, can give me more stress
- Sometimes connections with others is not always good

For the religious domain, 2 items were deleted. For the item “My religion informs my identity,” 3 participants found this statement hard to understand, 7 found it unclear, and 2 found the statement offensive. The following is a list of some of the participant’s verbatim quotes pertaining to this item.

- That is kind of hard to understand
- I can’t really understand that one
- Thinking about religion, I really don’t like that, it is a relationship
- I really don’t like that question, my spirituality informs my identity, my beliefs, not my religion

For the item “My religion has increased my understanding (of my illness, life, etc.),” 4 participants found this statement hard to understand, 6 found it unclear, and none found the statement offensive. The following is a list of some of the participant’s verbatim quotes pertaining to this item.

- My God helps me understand
- Understand life, not illness
- I don’t think my religion has helped me understand my illness.
- I say, my religion has got better because of my illness

Revision of items

Overall, a total of eight of the 53 items were revised after discussion by the research team. For the spirituality domain, 2 items were revised. For the item “Connecting with others is important to me,” no participant found this statement hard to understand, but 3 found it

unclear, and 2 found the statement offensive. The following is a list of some of the participant's verbatim quotes pertaining to this item. The suggested revision to the item was "the connection with higher power is important to me."

- Not really, it is connecting with God
- I don't need connections with others
- I need more spiritual help not other help

For the item, "I feel less stressed when I connect (with myself, others, nature, a higher power, etc.)," no participant found this statement hard to understand, but 3 found it unclear, and none found the statement offensive. The following is a list of some of the participant's verbatim quotes pertaining to this item. The suggested revision to the item was "I feel less stressed when I connect with a higher power."

- Need to lean on a higher power
- Relying on the him [Lord] decreases my stress
- Other people can cause me to have stress
- I don't always want to talk to people, that causes more stress

For the illness domain, 5 items were revised. For the item, "I have a greater appreciation for my life," 3 participants found this statement hard to understand, 4 found it unclear, and none found the statement offensive. The following is a list of some of the participant's verbatim quotes pertaining to this item. The suggested revision to the item was "I have a greater appreciation for my life since my illness."

- Because of what?
- I appreciate the Lord taking care of me
- It sure did- God be putting me through a test to see how much you can really take and now I have more strength

For the item, "Connecting (with myself, others, nature, a higher power, etc.) became more important and valuable after my illness," no participant found this statement hard to understand, but 1 found it unclear, and none found the statement offensive. The following is a list of some of the participant verbatim quotes pertaining to this item. The suggested revision to the item was "Since my illness, connecting with people has become more important to me."

- What do you mean, connecting with whom?
- Connecting with others is always important
- Able to share with others how I was an overcomer

For the item, "I believe that there is purpose for my illness," 1 participant found this statement hard to understand, 4 found it unclear, and 2 found the statement offensive. The following is a list of some of the participant's verbatim quotes pertaining to this item. The suggested revision to the item was "My illness gave me new reasons to live."

- I never thought of it as a purpose for my illness
- There is purpose for my life, but illness?
- I know there is a reason- a lesson or purpose for me
- There is a reason for everything

For the item, “My quest for connection (with myself, others, nature, a higher power, etc.) increased after my illness,” 3 participants found this statement hard to understand, 6 found it unclear, and 1 found the statement offensive. The suggested revisions to the item required having two items to replace this one item. The first suggested item was “Since my illness, I seek better relationships with others” and the second suggested item was “My illness strengthened my connection with a higher power.” The following is a list of some of the participant’s verbatim quotes pertaining to this item.

- He (God) brought me through it
- So I was seeking a better relationship after my stroke with my children
- I have always wanted to be with others, but illness made it more.
- With my Lord, I did not have to seek that because I have had that all my life

For the item, “I yearn for a connection with a higher power,” 3 participants found this statement hard to understand, 6 found it unclear, and 3 found the statement offensive. The following is a list of some of the participant’s verbatim quotes pertaining to this item. The suggested revision was “I strive for a connection with a higher power.”

- Yearning is like worrying
- What that mean? I don’t know what yearn mean, I already have the connection
- Strive to know if you are connecting with God- better word than yearning
- He (God) has always been there

For the religious domain, 1 item was revised. For the item, “Formal religion practice is important to me,” 1 participant found this statement hard to understand, 2 found it unclear, and none found the statement offensive. The following is a list of some of the participant’s verbatim quotes pertaining to this. The suggested revision was “Religious practice is important to me.”

- What is formal?
- What do you mean by formal?

Overall, thirty-seven items were retained. Eight items were revised. Eight items were deleted. See Table 1. Items in the illness domain required the most modifications or deletions. The religious items required the least modifications or deletions.

Discussion

Customarily, qualitative data is used for the creation of items. For this study, the qualitative data was used to assess the items on the original PSS Healing instrument. Through a

culturally focused approach, the investigation of individual items provided steps for creating more culturally applicable items based on the perspectives of aging seriously ill African Americans.

For the seriously ill AA elder, the current findings suggest a strong link to their connection with a higher power, whether the item was in the spiritual, illness and/or religious domain, as evidenced in their qualitative comments. This connection to a higher power helped them deal with stress, was important and valuable, and gave meaning to their life. The current findings also support the implication that this connection to a higher power was present prior to their illness, but it became “more important” through their illness process. Items were found to be offensive to these participants when referring to the connection to a higher power was “because of the illness.” Their input suggested that they “already had this connection” with a higher power, and that the illness in some ways strengthened this connection. Cultural input, the strong link to a higher power, provided evidence for the modifications that were made to each individual item.

Cultural refinement of instruments should incorporate the input of the expert, in this case the AA elder. Items that were poorly worded, ambiguous or culturally inappropriate were either deleted or revised. Some of the items lacked clarity and understanding pointing to the need to eliminate or revise the items for improving the PSS Healing instrument towards a more culturally sensitive measure of PSS healing. With the use of cognitive interviewing methodologies, the analysis of the PSS healing items, using the qualitative input from AA elders, led to important modifications in the cultural refinement and continued development of the PSS Healing instrument.

Since instrument development is a continual process, the suggested revisions and deletions based on the expert input of seriously ill AA elders were provided to the research team members at PPCS NIH Clinical Center. Simultaneously with the study presented here, the instrument refinement process has continued at the PPCS NIH Clinical Center. The instrument continues to be tested and further modifications have been and are being done on the psychometric properties to improve both validity and reliability of the instrument.

A known limitation was the small (N=15), homogeneous sample of only seriously ill AA elders (60 years or older) who were recruited from one geographic region. However, the input from these 15 participants provided culturally focused refinement to 16 of the 53 items. Next steps would be to retest the instrument with the newly revised items using the cognitive interviewing methodological approach. For continued refinement of the PSS Healing instrument, testing would need to be done in a multitude of different populations such as: same population in other parts of the country, a younger AA population with serious illness, and larger and more diverse samples of other seriously ill minority populations. Further testing with these broader samples would provide continued improvement of the linguistic and pragmatic validity of the PSS Healing instrument. Further studies, with the input of a variety of ethnic experts in a variety of contexts, will lead to improved cultural sensitivity of the individual items, thus enhancing the content validity of the overall instrument.

Conclusions

This systematic approach provided for informed decision making on which items to retain, revise or delete as part of early phases in the PSS healing instrument development. Most importantly, the process of instrument review by a sample of participants drawn from a purposive minority population can improve the cultural sensitivity of the measures for aging seriously ill African Americans. For this study, linguistic validity was enhanced through the incorporation of the expert input of the seriously ill AA elders via cognitive interviewing methodologies. The pragmatic validity, using both the research team and participants' input developed new knowledge that can be applied for action. The action, in this study, was to improve the content validity of the PSS Healing instrument. This study provided evidence for the development of more culturally relevant, clear and appropriately worded items thus enhancing the content validity of the PSS Healing instrument.

Contributions from multiple sources create a more valid tool. Focusing on a culturally focused framework of linguistic and pragmatic validity, the continued use of cognitive interview methodologies for instrument development provides needed evidence for building content validity and cultural applicability of instruments. The steps, in this study, have provided evidence towards creating a more valid and culturally sensitive tool for both research and clinical practice.

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Table 1

Retain, Revision, Deletion summary

Overall N=53	Spiritual (N=19)	Illness (N=18)	Religious (N=16)	Totals
Retain	14	10	13	37
Revise	2	5	1	8
Delete	3	3	2	8