



Original article

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.

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.

1. Introduction

Culture influences health behaviors and the meaning of illness (Andrews & Boyle, 2008; Leininger & McFarland, 2002; 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 multi-dimensional 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 cultural applicability of the items on the PSS Healing instrument. These steps provide input on cultural relevance, clarity, and

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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).

1.1. 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 (Andrews & Boyle, 2008; Leininger & McFarland, 2002; National Consensus Project for Quality Palliative Care, 2013; Purnell & Paulanka, 2008).

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., 2013, 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 (Coats, Crist, Berger, Sternberg, & Rosenfeld, 2015; Skeath et al., 2013). The inability to provide physical healing or “cure” of all patients with serious illnesses creates an 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.

1.2. 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, Nadarajah, Skeath, & Berger, 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., 2013). The second study used a sample of cardiac rehab patients (Nadarajah, Berger, & Thomas, 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).

1.3. 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., 2007).

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., 2007). Some literature even supports cognitive interviewing in instrument development as a fundamental part of the process (Drennan, 2003; Fowler, 1995; Knafl et al., 2007). In addition, when developing new instruments, scientists advocate that appraisal of such tools should be performed in diverse samples (Barroso & Sandelowski, 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).

2. Methods

2.1. 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., 2007). 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., 2007).

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

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