

African American Elders' Serious Illness Experiences: Narratives of "God Did," "God Will," and "Life Is Better"

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Abstract

The foundation of culturally sensitive patient-centered palliative care is formed from one's social, spiritual, psychological, and physical experiences of serious illness. The purpose of this study was to describe categories and patterns of psychological, social, and spiritual healing from the perspectives of aging seriously ill African American (AA) elders. Using narrative analysis methodology, 13 open-ended interviews were collected. Three main patterns were "prior experiences," "I changed," and "across past, present experiences and future expectations." Themes were categorized within each pattern: been through it . . . made me strong, I thought about . . . others, went down little hills . . . got me down, I grew stronger, changed priorities, do things I never would have done, quit doing, God did and will take care of me, close-knit relationships, and life is better. "Faith" in God helped the aging seriously ill AA elders "overcome things," whether their current illness or other life difficulties.

Keywords

aging; African Americans; narrative analysis; palliative care; cultural competence, religion/spirituality; southern United States

Culture influences health behaviors and the meaning of illness (Andrews & Boyle, 2008; Leininger & McFarland, 2002; Purnell & Paulanka, 2008). Gathering data about cultural values, attitudes, beliefs, and/or preferences related to psychological-social-spiritual (PSS) healing for seriously ill African American (AA) elders is necessary as the basis for patient-centered palliative care PC (Center to Advance Palliative Care, 2010 [CAPC]; Evans & Ume, 2012; National Quality Forum [NQF], 2012). There is some knowledge about barriers to adequate PC for AA elders with serious illness, but the cultural aspects of PSS healing have been sparsely studied (Cohen, 2008; Evans & Ume, 2012; Johnstone & Kanitsaki, 2009; Teno et al., 2004; Welch, Teno, & Mor, 2005). In addition, research analyzing cross-cultural differences in psychological, social, and/or spiritual domains is limited in scope, quantity, and location (Cohen, 2008; Evans & Ume, 2012; Johnstone & Kanitsaki, 2009; Welch et al., 2005).

Through a narrative approach, cultural aspects of PSS healing for seriously ill AA elders can be discovered by listening to these participants' stories. A narrative approach draws together the complexities of serious illness experiences and the cultural meanings of the illnesses by collecting and analyzing stories of

aging, seriously ill AAs. The purpose of this study was to describe psychological, social, and spiritual experiences of healing for AA elders with serious illnesses of heart failure, cancer, stroke, and/or diabetes. Using the qualitative method of narrative analysis, the specific aim was to describe categories and analyze patterns of PSS healing from the perspective of aging AA elders with serious illness.

Background

The foundation of narrative inquiry is based on storytelling. The stories of one's experiences—past, present, and future (Clandinin & Connelly, 2000; Polkinghorne, 1988; Riessman, 2008)—provide an avenue to "understand experiences of stories lived and told" (Clandinin & Connelly, 2000, p. 20) as a partnership between storyteller and receiver. The complexities of serious illness require a narrative approach. Illness stories have been

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shown to provide rich details of the multiple complexities of one's beliefs, values, emotions, and attitudes (Bury, 1982; Frank, 1995; Kleinman, 1988; Riessman 1993, 2008).

Through a cultural focus, stories describe how human beings understand experiences of illness in their lives (Clandinin & Connelly, 2000), giving the receiver a view of how the storyteller expresses and organizes these experiences into a meaningful whole (Kleinman, 1988). Storytelling is a prominent and highly valuable ritual in AA cultures (Banks-Wallace, 2002; Cannon, 1995; Champion, Katz, Muldrow, & Dail, 1999; Gates, 1989; Haight, 1998).

Furthermore, although comprehensive PC for patients with serious illness improves quality of life, quality of care, and patient satisfaction, the growing population of AA elders with serious illness report disparities in the receipt of PC, dissatisfaction with that care, and care inconsistent with their wishes, leading to decreased quality of life and increased suffering (Cohen, 2008; Evans & Ume, 2012; Johnstone & Kanitsaki, 2009; Welch et al., 2005). In addition, little is known about the AA elders' cultural values and beliefs about the psycho-social-spiritual dimensions of palliative and end-of-life care (Evans & Ume, 2012).

Disparities in palliative and end-of-life care are because of lack of integration of culturally sensitive psychological, social, and spiritual healing for AA elders with serious illness (Evans & Ume, 2012; Welch et al., 2005). Therefore, for aging, seriously ill AAs, narrative storytelling can provide in-depth views of illness experiences (Frank, 1995) in a culturally congruent approach.

Theoretical Framework and Conceptual Definitions

PC principles focus on patient-centered care of seriously ill people (National Consensus Project for Quality Palliative Care [NCPQPC], 2013; NQF, 2012). As many of the concepts discussed are complex, the following conceptual definitions have been provided. PC is defined as the "anticipation, prevention and relief of suffering; to support the best possible quality of life for patients and their families, regardless of the stage of the disease" (NCPQPC, 2013, p. 9), not just care provided at end of life but across serious illnesses. Serious illness is "a persistent or recurring condition that adversely affects one's daily functioning or will predictably reduce life expectancy" (NCPQPC, 2013, p. 8). Healing is defined as a subjective and multidimensional concept that creates a "sense of wholeness as a person" despite one's illness (Mount & Kearney, 2003, p. 657). Suffering is defined as an "unpleasant, emotional experience that can be psychological, social and/or spiritual" (Ferrell & Coyle, 2008, p. 246).

The foundation of culturally sensitive patient-centered PC is formed from one's social, spiritual, psychological, and physical experiences of serious illness. Physical aspects of care include: pain, other symptoms, and side effects which are managed based on the best available evidence. Here, attention is given to disease-specific pain and other symptoms which include pain, but also non-pain symptoms such as: shortness of breath, nausea, fatigue and weakness, anorexia, insomnia, anxiety, depression, confusion, and constipation, treatment side effects, and functional capacities which are documented through a systematic process (NCPQPC, 2013). Social aspects of care include the following: Comprehensive interdisciplinary assessment identifies the social needs of patients and their families to include family structure and geographic location; relationships; lines of communication; existing social and cultural networks; perceived social support; medical decision making; work and school settings; finances; sexuality; intimacy; living arrangements; caregiver availability; access to transportation; access to prescription and over-the-counter medicines and nutritional products; access to needed equipment; community resources, including school and work settings; and legal issues (NCPQPC, 2013). Psychological aspects of care include the following: ongoing assessment of psychological reactions related to the illness including but not limited to stress; anticipatory grieving; and coping strategies of the patient and family evaluating the understanding of disease, symptoms, side effects, and their treatments; as well as assessment of caregiving needs, capacity, in addition to assessment of psychiatric illnesses, such as severe depression, suicide ideation, anxiety, delirium (NCPQPC, 2013). Spiritual, religious, and existential aspects of care include the following: Periodic reevaluation of the impact of spiritual/existential interventions and patient-family preferences should occur with regularity and be documented to include, but is not limited to, life review, assessment of hopes and fears, meaning, purpose, beliefs about afterlife, guilt, forgiveness, and life completion tasks by identifying religious or spiritual/existential background, preferences, and related beliefs, rituals, and practices of the patient and family consistent with the individual's and family's cultural and religious values (NCPQPC, 2013).

PC delivered through this frame provides approaches to decrease suffering and, in turn, to facilitate PSS healing for seriously ill AA elders while achieving the overall goals of PC. 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). Some patients have shown PSS healing even when faced with physical progression of their serious illness (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 that provision of PC can contribute to one's PSS healing. Among these multidimensional concepts in serious illnesses, there is perpetual movement back and forth on the healing/suffering continuum (Mount, Boston, & Cohen, 2007; Mount & Kearney, 2003; Paterson, 2003). Formed from these conceptual definitions to guide this study, a culturally based PC conceptual framework was used. Through this conceptual framework, the approach to PC integrates cultural beliefs and values of PSS healing/suffering on an ever shifting pendulum centered on culturally sensitive patient-centered PC (Andrews & Boyle, 2008; Leininger & McFarland, 2002; NCPQPC, 2013; Purnell & Paulanka, 2008).

Method

Design

A descriptive design with narrative analysis methodology was used for this study, providing a culturally congruent approach of storytelling for this vulnerable population. Narrative analysis requires not only looking within individual stories but also across the collection of stories. The stories must be examined as "moving ground" without a "master narrative" (Riessman, 1993, p. 15). Instead, the receiver of the story must develop a "meta-story" (Riessman, 1993, p. 13) or "overarching storyline" (Riessman, 2008, p. 78). This meta-story of each individual's story incorporates details "about what happened, editing and reshaping what was told and turning the findings into a new text, a co-constructed "hybrid story" (Riessman, 1993, p. 13). In this hybrid co-construction of story, the teller must persuade the receiver about the course of and perception about events (Riessman, 2008). This receiver must reinterpret the teller's story even though she was not present at the events and does not have the ability to know the narrator's inner emotions, thoughts, or reasons for action. In this study, the participant who had been diagnosed with colon cancer 30 years ago told the most detailed story. See Box A for an example of a co-constructed hybrid story.

Box A: Mary's Hybrid Story

It was the "year of 1984, the month of January," when the story of illness begins, when she first developed signs of her colon cancer. On the particular Saturday before symptoms occurred on Sunday, she spent the whole day getting groceries, ironing for husband, her youngest daughter and for herself for "making sure" her family was "situated . . . fed . . . everything." Typically, they would go

visit her parents on Sunday, but this Sunday was different than the usual Sundays of visiting her parents. The family had been to Sunday school and instead of visiting her parents, her spouse asked her to go with him to an afternoon program where he sang in the choir, because of this, they had to eat out. While eating out, she went to the bathroom and had a "gush" that "looked like the bloody sea." She became scared "in a sense" but did not tell anyone or go to the hospital at that time. Prior to this, she also had made an appointment to see the doctor on Monday. So, they went on to the church program. That evening, she had a few more "incidents" of blood, so she called her mother who told her "that was serious" and urged her to go to the doctor. She assured her mother that she had an appointment with the doctor for Monday.

On that Monday, she did go into that day and stayed home and prepared dinner for that day. Once her spouse had went to work, and she had the dinner done, she called and told him that she was going to the doctor's appointment. He became concerned after telling him about the bloody stools and eventually came home to take her to the doctor when she began feeling weak. She still believed she "was alright" at that time. As she reflects on what happened after this, she now realizes she was "weak" and was not all right. Once her husband was coming home to take her to the doctor, she checked on the food, showered but on exiting the shower, fell off the commode. Her husband then came in and found her on the floor, helped her to the bedroom and called an ambulance. She remembers thinking "what you going to do with an ambulance?" and the paramedics discussing her physical state of shock and urgency to "get her out of here," moving the car, and in her perspective, driving her slowly to the hospital and how this ride "was fun" and as a child and young lady "she would have never rode in ambulance."

Participants and Setting

Once the University of Arizona institutional review board approved the study, participants were recruited from urban Jackson, MS, through the following two community recruitment venues. The first recruitment site was a University of Mississippi primary care clinic in a Jackson midtown community, University Nursing Associates provides Community Access to Health and Education (UNACARE) clinic. The second recruitment site Abundant Living Community Organization (ALCO) is a non-profit congregational health nursing society based in Jackson, MS, representing church-based health and wellness programs throughout the state of MS with a mission of reducing disparities for AAs.

Key stakeholders in both of these sites notified potential participants of the study. If a participant was interested in enrollment, the key stakeholders facilitated

contact to the first author. From there, the first author described the study, completed the informed consent process, and coordinated the interview. The first author was solely responsible for screening and obtaining consent from all participants. The participants had the opportunity to decline at the screening meetings, as well as before, during, and after the interview had been conducted. No participants declined to participate once screening occurred. “Thank you” gift cards with the amount of US\$20 were given at the completion of the interview. Twelve of 13 interviews were collected in the participants’ homes. One interview was conducted in an individual private classroom at a senior center.

A purposive sample of 13 AA elders with serious illnesses was recruited for this study, and 13 audio-recorded narrative interviews were collected. The demographic details are delineated in Table 1. Consistent with qualitative methods, a range of 10 to 15 participants was planned. This range allowed for continuing data collection until data saturation was achieved, which occurred after 13 interviews.

All participants were 65 or older, self-reported as AA, and had one or more of the following serious illnesses: cancer, stroke, heart disease (limited here as heart failure), and/or diabetes, diagnosed with their illness for longer than 3 months, and English speaking. Participants were excluded if they were deaf or unable to comprehend and/or answer interview questions or Mini-Mental Status Exam (MMSE) score less than 9 (Folstein, Folstein, White & Messer, 2010). Prior to the interview as part of the screening process, the first author administered the MMSE to each participant. No participants who volunteered were excluded. The participants, despite their illnesses, were all independent in all their activities of daily living, with three requiring assistance with their instrumental activities of daily living.

Data Collection

All 13 stories were collected by the first author, the novice nurse researcher, from January 2014 through December 2014, through audio-recorded, open-ended interviews. The interviews lasted an average of 47 minutes (range = 15–82 minutes) for a total of 616 minutes of audio-recorded transcripts. The interview was divided into sections that began with an open-ended question: “Tell me about your illness.” When the interviewer perceived that the story was complete, the interviewer then used prompts to query about emotional, social, or spiritual dimensions of the participants’ illness experiences with prompts such as, “How has your illness changed you emotionally?” The final segment of the interview gathered the demographic information such as age, time since diagnosis,

Table 1. Demographic Table.

Participant	Gender	Illness	Diagnosed	Faith
1	F	Diabetes	3 months	Baptist
2	F	Colon cancer	30 years	Baptist
3	F	Diabetes	25 years	Baptist
4	F	Diabetes	12 years	Baptist
5	F	Heart failure	4 years	Methodist, attend Baptist sporadically
6	F	Stroke	2 years	Baptist
7	F	Cancer	14 years	Baptist
8	F	Stroke	2 years	Baptist
9	F	Cancer	3.5 years	Baptist
10	F	Stroke	20 years	Baptist
11	F	Cancer/diabetes	4 years	Baptist
12	F	Cancer	2 years	Baptist
13	M	Heart failure	Initial Diagnosis 20 years; 3 years severe exacerbation	God of Abraham

education level, marital status, insurance status, and religious tradition (see Supplemental file for Interview Guide).

Data Management

During transcription, the first author assigned numbers to each participant and de-identified the interviews. For confidentiality, only de-identified transcripts of interviews were available to the research team. The master de-identified transcripts were kept on the first author’s password-protected computer and inputted into NVivo, a qualitative data analysis software program. During the analysis phase and for manuscript purposes, pseudonyms were assigned to each participant (see Demographic Table 1).

Through an iterative process, data collection and data analysis occurred simultaneously and continued until data saturation occurred, defined as occurring when no new patterns or structures emerged with subsequent interviews (Lincoln & Guba, 1985). After each interview, the first author audio-recorded her field notes immediately after each interview. Then, the first author transcribed every interview and field note. The interviews were transcribed verbatim to reflect the “voice” with words exactly as the participant said them. The field notes were used to incorporate “co-construction” of data through the interactive interviewing procedures (Riessman, 2008, p. 23) and included the following: descriptive observational notes of setting, place, and time and personal reflective notes of

feelings, problems, ideas, impressions, and biases (Riessman, 2008). Through the process of collecting these field notes, the first author kept a detailed audit trail to decrease possibilities of personal biases (Lincoln & Guba, 1985). Moreover, methodological and analytical memos were used for recording decisions related to refining and defining codes, patterns, or categories as a way to document communications from the research team. The research team consisted of two experienced qualitative nurse scientists, two experienced physician scientists with relevant content expertise, and one novice nurse scientist. All members were Caucasians. Due to the lack of being a cultural insider, the first author realized her “subject position” (Barker, 2012) and employed the expertise of a cultural consultant, an AA and Mississippi native who was also an experienced qualitative nurse scientist.

Data Analysis

Once the first author transcribed the interviews, the second author—one of the experienced qualitative nurse scientists—read all the de-identified transcripts. The first and second author participated in weekly analysis meetings. Using two authors to analyze the verbatim transcripts provided a reduction in the bias of the formation of the meanings and structure of the stories.

Next, from the entirety of the full transcribed interview, co-constructed “hybrid stories” or “meta-stories” (Riessman, 1993, p. 13)—shorter summary stories of each participant’s stories of the illness experiences—were written and rewritten through several iterations with the second author. Co-constructing hybrid stories was necessary to condense the transcripts to the narrative pertaining just to the participant’s illness meta-stories. Then, these meta-stories were shared with the research team for expert input on the overarching patterns/themes found within these hybrid or meta-stories. Co-construction defined here as two separate actions. The first action is one of co-construction that occurred during the actual interview process of “facilitating and responding” (Riessman, 2008, p. 23) within the interactive process between the interviewer and the participant to construct the initial narrative. The second action was the condensing process, hence taking the entirety of interview and creating a “meta-story” (Riessman, 1993, p. 13) focused on the participant’s illness experiences, an iterative interpretive process.

Then, using Labov’s (1972) narrative elements, the meta-stories were analyzed for structural patterns of orientation, complicating action, evaluation, resolution, and coda. The structural analysis allowed the first and second author to look across the meta-stories, creating a process of providing “attention to both the language of the illness

stories but also the role of the narrative form within the illness stories” (Riessman, 2008, p. 75). For the thematic analysis, an inductive emic approach of coding included the participants’ actual words for naming the codes (Braun & Clarke, 2006). First, open coding was used allowing the emerging codes to come directly from the transcripts (Braun & Clarke, 2006; Riessman, 1993). The preliminary codes of experiences emerged from reading the transcripts line by line, both manually and electronically within NVivo. Coding across two separate avenues allowed for an in-depth look at each transcript plus an additional check for accuracy of the line-by-line coding. Once the initial codes were chosen, the transcripts were read and reread through a “recursive process.” This recursive process was defined as “a movement back and forth through” the data—a coding process that created the thematic analyses (Braun & Clarke, 2006, p. 86). The processes of this thematic analysis allowed the first and second author to categorize recurrent experiences (Braun & Clarke, 2006).

Throughout the entire analytical process, the categories/patterns were refined and defined at the weekly meetings between the first and second author. Once these preliminary findings were decided on between the first and second author, the findings were shared with the third, fourth, and fifth authors. After receiving input from the entire research team, the findings were refined, as presented here. The exemplars used in the findings below are verbatim, in an effort to reflect the “voice and words” of the participants and not the authors.

Rigor

Trustworthiness is the accepted measure of rigor in qualitative research (Barroso & Sandelowski, 2001; DeWitt & Ploeg, 2006; Leininger, 1995; Lincoln, 1995; Lincoln & Guba, 1985; Morse, 1991; Sandelowski, 1986). Sandelowski’s criteria for trustworthiness (credibility, applicability, consistency, and neutrality) were used for this study. Credibility was achieved through the use of the reflective field notes kept by the first author and a research team approach for arriving at the findings. This process allows the authors to recognize and separate his or her own thought processes from those of the participants in an attempt to stay true to the voice of each participant. For applicability, detailed memos were kept by the first author, then shared and reviewed by the second author. To not unduly influence the categorical thematic analysis, the themes arrived at were labeled with the actual words of the storyteller. Consistency was met by providing detailed descriptions of the data collection, data analysis, and verbatim excerpts from the participants’ interviews within this manuscript. Neutrality occurs when there is “freedom from bias in both research

process and product” (Sandelowski, 1986, p. 33). In this manuscript, particular steps were detailed so others can see how the authors achieved credibility, applicability, and consistency. The authors recognized the possibility of personal biases but attempted to portray the subjective experience of the aging, seriously ill AAs as part of the interpretive research process.

Findings

Past, Present, and Future: Stories of Experiences

From using Labov’s narrative elements, all 13 meta-stories had similar elements of narrative, although not all stories were told in the same linear fashion. From these meta-stories, the thematic analysis materialized. In these meta-stories, the participants all reflected on past and present experiences and future expectations. The following structural patterns were evident both within and across all 13 narratives: “Prior experiences,” “I changed,” and “across past, present experiences and future expectations.” Then, thematic categories were organized under these three structural patterns, providing an inductive classification of the AA elders’ narratives of living with serious illness (see Figure 1).

Prior experiences. Stories of prior experiences were not necessarily about the elders’ illnesses but instead often suggested associations with how strength and resilience were gained in other ways. “[I’ve] been through it . . . made me strong,” “I thought about . . . others,” and “went down little hills . . . got me down” are the three thematic categories within the structural pattern of prior experiences.

Each narrator told stories about the following: difficult life experiences unrelated to his or her current illness, knowledge gained from observing other people’s illnesses, and personal emotional influences of their illness. These prior experiences stories were not queried from the interviewer; instead, all 13 participants volunteered these stories.

“Been through it . . . Made me strong.” All 13 participants’ pasts were still a part of their present lives—a “reframing of the past to make sense of the present and provide an orientation for the future” (Mattingly & Garro, 2000, p. 7). Their past experiences were financial problems, prior illnesses they had or that others close to them had, work difficulties, male/female discrimination, White/Black discrimination, and even stories that went all the way back to “rough” childhood memories. One participant told a story of how as a child, she raised both her sister and brother because her mother was absent—making her stronger.

I was kind of rough when I was little, cuz I really had to raise my brother and my sister because my mother wasn’t around, but we made it through, with the Lord help, we made it

through . . . I believe bring my strength along, raising them . . . like I said when we were young, we had it rough, we had no light, no water, we had to tote wood to make a fire.

Another participant told a very detailed story of a prior illness event. A story of how, through her physical rehabilitation, she returned to walking after being hit by a car in her 30s.

I can get up and take care of myself and do for myself because I have done it, I have, before all this happened to me, I had got hit by a car and I was paralyzed, oooo, for a long time and all my pelvis and my knees were broke and God brought me back to walk and I didn’t sit down and use the bathroom, I used to get on my knees and crawl to the bathroom, I couldn’t walk, I would crawl.

From the stories, we can begin to see how these participants have gone through some difficult times. These experiences helped them develop strength at that time, which now provided strength to deal with their current illness(es).

“I thought about . . . others.” Every participant recounted stories of others’ illness experiences and how this knowledge of others’ illnesses had an effect on their personal experience of their current illness. One participant had experienced her sister’s death from high blood pressure, thus creating urgency for her to seek treatment.

O.k. really, the scary part is afterward, you then know what is happening to you, ummm, I had had two sisters that died right like, one this year and one next year . . . One sister was never able to . . . get her BP down, but anyways, we lost her.

In addition, another participant watched others live with physical deficits after a stroke, creating a drive to work extremely hard during her physical rehabilitation.

What you try peoples to understand and see that this is death, you know, you don’t, some strokes you don’t get over, a lady in my church, during the time I am going to rehab, she had had a stroke and she told me one Sunday, all I want to do is get back able to be in the choir, cuz she sung in the choir, I wanted to do that, she say, I’m so tired of this, people having to move me around and stuff, and she say, why didn’t it happen to you, how did you get better, I said I worked so hard, I worked so hard, this is not going to beat me, it is not going to beat me, I am not going to stop walking on my leg, I don’t want a cane, so I did, you have, I set my goals high.

These prior experiences of reflecting on other’s illnesses provided a place of reference for them when framing and dealing with their current illness.

“Went down little hills . . . got me down.” When any of the participants described their negative emotions, words such as “fear,” “worry,” “scared,” “got me down,” and/

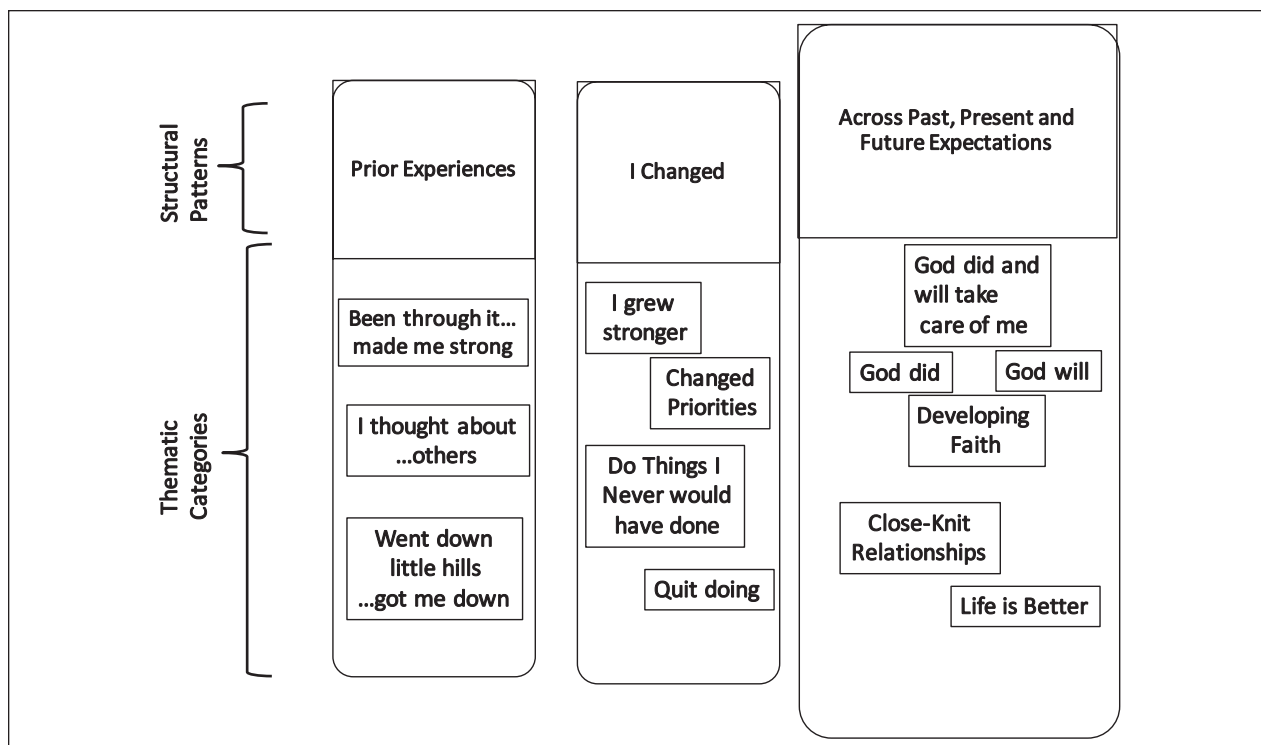


Figure 1. Past, present, and future: Stories of experience.

or “depression” was used in the stories. All participants felt these emotions throughout different times of their illness—at time of diagnosis, after returning home from the hospital stays, or even in present day when they are physically affected by their illness. However, when they used more negative words, they followed up immediately with a story of how they moved past these more negative feelings, best told by this participant.

This participant’s heart failure left her with decreased physical capabilities (weakness, swelling in her legs, and shortness of breath requiring oxygen off and on) and, therefore, dependence on others. Yet, with time, she did not let those changes “get her down” and “bother her” anymore and continued to push herself to engage in the things she can do. She reflected that her illness did cause some negative emotions, “I kind of let it get next to me, and I kind of just went down little hills,” but she prayed to the Lord to “help her feel better” and how she “gets up and starts moving and try to do a little something.” She described how her negative emotions were changed despite her physical changes of dependence on others.

You know, I couldn’t get around and go where I wanted to go, you know, like the store and buy my groceries and buy my stuff like I used to, that kind of got me down always depending on somebody else to go to the store but they still don’t get what you really want, so that is what I have to do now, I have to depend on my niece to go to the store for me

and stuff, but now I that got used to it, it don’t bother anymore, I just go with whatever she brings.

As we hear the stories of how these participants transitioned from the negative to the positive, we can begin to understand how their individual strengths helped these seriously ill AA elders deal with the difficulties caused by their illnesses.

“I changed.” The next structural pattern identified included stories of how the participants’ lives had changed because of their illness. Their illness has made them a different person. Stories of change were also told by all 13 participants. These changes, for these seriously ill AA elders, were classified into the following thematic categories: “I grew stronger,” “changed priorities,” “do things I never would have done,” and “quit doing.” With any serious illness, there are negative effects. These were expressed through stories of depression, decreased physical capabilities with remaining disabilities (need O₂, weakness, wear attends, paralysis), loss of body image, pain, shortness of breath, and fatigue.

Despite the negative effects of their illness, the participants told multiple stories of how they learned something with a new sense of self, changed behavior, or new perspective on life. Yet at different phases of living with their illness, the effects of their illness had been both negative

and positive. The storytellers' emotions (i.e., evaluation; Labov, 1972) begin to emerge as they discussed how they have learned to adjust to their illness. These evaluations of their illness(es) are the "soul" of their stories (Riessman, 2008 p. 85). Their evaluations developed through their personal understanding of their past life experiences and their current situation (Mattingly & Garro, 2000).

The changes that occurred led to positive growth, and then was expressed through stories of restored relationships, closeness to family, improved communication with others, learned patience, positive behavior changes (healthy diet, quit smoking, quit drinking), increased strength to accomplish things they would not have done prior to their illness, priority of helping others, stronger faith, and changed priorities. Through just a few of their exemplar stories, one can begin to see how the negative effects of their illness were turned into creating something positive from the negative.

"I grew stronger." The theme "I grew stronger" resonated within every participant's descriptive story of how they became stronger. These stories show the reader how these participants, even through the negative effects of their illness, became stronger psychologically, socially, or spiritually.

For one participant, she told how her illness "made her a stronger person" because she used to be a person "who was fearful of anything." She became "stronger in prayer" and began "to understand prayer just a little better" and learned to "get closer to God" as she "adjusted to many things in life." After asking her "if she felt her illness has made her a different person," she replied,

It made me a stronger person because there was a time, my mom is dead and gone, so she cannot tell you anything about me, I was fearful of anything like going to the doctor and so many other different things and then to have some type of surgery and having cancer where they going to cut your body here and all that, I couldn't have dreamed of that.

Mabel shared her story of how God healed and guided her and how this strengthened her faith. When asked whether "any of your beliefs about God or faith have changed because you have faced illness," she responded,

Yes, it has, it made it stronger, because a lot of things, what made it stronger, is knowing that God would do this, because it happened to me, you know before it happened to me, I couldn't even imagine, healing my foot, I couldn't imagine him healing my breast, I couldn't imagine him healing anything, you know because I didn't have that, I had not went through that experience, so once you, when you don't go through something, you don't just dwell on that, like if I get this way, will God do that, but when it happens, you go

through with a stronger faith then when God heals you, that is what you mind have to know what God goin' do, and when God do it, your mind have to know that God did it, not the doctor, not you, but God did it.

"Changed priorities." Priorities and goals of all 13 participants changed after their illness. One participant, a two-time breast cancer survivor, said her illness caused a change in her priorities.

Yes, you learn how to prioritize, I prioritize much better and certain things became much more important than other things, I was always active in church anyway and I was with a mission and I loved Sunday school so when Sunday school at 11:00 service and I did some volunteer work, so that all became much more important to me . . . it just made, your wants and your desires are different and your goals are different.

"Do things I never would have done." For nine of the 13 participants, stories were told that detailed the change as participating in activities they would have never done prior to their illness. One participant told a story of how after her stroke she did things she had never done before, reflecting a new positive change in her.

Before I had the stroke, I did not definitely get up I didn't like churches all full and going to get up and say something, I just could never do that, but now I can, I can stand up and tell everybody what God done for me.

"Quit doing." For seven of the 13 participants, their decreasing physical health or new diagnosis of illness stimulated positive behavioral changes. One participant stopped smoking after his pacemaker was placed. He said, "When he put that pacemaker in, I quit everything, I said I am not doing no more, this that or the other, you know, I am going to keep on the straight and narrow, and watch my back." Another participant, after her stroke, learned to slow down and quit doing as many things as she had prior to her stroke.

It (the stroke) was a tap on the shoulder, you know, you be still, and really and truly, I had, I was sick, running hospitality manager at my church, you know, I we, I did that and I taught Sunday school in the mornings with the kids and I was work with the youth ministry, I did all of this, it was too much, it was and my husband, why don't you let somebody else, and I said, no I didn't but that's when I know that God stepped in.

"Across past, present experiences, and future expectations." The last structural pattern—across past, present experiences, and future expectations—included the thematic categories of "God did and will take care of me," "close-knit" relationships, and life is "better." Every participant told stories that incorporated these three thematic categories.

“*God did*” . . . and . . . “*will take care of me.*” Cutting across past and present experiences and future expectations, stories of faith and reliance on “God” were the most prominent thematic category, present in all 13 narratives. Their “internal subjective sense of their private life story . . . organized their understanding of their past life, their current situation, and their imagined future” (Mattingly & Garro, 2000, p. 15). For the seriously ill AA elders, it was the belief that “God did” help them and “will help” them “overcome things” as a part of their “developing faith” in God.

The narratives about God were told from many different angles: participating in religious activities, such as church and/or relationships with others in their church; believing that God will take care of them; past prayers to God for themselves or others, or communication with God in the present about hopes for the future. All of these narratives demonstrated the importance of God in their lives. This thematic category was further broken down into the following subthemes: “God did,” “God will,” and “developing faith.”

“*God did* . . .” The stories about past prayers answered, where “God did” take care of them were described in many stories of past experiences. God’s provisions during their past, contributed to their “growing” faith in how “He/God will” take care of them in the present and the future. . . One participant, for instance, told a story unrelated to her illness of how God helped her quit smoking:

I asked Him [God] to take that away from me . . . so I got on my knees and take it away and it just went away and . . . you tell people how God helped you and they don’t believe you, I say there is only one person that can take this away from you, and that is God and no patch, no gum, no nothing can take that away from you, only one person can take the taste away from you and that is God.

Both during and after her stroke, another participant discussed how she felt God, coupled with her “hard work,” was responsible for her post-stroke recovery. Her stroke had left her with decreased physical function in her left upper and lower extremities, difficulty speaking, and difficulty swallowing. Presently, she has minimal functional deficits, uses no assistive devices, and no speech or swallowing difficulties.

First of all, I had God, that was head of my life, I know we, I was praying, I say lord please let my limbs, get my limbs, do my limbs, please let me able to speak like I always did and you know I did, before I decide to do anything, I would pray . . . you know, I was praying why they were running the tests . . . and God come back and he didn’t want to leave me like that, so he come back and I started to heal, my limbs, first my legs I started using my legs, and my arm, they just return, the last thing I had to work so hard on was my mouth,

. . . I know that it wasn’t the therapy, I knew it was God . . . and I just thank him so much, that was a tap on the shoulder.

“*God will* . . .” One participant, a heart failure patient, reflected on his reliance on God for his future. When his breathing worsened 3 years ago, he experienced “facing the end” of this life. It was during this experience, he asked God to “at least give me” 10 more years. He had been hospitalized after his breathing difficulties significantly worsened to the point of requiring oxygen and requiring a wheelchair. During that hospitalization, he was “told” by his physician that he was to be enrolled in hospice. He then left that hospital against medical advice and found another hospital and a new provider, who implanted a defibrillator. He stated,

Let’s get the best people we can find and fight it to the end, and you don’t have that support, you will give up, and once you give up, God will give up (chuckle). You wanna die, He going to let you die, if you wanna to live, He will help you live.

Because the new provider gave him the pacemaker option instead of “giving up,” he reported being virtually symptom-free today, requiring no oxygen and ambulating without assistive devices. “God did and will” help him are shown here.

I am a spiritual person, I asked God to at least give me my 75, you know, years, don’t take me away from here when I got people that I need to help, you know, I got grandchildren and stuff and he granted my wish, so here I am and, umm I am under his protection, He did it all, all of it.

All participants integrated reliance on God in their stories of illness, as he stated, “You don’t have to worry about me because God going to take care of me.” For some, their faith in God was strengthened through their illness experiences. Their abilities to cope with illness were founded in this faith in God’s taking care of them and then related in stories of how God did take care of them.

“*Developing faith.*” This “developing” faith in “God did” . . . “he will” is reflected in one participant’s “miracle” story. This particular participant was diagnosed with colon cancer 3 years ago, in 2010. Her cancer at that time had been removed surgically with no further treatments required. However, in September 2013, “they stated that the cancer [had] spreaded to [her] liver,” based on results from a CT scan. She further noted that the oncologist at that time wanted to treat her with chemotherapy and radiation, and her surgeon said, “It was too large for him to attempt to remove it.” She was leery of these types of treatments because she had recently

watched her daughter “in and out of the hospital for 6 months” while receiving both treatments for pancreatic cancer and then die. During this time, she had several appointments with the oncologist but never started these treatments; instead, a friend had brought her some nutritional supplements, which she started taking, and during a visit with her oncologist in “January or February” of 2014, she was told that her “blood tests [had] all normalized.”

I wanted to get up and shout and praising the Lord because I just felt it, it had been a change, I felt just like He (Lord) was saying, I got your back, you just go on, I got your back, if you believe in me, trust me, I got you . . . so then I, when I was looking at her so strange, I guess she, I couldn't believe the same lady that told me, the same doctor that told me in six months, I could be gone, and now was extending my time for visits, and she didn't see nothing wrong (on the blood work); so I think that is miracle to me.

As her illness and blood tests normalized, this participant's story describes how her faith “developed” by doing “a lot more leaning on Him.”

And that's another revelation that the Lord says, your spirit can carry you a long way and see I was always ready developing a strong spirit in believing . . . I been, I am a believer anyway but you know being human sometime I would believe, don't be as strong as it should, so I guess since then, I have really put my belief into action, so you know, and then I just feel that the Lord, he say, he will lead you and guide you if we trust and lean on him, so I think I been doing a lot more leaning on him.

“Close-knit” relationships. Narratives of the seriously ill AA elder's relationships were present in all 13 stories. The prominence of the relationship narratives wove in past, present, and future stories. At the first occurrence of the illness, the participants detailed all the support they received during the acute event of their illness. If the illness significantly affected their functional status (e.g., unable to grocery shop anymore) or caused physical changes (e.g., colostomy, breast removal), then detailed stories were told about how others helped them through these difficulties.

One participant described her communities as church, home (geographical location), and family. These supports have been part of her past, her present, and her expectations for her future.

We just enjoy one another, I do, I don't whether they enjoy me or not, but I do . . . I come into this community nineteen and sixty-five and I have been here ever since . . . yes, we can call on one another, right here in the community and it is so amazing . . . I can say with my family we are close knit.

After one participant's first stroke, a relationship between this participant and her sister was mended after 5- to 6-year period of estrangement. Since this first stroke, she has had a second stroke that left her with some residual speech difficulties. The restoration of their relationship can be seen through the story told by her and her sister. After her first stroke, the participant stated, “I guess I felt a little guilty and wanted to work through issues and stuff” with her sister. Despite the estrangement, the sister called and visited the hospital after her first stroke. This participant described how she felt from that time on, they “connected on some level” even though she “thought she [the sister] wouldn't come” to the hospital. Their relationship has been restored, and both the participant and her sister credit the participant's stroke for the restoration. She stated “it [the relationship] wouldn't have” improved without the stroke happening.

Life is “better.” Through reflections, strong beliefs that God's presence in their lives provided a place for them to “move forward” and “be all right,” all 13 participants have continued to live with positive outlooks despite facing their future “end” (death) without significant “fear, concern, worry” with the difficulties they face every day because of their illness. As they have learned from their experiences of illness or other life difficulties, this “life is better” outlook is told as a process that occurred and is presently occurring. There are things they have to “do every day” like take their medicines, watch their eating, depend on others to do their driving and shopping, yet they still have transitioned to a more positive outlook despite the changes caused by their illness.

For one participant, she knows things are “better” because “God will take care of her” and she is “happy” and does not “have anything to worry” about.

But it is *better*, I only thing I can say, uhh, now I am happy, I don't have anything to worry about it, I don't worry, I might worry about a bill every once in a while, . . . and so, it is a lot better, but I don't want to depend on nobody but God, I don't want my grandkids taking care of me, I don't want my daughter taking care of me, I want to do everything myself . . . so I tell them, you don't have to worry about me, because God going to take care of me.

After two ICU experiences of being in a “coma” for heart failure, one participant's story demonstrated her will to live despite the functional limitations caused by her illness. She can be “better than before” even when faced with the physical challenges.

Yeah, better than before, you have a better outlook on life, you think about other people's more than you think about me, to me, I think about other's more than I think about myself, cuz like I say there are some people's more iller than

you is, they can't even get around their house, they have to have somebody help them, you know . . . to do . . . everything, so that is the reason I say, don't have a bad outlook, cuz somebody iller than you is, cuz I can still bathe myself, cook for myself, feed myself and all that . . . [sit on the front porch] . . . yeah, move on forward, just can't just sit there and think about your illness, cuz if you do it going to get you down, you really, if you, can't give up, like a lot of people you know old our age, we just think we can't do nothing and we just give up on life and tell God to come on an take me on home (Laughter) I am not going to tell him that, he can take me home when he get ready, but I ain't ready to go, you know we got to go but no one is every really ready to go, like some of us is, but I ain't ready to go, I want him to leave me here as long as he can, uhh, 99.

The Omission of Healing and Suffering

Through the “narrative tool” of overreading (Poirier & Ayres, 1997), one of looking within and across the narratives and reading “between the lines” (Ayres, 2000, p. 362), the first author recognized the absence of “suffering” and/or “healing” in the stories told (Ayres, Kavanaugh, & Knafl, 2003). The terms *suffering* and *healing* were terms not used by the participants. Despite the fact that the concepts of healing and suffering are foundations to the framework in this study, the experiences were stories that did not include suffering/healing.

For these AA elders, serious illness was not portrayed as suffering, but one more of life's difficulties. Even more so, their serious illness was less difficult than some of their prior difficult experiences. Yet, only one of the 13 participants used the word *suffer* in relation to self in reference to physical suffering: “suffering with my lungs.” Five other participants used the word *suffer(ing)* in reference to how other's had suffered. These participants did not discuss “suffering” in relation to their own illness. Instead, if negative aspects of their illness were discussed (i.e., “went down little hills”), their stories quickly changed to optimistic language to show how they “had learned” or “how God” helped them deal with their illness. Therefore, when they used negative language such as “fear,” “worry,” or “scared,” they used these words to contrast how they had moved past the negative.

Six participants used a form of the word “healing.” When they did speak of healing, it was discussed only in relation to physical or spiritual healing. One participant used the word in relation to spiritual healing when referring to prayer for others: “Our reward is praying for others, because as we pray . . . others are to be strengthened and to be healed.” Five participants told stories of physical healing, based on how God provided this healing. For example, Elanda said after her stroke, “God come back,

and he didn't want to leave me like that, so he come back and I started to heal, my limbs, first my legs I started using my legs, and my arm, they just return.”

Discussion

Overall, the narratives from these seriously ill AA elders are stories of remarkable strength. Through detailing difficult life experiences, which occurred before the diagnosis of their illness, participants shared stories of a growing internal strength that started well before the onset of their serious illness. All of life's experiences helped them develop this strength, which now provides a point of reference for them within their current serious illness. Within these experiential stories, one begins to understand how participants frame their current illness experience, measure the level of difficulties they are currently experiencing, and construct a positive outlook for their present and future. Participants' reflections on their experiences before the onset of serious illness occurred for all 13 participants. Internal strengths from his or her past experiences are a part of who he or she has become.

Interestingly, the focus of many of their stories did not dwell on their current illness. All AA elders' stories discussed psychological, social, and spiritual domains in their review of their life experiences. Even though they told how their illnesses had negatively affected the whole—physical, psychological, social, and/or spiritual—the negative experiences of illness were turned to a new positive perspective on life. With the passage of time and while learning how to adapt, the participants reflected on how they “stay[ed] positive” throughout all of life's difficulties, not necessarily the development of PSS healing as a result of their serious illness.

The participants' outlooks that “life is better” were united with their adjustments to illness through their strong reliance on faith in God. For these seriously ill AA elders, spirituality was part of being connected to their strong faith in God. Their spiritual values/beliefs offered meaning and purpose in life which is consistent with previous research findings (Koenig, 2009; Nadarajah, Berger, & Thomas, 2013; Puchalski et al., 2009; Skeath et al., 2013; Young, Nadarajah, Skeath, & Berger, 2014). This faith helped restore balance or provided opportunities for growth in their faith in God's provision for their lives. This reliance on God had been influential in dealing with not only their current serious illnesses but also other life difficulties they had faced. Consistent with previous research findings, this reliance on God was an extremely important part of their lives (Agarwal, Hamilton, Crandell, & Moore, 2010; Black & Rubinstein, 2009; Hamilton, Powe, Pollard, Lee, & Felton, 2007; Hamilton, Stewart, Crandell, & Lynn, 2009; Holt, Oster, Clay, Urmie, & Fouad, 2011; Shellman, 2004; Taylor, Chatters, & Joe, 2011).

Moreover, participants' stories did not focus on suffering and healing. In some of the previous literature, suffering has been reported when there was uncertainty (Popoola, 2005) or increased physical comorbidities (Porter et al., 2006). For these participants, even in the face of uncertainty or decreased physical function, strength in their faith was always present. Consistent with Warren-Findlow and Issel's (2010) study with AA women with chronic heart disease, the elders in this study also managed all the consequences of their illness even in the face of physiological worsening of their illness. This was expressed best by Alice "You just got to go through, and it's got to be a made up mind, that I am going to accomplish whatever you set out to do." The AA elders did not use the term *healing* unless they were using the word in the context of physical healing, and they did not speak of suffering in relation to self, with the exception of George—and this was only physical suffering.

This is significant because both concepts, suffering and healing, are part of the study's theoretical framework. Rather, the foci of the stories were on spiritual growth coupled with their developing faith in God, requiring an adjustment to the theoretical framework guiding the study. With narrative analysis, the stories must speak for themselves. Based on the findings from these narratives, the terms *spiritual growth*, *improved psychological strength*, or *stronger faith* would be more appropriate terms for future studies instead of healing or suffering. Research has shown that serious illnesses provide opportunities for growth—PSS healing (Nadarajah et al., 2013).

Consistent with the literature on post-traumatic growth—"a learning through a struggle" (Bonnano, 2004, p. 2; Tedeschi & Calhoun, 1996)—PSS healing has been linked to post-traumatic growth (Koenig, 2009; Skeath et al., 2013; Tedeschi & Calhoun, 1996; Young et al., 2014). For the participants in this study, growth did occur throughout their life, but the growth occurred from many different avenues, and growth was not only in relation to their illness. The strong undercurrent of strength and resilience was ever present throughout their narratives, both in their past and present experiences and future expectations. Relying on a positive psychology focus, they reframed their adversity from one of hardship to one of appreciation (Seligman, 2009). For these elders in this study, similar to some of the literature, these participants' growth came from facing life's difficulties built through their reliance on religiosity and/or spirituality (Koenig, 2009).

From the physiological, psychological, social, and spiritual dimensions of the framework, the most dominant dimension, discussed by the narratives of these aging seriously ill AAs, was the spiritual. Their beliefs in God's presence have been and will always be with them.

Consistent with prior research within the culture of AAs, the domain of spirituality plays a large role in how they link meanings to their illness through spiritual beliefs/values (Agarwal et al., 2010; Hamilton et al., 2007; Holt et al., 2011; Taylor et al., 2011).

The participants' growth came from "going through" life difficulties, which in turn helped them develop "strength" from their reliance on their "faith in God," which helped them achieve the "life is better" outlook. "God did and he will take care of me" was the most prevalent theme throughout all 13 stories. This theme not only related to their illness but also to "other" life difficulties. These findings in an AA population, in and of themselves, were not surprising.

Previous literature has shown the spiritual dimension to be an important part of AAs' cultural values and beliefs (Agarwal et al., 2010; Hamilton et al., 2007; Holt et al., 2011; Taylor et al., 2011). Even though this knowledge is well documented, the incorporation of spirituality into the care for seriously ill AA elders is lacking (Evans & Ume, 2012; Otis-Green et al., 2012). For example, families of seriously ill AAs were more than two and a half times as likely to report at least one concern in receiving their desired level of spiritual or emotional support at end of life (Welch et al., 2005). Thus, there is great need for improvement toward providing culturally competent palliative and end-of-life care, which should include spiritual care in this case. Through an evolving culturally based conceptual framework, the approach to PC would integrate the preferences of patient's cultural beliefs and values (Andrews & Boyle, 2008; Leininger & McFarland, 2002; NCPQPC, 2013; Purnell & Paulanka, 2008).

Conclusion

Although there are a variety of conceptual variations within narrative inquiry approaches, the assumption is that via storytelling, the voices of those living with serious illness can be heard from the unique perspectives of the individual themselves, in this case, the seriously ill AA elder (Riessman, 1993, 2008). Knowledge of the following themes provides an understanding from the perspectives and experiences of seriously ill AA elders: "been through it . . . made me strong"; "I thought . . . about others"; "went down little hills . . . got me down"; "I grew stronger"; changed "priorities"; "do things I never would have done"; "quit doing"; "God did and will take care"; "developing faith"; "close-knit" relationships; and "life is better."

Stories of past experiences were not necessarily about the elders' illnesses but instead often suggested associations with how strength and resilience were gained. Stories of belief, faith, and reliance on "God" appeared in every narrative. It was the "faith" in God that helped them

“overcome things,” whether the thing to overcome was their current illness or other life difficulties. The most prevalent story of “God did and will take care of” created the outlook that “life was better,” despite the circumstances as they “leaned on Him [God].”

Through a storytelling process, a narrative “knowing” between narrator (patient) and receiver (provider) can be accomplished (Polkinghorne, 1998, pg. 111). In this way, prior past experiences, present and future expectations of seriously ill patients can be known. This narrative knowing process forms an increased understanding of the patient’s perspectives allowing for the opportunity to provide patient-centered PC. Through narrative knowing, practitioners provide and can tailor culturally sensitive care through assessing the already present intrinsic strengths of the elder as heard by their stories. The care provided must be built using the strengths of the elder from both where they have found “strength” and how they see their “life as better.” By framing both future research efforts and clinical practices through a narrative knowing framework, new knowledge can provide the ability to provide culturally sensitive patient-centered PC for AA elders with serious illness.

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