Published in final edited form as:
Geriatr Nurs. 2020 ; 41(4): 468–473. doi:10.1016/j.gerinurse.2019.08.001.

Adapting to chronic pain: A focused ethnography of black older adults

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Abstract

This study aimed to understand the coping strategies used by a group of Black older adults to manage chronic pain. To this end, a focused ethnography was completed within a senior housing facility. Following participant observation, 106 residents completed informal interviews and surveys comprised of a demographic tool, the Brief Pain Inventory, the PROMIS Global Health scale, and the Psychological Stress Measure – 9. Further, a subset of 20 participants that reported daily pain completed formal semi-structured interviews, which were recorded and transcribed. Descriptive statistics were completed on survey data while interviews were analyzed contextually and thematically. The adaptive coping strategies used by participants to manage pain included: remaining positive, remaining active, being engaged in the community, prayer/meditation, and maintaining positive support systems. Effective coping strategies lead to compensated levels of adaptation for participants. A middle range schema of pain is presented that may guide future nursing pain management practice.

Keywords

Minority health; Health status disparities; Pain management; Health behavior

Introduction

More than half of Black older adults are estimated to be living with daily pain that causes various levels of disability and diminished quality of life.[1,2] Although pain is not a normal anticipated aging change, the increased prevalence of advanced chronic disease among older adult populations often leads to secondary physical discomfort and reduced mobility. In fact, poorly managed pain is a leading cause of disability worldwide.[3–5] Black older adults in particular are likely to experience worse health and functional outcomes than comparative White populations placing them at significantly higher risk for future pain-related disability.[6,7] Pain and its related incapacitation has long been recognized as a health-related source of stress requiring significant adaptations to maintain optimal levels of functioning.[8] Therefore, effective pain management practices must sufficiently address both physical pain management and cognitive pain adaptation, or how individuals can live and

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maintain a quality of life despite persistent pain. To this end, studying the pain management experiences, and related behaviors, of affected populations, from their own perspectives and within their own environment, can provide important information about how specific pain management behaviors result in particular health and quality of life outcomes. The following ethnographic study examined the daily pain management experiences of a group of community dwelling Black older adults.

Background

For many Black older adults, the overall management of pain has been consistently poor. It is estimated that half of the nearly 5.9 million Black adults over the age of 60 who are currently living in the United States experience persistent daily pain that has lasted more than a year.[9,10] Advanced chronic diseases such as osteoarthritis, diabetes, and congestive heart failure, which are prevalent within the Black community, are likely contributors to this pain burden.[11] When combined with obesity, another widespread risk factor for pain among Black adults, the likelihood that Black adults will experience pain that diminishes quality of life significantly increases.[12] Although Black older adults have been noted to report higher levels of pain, suffering, and depressive symptoms compared to other US populations, they also report greater difficulty expressing pain concerns in ways that are believed by providers, perhaps evidencing some institutionalized racial bias.[13–15] Further, if Black older adults receive pharmacological pain treatment interventions, the prescribed dosages are often lower than the recommended levels for their pain resulting in additional unmet pain needs.[14,16,17] Despite these numerous challenges, and the likelihood that the stress of ineffective pain management diminishes quality of life, Black older adults continue to be observed as functional and actively engaged members of their communities who serve in a variety of roles–particularly as caregivers for both spouses and grandchildren.[14,16,18] By understanding the specific health-related behaviors used by Black older adults to cope with daily pain, nurses can develop and encourage specific actions that not only improve pain management practice, but also optimize health.

The purpose of this study was to examine the specific strategies used by a population of low-income, community dwelling, Black older adults to manage chronic pain. More specifically, we questioned, how do Black older adults cope with pain, and particularly, what are the relationships between pain management and health related quality of life? It was proposed that through the exploration of pain management experiences, effective coping strategies could be identified that would facilitate the development of care practices likely to improve both care outcomes and health related quality of life for Black older adults with persistent pain.

Theoretical framework

The Roy Adaptation Model (RAM)[19] was used as a framework for study development–particularly conceptualizing the phenomena of coping, and determining the most appropriate method of inquiry. Roy's model expands the widely accepted concept of coping introduced by Lazarus and Folkman[20] as using cognitive and behavioral efforts to manage taxing demands on the internal and external resources of a person, to include human and environmental integration, or adaptation, as an outcome of effective coping. The Roy model proposes that humans are holistic adaptive systems that are in persistent interaction with their environments. Particular stimuli, such as pain, will illicit responses that the system must respond, and subsequently adapt to, in order to maintain optimal functionality. Ethnography provides an effective means of understanding how humans interact with their environments and cope pain.

Design and methods

Study design and participants

Ethnography is a research technique rooted in anthropology and used by nurses in a focused manner to study the specific health practices of various populations.[21] It evaluates the purposeful acts of people in different situations to gain an understanding of meaning and pattern in life within the context of culture and from an in-group perspective.[22] Observational data on behaviors and artifacts–things made and used–are recorded and described in a field note journal along with the researchers ideas and thoughts about the data. In addition, interviews are used to clarify observed behaviors and gather more detailed information about health practices. Participants may also complete questionnaires to provide additional descriptive information. This collection of data from multiple sources creates redundancy and triangulation, or the cross checking of data between sources. Further, the use of a field note journal to record observational data and separate it from the researchers thoughts and ideas helps to establish the truth-value and consistency that leads to research trustworthiness.[23] Analysis takes place concurrently and repeatedly throughout data collection until patterns become apparent.

A focused ethnographic research design, as described by Robinson,[21] was completed over 10 months in a predominately Black, urban, public-housing facility where more than 400 persons aged 55 and older reside in one or two bed-room apartments. Inclusion criteria for participation in surveys and interviews was as follows: (1) current resident of the senior housing complex, (2) age 55 and older, (3) able to speak and understand English, and (4) self-identified as Black/African–American. Evidence of cognitive impairment was an exclusion criterion. Cognitive screening was conducted prior to survey completion by a nurse using the Animal Naming Test.[24] The Animal Naming test evaluates semantic verbal fluency–a component of long term memory that allows the recall of knowledge of objects, facts, words and their meaning. A score of less than 14 evidences cognitive impairment.

Ethical considerations

The study protocol was approved by the Wayne State University Institutional Review Board. Both residents and staff were notified about the study prior to its initiation at scheduled informational meetings and through flyer postings throughout the residence in common areas. In addition, flyers were distributed during meetings and social events at the facility, and information was posted within the resident newsletter. Following appropriate notifications, population observations were initiated in common areas both inside and outside of the facility. During the observational periods, the researcher wore identification in plain site and completed debriefing with anyone in the area prior to recording observations in the field note journal. Debriefing occurred again whenever someone new entered the area. In addition, all individuals were provided an opportunity to opt out of having behaviors captured. After periods of observation, the researcher clarified observed behaviors with informal interviews–the notes of which were also documented within the field note journal. Following an initial observation period of two weeks, residents were invited to complete survey and prescreening questionnaires. Written informed consent was obtained prior to survey completion and included consent to participate in formal recorded interviews if invited by the researcher. Participants were invited to complete a formal recorded interview if they had moderate to severe daily pain as evidenced by survey responses, and were determined to be a “good reporter,” or someone willing and able to provide in-depth information about their daily pain management experiences. Participants were compensated $10 for completing surveys and $20 for completing formal recorded interviews. In total, 106 residents completed surveys and a subset of 20, completed formal recorded interviews (see Table 1 Interview Prompts). SPSS Statistics Version 22 (IBM, Armonk, NY) and NVIVO 10 (QSR International, Melbourne, Australia) were used to organize and thematically analyze data following the process described by Robinson.[21] Results were confirmed through subsequent participant interviews. Two individuals declined to have observations recorded, two were excluded based on evidenced cognitive impairment, and one was excluded related to age under 55. Further, four individuals opted out of completing surveys after initial screening was completed.

Measures

Surveys were completed by residents ($n = 106$) to provide descriptive information about the population, their average pain and stress levels, and self-rated health. Survey measures included a demographic questionnaire, the Patient Reported Outcomes Measurement Information System (PROMIS®) Global Health scale-short form v1.2,[25] the Brief Pain Inventory-short form (BPI),[26] and the Psychological Stress Measure-9.[27] Demographic information collected included gender, age, marital/cohabitation status, religious affiliation, and presence of chronic disease. The PROMIS Global Health-short form is a validated 10-item questionnaire that assesses self-reported physical and mental health.[28] The Brief Pain Inventory-short form is a 9-item tool that has been validated to measure pain intensity and pain interference in seven key areas of quality of life.[26] Finally, Psychological Stress Measure (PSM-9) is an additional validated 9-item tool designed to measure psychological stress caused by events and circumstances that increase the psychological and/or physical demands of the person.[27]

Results

All study participants, $n = 106$, identified as Black or African American and the majority (62.3%) were female. Although ages ranged from 55 to over 85, the most common age range was between 60 and 64. Common health conditions included hypertension (68.9%), osteoarthritis (58.5%), diabetes (36.8%) and depression (25.5%). Approximately 86 percent of the sample reported severe pain. Pain treatment practices used by participants included use of assistive devices, exercise, and both pharmacological and non-pharmacological treatments. Further details of pain treatment practices are discussed elsewhere by Robinson-

Lane and Vallerand (2018). The PROMIS Global Health short form (PROMIS) asked participants to rate their overall health, quality of life, mood, physical health, and social relationships using mostly five-point scales that range from excellent (5) to poor (1), or completely (5) to not at all (1). Participants with pain ($n = 91$) had average global physical health (GPH) scores of 36, which in comparison to an estimated average US population score of 50, indicates that these participants rated the quality of their physical health as being 28% lower than the population average. In contrast, participants that did not have daily pain ($n = 15$), had an average GPH of 52, or about 4%, higher than estimated population averages. Interestingly, the Global Mental Health (GMH) scores were generally much higher for the entire cohort.

Participants experiencing pain had an average GMH score of 44. Again, in comparison to estimated population average scores of 50, these participants rated their health related quality of life as only about half of a standard deviation lower than population averages (about 12% less). Patients without pain reported their quality of life to be about two percent above population averages (GMH = 51). In addition to providing information regarding how they self-rated various dimensions of quality of life, participants rated their stress over the past few days.

The Psychological Stress Measure short form, the PSM-9, measured psychological stress on an 8-point Likert scale. Participants ranked 9 stress variables over the past 4–5 days from 1 (not all), to 8 (extremely). Examples of items included: “I feel rushed; I do not have enough time,” “I feel preoccupied, tormented, or worried,” and “I feel a great weight on my shoulders.” The questionnaire items were developed from descriptors of stress gleaned from focus groups (Lemyre and Lalande-Markon, 2009). Scores could range from nine to 72 with higher scores indicating higher levels of stress. The 15 participants with no pain reported an average PSM-9 score of 19 with the most common score being 20. Participants that did have pain, and completed the form ($n = 86$), reported nearly twice as much stress, with an average score of 36 and the most commonly reported score of 48. Participant observations and interviews provided further insight into the specific means by which elders with pain used positive coping strategies to maintain and optimize their mental health despite physical health challenges. These coping strategies included things such as maintaining a positive mindset, relying on faith to provide motivation and hope, staying active, being engaged in the community, praying/meditating, and maintaining positive support systems.

Maintain a positive mindset

One of the most robust themes that emerged from the study was the need of persons with pain to maintain a positive frame of mind despite adversity. In fact, remaining positive as a means of dealing with life’s various stressors, including pain, was referenced by participants on 19 different occasions. One interviewed participant, for example, lived with severe chronic pain in his knees for over eight years. The pain diminished his ability to walk, stand, and easily navigate several stairs. His decreased mobility also significantly limited his ability to earn a living in his self-described profession as a “handyman.” This was further compromised a week after he moved into the older adult residence when his car was stolen. His response to the overall situation echoed many of the other resident’s responses who found themselves also unable to function at the capacity they had before due to pain. He said, “No point in crying about it, because nothing I can do about it anyway.” He went on to say, “I just quit worrying about anything, I just say the hell with all of it… No, I just decided whatever it is, it isn’t worth it. If I can take care of it I will, if I can’t then I won’t, but I’m not going to worry about it.” When asked about how he got to this space, where he did not allow worry to consume him, he responded, “Nothing monumental occurred. It’s just that I woke up one morning and I decided I’m not worrying about anything more, or I’m not going to let anything worry me.” (Participant 1).

This participant, like many others, had come to an understanding that there are some things in life that you just could not control, but what you could control was how you responded to the challenges life brought you (field notes). Participants believed that pain was an uncontrollable circumstance that required adequate self-management in order to live. As another participant who lived with daily pain from rheumatoid arthritis stated, “I wanna live as long as I can, and I have to help myself…I have to make it happen” (Participant 2). Although a rheumatologist was seeing this woman, she was not satisfied with her treatment plan, which included receiving injectable steroids. Instead, she remained focused on daily exercise, predominately walking, as a means to reduce pain, build strength, and maintain mobility (field notes). In fact, many participants found exercise to be an effective means of coping with pain.

Keep moving

The second theme identified in the study was the critical role of continued movement in pain management practice. Participants were determined not to allow pain to stop them–it only slowed them down. Nearly every mobile senior with pain (13 sources) said, “Keep moving.”

One woman for example had moderate to severe daily pain that she described as being all over her body (Participant 2, field notes). At times, her pain was so severe that she remained confined to bed (field notes). Besides continuing work a part-time job, the woman participated in a facility-based walking group as much as she could and engaged in religious service activities that required frequent walking (Participant 2, field notes). To remain as active as she was, she often had to make accommodations for herself. For example, when walking, she had to take frequent breaks, so she often chose to walk alone rather than with groups during scheduled walking activities. Interestingly, when asked in a formal interview how pain changed things for her, the woman responded, “It hasn’t slowed me down, for one…I refuse to slow down. I just got that attitude, ‘If you don’t use it, you’re gonna lose it.’ So I just like to keep busy” (Participant 2).

Several residents reiterated the idea that decreased mobility due to pain had to be resisted and countered with continued activity. As another person stated, “pain don’t stop … the pain come, I just keep going on” (Participant 3). Another added, “I keep right on going. One time I had gout … worst than I had now, where I limped…I limped it by. I limped right on, and kept right on going… As long as I can move, I’m gonna keep right on moving” (Participant 4). Residents were determined to remain active and thereby remain independent. Social engagement often facilitated their continued physical activity.

Be engaged

Being engaged in the community was an important, and often natural task, of many of the residents (8 sources, field notes) – most of whom lived alone (83%). When asked why residents were regularly observed in groups within common areas, one participant noted that being connected “filled a void” by giving people something to do. He went on, “Let’s face it, none of us are young anymore, so we all need something to do, to occupy ourselves. (Participant 1, field notes). Another participant agreed, noting that the many activities with others were a welcome distraction. She stated, [When] you get involved in something, you kind of get your mind off of your own problems. Keeps your mind, keep your pains, any hurts, kind of, out of your mind. Keep you from thinking. When you’re involved into something you kind of just lose your mind into it, and you don’t feel [the pain] that well, that much. (Participant 5, field notes).

Older adults were engaged in a variety of ways including assisting with daily lunch preparation, being a part of the building governance board, and participating in church services or related ministries that demonstrated faith through action (Participants 3, 5, 6; field notes). The residents volunteered at elementary schools, gave rides, helped with groceries, and even handed out handmade jewelry just to initiate conversation (field notes). Engagement was a means of staying connected to their community and recognizing their own value within the community. This demonstration of agape, or selfless love to others, is the basis of spirituality and connected to the more specific use of religious coping within the group.

Stay prayed up

Faith played a major role in the lived experience of the Black American older adults participating in this study. About 74 percent of the sample identified as Christian. On any given weekday afternoon, one would hear the familiar melodies of gospel music belted out by a makeshift choir (field notes). Many of the participants of the study began their day with prayer and quiet meditation that often included the reading of religious texts, such as the bible and Our Daily Bread, an annually distributed book that provides daily biblically based reflections (field notes). “You have to stay prayed up” was common phrase used by participants that referenced the need to be engaged in regular prayer to manage daily stressors (field notes). Faith encouraged participants to express gratitude and empowered them to deal with pain as optimally as possible. They felt blessed to be alive and understood that life in general would not be easy (field notes). As one participant said, “My faith played an important part in the healing I believe. Not that I believe, I KNOW my faith carried me through…I know that there is strength in faith” (Participant 12).

Another common saying, “God is good,” was used frequently by the older adults in the study and is derived from church. In church, the minster will tell the congregation, “God is good,” and the congregation responds, “All the time.” He will then say, “And all the time…” “God is good” is the final response. This call and response is used to reinforce to membership that no matter what was happening in life, whether there were good times or bad times, joys or sorrows, God is ever present and bestowing blessings upon his followers. Unsurprisingly, when the adults at the facility would talk about difficulties they were experiencing, they would often end by saying, “But God is good” (field notes). For example, when one participant confided that her husband died two-years ago, she followed that by saying, “But God is good” (Participant 5). When another woman spoke about the difficulties she faced in recovering from a stroke that left her immobile, she noted that her mindset allowed her to deal with the tough things that came her way–that and Gods help (Participant 7). Faith was an imbedded part of the culture for most of the participants. Deep faith seemed to help to mediate stress and motivate elders to keep going. Continuing forward often meant learning to live with pain, which often required the love and support of family and friends.

Keep good people near

Family and friends were most often the individuals the participants of this study noted they spoke with about their pain (17 sources). Interestingly, participant interviews, both formal and informal, revealed that talking about pain was not something participants actually engaged in very often. The participants did not want to consume others with their problems. As one man mentioned, “They [my family] don’t need me on their mind…They know what I’ve been through and it ain’t solved–so they know I just rough it out…. I mean what can they do” (Participant 8). Participants also believed that was better to keep complaints about pain to themselves (field notes). However, any conversations about pain that did occur happened within the context of discussing medications or treatments that had been used successfully by others to reduce pain (field notes).

Most participants found great joy in relationships with family and friends (17 sources). These informal support networks of relatives and close associates provided listening ears, encouragement, opportunities for socialization, direct physical support as needed, and meaningful distraction from pain (15 sources, field notes). For example, Participant 1 noted that after a hospitalization for appendicitis and an embolism, he was in a weakened state that required the use of a wheelchair. His wife, whom he referenced as the person that motivated him, threw the wheelchair out and said he needed to get up. He did, and credits predominately his wife for his speedy recovery. Participant 9 spoke about her mother and her son being great supports to her as she struggled with the challenges of pain and limitations to her mobility. Participant 10 felt that her grandkids were her motivation to keep going. She loved to spend time with them so she would get up, take her medicine, and “get herself together” to do just that (Participant 10). Others found motivation in the stick-to-itiveness demonstrated by senior family members who had to deal with significant changes in health and mobility (Participants 11, 12; field notes).

For participants, without close family, they relied upon friends. The facility provided residents with a variety of opportunities to make new connections and friendships (Participants 5,6, and 12, field notes). Acquaintances in the building would motivate one another to exercise, shared information, provided recommendations on health practices, and simply were available to listen as needed (field notes).

Discussion

Humans learn to reduce negative health outcomes with specific cognitive and behavioral efforts, or in other words, they learn to cope. The participants of this study used a variety of mechanisms to cope with unmet paid needs. According to the Roy Adaptation Model (Roy, 2009), chronic pain is a type of focal stimulus, or one that is in the most immediate awareness of the individual, that disrupts the integrated state of the human adaptive system. Other stimuli that contributed to the overall pain experience for participants, or contextual stimuli, included diminished functional status and multiple chronic diseases. An underlying stressor that participants did not appear to be aware of that effected their overall situation, or residual stimuli, was a fear of dependence. This fear of being reliant upon others in order to function seemed to be a primary motivator for the elders in continuing to be physically active. These combined stimuli can lead to a compromised level of adaptation, if effective coping does not take place.

The specific, acquired/learned, coping strategies employed by the participants may be categorized into four different adaptive modes as described by Roy (2009): physiologic, self-concept, role function, and interdependence. Within the physiologic domain, behaviors were employed to meet specific physical needs of the human body and included the use of assistive devices, exercise, analgesics, and non-pharmacological treatment interventions (field notes). The use of prayer, meditation, and stick-to-itiveness may be classified as strategies related to the self-concept mode, which encompasses the spiritual and psychic integration of the human system. The high level of community engagement by participants falls neatly into the role function mode, which describes the expectations of individuals within society and the need to achieve social integration. Finally, the interdependence mode, which is comprised of behaviors related to the giving of love, respect, and value, includes participant engagement with family and friends as part of their informal support networks.

These combined coping strategies in totality allowed the participants to reach individual states of adaptation at the compensatory level whereby cognitive and emotive channels, or what Roy refers to as cognator subsystems, were actively engaged. The outcomes of these effective coping strategies included: decreased psychological distress (lower global mental health scores and only mild to moderate stress levels), spiritual well-being (continued engagement in religious activities), and ability and satisfaction in caring for others (continued engagement in caregiving activities) (see Fig. 1). The observed outcomes mirror those described by Roy[29] in her Middle Range Theory of Coping.

The primary objective of this work was to understand the experiences of a group of Black American older adults managing pain. It was anticipated that the findings from this study might provide insights for nurses on how to improve pain management practice. A Middle Range Schema of Coping with Pain is presented that may be used a guide for future nursing practice. Interestingly, nurses were not mentioned by any of the participants as primary interventionists, or persons they sought assistance from directly, in pain management. During discussions about pain management, or even health care in general, participants usually referenced the physician. The lack of recognition of the role of nurses in pain management practice points to the need for nurses to be both visible in care, and more vocal regarding their role in care. For example, nurses should clearly introduce themselves as nurses, and describe not only how they are going to provide care for individuals, but also, detail what the patient can expect from them. Additionally, increasing the use of follow-up telephone calls may be an effective means of allowing nurses and patients to communicate more readily about important issues such as medication usage, recommendations for effective non-pharmacological treatments. It is possible that phone calls by nurses may reduce the need for some in-office follow-up visits; which some participants found to be costly and unnecessary (field notes). Further, the lack of acknowledgement of the role of nurses in pain management also illuminates a practice gap that may be best addressed by community/public health nursing practice.

Community health nurses oftentimes have increased access to the home environment of patients, which allow for thorough assessments, culturally responsive interventional strategies, and realistic conversations regarding pain needs and pain management practices. It is also likely that increasing follow-up nursing visits with patients reporting chronic pain would result in overall decreased pain, improved medication use, decreased overall disability, and a reduction in related health care costs.

Conclusion

Learning to live with daily pain that reduces function is a reality for many Black older adults. The participants of this study found that through prayer and meditation, continued social engagement, reliance on support systems, and continued activity despite discomfort, they could maintain their independence and maintain a measure of quality of life. Many opportunities exist for improvement in the clinical management of pain among Black older adults. Nurses are well suited to take the lead in addressing pain management concerns across all domains of care for older adults with pain. Although chronic pain can be quite difficult to manage effectively, the personal experiences of managing pain shared by the participants of this study may be used to consider how to integrate more culturally responsive pain treatment interventions into practice.

Acknowledgment

The author is grateful for the direction and assistance of Drs. April Vallerand, Feleta Wilson and Karen Tonso in completing this work.

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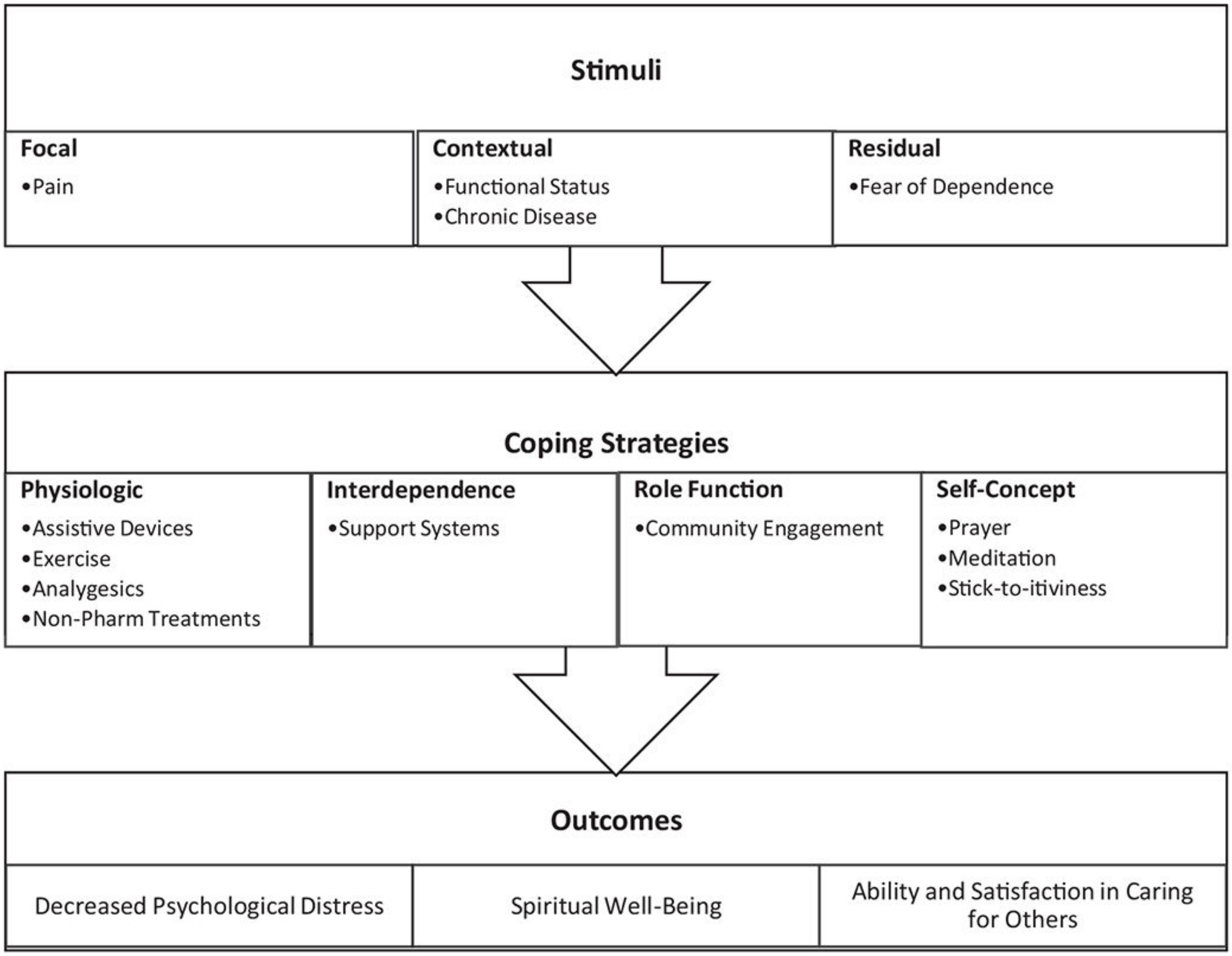

Fig. 1.

Schema of a middle range theory of coping with pain.

Table 1

Interview Prompts

Key event
Do you find that you are able to get out much?
Prompts:
• Can you tell me about all of the places that you are able to get out to?
• Are there any others?
• What activities do you usually participate in?
• Are there any others?
Segue 1:
So, when I was observing residents, I noticed that many folks tended not to move so fast or really not at all in some instances. Can you tell me why you think that might be?
Segue 2:
Can you tell me about your pain?
Interviewer directives: For each of the types of pain ask “How do you manage that?”
Prompts:
• Does anything else hurt?
• Of the types of pain you have described, which ones would you say bothers you the most.
Segue 3:
I’m curious about all of the ways that you feel like pain effects your health. Can you tell me about that?
Prompts:
• Are there other ways you think it effects your health?
• What are the most bothersome ways that pain effects your health?
• How do you manage each of those ways?
Interview directives: For each type of health effect ask “How do manage that?”
Segue 4
I’m wondering who you talk to about your pain?
Prompts:
• Are there others you talk with?
• What is something you might say when you are talking about your pain?
Interview directive: If a doctor or nurse is mentioned as a person that is spoken to regarding pain, ask “What do you tell your doctor or nurse about your pain.”