Psychosocial Distress: A Case Study of a Male African American Veteran with End-Stage Colon Cancer

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**Recommended APA Citation**
[https://doi.org/10.46743/2160-3715/2015.2228](https://doi.org/10.46743/2160-3715/2015.2228)

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Abstract
This in-depth single-case-study explored the emergent trauma of psychosocial distress of an older male African-American veteran after being diagnosed with end-stage colon cancer. Using a qualitative case study methodology, three in-depth interviews were conducted which identified the following five themes: (1) the emotional impact of being diagnosed with cancer, (2) experiencing inescapable loss of control and independence, (3) adjusting to nursing home placement, (4) lacking social support, and (5) navigating complicated services. The findings expand our understanding of the need for identifying and managing psychosocial distress. Implications for behavioral health practitioners are discussed.

Keywords
Psychosocial Distress, Older Adult, African-American, Advanced Cancer, Qualitative, Case Study

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Psychosocial Distress: A Case Study of a Male African American Veteran with End-Stage Colon Cancer

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This in-depth single-case-study explored the emergent trauma of psychosocial distress of an older male African-American veteran after being diagnosed with end-stage colon cancer. Using a qualitative case study methodology, three in-depth interviews were conducted which identified the following five themes: (1) the emotional impact of being diagnosed with cancer, (2) experiencing inescapable loss of control and independence, (3) adjusting to nursing home placement, (4) lacking social support, and (5) navigating complicated services. The findings expand our understanding of the need for identifying and managing psychosocial distress. Implications for behavioral health practitioners are discussed. Keywords: Psychosocial Distress, Older Adult, African-American, Advanced Cancer, Qualitative, Case Study.

The prevalence of psychosocial distress among cancer patients is a significant problem. At least 30% to 45% of all cancer patients experience some form of distress, with much higher rates (70%) of distress found in patients with late-stage illness (Iconomou, Mega, Koutras, Iconomou, & Kalofonos, 2004; Loscalzo & Clark, 2007; Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001). Emotional distress is likely to occur among patients with a poor cancer prognosis, which indicates a need for addressing the psychological impact of having a terminal illness (Mystakidou et al., 2012); and, when end-stage cancer is diagnosed unexpectedly, the impact of illness can suddenly change a person’s life and trigger past experiences with trauma. This issue is more complex for older Vietnam veterans who have previously experienced trauma and loss, having to adjust to everyday circumstances after military service earlier in their life. Some research suggests that prior experience with death and loss earlier in life can influence a re-experiencing of trauma and can alter attitudes toward death and dying (Song, Ratner, Bartels, Alderton, Hudson, & Ahluwalia, 2007). Additionally, being diagnosed with end-stage cancer can exacerbate past psychological distress that was perceived as under control (Frazier & Caston, 2014).

An important area of psychosocial cancer care focuses on poor health outcomes for disadvantaged populations. Due to health disparities such as low socioeconomic status and lack of preventive medical care, African Americans experience late-stage cancer diagnosis and high rates of death (DeSantis, Naishadham, & Jemal, 2013; Ward et al., 2004). In addition, daily stressful life-events as well as chronic stress that extends over time tend to have a substantial impact on health, especially among African Americans (Davis, Myers, Nyamathi, Brecht, Lewis, & Hamilton, 2014; Geronimus, Hicken, Keene, & Bound, 2006). As African Americans age, they also experience various psychosocial issues, along with chronic health problems, that impact life transitions and cause distress. For example, they can encounter food and housing insecurity, lack appropriate resources, and have difficulty accessing social services, complicating these problems and contributing to negative outcomes.
In addition to the complex circumstances that older African Americans face, many who served in the United States military are aging and need additional medical care. Consequences of military service intensifies life circumstances placing older veterans at higher risks for depression, post-traumatic stress disorder, and experience other problems such as divorce and social isolation, which is especially possible for veterans who were exposed to combat, adding to chronic stress (MacLean, & Elder, 2007). Even though aging veterans may be entitled to health care benefits from the Department of Veterans Affairs, many do not use these services (Nelson, Starkebaum, & Reiber, 2007) leaving older African American veterans particularly vulnerable.

For older veterans, other factors influence distress, for example, having comorbid medical conditions like hypertension and diabetes along with advanced cancer as well as geriatric symptoms consisting of fatigue, falls, and weight loss, all of which contribute to the complexity of care. Economic issues and financial pressures like inadequate health insurance and the lack of an income to pay for services further complicates the psychological well-being of seriously-ill, older adults, especially among older minority patients (LaVeist, Nickerson, & Bowie, 2000). Patients from racial and ethnic minority populations often experience greater incidence rates of cancer, more severe cancer burden, and worse health outcomes than their nonminority counterparts. In particular, according to a 2013-2014 American Cancer Society report, African American men have higher incidences and death rates for all cancers (American Cancer Society, 2014). Furthermore, homeless and precariously housed ethnic minorities, many who are older military veterans, are extremely underserved for cancer care and suffer worse health outcomes than securely domiciled populations (Asgary, Garland, Jakubowski, & Sckell, 2014; van den Berk-Clark & McGuire, 2013).

Various psychosocial issues arise that influence everyday life and contribute to distress. Although a cancer diagnosis alone can incite emotional distress like anxiety, fear, frustration, and sometimes depression, there are other day-to-day concerns that can also overwhelm cancer patients (Institute of Medicine, 2007). For example, maintaining independence over daily matters like grooming, housekeeping, grocery shopping, and cooking which can become increasingly difficult when an individual encounters a medical problem that is serious enough to generate thoughts about dying. As the individual begins treatment, family life, work life, and social responsibilities must be adjusted to accommodate a medical regimen. The ramifications of advanced illness and treatment increase patients’ suffering in physical functioning and can cause difficulty with family engagement and interactions with friends, as well as in the community (Krikorian, Limonero, & Mate, 2011). Economic stress can also arise during this time (Ell, Xie, Wells, Nedjat- Haiem, Lee, & Vourlekis, 2008; Yabroff, Lund, Kepka, & Mariotto, 2011). The physical impact is, at times, the most difficult problem to deal with because the side-effects of treatment create changes in the body and induce intense physical pain (Adler & Page, 2008). More importantly, for older cancer patients, especially those with multiple comorbidities and poor symptom management, the impact of cancer treatment can trigger serious declines in functional status that lead to dependence on others (Hurria et al., 2009; Van Cleave, Egleston, & McCorkle, 2011).

Psychosocial distress in end of life (EOL) cancer care is recognized as an unpleasant or negative emotional experience involving physical, psychological, social, and/or spiritual issues, leading to impaired physical and emotional functioning and limitations in patients’ ability to cope with the course of illness (National Comprehensive Cancer Network, 2010). Distress extends along a continuum that progresses from moderate feelings of concern, worry, and sadness to severe despair that impedes physical and emotional functioning.
Distress is related to individuals' unmet needs vis-a-vis the dying process and is associated with pain and symptom management, psychological and emotional support, and patient-provider communication (Morasso et al., 1999). When patients experience moderate to severe distress, national guidelines strongly recommend and require accredited cancer programs to identify psychological, behavioral, and social concerns that may interfere with patients' ability to successfully cope with and fully participate in healthcare decision making (American College of Surgeons Commission on Cancer, 2011). However, not all cancer treatment facilities evaluate psychosocial distress before a patient exhibits extreme distressing symptoms (Keating et al., 2010).

Sociodemographic and economic factors contribute to the gaps in psychosocial distress management for cancer patients, making patients vulnerable and susceptible to undesired health outcomes since these patients may not receive the needed services. For example, African-American patients experience barriers to effective patient-provider communication, leading to misinformation about treatment options and under-treatment of pain (Green et al., 2003). While racial and ethnic disparities impact service gaps, other factors also affect the management of psychosocial distress. Misperceptions and negative views about older, seriously ill patients produce problems for older adults as they interact with the healthcare system and limit the services they receive (Williams, 2007). Older patients are at risk for experiencing discrimination and missed diagnoses of distress due to providers’ ageist perceptions about expected psychosocial problems for this population (Waxman & Carner, 1984). In addition to ethnic/racial disparities and age discrimination, being a veteran exposes patients to treatment barriers that interfere with effective care. In fact, older veterans with advanced cancers have unique needs for comprehensive psychosocial care since they likely need to manage other chronic health conditions like heart disease, diabetes, and renal failure, while managing cancer treatment. The intersectionality of race, age, and veteran status make older, African-American veterans especially vulnerable to experiencing gaps in psychosocial care, yet very little research exists to identify the psychosocial needs of this distinct population (Moye, Schuster, Latini, & Naik, 2010). Therefore, the purpose of this study identifies important factors that influence psychosocial distress within the multiple layers of vulnerability for an older male African American veteran with end-stage colon cancer.

The primary author has focused her research on the intersection between health and behavioral health in end-of-life care, specifically with vulnerable populations experiencing psychosocial distress and barriers to cancer care. The secondary author has extensive research experience with minority populations in end of life care. Both co-authors have published extensively and continue to conduct research in cancer care among minority populations, along with a special interest in Latinos and African Americans facing health disparities. The expertise of the third author in the areas of aging, housing and African American health disparities have contributed extensively. All of the authors have an established collaborative research and have presented annual papers at national and international conferences. As a result, this project evolved out of our common interest for examining in-depth experiences of older minority individuals with complex medical needs who could benefit from psychosocial interventions. Our single case study highlights the serious nature of suddenly being diagnosed with end-stage cancer impacting life-transitions after diagnosis and contributing to psychosocial distress. This paper stems from a larger research study conducted with older veterans and healthcare providers that explores the impact of psychosocial distress and end-stage cancer. In the future, we plan to explore how distress impacts decision making at the end of life.
METHODS

Study Design

This single-case study explored various factors that influenced psychosocial distress for Charles (pseudonym), an older male African-American veteran who had recently been diagnosed 10 months earlier with advanced stage IV colon cancer with metastases to his lungs and liver. As a naturalistic inquiry, case study research presents an opportunity to investigate a unique case allowing for an in-depth exploration of a particular phenomenon from within an insider perspective, in the context of real-life circumstances (Lincoln & Guba, 1985; Padgett, 2008). Case study methodology is particularly useful for identifying a rich description of detailed problems and assist to explicate sociocultural factors that indicate what is at stake for the individual, especially for those issues that impact illness and medical treatment (Kleinman & Benson, 2006). The Department of Veterans Affair’s (VA) Institutional Review Board in California granted prior approval for this study.

Sampling and Recruitment

This individual case was selected from a larger study in order to explore the depths of psychosocial distress among a male, older African American veteran who was suddenly diagnosed with end-stage, metastatic cancer that completely impacted his life. The larger study was designed and collected data to explore various types of psychosocial distress among 27 older male veterans over the age of 50 with advanced stage cancer who had been seen by the palliative care team. Additional eligibility criteria for the larger study were based on responses to two questions that providers (oncologist or nurse) answered about patients before they were recruited for the study: (1) Would you be surprised if this patient died within a year (Moss et al., 2010); and (2) Has a provider talked with the patient about the severity of their illness? If the provider was not surprised, indicating the possibility of dying within a year, and had agreed that an end-of-life conversation had taken place, then the participant was eligible for the study. Participants also completed a Distress Thermometer (DT) screening tool that indicated: (1) the level of distress on a visual scale from 0 to 10, with 0 being not distressed at all and 10 being extremely distressed; and (2) the type of distress experienced using a problem checklist (Holland et al., 2013; National Comprehensive Cancer Network, 2012). Participants also completed a Vulnerability Elders Survey (VES-13) to identify the basic level of functioning, self-rated health, and physical disability/frailty, which indicated a risk for health deterioration (Saliba et al., 2001). Any score above a 3 on the VES-13 indicates high vulnerability, risk of death, and functional decline in older people (Min, Elliott, Wenger, & Saliba, 2006).

Data Collection and Analysis

The primary author collected three open-ended, hour-long interviews with Charles with a sustained effort over time. A semi-structured interview guide was used to ensure that Charles talked about his experiences with end-stage cancer, explored any issues that contributed to psychosocial distress, and discussed his main concerns regarding the severity of having a terminal illness. Interviews were audio tape-recorded and transcribed verbatim into Word documents for analysis. Data were analyzed using Atlas.ti software using a thematic analytic method to identify unique themes in the data (Braun & Clarke, 2006). Two coders independently identified patterns in the data and then came together to ensure that emergent concepts formed a comprehensive narrative picture of the cancer experience and
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explicated the most significant psychosocial factors that caused distress for Charles. Elements of trustworthiness and authenticity were ensured by purposive sampling that identified a specific case with unique qualifiers of age, veteran status, and illness severity, using a prolonged engagement and multiple coders to ensure the credibility of the findings (Guba, 1981).

**PARTICIPANT DESCRIPTION**

Charles was a 65-year-old Vietnam veteran who was born in Alabama and lived on the road, working as a truck driver most of his life, sleeping in his truck, and moving from place to place. While the West Coast was a central stopping point for Charles, he often moved around throughout the United States. More accurately, Charles was precariously housed, chronically homeless for many years, since he had started driving a truck back in the 1980’s. When asked, “Where were you living before you were diagnosed with cancer?” Charles said,

I was homeless because I was staying in my truck…I was really trying to leave. [But] They got me out here, when they diagnosed me…I was kind of stuck. I couldn’t go nowhere. They wanted to evaluate me and all that stuff like that…Basically I’ve been homeless ‘cause I just move around the Country. You know what I’m saying? All around the country in my truck. [But] I lost all of that. I got here and they said that I got cancer and I couldn’t get back out there.

Charles explained that when he was diagnosed with cancer a nurse asked,

…simple questions like, "If I had a place to stay at, could I leave here?" …That really pissed me off, really had me upset there, because I don’t have [pause]. The only thing I did have when I had my job, was my truck. And, I don’t have that anymore, cause I lost that when they diagnosed me with this thing. So I wouldn’t have any place to stay at because I'm from Georgia, kind of far away.

Since beginning cancer treatment in a VA Medical Center, Charles had been staying in one of the VA Nursing Home Care buildings in order to access cancer treatment while maintaining stability. At the time of the first interview, Charles had lived in the nursing home for six months.

**ENVIRONMENT**

The large VA nursing home facility serves many veterans in need of skilled nursing care that provides a wide range of patient care services. While many veterans in this facility are dependent on nursing staff and in need of 24-hour care, some veterans have lower intensity needs and can independently move in and out of the building throughout the day while attending medical appointments. The building is located on a large property within the Department of Veterans Affairs and has the appearance of a military base, designed in the early to mid-1950’s. Since been remodeling, the appearance is much like a hospital with three floors and shared rooms. Each room houses two to four veterans at a time. The hallways are somewhat narrow, with many rooms located far down the hall, away from a
nurse’s station. During the first interview, Charles was staying in a room with four beds. However, during follow up interviews he had relocated to a room with two beds.

**FINDINGS**

Charles’s distress level, during the week before the first interview, reached a level of 9 out of 10 on the DT scale, indicating extreme distress. On the problem checklist, he indicated that he had been experiencing practical problems concerning housing and finances, emotional problems of depression, sadness, and loss of interest in activities, and several physical problems getting around, for instance, using a walker. He had difficulties with eating, constipation, fatigue, nausea, dry skin, memory loss/concentration, and tingling in his hands and feet. Charles scored a 7 on the VES-13 survey which indicated that he was highly vulnerable, at a high risk for death and functional decline. The following themes reveal other factors, in addition to physical functioning, that contribute to his vulnerability and psychosocial distress.

Charles talked a great deal about his psychosocial distress and the things that concern him the most. Table 1 presents a summary of key issues Charles raised about the cause of his distress. When asked about his immediate concerns, he replied, “Trying to get me a place to stay at so I can get out of here. So I can be getting on out of here to do my own thing.” While Charles knew that he had been diagnosed with a life-limiting disease, he was more concerned about the loss of independence and control over the way he chose to live. The following themes provide a description of significant factors that triggered his psychosocial distress: (1) the emotional impact of being diagnosed with cancer, (2) experiencing inescapable loss of control and independence, (3) adjusting to nursing home placement, (4) lacking social support, and (5) navigating complicated veteran services.

**Table 1. Factors Triggering Psychosocial Distress**

<table>
<thead>
<tr>
<th>Themes</th>
<th>Subthemes</th>
<th>Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discovering cancer</td>
<td>Confusion</td>
<td>No physical indications of cancer, lack of pain.</td>
</tr>
<tr>
<td>Diagnostic Delays</td>
<td>Limited resources contributes to delays</td>
<td>Public safety-net healthcare system lacked diagnostic equipment, sent Charles to another setting, but they did not have the resources, then accessed emergency department.</td>
</tr>
<tr>
<td>Emergency Department</td>
<td>Subsequent, severe back pain led to ED visit</td>
<td>Rapid series of tests led to diagnosis of advanced colon cancer with metastases to lung and liver.</td>
</tr>
<tr>
<td>Loss of Control</td>
<td>Entering medical system triggered losses</td>
<td>Loss of job as truck driver, loss of truck/housing.</td>
</tr>
<tr>
<td></td>
<td>Changes in physical functioning</td>
<td>Loss of teeth, inability to chew food.</td>
</tr>
<tr>
<td>Lack of Housing</td>
<td>Living in a truck, experiencing homelessness</td>
<td>Truck driver for 30 years, no longer able to stay in his truck. Dramatic change in lifestyle.</td>
</tr>
<tr>
<td>Nursing Home Placement</td>
<td>Living in a skilled nursing facility to get treatment</td>
<td>Problems living in a shared room, no privacy, issues with roommates, other veterans more dependent on staff with bowel and bladder incontinence.</td>
</tr>
<tr>
<td>Limited options</td>
<td>Needs treatment, must stay in nursing home to access treatment</td>
<td>Wished he could leave, tried to access services to assist with rent for housing, unable to access services, felt trapped.</td>
</tr>
<tr>
<td>Lack of support</td>
<td>Raised by friends, without family</td>
<td>Friends who raised him have passed away, no one to turn to.</td>
</tr>
<tr>
<td>Difficulty navigating services</td>
<td>Complexity of accessing appointments and other services</td>
<td>Attempted follow up with dentistry, had difficulty, asked for help and denied access to VASH</td>
</tr>
</tbody>
</table>
Theme One: The Emotional Impact of Being Diagnosed with Cancer

At the beginning of the first interview, Charles explained that he was confused about being diagnosed with terminal cancer, because he didn’t feel sick. Prior to his diagnosis, he was driving his truck and making deliveries when he thought about seeing a doctor for a medical checkup.

Yeah, I was [actually] living in my truck. Yeah. And I wasn’t feeling no symptoms, I...um...you couldn’t tell that I had it, cause the only reason why...the reason that I found out was...Okay, like I came in one day, I said I’m gonna go down and get a check up, you know. So, I went down to the [public] clinic, and then they told me, “We found some unusual spots on your lungs.”

After learning about the irregularity of his medical tests and that something could be wrong with his lungs, Charles became upset. He went through a series of medical appointments and resulting delays before learning about the severity of his illness. Part of the problem was that the Public Health Care Safety-net System did not have the resources to accurately diagnose his health problem. Over the course of a month, Charles went from the public clinic to the public hospital and then to the emergency room at the Veterans Affairs Hospital before receiving the diagnosis of stage IV colon cancer with metastasis to the lungs and liver. The following excerpt describes the trauma he experienced by encountering barriers that delayed his diagnosis. This issue is especially problematic for low-income people with limited access to quality medical facilities. Charles explained,

They can’t diagnose it to tell you exactly what’s happening yet cause they didn’t have the equipment. [The provider said], “So, what I’m gonna do is, I'm gonna send you over to the County Hospital.” So, I went over there and they gave me a more thorough exam. And, I'm telling myself, I don’t feel bad, as far as my lungs go. I know that if the lungs have something to do with it, and breathing and all that. But, I ain't feeling nothin, nothing at all as far as like cancer! But, they said, “No no no, you’re going to need this, that, and the other thing.” And then, the people at the County told me to come back over there in about a month’s time.

It was clear as Charles explored the physical signs that indicated to him that something was wrong that he needed help. However, when he followed instructions and sought care, he received insufficient treatment. He continued,

But, so in about a month’s time, I was staying down in a hotel, and I was feeling...um, I was having back problems. My back was bothering me. So, I went down to the VA [clinic], and they gave me some ibuprofen for the pain. That was on Friday. And, then he said to come back on Monday, and he would give me a more thorough exam on it. So, I went back there on Monday. At first he gave it [the pain medication, ibuprofen] to me, and then I was having problems. I was really hurting. My back started hurting me, my stomach started hurting me, and all that stuff. So, I went back to see my primary doctor, you know, just like the emergency doctor that gave me the ibuprofen. Then, when I went back to see my primary doctor, he said that being that it's Friday, he wasn't gonna do anything for me. But, you know, he told me to, "Just get off the ibuprofen if it’s really that bad, and let's wait until
Monday when you come back.” So, that Monday, he said that they didn’t have the equipment down there neither. So, he said, “I’ll let you...you have to come out here to this VA hospital and they can really get to you [help] because they’ve got everything you need.” So, I got out here, and I’ve been stuck here ever since.

When Charles went to the emergency room at the VA Hospital, the attending doctor admitted him to stay overnight. After two days, he was given the news of his cancer very abruptly. In his tone and expression, it was clear that Charles was shocked and confused about the bad news the nurse had nonchalantly delivered. He recalled,

So...this lady came in, by the second day that I was out here, and said, "You got colon cancer, and you have liver cancer, and lung cancer. You don’t have much time. You might be gone today or tomorrow or next week. But, the only thing that we can do is make you as comfortable as possible." What they’re telling me was that ...I was at the verge of dying. And, uh, I didn’t know. I should’ve had some type of indication, something!

While Charles was extremely resourceful in seeking medical attention as he followed up with each appointment he was provided, he ultimately ended up in the VA hospital emergency room, seeking help for his pain.

Theme Two: Experiencing Inescapable Loss of Control and Independence

Several factors contributed to the loss of control and the uncertainty that Charles experienced after being diagnosed with advanced colon cancer and starting cancer treatment. While he began to receive treatment in the Veterans Affairs Medical setting, Charles could not continue to work, drive, or sleep in his truck, which he had been doing for the past 30 years or so. This pattern was his norm, and yet a cancer diagnosis was the biggest disruption that had happened to him since he returned home from Vietnam. Along with his terminal cancer diagnosis, he was now faced with the challenge of finding a place to reside that was close to the medical center where he would receive treatment and attend multiple weekly medical appointments for chemotherapy.

I was homeless because I was staying in my truck...[Then] they got me out here, when they diagnosed me and they got me here at the VA hospital, I was kind of stuck. I couldn’t go nowhere. They wanted to evaluate me...So, I couldn’t go nowhere.

As a veteran, he was eligible to be housed at the skilled nursing facility. With no other options for housing to access treatment, living in the nursing home created new problems for Charles. He lost his sense of independence, privacy, and routine which created another level of distress. Stuck in the nursing home for treatment, Charles became instantly dependent on VA services.

Charles also experienced a series of other losses associated with his disease. Due to a rapid decline in physical functioning, he had to learn to use a walker for ambulation. To compound the problem, Charles lost all his teeth and experienced subsequent weight loss. About these treatment effects, he stated,
I lost my teeth...That was some of the side effects that I had. They told a lot of people, “When they’re targeting those [cancer] cells...you might be able to live longer than you’d expect, if...Depending on how you take the medicine.” Like the chemo medicine and all the pills...But, my hair’s not falling out, nothing like that....But, I’m still having issues, and I’m not eating, not because I don’t have an appetite. It’s just that I have bad gums [no teeth] and bones sticking out. I’m supposed to get dentures, but I’ve got bones that’s preventing me from biting down...And, I’m not eating because I can’t chew my food. The only thing that I can eat is the soft foods...And, I’m about to burn out on that...So, I’m losing weight. I want to eat more, but...It’s a problem. When I chew, see, what happens is that I got a bone here [sticking out] and a bone over here [on the other side] that is really low. Every time I try to bite down, I feel it [a sharp pain]...The bones are sticking out and it hurts. And, every time I try to chew it, I hit that bone right here. So, I just do it [chew] with my tongue.

It is unclear if and when Charles will have his teeth fixed. It seems that he has tried to see the dentist at the VA to help him get dentures, but he does not know when this will happen. While the oncologist has told him that they made a referral for him, Charles keeps waiting to hear from a provider about fixing his teeth.

**Theme Three: Adjusting to Nursing Home Placement**

For the first time in more than 30 years, Charles had a room and a bed in the VA nursing home. He talked a great deal about the circumstances of his housing while working as a truck driver, sleeping in his truck, and staying at hotels at times. Most of the time, he was traveling around from state to state. He was not greatly concerned about being homeless because he had transportation and a place to stay. He liked the flexibility of driving around by himself. After being diagnosed with cancer his housing circumstances were problematic and distressing, more than his previous years of homelessness. He was left with only one option for housing, a room that the VA could provide. The following comment demonstrates the culture shock that Charles experienced after moving into the nursing home, the frustration he felt about not being able to leave, and his belief that he did not seem to belong there:

My roommates and people that was there were all messed up and feeling sick like that...If I had a place to stay at, then I could leave here...They said, “Yeah, you can do that.” And, that really pissed me off, really had me upset right there because like I said, I don’t have a place to stay. The only think that I did have was my job and my truck. And, I don’t have that anymore, cause I lost that when I was diagnosed with this thing. So, I wasn’t able to have any place to stay at. I’m from Alabama and that’s kind of far away.

For the first time in his life, Charles had a roommate staying next to him in the nursing home. This was extremely difficult for Charles to adjust to, because he was accustomed to living and sleeping on his own terms, in his truck. In order to receive treatment, living in the VA skilled nursing home was required just like it was for other veterans who were dependent on 24-hour nursing care. While Charles maintained an ability to get up out of bed and walk using a walker to get around from place to place by himself, other older veterans around him were not able to ambulate. The obvious disparity was discouraging and anxiety-producing.
The fact that he was housed with veterans who were incontinent of bowel and bladder frustrated him to a maximum degree.

I was put in a room with somebody that was like bedridden, or something like that. And, then when they would have a bowel movement and they’d got to come over and clean him up, and I got to smell that. I felt that I had been in a situation that I was in, that I could do better in my own place, that I don’t have to breathe that, all that sickness, cause all that was making me sick...Every morning smelling homeboy, they were cleaning him...That was making me more sick than anything... I wasn’t feeling sick, but eventually, you know, I mean like it was stressing me out because that’s basically what it was. But, the stress would make me really upset.

Additionally, Charles was upset by the fact that some veterans had the flexibility to come and go from the nursing home to receive treatment and then return home; however, he could not. He lacked alternative housing, which made him extremely upset. Having little control over his situation, Charles was unable to settle into his new surroundings and adjust to the nursing home environment.

I asked questions, and then I was able to find out that I ain’t even gonna get out of here. So, what I was thinking about doing is going out there [pointing outside the building] and getting my own damn tent, and then I could come back [and forth]. Yeah, I’d do that if it was feasible. But, I said, “Shit. I wanna get out of here, I want to get out to a place to stay at.” And, then I could cook my own food...do whatever I want.

**Theme Four: Lacking Social Support**

Part of the problem that contributed to the lack of social support was that Charles was raised by friends; and he had been by himself for many years growing up. Charles really did not have any family. He attributed his unsettling circumstances to the lack of having family. Most of his friends were of advanced ages when he was a child and had since passed away. While trapped in an undesirable health/housing situation, Charles reflected on relationships from his past.

It didn’t bother me [being without family]. I was sort of adopted anyways. The people that raised me, they had been from up North, in North Carolina and before the independence came in Georgia. I was staying in Georgia, in the winter months, and then in the summer months, I’d go up [North]. And everyone had been [older]. Most of them were elderly people. Most of them was like 60, and the lady, she was like 58, and the guy was like 60. So, they let me stay with them. They was like, “You can stay with me.” But, they basically...[they said], “Go to school, come home, and go to bed.” Go to Church, and you know, that was basically it. I never got to go out with friends and stuff like that...[But] I was able to get away from that shit, yeah. I went to the Job Corps and then I went into the service...When I came back, everyone had passed away, you know, everyone who had brought me up.
Theme Five: Navigating Complex Veteran Services

Under these complex circumstances, Charles experienced difficulty in navigating services for veterans. Although he was finally able to access care through the VA emergency department, he found himself uncomfortably situated in a complex medical system that cared for veterans. He experienced difficulty receiving follow-up care with some providers, like his dentist. Additionally, after entering the nursing home, Charles attempted to access housing assistance from the Housing and Urban Development and Veterans Affairs Supportive Housing (HUD-VASH) program so that he could restore his independence before he died. He signed up with VASH; however, due to the severity of his illness and highly complex need for medical services with multiple and weekly medical appointments, he was denied housing assistance.

I tried to sign up for VASH. And, VASH said that they can’t help me because of my medical problems, so I feel like I was being tied down. I didn’t like that...They said it was for the medical problems...not being able to...they don’t know if I’ll be able to get back there in time...I was in the building, through the screening process. They had accepted me, and then they told me to wait 30 days. And then, I went back over there after my 30-day time. And they said, “No, no, no. We found that your medical problems prevent us from helping you out, because of the fact that um...you know, the medical problem.” You bet I was shaking my head when I came out...I felt like, “Well, shit!”

Even though Charles was resourceful and persistent in attempting to access services, he ran into continuous barriers that he could not navigate. At the time of the last interview, Charles reported that a social worker in the nursing home was talking with the VASH program, asking them to reconsider his case.

DISCUSSION AND IMPLICATIONS FOR PRACTICE

The goal of this single-case-study was to shed light on the compounding experience of psychosocial distress that emerges for an older seriously ill, male African American veteran diagnosed with terminal cancer. From this case study, an in-depth exploration of one older veteran’s experience during and after late-stage cancer diagnosis demonstrates the spiraling effect that leads to a traumatic, distressing sense of psychosocial loss, frustration, and despair. Such a close look at this man’s life also reveals a temporal dimension since the patient in this study explored his experiences with pre- and post-diagnosis of a serious, life-threatening condition that contributed to further instability in his life. Additionally, the progression of the theme that indicate the most significant topics for Charles suggest a linear pattern of distress accumulation that builds as a result of successive losses of stability, independence, and control after diagnosis and through cancer treatment.

Charles was surprised to learn about his life-threatening cancer diagnosis, which was not detected until the disease had progressed into the late stages. This finding is consistent with previous research which highlights delayed screening detection, and treatment as major contributors to poor survival rates for older African-American adults (DeSantis, Naishadham, & Jemal, 2013; Ward et al., 2004). Disparities in health care are important concerns, particularly for African-Americans who have experienced social inequities, including racial discrimination and cultural barriers (Carrion, Park, & Lee, 2012; LaVeist, 2005; LaVeist et al., 2000). Additionally, such disparities are compounded by age. Gaps in health status
widen with African Americans experiencing a cumulative disadvantage in life-course health trajectories, with significantly poorer health over time than Whites (Whitfield & Baker, 2013; Shuey & Willson, 2008).

Behavioral health providers like social workers and psychologist need to know how to assist African-Americans with end-stage cancers and support them in navigating the complicated medical health care system while aiding them in making medical decisions that determine their course of treatment. Health care navigation is particularly important for social workers to understand because of the disparate circumstances that minority populations deal with when diagnosed with end-stage cancers (Nedjat-Haiem, Carrion, Ell, & Palinkas, 2012). Since health provider assumptions can also affect interactions between African-Americans and their providers, contributing to miscommunication and the delivery of substandard care, behavioral health interventions necessitate the understanding of these critical factors. This is especially so, given that African-Americans are more likely to develop and die from cancer than any other racial and ethnic group (American Cancer Society, 2014).

This study also describes the various life transitions and chronic problems that activated psychosocial distress after the beginning of treatment and seeking help for problems that arose over the course of treatment. A recent study found evidence of an association between life events and the development of colon polyps in older African-American adults, suggesting that psychosocial factors may be a risk factor in the development of a precancerous process (Ashktorab et al., 2013). Participant descriptions from the current study highlight the role of psychosocial factors such as housing insecurity and the lack of social support in exacerbating cancer-related distress. Charles differentiated himself from other residents at the VA nursing home and wished to regain a sense of independence by moving out of the facility and into an alternative housing situation, like an apartment or hotel, which was not possible. Similar to research already documented, trauma is inherent in housing transitions and is intertwined with the complexity of health situations, especially with chronically ill older adults (Wingate-Lewinson, Hopps, & Reeves, 2010). Some precariously housed older adults move into hotels to be close to medical treatment and to achieve a sense of stability. More importantly, these issues of housing insecurity and lack of social support impacted Charles’ peace of mind and the ways in which he accepted care at the end of his life. He was faced with a series of psychosocial problems as he began to deal with dying.

It is essential for behavioral health care providers (social workers and psychologists) to assess the type of support African-Americans prefer to receive, given the pivotal role of culturally competent care in the total cancer experience. Identifying the obstacles to accessing knowledge and information regarding psychosocial support, treatment options, and decision making when confronted with an end-stage cancer diagnosis is central in the collaboration of services within the treatment team (Carrion et al., 2013; Nedjat-Haiem, Carrion, Ell, & Palinkas, 2012).

The findings in this study also demonstrate how difficult it was for this older veteran to seek services and to deal with the complexity of the changes that impacted his life after diagnosis and the circumstances of sudden, uncontrollable loss, while living with the fact that he was dying. His poignant narrative also raises significant social justice issues contributing to a sense of urgency to implement new policies and conduct additional research to explore this multi-faceted problem for older veterans. As Charles began treatment for advanced cancer, he was faced with the circumstance of needing housing in the VA nursing home in order to receive treatment and without which he would not have been able to access medical care. This case study highlights the various components of an individual’s life that are essential for health and behavioral healthcare providers to address. Providers are compelled to examine the innumerable events that transpire in the life of a veteran. As a society, we are
indebted to the numerous men and women who have been physically and psychologically wounded while fulfilling their commitment to serve their country. Providers must have advanced training to assume a professional obligation to advocate, negotiate, and intervene, ensuring that older veterans and their families obtain the scope of services that they urgently need at the end of life (Nedjat-Haiem, Carrion, Cribbs, & Lorenz, 2013; Werth, Gordon, & Johnson, 2002).

References


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Article Citation