

PEER-REVIEWED ARTICLES

Just Give Me Hope: Lived Experiences of Medicaid Patients With Advanced Cancer

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The purpose of this phenomenological exploration was to describe the lived experiences of persons diagnosed with advanced cancer who receive Medicaid. Themes emerged from the transcribed interviews of 10 participants in accordance with the cancer trajectory. Before diagnosis, participants were uninsured or underinsured and had more severe symptoms prior to late diagnosis. Upon diagnosis, they desired hopeful, respectful communication and experienced strong emotional reactions. There was also an abrupt change in the use of health care resources. During cancer treatment, they experienced social isolation from family and friends while receiving strong psychosocial support from the health care team. Throughout the cancer trajectory, they focused on living, reclaiming normalcy, and expressed resiliency and spirituality. Findings support the need to recognize the “fighting spirit” of patients regardless of prognosis or socioeconomic status; the impact of hopeful, respectful communication; and the value of oncology social work assistance when navigating the cancer experience. Lack of health care coverage prior to severe symptoms prevented

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earlier diagnosis and contributed to poor physical outcomes. Medicaid eligibility enabled these patients to receive quality health care and focus on living beyond cancer.

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The plight of the poor and uninsured confronted with serious, life threatening illness has been at the forefront of recent debates and efforts directed toward health care reform. Approximately one-third of all Americans under the age of 65 are uninsured (Riedel, 2009); a number estimated to be about 43–46 million (Institute of Medicine [IOM], 2009; Riedel, 2009; Wilper et al., 2009). Numerous studies have demonstrated that uninsured cancer patients are more likely to be diagnosed at an advanced stage, suffer poorer health outcomes, experience greater limitation in quality of life, and die prematurely (IOM, 2009). Typically, the poor are more likely to be uninsured than those with higher incomes (Daly, Oblak, Seifert, & Shellenberger, 2002).

Often it is assumed that they are unemployed, but 80% of the uninsured live in a family where someone works (IOM, 2009). However, they tend to have lower incomes than those with insurance (Daly et al., 2002). One-fourth of workers are not offered health coverage through their employers and many of these remain uninsured because they cannot afford the high premiums of nongroup insurance (Riedel, 2009). Even when the employer offers a health insurance benefit, the employee may not be able to afford the out-of-pocket expenses and/ or the co-payments associated with health care. A serious illness may result in the inability to maintain employment with subsequent loss of employer-subsidized health insurance. The cost of maintaining one's own health insurance is often unaffordable.

Medicaid, a joint program between the federal and state governments, under Title IX of the Social Security Act, was created as a health care safety net for the poor, but only 2 out of every 5 poor people (as defined by federal poverty standards) are covered by Medicaid (Inglehart, 2010). Studies have shown greater mortality among Medicaid beneficiaries than those receiving employer-sponsored health insurance (Kelz et al., 2004; Koroukian, Beaird, Madigan, & Diaz, 2006; Kwok et al., 2010; Sorlie, Johnson, Backlund, & Bradham, 1994), and cancer-related health care disparities among those receiving Medicaid are also well-documented (Bradley, Given, & Roberts, 2003; Koroukian et al., 2006; Roetzheim, Gonzalez, et al., 2000; Roetzheim, Pal, et al., 2000). Studies have also shown that those who enter Medicaid due to a cancer diagnosis are more likely to present with metastatic disease than those enrolled in Medicaid prior to their cancer diagnosis, and Medicaid enrollees

are 2 to 5 times more likely to be diagnosed with late stage disease than non-Medicaid enrollees (Bradley et al., 2003; Halpern et al., 2008; Koroukian et al., 2006; Perkins, Wright, Allen, Samuels, & Romano, 2001).

While the facts and numbers paint a grim picture related to health care outcomes for the poor, the uninsured, and those on Medicaid, few have studied the actual experiences of these individuals as they interface with the health care system. Moller (2004) journeyed into the lives of the dying poor and challenged others to step "out of the box" by connecting with the actual life experiences and needs of this population. In this ethnography, the stories of persons dying in inner-city poverty with the goal of giving a voice and providing a face to their lives and suffering are shared. Williams (2004) interviewed young patients of low socioeconomic status who were terminally ill with cancer in an effort to raise awareness about their experiences and related existential suffering. Song and colleagues (2007) conducted in-depth interviews with homeless persons to explore their concerns and desires for end-of-life care. Hughes, Gudmundsdottir, and Davies (2007) used interpretive phenomenology to study the experiences of 14 poor urban dwelling adults living with advanced cancer.

While these studies lend insight into the lives of poor, seriously ill patients, a better understanding of the experiences of those who are poor and eligible for Medicaid is needed. As stated earlier, these persons are the poorest of the poor. After eligibility for Medicaid has been met and benefits begin, these patients are fortunate enough to have their medical expenses covered by a third party payer, yet they remain in poverty. In an effort to learn more about their experiences with the health care system both before and after Medicaid eligibility, in-depth interviews were conducted with 10 patients diagnosed with advanced cancer who became Medicaid eligible after their diagnosis. Issues explored included patients' health care experiences both before and after the cancer diagnosis, events leading to their Medicaid eligibility, and their subsequent experiences with health care providers; as well as their sources of support, goals, and perspectives related to life-threatening illness.

METHODS

Research Design

Because of the exploratory nature of this work and the desire to present a detailed view of the topic from an emic perspective, qualitative inquiry using in-depth semi-structured interviews was deemed the most appropriate approach (Creswell, 1998; Padgett, 1998). A phenomenological perspective was assumed in an effort to capture the perspectives of participants and to describe their lived experiences while bracketing researcher preconceptions (Kvale, 1996). The phenomenological perspective, which attempts to

describe the meaning of the lived experiences for several individuals about a concept or the phenomenon (Creswell, 1998), allowed identification and description of the subjective experiences of our participants. In terms of data collection, this approach allowed participants to take the interview in their own directions. In terms of analysis, using the phenomenological concepts of “*epoche*” (refraining from judgment; Quinn Patton, 2002) and bracketing (identifying the data in pure form; Quinn Patton, 2002) captured of the essence of the cancer experience of those with advanced cancer on Medicaid. It should be noted that the researchers have over 35 years of combined experience in oncology social work (TJS and BAH), and oncology and hospice nursing (BAH), and that this experience shaped how the data were gathered and analyzed.

Procedures

A purposeful sampling approach was used to recruit participants diagnosed with advanced cancer, currently receiving Medicaid benefits and physically able to participate in a 45–60 minute interview. A Medicaid case manager and three oncology social workers at the university cancer center identified and approached eligible individuals and asked if they had interest in participation in a research study. The researchers contacted those interested, explained the research, and secured consent (100% of those expressing interest agreed to participation). This approach respected patient confidentiality and assured that those approached met study criteria. Because Medicaid eligibility and the physical status of patients with advanced cancer are both subject to abrupt change, having the professionals identify patients on their caseload currently meeting study criteria facilitated timely and appropriate recruitment.

Data were collected from January through October 2009. Following an informed consent process approved by the University of Louisville’s Human Subject Protection Program, we conducted in-depth open-ended interviews with each participant. In order to ensure that important topics were addressed, we employed a semi-structured interview approach using a purposed sequence of themes and suggested questions (see Appendix 1 for the interview guide). We remained open to changes in sequence and forms of questions depending on the responses and stories offered by each participant. Topics explored included health behaviors, process of diagnosis and disease trajectory, reactions to diagnosis, Medicaid eligibility process, treatment experiences, relationships with health care providers and Medicaid, decision making, goal setting, social supports, values and needs, and quality of life. In 8 of the 10 cases, interviews were conducted jointly by two members of the research team (BAH and TJS). Interviews were recorded and the tapes were transcribed verbatim by a professional transcriptionist who was not involved in the data collection.

Analysis

A modified version of Colaizzi's framework for phenomenological analysis was used (Colaizzi, 1978; Sanders, 2003). Because of the physically fragile nature of the participants, it was necessary to do member checking as a first rather than last step in the analysis. This proved to be essential in that three of the study participants died prior to completion of the data analysis. Therefore, as soon as the interviews were transcribed, they were read and summarized for main themes or messages and reviewed with the participants. In all but one case (wherein the participant died prior to the follow-up), this review was conducted to verify that the summary truly captured the participant's experience.

The steps involved in the analysis were therefore as follows:

1. In addition to conducting the actual interview, interview transcripts were independently read by the researchers (TJS and BAH) to gain a sense of the whole.
2. Main thoughts in each interview were summarized and reviewed with the participant.
3. Transcripts were independently re-read (TJS and BAH) with the goal of identifying statements of significance.
4. Statements of meaning were then grouped according to general themes.
5. Peer debriefing meetings were held (TJS, BAH, and ACF) in which consensus was reached as to the significant clusters of themes in the data.
6. Significant statements were extracted, describing each of the themes to develop an exhaustive description of the investigated phenomenon.
7. This exhaustive description was then reduced to an essential structure.

For the purpose of analysis, each participant interview was printed on a different color paper. Significant statements were cut out and grouped according to the theme structures. This iterative process of de-contextualization and re-contextualization resulted in the findings.

RESULTS

Participants

Participants were recruited until researchers agreed that data saturation—the point at which themes become repetitive (Rubin & Rubin, 2005)—was achieved. In other words, ideas/responses were repeated in 10 people with no new themes emerging in the last interviews. The final sample consisted of eight women and two men, all residents of Kentucky. The mean age of participants was 44 (median = 45.5); six were Caucasians and four were African Americans. Site of cancer varied (three breast, two colon, and five

others—brain, vulvar, cervical, liver, and peripheral nerve sheath). Table 1 displays the demographic description of the sample.

The themes emerged into a chronological sequence of the main events in the trajectory of the cancer experience (see Figure 1): before cancer, the diagnosis, and cancer treatment. The theme of living beyond cancer was present throughout the trajectory. Participant names were changed to protect confidentiality.

Before Cancer

Two consistent themes, lack of adequate health insurance and delay in seeking treatment for symptoms, emerged as characteristic of the time before the cancer diagnosis.

UNINSURED OR UNDERINSURED

Although 9 of the 10 participants were employed or were dependents of employed heads of household, all either had minimal or no health insurance at time of diagnosis. When asked if he had ever had health insurance before his cancer, Melvin, an ex-convict who grew up in subsidized housing, laughed, indicating the question was ridiculous, and said, “No, no, my goodness no! This is the only time I’ve ever had insurance, because I have cancer.” Lora, who had worked at Wal-Mart, and was offered employee health insurance, stated, “I couldn’t afford the premiums. They were too high and would have taken away most of my paycheck. I had kids to feed.” Similar responses were expressed by the others. Most had worked in minimum wage jobs and even when health insurance was offered, they were unable to afford it.

SEVERE SYMPTOMS AND LATE DIAGNOSIS

In all but two cases, participants allowed their symptoms to escalate before seeking medical care. In Sarah’s case, diagnosis followed an accidental injury. Lynn found an asymptomatic lump in her breast 6 months following a suspicious mammogram. The other participants had no consistent medical care and were either evaluated in the emergency room or during a clinic visit precipitated by an acute pain episode. All 10 had advanced cancer at the time of diagnosis. Linda knew about and lived with three growing vulvar cysts for years because she could not afford medical treatment; yet she was traumatized by how she discovered her cancer:

I woke up one morning and when I went to the bathroom I was covered in blood. The cysts had ruptured. So I hurried with my mom to the emergency room. They had never seen nothing like that before. So they sent me to a gynecologist and 2 days later I was diagnosed with cancer.

TABLE 1 Demographics

ID#	Name*/Sex	Age	Race	Cancer site	Monthly income	Other	Caregiver	Family status	Themes***
1	Melvin/M	59	B	Liver	\$637, disability	Food stamps, assisted housing	Daughters	Divorced, children grown (2 daughters, 7 grandchildren)	1, 2, 3, 4, 5, 7, 8, 9, 10, 11
2	Sara/F	23	W	Peripheral nerve sheath tumor	\$600, disability	Father's retirement \$1,200/mo	Mother	Young adult living with parents, brother; diagnosed at 17	All
3	Shelly/F	36	W	Breast	\$1,000, disability	Husband's disability of \$400/mo	Husband	Married with 2 children at home (ages 18 & 8), parents live close by	1, 2, 3, 4, 5, 7, 8, 9, 10, 11
4	Lora/F	47	B	Colon	\$0 applied for disability, some support from children's father	Section 8 housing, food stamps	Mother	Single mother of 2 boys (17 & 13), worked at Wal-Mart until ill	All
5	Mary/F	45	W	Cervical	\$700 disability	Money from ACS** (\$200 one time)	Sister	Lives with sister; 1 daughter, 1 grandchild; separated for 14 years	All
6	Linda/F	49	W	Vulvar	\$697, disability		Mother	Single, no children; lives with mother; has brother	All
7	Sam/M	38	W	Brain	\$1,300 wife & son's disability	Food stamps	Wife	Married father of 2 sons at home, wife disabled by metastatic breast cancer	All

(Continued)

TABLE 1 Continued

ID#	Name*/ Sex	Age	Race	Cancer site	Monthly income	Other	Caregiver	Family status	Themes***
8	Anita/F	46	W	Breast	\$1,500/ disability	Food stamps, church help at first	None, sister who lives out of town is closest	Single	All
9	Ellen/F	54	B	Anal	\$500/ disability	Food stamps	Sister	Single, 2grown children; lives alone except when grandchildren visit	All
10	Lynn/F	43	B	Breast	\$1,500/ disability	Food stamps	Oldest daughter	Lives with 3 children	All

#*Names changed.

**ACS—American Cancer Society.

*** 1—Uninsured or Underinsured; 2—Severe Symptoms and Late Diagnosis; 3—Desire for Hopeful, Respectful Communication; 4—Emotional Reactions; 5—Change in Health Care Resources and Utilization; 6—Social Isolation from Family and Friends; 7—Psychosocial Support of Health Care Team; 8—Focus on Living; 9—Reclaiming Normalcy; 10—Resiliency; 11—Spirituality.

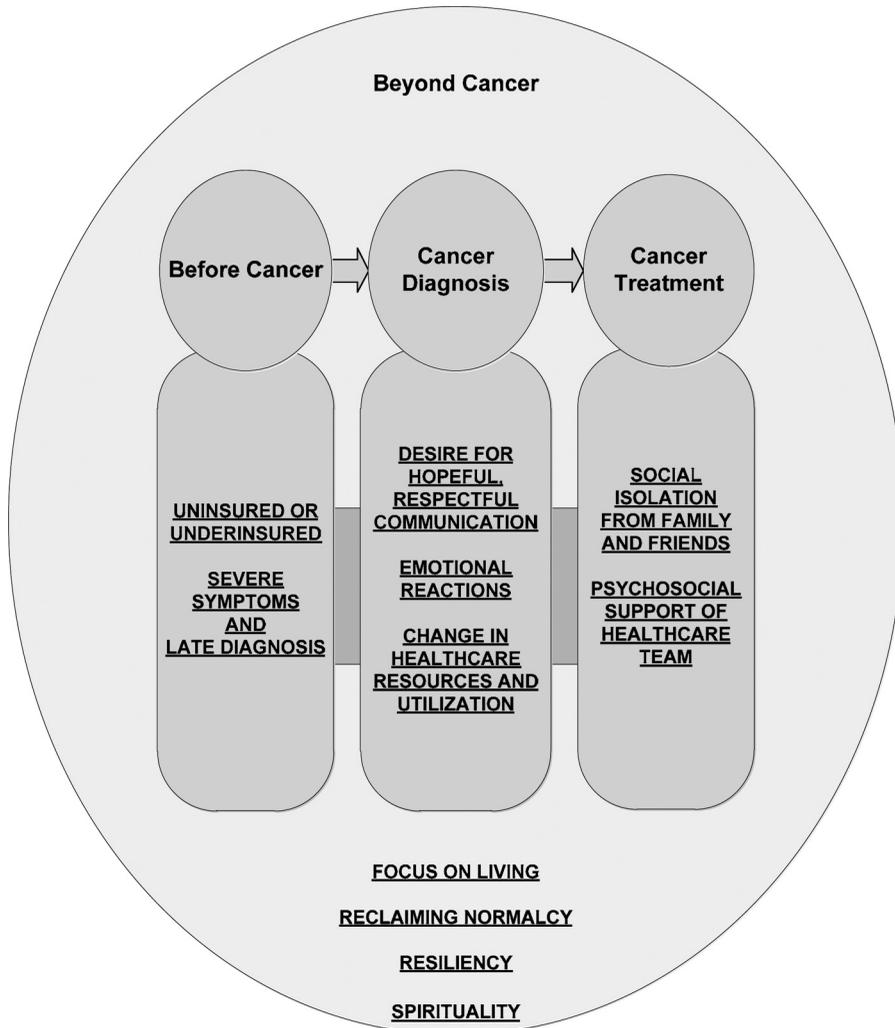


FIGURE 1 Themes along the cancer trajectory.

Lora described similar severe symptoms that finally outweighed her fear of medical bills. When her abdomen grew so large that people started asking if she was pregnant, she decided to seek health care: “I kept feeling weak, and my stomach was getting bigger and hurting. I went in the emergency room one night because I couldn’t get out of bed. They gave me a colon test and that’s how they knew.” Mary, who had never had health insurance and had always avoided medical care, was not diagnosed until her cancer was advanced because she normalized her symptoms: “I always had heavy, irregular, periods so I really didn’t think much about that. I could actually feel the tumors on my ovaries so I went to the doctor. I had one that was 8 centimeters. I was bleeding heavily.”

Anita, who had never had consistent health insurance and had always put off screening, explained how she waited to go to a clinic:

Toward the end of September I felt a lump. By the time I went to the clinic, I put my arms up and saw the tumor bulging on that side of my breast. It started turning dark pink, and then red, and I thought maybe it is just an infection, or something. The clinic doctor sent me to the cancer center.

Ellen, who actually had health insurance but chose the occasional health clinic visit due to high co-pays, normalized her symptoms for many years before seeking health care:

I had pain in my bottom but I was always in pain and I just figured I was getting old. A lot of people have problems with their bowels and I thought that was it. I'd take some Milk of Mag and it would ease off. But this time, when I took it, it didn't ease down so my family brought me to the hospital. I found out that I had cancer when they X-rayed and it was in my back.

Participants seldom, if ever, received routine health care or preventive screening and knew little about navigating the health care system. Even those with insurance admitted to avoiding medical care due to high co-pays. Therefore, treatment was not sought until symptoms were out of control.

Cancer Diagnosis

The time around diagnosis was overwhelmingly characterized by the participants' views of the quality of communication related to the diagnosis/prognosis, their emotional reactions to the diagnosis, and their change in health care resources and utilization.

DESIRE FOR HOPEFUL, RESPECTFUL COMMUNICATION

The giving of diagnosis was a significant event for all participants. If not given with a hopeful, respectful approach, it was viewed as a horrendous experience as captured in the following statements.

Sam, hospitalized for disabling dizziness and headaches, was leaving the hospital when told of his diagnosis: "I was headed to rehab... the surgeon showed up and told me as I was walking out the door. He said, 'it's a pretty bad cancer. I'm glad I caught you before you left' and that was it." Mary described first receiving the news from a hurried doctor who did not communicate in a patient-centered manner:

I didn't like how the first doctor told me. I asked her to wait until my boyfriend got there to tell me the results, but she didn't. She just said "you

have cancer and it's incurable." She wasn't a bit kind about it. . . . I just started crying.

But when the oncologist came and spent time with her, allowing her to ask questions and develop a hopeful plan, she was much more satisfied.

Lora experienced similar differences in the way her news was communicated by two physicians:

It wasn't professional. . . . it wasn't even the doctor who was supposed to tell me I had just got my dinner and I had a couple of friends sitting there and he sat on the edge of the bed and said he had to talk to me. He blurted it out. Everybody just walked out in the hallway to cry. My other doctor didn't like the way he told me. He told me "don't give up," you know, "fight."

These experiences were notably distressing for these individuals. All expressed hopes that other patients not have to receive a cancer diagnosis in this way.

When the news was perceived as having been delivered well, participants appreciated honesty tempered with hopeful reassurance. Ellen described how this approach was taken by her health care team when she learned she had cancer:

They were so sweet to me. It was just like a word. I cried for a while then the doctor said "you know we've got the chemo and radiation." He didn't make me feel like this was the end . . . he just gave me fantastic hope

Lynn appreciated her physician's direct honesty:

When the doctor told me she was straightforward. I just thought she was doing her job. There was no point in leaving me lingering. I'm just glad she gave me the heads up so I know what to look forward to.

Lora felt as though her oncologist was compassionate and helpful:

He just told me to fight it . . . don't give up. He was real nice. He said "if you ever need me, call me up. I'm on call 24 hours. If there is something that you don't understand and I don't understand, I'll find out for you."

Anita received her diagnosis over the phone, but it was delivered in a way that she found comforting and optimistic:

She called me at home and said "Are you by yourself? Do you want to have somebody with you?" I said no, just tell me. She was very good. She had even given me her pager number and told me if I needed her

or had any questions to page her. It wasn't just given bluntly. She was sympathetic in sharing the news with me.

These positive experiences outweighed any prior negative experiences for the participants. In evaluating the responses of all participants, positive and hopeful communication at the time of diagnosis seemed to decrease both the level and duration of distress reported.

EMOTIONAL REACTIONS

Regardless of how given, the initial diagnosis was emotionally traumatic. Lynn spoke of how her world was altered: "It just changed my life completely. It seemed to me it just turned my whole world upside down." Shelly expressed similar feelings upon learning she had cancer: "The whole word 'cancer,' period. Just everything about it. It changes everything. Nothing's the same. You don't feel the same. You don't look the same." Lora struggled with overcoming depression and accepting the reality of her disease: "At first I was depressed . . . I was really feeling down because I was like, 'why me?'" Melvin also fought depression: "I got very depressed because they gave me a terminal situation." Mary had difficulty finding words that could adequately describe how she felt: "Oh, it was bad. You can't explain it to someone, it's devastating." Regardless of the manner in which they were told or what they expected, the actual diagnosis of cancer was a shock and disappointment to each of our participants.

CHANGE IN HEALTH CARE RESOURCES AND UTILIZATION

Most of our participants described being fearful of the costs of treatment and having treatment denied due to their inability to pay; however, all of our participants were quickly deemed eligible for Medicaid and other resources. The oncology social workers in the hospital and clinic were essential to the process. Each participant went from having little or no access to the health care system to intense involvement for an extended period of time. Anita appreciated the way her oncology social worker alleviated her fears around access to and payment for treatment: "I met with the social worker the day of my mammogram. She said, 'Don't worry about that (having no insurance). We're going to get that covered, just focus on you right now.'" Anita was also very grateful for her Medicaid:

It has been wonderful . . . it has taken care of all my medical costs and I only pay \$1 for my prescriptions. They even pay for transportation. Sometimes I have to wait for an hour or more for them to come, but I don't mind because it's free, I'm not the only one . . . I'm just grateful.

Mary, who was overwhelmed with her diagnosis and the need to make so many decisions around treatment and health insurance, expressed similar relief: “When I was in the hospital the first time a social worker came and talked to me and she did it all . . . I was surprised they could help me that much.” Mary, too, was grateful for Medicaid: “They’ve always paid for everything . . . I’ve never had a problem since getting Medicaid.”

Linda felt completely cared for by her oncology social worker:

The social worker has done a lot of things for me . . . I got Medicaid 2 months after diagnosis and she did every bit of it . . . She called around and got someone to cut my grass . . . Mainly, she has been there when I needed to talk. I can call her anytime . . . God, I love her.

Linda explained how her use of the health care system changed with Medicaid coverage:

I don’t have to sit and wonder anymore. If something happens to me I can go to the doctor. I don’t have to wait for it to get really bad and then run to the emergency room . . . that’s an awful feeling.

Ellen appreciated how soon her financial and health care concerns were addressed: “My social worker made things happen pretty quickly.”

Similar experiences with oncology social work and supportive services were described by all participants. The assistance, knowledge, and skills of these supportive individuals, and timely access to Medicaid benefits allowed participants to focus on treatment and recovery rather than procurement of insurance and other resources.

Cancer Treatment

Themes most characteristic of the cancer treatment phase of the trajectory were social isolation and psychosocial support of the health care team.

SOCIAL ISOLATION

As participants transitioned into the treatment phase, they began to notice social and relational changes. With diagnosis, they experienced initial rushes of support from others, but as treatment commenced, social interactions with others outside of the health care team diminished.

Lynn was disappointed by what she perceived as her friends’ inability to accept the changes she was going through:

. . . they said, they “didn’t want to see me looking bad.” You know a lot of people lose weight and I had already lost my hair, which wasn’t a big deal. I ended up getting used to it. But they just thought I was going

to be all skin and bones. . . . if one of my friends had cancer I would have been there for them.

Sara, the youngest participant, found it difficult to watch all of her friends moving on with the normal developmental transitions of young adulthood while she felt left behind:

My high school friends stopped contacting me. They went to college, I never heard from them again. That was pretty bad and lonely. . . . only two or three people are still hanging with me. Now I have to go find new friends.

Linda struggled with self-consciousness over the changes in her physical appearance after chemo; these things made it difficult for her to reconnect with people:

I need to get my life back together. We had a family reunion, and I felt so uncomfortable I had to leave. I don't even like anybody coming over . . . when they get there I just don't have anything to say to them. . . . I feel weird A good friend stopped by to see how I was doing. I felt so stupid with him sitting there. I couldn't even look at him or talk to him. I just wanted him to leave. I guess he finally felt that, too, and he left. Before I got sick I never was like that.

All participants expressed sadness over the changes in, or loss of, their social interactions with others.

PSYCHOSOCIAL SUPPORT OF THE HEALTH CARE TEAM

During cancer treatment, as at the time of diagnosis, participants appreciated hopeful attitudes, communication, and psychosocial support from the health care team. Overall, the patients felt included in care planning, respected, and supported by clinicians. Ellen thrived on the encouragement she received from her health care providers:

They were sweet as they could be They were taking care of me and saying, "Keep coming, it's getting better and better. Look at you now, it looks real good." They would talk to me, encourage me . . . give me hope.

Lynn was extremely thankful for the hope and respect tendered by her health care team:

. . . if it hadn't of been for them (health care team) just being honest and walking me step-by-step, I don't think I could have made it. They helped me. After my friends deserted me, I needed somebody and they were the

ones that gave me the words of encouragement, outside of my own family. I appreciate that.

Ellen felt respected by her health care team who treated her as if she was the only patient they had: “They didn’t talk me down. They make everybody feel like they’re special. That’s the way they made me feel and they still do.” When they did not feel respected and supported by health care providers, participants described the experiences in detail. Melvin, the ex-convict, felt isolated, uninformed, and discriminated against when his calls were not returned for over a month:

I said, “Write me a letter, tell me something, let me know.” Then I got to the point where I finally said “Look, . . . is it my age? Is it racial? What is it? I probably said something that you didn’t like, because I can be demanding but I’m only asking you to do your job, that’s all. If you don’t like that . . . you need to find you another occupation.” They neglected me . . . and discriminated against me. Then I called this other nurse and told her and asked her [for] help, and she called the same day It speaks for itself.

Mary struggled with trusting members of her team when they appeared to be so young and inexperienced. When they were also disrespectful, her mistrust and anxiety were exacerbated: “I think that sometimes in a university [teaching] hospital it’s pretty scary when you have children working on you.” Other than these two negative descriptions, participants expressed appreciation for the hopeful, respectful, patient-centered approach of their health care team.

Beyond Cancer

Four main themes surfaced throughout all interviews, revealing the overriding goal of living beyond cancer: focus on living, not dying; reclaiming normalcy; resiliency; and spirituality.

FOCUS ON LIVING

Even with advanced disease, participants overwhelmingly wanted to focus on living beyond their cancer. Melvin decided to focus on living when he lived beyond his prognosticated “day of death” multiple times:

They gave me a terminal situation. . . . and the next thing I know I’m hearing all these dates. I just said “Don’t even say that to me no more.” It’s a God thing. It’s in His hands. It’s His call. Professional opinions I respect and appreciate, but He’s got the best one of all. If I see you tomorrow fine. If I don’t, I ain’t mad cause I’ve done everything: a lot of bad, a

lot of good, but I done lived. I made my own choices. . . . and that's what I'm gonna do now.

Sara put it simply when describing her focus on living: "My heart is still beating, so I'm moving on." Linda did not even want to discuss her prognosis; she just wanted to live and fight: "If they tell you you've got 3 months, what are you going to do for 3 months? You're not going to be a happy person and nobody else is going to be either." Even as they accepted that they had terminal cancer, these participants chose to cope and remain hopeful by living.

RECLAIMING NORMALCY

Participants sought to focus on and resume the parts of their lives drastically changed or lost after their cancer diagnoses. Sara, diagnosed in her last year of high school, mourned the loss of her senior year and the transition to college: "I miss school; if I could be back in the world right now, I'd be in school studying . . . something, anything. I never thought I'd miss school but that's what I miss." Sam was anxious to get back to his role as husband, provider, and father of two: "I'd like to see myself good to go. You know, get on back to my life." Lynn was adamant that she be able to reclaim her work as this was a vital part of her identity: "I want to go back to work. If the doctor says I can go back to work, then I want to go back." Many others expressed similar hopes which centered on a return to fulfilling their various social roles.

RESILIENCY

All participants displayed a positive capacity to cope with the stressors associated with the cancer experience. Melvin focused on all of his prior successful adjustments to difficult life experiences in order to cope with his cancer: "I've been through too much in my life, I just can't bow down. I can't just throw in the towel." Ellen allowed herself to cry as long as she needed to, then she moved on to fighting her illness: "You have to get it out of your system and then you're ready to face what you have to face." Lora focused on fighting and the latest news about her treatment success:

Don't give up; fight, because people have second chances So I'm one of those people who wants to have a second chance As time went on, coping with it started getting a little better. Every time they (providers) give me some good news it makes me feel better.

Mary lost her appetite and over 100 pounds because of her illness, but she finally realized that if she wanted to live, she was going to have to eat:

“I hadn’t had nothing but one bite to eat a day. I finally just got up and went to the mirror and looked at myself and said ‘I’m going to die,’ and I started eating.” Although realizing the seriousness of her illness, Mary chose not to concern herself over things she could not control; instead she chose to be thankful for what she did have—time and family: “I always look at it like it could always be worse. I can say I love you to my family and spend time with my grandkids.” The youngest participant and her mother used humor as a major coping mechanism as evidenced in this statement related to her prognosis: “I asked them, ‘So do I have an expiration date?’ They didn’t get it. They went, ‘oh . . .’” And her mother’s sarcasm in this statement: “She’s really quite remarkable. She should be dead. Hey, are you alive or dead today?” Resiliency, in one form or another, was evident in all interviews.

SPIRITUALITY

A universal source of coping for the participants was finding meaning through inwardly focused contemplation, meditation, prayer, and religion. Anita felt as though cancer was a gift in that regard: “I call it my blessing a lot of times. It brought me back spiritually in touch to where I just have more faith.” Sam, having struggled with the lifelong illness of his child, and his wife’s breast cancer, faced his own cancer fearlessly because of faith in God: “I never really worried about it. I knew it was going to be taken care of. I’m a firm believer that if they (health care providers) can’t take care of it, God can.” Melvin drew from his lifelong faith instilled by his mom: She said “Boy, get that Bible and go in there and sit down and read. He ain’t going to put no more on you than you can bear.” Lynn, reflecting on the way she lived her life before cancer, was thankful for a new sense of clarity and strength: “It’s like every day that I get up I have to thank God for giving me strength. Before it was just like I would just get up and go to work, I didn’t have a care in the world, but when you have cancer . . . you think a whole lot different.”

All participants either came to the cancer experience with a strong sense of spirituality or employed a newly discovered spirituality to adjust to their new life situation.

DISCUSSION

This study sought to understand the unique experiences and needs of Medicaid recipients with advanced cancer. Participants were all diagnosed with advanced disease and enrolled in Medicaid post-diagnosis. This was consistent with prior quantitative findings showing that such patients are more likely to have metastatic disease than those diagnosed while on Medicaid (Bradley et al., 2003; Halpern et al., 2008; Koroukian et al., 2006; Perkins et al., 2001). Because of their socioeconomic and insurance status,

participants had advanced disease at time of diagnosis, thus hindering their potential for successful treatment or cure of their disease. This finding is timely in the context of the continuing debate about national health insurance. One can only speculate on how having health insurance prior to rather than post-cancer diagnosis may have altered their outcomes. Although many people delay medical intervention when they fear the cause of their symptoms, late diagnosis is known to be more frequent in those who are poor or uninsured (IOM, 2009).

This study shares some similarities with other qualitative studies of persons living in poverty who became seriously ill. As with Moller (2004) and Hughes et al. (2007), many of the participants in this study had experienced struggles and serious difficulties throughout their lives. For example, the married couple interviewed individually (she with breast cancer, he with brain cancer) also had a disabled child. When her breast cancer was diagnosed, she was also pregnant and had to choose between carrying her unborn child or receiving aggressive treatment for her cancer in the hope that she would survive to raise their disabled child. Another participant admitted he had led a tumultuous life and made many mistakes. When diagnosed while incarcerated, he felt “dumped” into the health care system on his own after release. Several were single mothers who had struggled to raise families while working in minimum wage positions. One was forced to move in with her sister, and during her cancer treatment her sister’s home burned to the ground. One participant, a licensed medical professional with a history of military service, had lost her job and license during an employment dispute, forcing her to work a minimum wage job. She delayed seeking medical intervention because, for the first time in her working life, she had no health insurance. While such struggles were shared by all participants, these incidents were not a focus or significant theme in interviews. Rather, they focused on overcoming disease and returning to their lives.

Like Moller’s (2004) participants, these patients were grateful for the care received. All expressed gratitude for Medicaid assistance and an appreciation for health care providers. Also, similar to Moller (2004), this study found “the emergency room (ER) is often the front door to healthcare” (p. xiv), in that half of patient’s entry into the medical system was via the ER. Like other studies (Moller, 2004; Williams, 2004), several participants experienced social isolation which increased their suffering. Another finding shared with both Moller (2004) and Song et al. (2007) was the significant role of faith and spirituality in giving patients strength and resiliency.

Similar to the Hughes et al. (2007) study of the urban poor living with cancer, patients focused more on living with cancer rather than preparing for death. Each patient had been approached about advance directives, yet none had completed the legal documentation. Several had outlived their prognosis and clearly stated they did not want any more estimations of their life span.

Unlike Moller (2004) and Hughes et al. (2007), participants did not perceive their interactions with health care providers to be disrespectful or uncaring except for infrequent occasions. This may be unique to the health care community or the particular setting for this study (a university cancer clinic providing care to the city's indigent patients). It is notable that the professionals treating patients at this clinic consistently communicated compassion and encouragement, and they are to be commended. The fact that participants did have health care coverage of some sort, albeit Medicaid, may have also contributed to more respectful interaction as providers may not have known the payer source (other than the oncology social worker who assisted with financial concerns).

Limitations and Strengths of the Study

While generalizability is not a goal of qualitative research, transferability of findings should be considered in light of a few limitations. First, all participants received care at the same cancer treatment facility and interacted with the site-specific health care teams of that particular center. These providers care for the community's indigent and are therefore well-versed in attending to those with limited resources. Participants were referred by the oncology social workers and case manager who assisted them during the cancer diagnosis and treatment experience, which may have contributed to the positive feedback related to the oncology social work role. While our sample size may be viewed as small, participants were recruited to the point of data saturation. The fact that the researchers had experience providing supportive care to cancer patients may have distorted the findings; however, every effort was made to suspend judgment and rely on verbatim transcripts. Strengths included an in-depth approach, and sample variability in age, gender, diagnosis, and race, while focusing on a specific understudied population (Medicaid eligible patients with advanced cancer).

For the participants who were uninsured when diagnosed with advanced cancer, Medicaid was the safety net that allowed them to receive adequate health care services from a consistent interdisciplinary team of health care providers. One can only hypothesize that the health care experience might be more devastating for those 3 out of 5 persons living in poverty but not eligible for Medicaid benefits (Inglehart, 2010). Participants were treated with respect and encouragement, and all maintained an attitude of hope and gratitude. Thanks to the assistance of skilled oncology social workers, they were able to apply for assistance, navigate the health care system, and have their basic needs addressed. This then allowed these participants to concentrate on their battle with cancer, a war they hoped to win. Interdisciplinary care involving oncology social workers who not only avoid stereotypes and assumptions about patients and address the "whole person"

response to life-threatening illness is an important experience that transcends insurance or socioeconomic status.

CONCLUSION

It is somewhat surprising that participants placed so little significance on their lives of poverty or their previous lack of access to needed health care resources. Rather, they responded to a dismal diagnosis much as one would expect of any human being. Other than late diagnosis, the experience of these 10 patients with advanced cancer was not shaped by dependence on Medicaid for health care coverage. After Medicaid eligibility, they were able to confront their disease while experiencing the human emotions, concerns, and resiliency one might expect of any person, regardless of socioeconomic and insurance status. Their battles with cancer were characterized by a fighting spirit fed by the hope and encouragement of supportive, compassionate health care professionals. While tremendous financial challenges and fears accompany the experience of serious illness for those with inadequate insurance and financial resources, after this is addressed and resolved, these issues are allowed to become secondary to the common human responses to a diagnosis of life threatening cancer.

REFERENCES

- Bradley, C. J., Given, C. W., & Roberts, C. (2003). Late stage cancers in a Medicaid-insured population. *Medical Care*, *41*(6), 722–728. doi:10.1097/01.MLR.0000065126.73750.D1
- Colaizzi, P. F. (1978). Psychological research as the phenomenologist views it. In R. S. Valle & M. King (Ed.), *Existential phenomenological alternatives for psychology*. New York, NY: Oxford University Press.
- Creswell, J. W. (1998). *Qualitative inquiry and research design: Choosing among five traditions*. Thousand Oaks, CA: Sage.
- Daly, H. F., III, Oblak, L. M., Seifert, R. W., & Shellenberger, K. (2002). Into the red to stay in the pink: The hidden cost of being uninsured. *Health Matrix*, *12*(1), 39–61.
- Halpern, M. T., Ward, E. M., Pavluck, A. L., Schrag, N. M., Bian, J., & Chen, A. Y. (2008). Association of insurance status and ethnicity with cancer stage at diagnosis for 12 cancer sites: A retrospective analysis. *The Lancet Oncology*, *9*(3), 222–231. doi:10.1016/S1470-2045(08)70032-9
- Hughes, A., Gudmundsdottir, M., & Davies, B. (2007). Everyday struggling to survive: Experience of the urban poor living with advanced cancer. *Oncology Nursing Forum Online*, *34*(6), 1113–1118.
- Inglehart, J. K. (2010). Entry point. *Health Affairs*, *29*(2), 230–232.

- Institute of Medicine. (2009). *America's uninsured crisis: Consequences for health and health care*. Washington, DC: National Academies Press.
- Kelz, R. R., Gimotty, P. A., Polsky, D., Norman, S., Fraker, D., & DeMichele, A. (2004). Morbidity and mortality of colorectal carcinoma surgery differs by insurance status. *Cancer, 101*(10), 2187–2194.
- Koroukian, S. M., Beard, H., Madigan, E., & Diaz, M. (2006). End-of-life expenditures by Ohio Medicaid beneficiaries dying of cancer. *Health Care Financing Review, 28*(2), 65–80.
- Kvale, S. (1996). *InterViews*. Thousand Oaks, CA: Sage.
- Kwok, J., Langevin, S. M., Argiris, A., Grandis, J. R., Gooding, W. E., & Taioli, E. (2010). The impact of health insurance status on the survival of patients with head and neck cancer. *Cancer, 116*(2), 476–485.
- Moller, D. W. (2004). *Dancing with broken bones*. New York, NY: Oxford University Press.
- Padgett, D. K. (1998). *Qualitative methods in social work research: Challenges and rewards*. Thousand Oaks, CA: Sage.
- Perkins, C. I., Wright, W. E., Allen, M., Samuels, S. J., & Romano, P. S. (2001). Breast cancer stage at diagnosis in relation to duration of medicaid enrollment. *Medical Care, 39*(11), 1224–1233.
- Quinn Patton, M. (2002). *Qualitative research & evaluation methods* (3rd ed.). Thousand Oaks, California: Sage.
- Riedel, L. M. (2009). Health insurance in the United States. *American Association of Nurse Anesthetists Journal, 77*(6), 439–444.
- Roetzheim, R. G., Gonzalez, E. C., Ferrante, J. M., Pal, N., Van Durme, D. J., & Krischer, J. P. (2000). Effects of health insurance and race on breast carcinoma treatments and outcomes. *Cancer, 89*(11), 2202–2213.
- Roetzheim, R. G., Pal, N., Gonzalez, E. C., Ferrante, J. M., Van Durme, D. J., & Krischer, J. P. (2000). Effects of health insurance and race on colorectal cancer treatments and outcomes. *American Journal of Public Health, 90*(11), 1746–1754.
- Rubin, H. J., & Rubin, I. S. (2005). *Qualitative interviewing: The art of bearing data*. Thousand Oaks, CA: Sage.
- Sanders, C. (2003). Application of Colaizzi's method: Interpretation of an auditable decision trail by a novice researcher. *Contemporary Nurse, 14*, 292–302.
- Song, J., Bartels, D. M., Ratner, E. R., Alderton, L., Hudson, B., & Ahluwalia, J. S. (2007). Dying on the streets: Homeless persons' concerns and desires about end of life care. *Journal of General Internal Medicine, 22*(4), 435–441.
- Sorlie, P. D., Johnson, N. J., Backlund, E., & Bradham, D. D. (1994). Mortality in the uninsured compared with that in persons with public and private health insurance. *Archives of Internal Medicine, 154*(21), 2409–2416.
- Williams, B. R. (2004). Dying young, dying poor: A sociological examination of existential suffering among low-socioeconomic status patients. *Journal of Palliative Medicine, 7*(1), 27–37.
- Wilper, A. P., Woolhandler, S., Lasser, K. E., McCromick, D., Bor, D. H., & Himmelstein, D. U. (2009). Health insurance and mortality in US adults. *American Journal of Public Health, 99*(12), 2289–2295.

APPENDIX 1: INTERVIEW GUIDE

Introduction to interview:

The purpose of this interview is for you to share the story of your illness so that others can better understand your situation and current needs and design programs that help meet those needs. I will ask you to tell me about some aspects of your illness, but please feel free to share anything you feel you want me to know.

First, can you give me some basic information?

- What is your age?
- What is your relationship status?
- Do you have children? How many?
- How many live in your household?
- Who would you consider to be your primary caregiver?
- What is your approximate monthly income? From what sources?
- Do you receive any other aid such as food stamps?

Please tell me about your health and health care before your cancer diagnosis.

Questions that might be asked to facilitate sharing:

- Did you consider yourself to be healthy? Why or why not?
- What health problems did you/have you had besides your cancer?
- Who provided your medical care? How did you pay for it?
- Did you get regular medical check-ups? If so, where? If not, why not?
- What did you do when you were sick?
- How were you treated by your medical care providers?
- Were you employed? Did you have health care benefits?
- Did you think you had healthy behaviors? If so, describe. If not, what did you do that you considered to be unhealthy.

Now, please tell me about your cancer starting with your first symptoms, how you found out it was cancer, and what has happened with your cancer since you were diagnosed or told that you had it.

Questions that might be asked to facilitate sharing:

- When did you first think something might be wrong with you?
- What symptoms did you have?
- What did you do about the symptoms?
- When did you seek medical care?
- Where did you go for that care and why?
- Where were you diagnosed?

- How were you told that you had cancer?
- What were your thoughts and feelings when you were told you had cancer?
- What were you told about the seriousness of your disease?
- If you had cancer earlier and this is a reoccurrence, how did you find out the cancer had come back?
- Describe how you were treated by your physicians? Nurses? Other health care providers?
- Who was most helpful to you in understanding your illness and deciding what to do? How were they helpful?
- What options or choices were you given related to treating your disease?
- Did you feel you were included in decision making? If so, how? If not, who made the decisions about your care and how were they made?
- Did anyone talk with you about advance directives? If so, who?
- Do you have an advance directive or living will? Why or why not?
- Did you have health care insurance before your diagnosis? When you were diagnosed?
- If you had no health care insurance, how did you pay for your care?

Please tell me how your cancer diagnosis has affected your:

- ability to function, perform work and other activities?
- income and worries related to money?
- pain and other symptoms such as nausea and fatigue?
- social and family relationships?
- your emotions?
- your religion or spirituality?

Are there other parts of your life that have been affected by your illness? If so, what are these and how have those areas been affected?

When did you become eligible for Medicaid?

Tell me about the factors or events that caused you to become eligible for Medicaid?

How did you feel about going on Medicaid?

Do you feel you are treated differently than others with private insurance when you go for health care? If so, how?

How did becoming eligible for Medicaid change things for you?

What has been the most difficult thing about your illness?

Are there other problems you have had since becoming ill?

What do you need the most right now related to your illness? Is that need being addressed by anyone? If so, who is helping you?

Who is available to help you when you are sick?

What is your worse symptom?

*How happy are you with efforts to manage that symptom?
Do you have other bothersome symptoms? If so, what are they?
Are you happy with efforts to manage these other symptoms?*

What is your biggest concern at this time?

What or who could help you with that concern?

What would you like to see happen related to your cancer?

How can your Medicaid provider best help you during this time?

If you could change anything about your illness experience so far, what would it be?

Is there anything else you would like to share?