Utilization of Religion and Spirituality by African American Cancer Patients in Coping with their Illness

Lee S. Caplan, MD, MPH, PhD
Cheryl L. Holt, PhD
Emily Schulz, PhD, PhD, OTR/L, CFLE
Penny Southward, MPPM
Victor Blake, MD, MTS

1st Annual Meeting of the Society for Spirituality, Theology, and Health
Durham, North Carolina
Thursday, June 26, 2008

Background and Significance

- African Americans experience health disparities in most chronic diseases, including cancer.
  - (American Cancer Society, 2007)
Background and Significance (cont.)

- Spirituality, religion, and faith
  - (Koenig, McCullough, & Larson, 2001)
  are all part of the spiritual context
  - (American Occupational Therapy Association, [AOTA], 2002)
  and are meaningful aspects of the African American culture.
  - (Chatters, Taylor & Lincoln, 1999)

Spiritual Context

- **Definition** = “the fundamental orientation of a person’s life; that which inspires and motivates that individual” (AOTA, 2002, p.42).
- **Examples** = “Essence of the person, greater or higher purpose, meaning, [and] substance” (AOTA, 2002, p.42).
Background and Significance (cont.)

- Well-established positive association exists between religion/spirituality and cancer coping.
- Less well-established is how they are related, which aspects of religion/spirituality are important for coping.

Background and Significance (cont.)

- Understanding the link between the spiritual context and health for African Americans would enable us to develop enhanced, faith-based, culturally-relevant interventions for this population.
Religion

- Entails structured worship and practice and involves theological beliefs.
- We defined religion as "an organized system of beliefs, practices, rituals, and symbols."

Spirituality

- More elusive to operationalize than religiosity
- May include transcendent experiences and can also include religion; having to do with "one's transcendent relationship to some form of higher power"
- In this paradigm, religion may be viewed as a component of spirituality
- We defined spirituality using a model involving connectedness to self, others, a higher power, and the world
### Definition of Spirituality based on Literature Review

- Experiencing a meaningful connection to
  - our core self,
  - other humans,
  - the world, and/or a
  - Greater Power,
- as expressed through our
  - reflections,
  - narratives, and
  - actions,
- within the context of
  - space and
  - time.

### Purpose

- The purpose of this study was to determine whether, and if so how, African American cancer survivors use religion and spirituality in coping with cancer.
Sample

- University of Alabama at Birmingham and Morehouse School of Medicine clinical sites were used to recruit participants
- 23 African American cancer survivors
  - Diagnosed with cancer at least 6 months ago but not more than 5 years ago
  - Any cancer site eligible except skin cancer
- 9 men, 14 women
- Aged 21-80 years (Avg. age: 59.19 years)

Study Procedures

- Face-to-face, semi-structured interviews
  - 26 open-ended questions and probes
- Two interviewers (African American females)
- Participants recruited from physician offices and completed 60-90 minute interview
- Interviews were audio taped and transcribed verbatim
**Instrumentation – Sample Questions**

| Q10. What has helped you to cope with cancer? |
| Q11. How, if at all, has religion and/or spirituality helped you to cope with cancer? |
| Q18. How, if at all, has religion and/or spirituality been negative for your coping with cancer? |
| Q20. Ok, now we’re going to talk just about spirituality: Spirituality may be defined as “experiencing a meaningful connection to our core self (spirit, heart, soul), other humans, the world, and/or a greater power as expressed through our reflections (thoughts), narratives (life stories), and actions.” Tell me your thoughts about that definition. |
| Q21. Now, let’s break down the definition and discuss its parts one by one. Tell me about any experiences you have had with meaningful connections over the course of your experience with cancer? |

**Data Analysis**

- An inductive process using an open coding method done by 7 independent reviewers
- Codebook developed for religiosity and spirituality themes
- Coders unaware of participants’ demographic data
- Categories and codes were grouped together based on analysis
Results

Religiosity themes that emerged included control over one's illness, emotional response, importance of social support, role of G-d as a healer, relying on G-d, importance of faith for recovery, prayer, scripture study, and how one makes sense of the illness.

Results (cont.)

• Spirituality themes reflected connectedness to G-d, self, others, and the world
• Participants reported gaining a new perspective on life as a result of their cancer experience
Religiosity Codes

- Religious Beliefs
  - R/S not Negative
  - Devil / Satan
- Religious Behaviors
  - Thanks to G-d
  - Prayer
  - Church
  - Bible / Scripture Study
- Control beliefs
  - Social Support
- Affective Response
  - Suffering
- Adaptation
  - Non R/S Coping
- Meaning Making
  - Death/mortality
- Faith / Belief
  - G-d - Healer
  - G-d — Help

Religiosity Themes

Religious Beliefs

- When asked whether religion/spirituality has ever had a negative impact on their cancer coping, participants overwhelmingly felt that it did not.

- Several participants indicated that the Devil (Satan) may be the cause of illness, by tempting one into sinful behaviors, and/or the cause of cancer recurrence through the same mechanism.
**Religiosity Themes**

**Religious Beliefs**

**Example quotes:**

- “[Religiosity] has never been negative to me for anything. I have been negative, but my L-rd has never been negative…”
- “…Just like G-d, the Devil is busy all the time and the Devil can act like G-d, and some people say I feel like the Devil can do good things, to trick you, he will act like G-d for me a minute, but once he get you out there to do whatever, he gets you and the next thing you know, everything else is falling down hill for the Devil…”

---

**Religious Behaviors**

- Some participants expressed the theme of being thankful to G-d and praising him daily; others thanked G-d for their medical team
- The role of prayer was viewed as important in coping with and recovering from cancer; in times of need, one could always pray and receive strength and coping; prayer was used to feel better and to cope with stress
- The prayers of others is also important in the cancer experience
- However, this patient also indicated that one must have a strong belief and faith for the prayers to be effective
- Many participants felt they received support by reading the Bible, including healing scriptures; this gave comfort and reassurance to some; Bible study was often done in conjunction with prayer
- Participants cited church attendance as a way of obtaining comfort
Religiosity Themes

**Religious Behaviors**

Example quotes:

- “I just went to pray about it & asked the L-rd that His will be done.”
- “I may tell one other person and that is my prayer partner. My prayer partner is a nurse and she can handle the burden.”
- “Well I can add that I thank G-d for people like Dr. [Name] and Dr. [Name], and these great doctors that we have today.”
- “…I am a strong believer of reading my Bible, I always had my scriptures I would read and you know I pulled through.”
- “…because when I read His word it gives me what I need to make me feel better you know to feel that I know that I can trust and believe into Him and His word…”
- “You have to pray, meditate, and go to church.”

**Locus of Control / Control Beliefs**

- Many participants indicated they did not feel they had control over their cancer, whether it would be cured, or whether it would recur.
- Some felt that G-d was in control of their illness prognosis and by realizing this, one could be freed of some of the stress of the situation.
- Many believed that one could will themselves well, that the mind holds great power, so that by thinking positive or negative thoughts or speaking positively or negatively, a person could influence prognosis.
- Participants did not want to claim or verbalize an ill feeling.
- Participants would cope by staying, speaking, and thinking positive.
- Perhaps the most important (along with support from G-d) aid to coping was social support, including family members and the church family, in the form of emotional support or instrumental support.
Religiosity Themes

Locus of Control / Control Beliefs

- Example quotes:
  - "...like I said it made me realize that I am not really in control of this. If I was in control I would not have had cancer, so I think that it makes you aware that you are not really in control, there is a higher power."
  - "When I got in the car I said G-d, I am not going to deal with this..."
  - "I just say that the cancer is not there. It is gone. If I accept it and say that I have it then I am speaking it on to myself. I speak it off me."
  - "A lot of times, I just takes it off my mind some times but you know it is hard to get off my mind. I sit around and my brother comes around and we play dominos and we play cards, you know, it is just something to do, to have something to do."
  - "And sometimes you can draw strength from other people."
  - "...my wife still does the carrot juice for me and we heard that carrot juice is pretty good you know for cancer..."

Religiosity Themes

Affect / Affective Response

- Participants reported experiencing an array of emotions in the context of their cancer experience:
  - from initial emotions such as anger, denial, shock, crying, embarrassment/shame, fear, and self-pity,
  - to feelings of acceptance, hope, staying positive, and the worry being replaced with a focus on living;
  - Some hid their emotions, feeling hurt on the inside while trying to appear strong on the outside
  - Others felt that their religion helped them to ease their fears
  - Participants reported suffering through effects of treatment, medication side effects, general symptoms and bodily changes
Religiosity Themes

Affect / Affective Response

Example quotes:

- “...Yeah, I did not talk to nobody, I didn’t say what the doctor said or nothing. I guess I was trying to accept it myself. I was in denial.”
- “...you don’t think...16 years old, I can catch cancer,... it never crosses your mind that it can happen to you so that was just a total shock for me...so I mean it was just a big surprise, just totally shocking.”
- “...Because of the pain I am suffering, they had me on pain medication..., at times it just don’t work and I just have to put up with the suffering.”
- “... Sometimes I get kind of tired because of the radiation treatment, I get exhausted, but that’s all part of it.”
- “... the chemo made me darker than my skin color that is just coming back and some places I still have dark patches...it's kind of like a bomb just kind of blew up inside of me and everything is just recovering from that explosion you know, my fingernails kind of turned black and they are kind of peeling off and are just like growing like that black part, peeling off and I got new nails growing, my hair is just now growing back...”

Religiosity Themes

Adaptation

- For many participants, having cancer involved learning to adapt to the disease
- Participants discussed a desire to return to a normal life
- The cancer often resulted in a limited ability to do things or participants had to do things at a slower pace than they were accustomed to doing them
- Participants also reported on secular things in their lives that helped them to cope, such as keeping busy, or focusing on the treatment regimen, or maintaining a healthy lifestyle; others went back to their normal routine
Religiosity Themes

Adaptation

Example quotes:
• “I’m dealing with it but it’s very hard. It’s very hard to deal with. But my life has come to a halt.”
• “...like right now I was out getting my resume back out just trying to start back working somewhere and I said that I would have a job next week...”
• “I used to could prepare dinner in 1 day, it takes me 3 now...”
• “My legs is aching and I go to hurting you know and I try to go fishing to keep myself amused by something...”
• “I just asked him different questions about the operation...”
• “All I could think was dying but at that particular moment and now I see you know if I do the right thing and try to do, live right and eat right...”
• “…did normal things because my house was clean before I went to the hospital. I had friends to go over.”

Religiosity Themes

Sense of Meaning / Meaning Making

• Participants felt a need to search for an explanation why this happened to them, often involving a frustrated or angry “why me” experience,
• later followed by an interpretation involving the context of one’s religion/spirituality;
  • G-d allows things to happen for a reason;
  • G-d would not put more on people than they could bear ;
  • G-d provided the cancer experience to enable them to provide testimony to others, or to strengthen them;
  • Many cited the L-rd’s plan;
  • Many cited idea that G-d would not allow a person to die until it was “their time”
• The experience of cancer resulted in participants realizing their own mortality, perhaps for the first time in a real sense; some wondered how long they had to live; others talked about fearing death
Religiosity Themes

Sense of Meaning / Meaning Making

Example quotes:

• “But my first thought was why me, at 58? When I had my mammograms every year and every year they would tell me the same thing, everything is okay.”
• “I believe it is for a reason that I go through this. It was supposed to happen.”
• “I think it plays a part in that I know that the cancer is not going to do anymore damage to me than the L-rd allows.”
• “And I’m like okay but, at that time I didn’t believe, I just was gonna die and then I’m like who gonna take care of my children and what I’m gonna do.”
• “Well, he told me, it was cancer…and it was a slap in the face more or less, death sentence right then, the thought was, what am I going to do, who should I call, what will I do? How long you know will I live?”
• “I look and try to help people and other times and other times I worry about the hurry of death, in other words about dying from this cancer.”

Religiosity Themes

• The role of having faith and a belief in G-d was viewed as highly important for coping, recovery, and in the avoidance of cancer recurrence
• Faith/ belief/ trust was also reported to bring strength and comfort
• When asked whether one’s faith had increased, decreased, or stayed the same since their experience with cancer, most indicated that their faith had increased
Religiosity Themes

Faith / Belief

Example quotes:

- “If you just keep faith, knowing that there is going to be a better day and things are not going to keep going down…”
- “…faith and prayer and knowing that through faith and prayer, everything will be alright. But you got to believe that, you can’t just say it, you got to believe.”

Religiosity Themes

G-d - Healer

- Participants viewed a strong role of G-d as a healer, either directly or through doctors and medicine
- Some felt healing could only occur with G-d and not through doctors alone
- Many felt that if they were healed, it was G-d’s will for them
- Others said that G-d gives the doctors and nurses the ability to heal or provides the technology for the treatments
Religiosity Themes

G-d - Healer

Example quotes:

• “...it just wasn’t the medicine it was just the prayers and the belief that I got and trusting and believing in His word that He would bring me through this...”

• “…it was severe for about 18 months and then it began to subside and I knew that the L-rd had stepped in to take care of whatever could not be taken care of by medicine. Because healing comes supernaturally and also naturally because the L-rd works through doctors giving them the gift of knowledge and the ability to use it...”

Religiosity Themes

G-d - Help

• G-d was seen as:
  • another person in the participants’ lives,
  • helping them to pull through; many mentioned that they would not have made it had they not been able to rely on G-d, and
  • providing insights or guidance.

• G-d would make things better, provide a great sense of comfort and strength, and perhaps helping to ease their stress

• The presence of G-d in their lives was viewed as important as social support from friends and family members, with some saying that G-d was there when nobody else provided support
**Religiosity Themes**

**G-d - Help**

**Example quotes:**

- “I am doing absolutely wonderful. G-d has been taking care of me.”
- “So I just believe whatever the Lord gives you He has already provided a means to deal with it.”
- “If it hadn’t been for G-d, I couldn’t cope with nothing.”
- “As you reading the Bible you got to trust the good master and He will help you pull through it, because sometimes you don’t have no one else but Him to help you.”

**Role of Religion in Cancer Coping and Quality of Life**
**Spirituality Codes**

- **Connections to G-d/ Relationship with G-d**
  - Closer relationship with G-d; Relationship with G-d
  - Important in Coping; Relying on & Conversing w/ G-d; Seeking G-d’s Presence

- **Connections to Others**
  - Family; Friends; Church
    - Others with Cancer; Treatment Team

- **Connections to Self**
  - Becoming a Better Person; Increased Self-Understanding
    - Self-Honesty & Self-Love

- **Connections: Negative**
  - Spouse-stress; Family-meddling; Friends-abandonment

- **Connections to World**
  - Helping Others; Giving to Charity; Volunteering
    - Giving Others a Better Cancer Experience

- **New Perspective**
  - New Perspectives on Life; Change in Priorities; Changing for the Better

- **Share Story**
  - Encouraging Preventive Health Behaviors; Offering Encouragement During the Treatment Process

**Spirituality Themes**

**Connections to G-d/ Relationship with G-d**

- Participants indicated experiencing increased closeness with G-d and stressed the importance of having a relationship with G-d when coping
- They also relied on and conversed with G-d and indicated a desire to seek G-d’s Presence
**Spirituality Themes**

**Connections to G-d/ Relationship with G-d**

**Example quotes:**

- “I think it has brought me closer to G-d. I have always had a very good relationship with G-d, but I feel that I am even closer because I am forever thanking Him.”

- “... being alone and just talking to G-d and seeking His presence ... I guess I can’t really explain it to you but if you have ever been in G-d’s presence you know it, you know it.”

**Connections to Others**

- Participants also reported on meaningful, positive connections to others (family members, friends, the church family, other cancer patients, the treatment team) as being important in their coping experience.
**Spirituality Themes**

**Connections to Others**

*Example quote:*

- “Knowing that my family is there for me... I have experienced a great connection with my children. And I have connected more with my children since I have experienced the cancer.”
- “But anyway the nurse ... was my guardian angel. She was so nice... [She] helped me to know what was going to happen to me.”

**Connections to Self**

- Many participants expressed experiencing a more meaningful connection to themselves through increased self-understanding, becoming a better person, increased self-honesty, and increased self-love, as a result of their cancer.
**Spirituality Themes**

**Connections to Self**

**Example quotes:**

- “… the cancer itself, it helped me to get in touch with me…”
- “We all have our, some character flaws or whatever, but, I try to make sure that the person I am, the person that I am becoming each day is a better person that I was yesterday.”
- “It gave me; it made me care more about me, take care, better care of me. I usually put everybody else first and not think about self and um love me more…”

**Spirituality Themes**

**Connections: Negative**

- Several participants noted that since their cancer experience, their relationships with others (spouse, family members, or friends) had become strained.
**Spirituality Themes**

Connections: Negative

**Example quotes:**

- “... when marriage problems come up. I have had quite a few. All I do is pray for that mountain to be removed and it does...”
- “... it seems as if they are picking they are meddling, ... and I don’t like that... my auntie and my sister them they act like I am some kind of glass bubble or something, like if you bust it something gonna happen...”
- “I lost a lot of friends so called friends come to find out.”

**Spirituality Themes**

Connections to World

- Participants reported experiencing meaningful connections to the world, through helping others, giving to charity, volunteering, and giving others a better cancer experience.
Spirituality Themes

**Connections to World**

Example quotes:

- “I started dealing with a lot of the charities and fundraisers, people doing fundraisers for cancer. That is one was that is really helping me deal with it...”
- “...In going through the treatment I have participated in several studies and you know um donated tissue for experiments...”
- “I am going to ... try to teach don’t do what I used to do.”

**New Perspective**

- Participants reported that they obtained a new perspective on life, experienced a change in priorities, or became a better person as a result of the cancer experience.
Spirituality Themes

New Perspective

Example quotes:

• “It has given me a more positive outlook. I encourage people.”
• “…the L-rd has given me the privilege to see things in a better light.”
• “Something is different about life to me now. I am dealing with it positively actually.”
• “I feel that my heart is open and I am more connected to the world, more giving.”

Spirituality Themes

Share Story

• Participants desired to share their cancer story with others; to encourage others to engage in preventive health behaviors; and to offer encouragement to others undergoing cancer treatment.
Spirituality Themes

Share Story

Example quotes:

- “I try to tell people about ... what I went through on my experience with this cancer, if I had knew 30 years ago, I never would have picked up the cigarette. I wouldn’t want to see a cigarette.”

- “…I feel I kinda got to share what I went through to other people to make them kinda see thing different and maybe they can change for the better.”

Connections to G-d:
- Closer relationship
- Relationship imp’t. in coping
- Rely on & converse w/G-d
- Seek G-d’s presence

Connections to Others:
- Family
- Friends
- Church family
- Other cancer patients
- Treatment team

Connections to Self:
- Increased self-understanding
- Increased self-honesty
- Becoming a better person
- Increased self-love
- New perspective

Connections - negative:
- Issues with spouse - stress
- Family members - meddling
- Friends - abandonment

Connections to World:
- Helping others
- Giving to charity
- Helping others with cancer
- Share story

Survivorship:
- Coping
- Quality of life

Theoretical Model of Spirituality, Cancer Coping, and Quality of Life
Discussion

• Participants had much to say about the role of religion and spirituality in coping
• This indicates that African Americans perceive these factors to play a strong role in their cancer coping and survivorship
• The findings underscore the value of the spiritual context for the support of well-being, quality of life, prevention of, and coping with disease in the lives of African Americans

Discussion (cont.)

• Clearly, the patients perceived a strong role of a higher power, their faith, and their own will, in their healing, recovery, and avoidance of recurrence; these, coupled with support from family and friends, comprised the main factors that were perceived to facilitate coping
Discussion (cont.)

• Appeared that many cancer patients when first diagnosed were confronted perhaps for the first time with their own mortality, experienced a range of negative emotions, reached for their faith, higher power (including prayer & scripture study), and others around them for coping resources, and were eventually able to make some sort of meaning out of their illness, to explain the “why me” question.

• Resolving “why me” struggle also appeared to help patients to cope.

Discussion (cont.)

• Findings suggest that African Americans coping with cancer may go through a spiritual transformation process which is influenced by the experience of cancer.
• The spiritual process seems to involve experiencing increased closeness with G-d and significant others (family, friends, church family, other cancer patients, treatment team), while at the same time experiencing some negative issues in relationships with others (stress, meddling, abandonment).

• From this process, they gain a new perspective on life; experience positive changes within themselves, and choose to reach out to the world in positive ways through volunteering, charity work, and sharing their cancer story to help others.
\textit{Discussion (cont.)}

- Combining the religiosity/spirituality findings, coping and adaptation to suffering from the cancer experience seems to come about by Divine and medical intervention, assistance from valued others, and gaining a new perspective about life and self.
- The new perspective is expressed through finding new ways of doing; using a reflective process for meaning making; and the subsequent sharing of one’s story.

\textit{Discussion (cont.)}

- From that new perspective, positive actions are taken to reach out to others and the world through volunteerism or donating to charity, which may indicate an increased quality of life.
- Therefore, religion/spirituality may be useful in fostering resilience, coping and adaptation in African Americans with cancer.
Conclusion

• This study, which used qualitative methodology, has laid a solid foundation and groundwork for further study.
• Limitations
  • Limited sample size
  • Limited generalizability of results
  • Results perhaps influenced by cancer stage

Conclusion

• Using the spiritual context with African Americans appears to be an effective approach in promoting their health and well-being
### Implications for Future Research

- Future studies should examine the specific role of the spiritual context in coping with cancer as well as other serious illness among other demographic subgroups (Hispanics/Latinos or Whites), from different religious backgrounds (Jewish, Hindu, Buddhist, Islamic, no religious background), among those living in different geographic regions.

### Implications for Future Research (cont.)

Future plans include:
- Addressing the long term effectiveness of using religious/spiritually-based materials with African Americans through quantitative research design.
Implications for Future Research (cont.)

- Measurement tool could be developed to assess the thematic factors identified in this research, and models of spirituality and coping could be tested.

- Results could then be used to develop and offer support interventions to help cancer survivors cope with their disease.

- Interventions could capitalize on factors that appear to facilitate coping, and be integrated into church-based and/or faith-based support groups.

References


References


Acknowledgement

This work was supported by a grant from the National Cancer Institute (#1 U54 CA118948-01).