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The role of social support in post-treatment surveillance among African American colorectal cancer survivors

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Abstract

Objectives—African Americans are less likely than other groups to receive appropriate surveillance after colorectal cancer (CRC) treatment. The objective of this study is to qualitatively explore the role of social support in post-CRC treatment surveillance and ultimately, inform interventions to promote surveillance in African American CRC survivors.

Design—Interviews were conducted with 60 African American CRC survivors recruited from the Cancer Care Outcomes Research and Surveillance (CanCORS) study and the Alabama Statewide Cancer Registry. Interviews were recorded and transcribed. Transcripts were reviewed and coded independently by the authors. The NVivo software package was used to facilitate coding and data management.

Results—Survivors were from 4 to 6 years post diagnosis, 57% female, 60% older than 65 years, 57% from rural Alabama, 30% with stage 1, 32% with stage 2, and 38% with stage 3 disease. Material and emotional social support from family and one's faith community were cited as playing an important role in coping with the disease and post-treatment surveillance. Survivors who reported being adherent with post-treatment surveillance recommendations (according to stage of disease based on self-report of colonoscopy, CT scans, and blood work) reported more religious material and non-material social support, and support from other CRC survivors.

Conclusion—In these African American CRC survivors, support from family, other cancer survivors, and the faith community was perceived as being important for adherence to post-treatment surveillance. Interventions to increase post-treatment surveillance in this population may be enhanced by including components that emphasize familial, other cancer survivor, and religious support.

Keywords

colorectal cancer; African American; guidelines; surveillance; colonoscopy

Colorectal cancer (CRC) is the second most commonly diagnosed cancer in the United States and the second leading cause of cancer death among cancers that affect both men and women (U.S. Cancer Statistics Working Group, 2013). Since 1980, incidence rates have been slowly decreasing among African American women (0.4% per year), while a more rapid decline (4.8% per year) occurred among African American men during 2003–2007 (Altekruse et al., 2010; American Cancer Society, 2011). However, African Americans continue to have the highest incidence of and death rates from CRC compared to other American racial/ethnic groups (USCS, 2013). Age-adjusted CRC incidence and death rates for African Americans are 13.4% and 9% higher, respectively, than the rates for Whites (USCS, 2013).

While improvements in CRC screening and treatment are partly responsible for reducing CRC incidence and death rates, post-treatment surveillance for survivors has also been shown to reduce CRC mortality (Scheer & Auer, 2009; Desch et al., 2005; Brooks et al., 2008; National Comprehensive Cancer Network, 2012; Hu et al., 2011; Salz et al., 2012; Rolnick, et al., 2005; Rulyak, et al., 2004). CRC surveillance tests consist of colonoscopies, sigmoidoscopies, and barium enemas. X-rays, abdominal CT scans, pelvic CT scans, and abdominal ultrasounds are also used when cancer is regional rather than local (Cooper et al., 1999). Research suggests that Whites are re-tested more often and sooner after CRC treatment as compared to African Americans (Rolnick et al., 2005). For instance, in an HMO population from Detroit and Minneapolis/St. Paul, 11% of African Americans received a follow-up test within 1 year of diagnosis, 48% within 3 years, and 58% within 5 years (Rolnick et al., 2005). In contrast, 21%, 64%, and 70% of White survivors received post-treatment surveillance tests over the same time periods. While the disparity in post-treatment surveillance rates between African American and White CRC survivors is clear (Salz et al., 2012; Ellison et al., 2003; Rolnick et al., 2005; Cooper et al., 2008; Elston et al., 2001), the reasons for this disparity are not clearly understood. Many factors may influence post-treatment surveillance such as physician-related bias, physician-patient communication, and/or patients' lack of understanding about the importance of post-CRC treatment surveillance. Social support is one of these factors. Research has suggested that social support and religious support may have a role in post-treatment surveillance.

Social support refers to the assets that individuals receive through their social connections (Rodriguez & Cohen, 1998) and has been shown to be associated with a number of health behaviors such as screening and access to care. This multidimensional construct includes emotional (e.g., caring and concern), informational (e.g., advice) (House, 1981), instrumental (e.g., tangible goods), appraisal (e.g., feedback) (House, 1981; Cohen & Janicki-Deverts, 2009), and belonging (e.g., sharing company) (Cohen & Janicki-Deverts, 2009) to an individual's social network. Previous studies have shown that social support is associated with many health-related outcomes, including mortality risk, especially among African Americans (Krause, 2011; Krause, 2006b), and also with health care seeking, for

example for preventive services such as cholesterol screenings and flu shots (Benjamins, Ellison, Krause, & Marcum, 2011). Furthermore, social support has also been shown to be beneficial for healthy behaviors such as diet and physical activity (Tang et al., 2008) and smoking cessation (Nollen et al., 2005).

Religious support is a type of social support that occurs specifically in a faith-based setting or context (e.g., provided by clergy and congregation members) (Kanu et al., 2008). Like general social support, religious support is multi-dimensional and includes factors like emotional and anticipated support, though in faith-based contexts (Krause, 2011; Krause et al., 2001; Koenig et al., 2001; Fox et al., 1998; Cohen & Janicki-Deverts, 2009; House, 1981). It is a vital part of the religious experience for African Americans (Krause et al., 2001; Taylor et al., 1996; Koenig et al., 2001; Fox et al., 1998), and may be an important factor in physical and mental health.

Those who have religious support, including care from congregations, spiritual interventions, and assistance from pastors and hospital chaplains, report better physical and mental health than those who do not (George, Ellison & Larson, 2002). Those who are part of a religious or faith community may also be recipients of additional and/or unique social support benefits (Ellison et al., 2010) such as more relationships and larger social networks (Musick, Traphagan, Koenig & Larson, 2000) that thrive because like-minded people with similar backgrounds and values often comprise religious communities (Ellison & George, 1994). Like general social support, religious support has been associated with a number of health-related outcomes such as physical activity (Kanu et al., 2008), lower risk of psychiatric disorders or depression (Ellison & Flannelly, 2009), and all-cause mortality (Krause, 2006). Associations between social support and healthy lifestyle behaviors among African Americans were more pronounced for those with a greater sense of belonging to their congregations (Krause, 2011; Krause et al., 2001; Benjamins et al., 2011; Fox et al., 1998). Congregational support has been linked to increases in cholesterol screenings and flu shots (Benjamins et al., 2011).

While there is a robust literature on the role of social and religious support on healthy behaviors in African Americans, far less is known about the role of social and religious support with regards to surveillance following a cancer diagnosis. In seeking to eventually narrow the gap in rates of post-treatment surveillance between African American and White CRC survivors, the Reasons for Low Follow-Up in Black CRC Patients (“Y So Low”) study examined the role of several types of social support in adherence to post-CRC treatment surveillance recommendations. The study sought to qualitatively explore the role of social support in post-CRC treatment surveillance and ultimately, inform interventions to promote post-treatment surveillance in African American CRC survivors.

METHOD

The Institutional Review Boards (IRB) for the University of Alabama at Birmingham and the University of Maryland, College Park approved the protocol for the Y So Low study. This multi-year in-depth interview study was conducted in 2008–2012.

Participants

Participants in this study were African American CRC survivors with stage I-III disease diagnosed during the period, 2003–2007. Participants were recruited from two sources. We recruited from cancer survivors who participated in the Deep South site of the Cancer Care and Outcomes Research and Surveillance (CanCORS) consortium funded by the National Cancer Institute. With the collaboration of the Alabama Statewide Cancer Registry, this site enrolled CRC patients beginning in October 2003 and targeted patients 3 months post-diagnosis. Potential participants for the Y So Low study were African American Deep South CanCORS participants who completed both baseline and follow-up surveys (N=98). Of these participants, we contacted 62 by phone (63%). Of these 62 individuals, 58 completed a screening survey and 55 agreed to participate in our in-depth interviews (89%). Twenty-four individuals were interviewed (44% of those who agreed).

We also recruited Y So Low study participants from the Alabama Statewide Cancer Registry. Registry personnel contacted the listed managing physician of each survivor by mail to obtain permission to contact the survivor. Permission to contact the survivors was obtained for 989 survivors. From a random list of 399 survivors, 150 were reached and completed the screening survey: 73 (49% of those reached) agreed to participate in in-depth interviews. The remaining 249 survivors were deceased, ineligible, or had inoperable bad phone numbers. From this subset, a total of 36 survivors were interviewed (49% of those who agreed).

Adherence status with follow-up recommendations since diagnosis and surgical resection was determined based on available guidelines from the American Society for Gastrointestinal Endoscopy (ASGE), the American Cancer Society (ACS), and the American Society of Clinical Oncology (ASCO) and was as follows (Scheer & Auer, 2009; Desch et al., 2005; Brooks et al., 2008; Davila et al., 2006):

- for persons with stage I CRC, adherence was defined as having 2 visits/year in the first 3 years post treatment, and 1 colonoscopy since surgical resection;
- for persons with stage II-III CRC, adherence was defined as having 2 visits/year in the first 3 years post treatment, and 1 colonoscopy and 1 CT scan since surgical resection.

The responses given by these participants in the original baseline and follow-up CanCORS surveys were examined to determine any association with compliance with post-treatment surveillance.

Y So Low In-Depth Interviews

Using an interview guide prepared by the investigators, one interviewer and one note taker conducted interviews with each study participant. In-depth interviews continued until investigators determined that saturation was reached, i.e., until upon the review of the transcripts no new information emerged (Glaser & Strauss, 1967). Interviews were conducted in the home of the participants or in another place of their choice over a period of eight months in 2009 and 2010. The guide covered the following topics:

1. Social support. Questions aimed at understanding the role of social support from family, religious communities, and also other cancer survivors;
2. Treatment experience. Questions aimed at describing how survivors felt about the care they received: participants were asked to describe how they found out about having cancer, the perceived effectiveness of their primary treatment, their relationship with doctors and other providers, their role in decision making, and satisfaction with care;
3. Knowledge about post-treatment surveillance requirements. Questions aimed at understanding what patients were told after completing primary treatment, what instructions were given to them about surveillance, and whether they were confident they knew what to do for follow-up;
4. Quality of life. Questions aimed at understanding the quality of life of the survivors that may prevent them from going to the doctor and get the recommended tests;
5. Barriers and facilitators. Questions aimed at understanding whether post-treatment surveillance tests were received, and what barriers and facilitators patients may have experienced. These included those at the health care structural and organizational level, accessibility of services and specialist care, and at the personal level such as faith and fatalism attitudes.

Topics for the guide were chosen based upon available literature on the barriers to colorectal cancer screening and surveillance (Greiner, Engelman, Hall, et al., 2004), the Behavioral Model of Access to Care (Andersen, 1995), and the Health Belief Model (Rosenstock, Strecher & Becker, 1988). In addition, a secondary analysis of CanCORS survey data to assess differences between adherent and non-adherent survivors in demographics, disease characteristics, health status, economic status, support and health care system characteristics was conducted. The results of this analysis further informed the development of the interview guide.

Y So Low In-Depth Interview Analysis

Interviews were recorded and transcribed verbatim. A codebook was developed based on initial review of transcripts by the investigative team using an iterative process. The codebook included name of the codes, or themes emerging from transcripts, definition of the codes, examples of text representing the codes, and exclusion criteria. Two pairs of coders (MP and AB; and MM and CH) independently reviewed the transcripts and applied their codes using the NVivo software to facilitate coding and data management. The coders were blind to the adherence status of the interviewee. Each pair of coders reviewed an initial 6 transcripts each and compared their coding, discussing discrepancies until they were confident that their coding was comparable (Kappa > 70%). We then calculated the frequency of use of codes in adherent and non-adherent responders and compared them using chi square tests. Finally, we selected text representative of the codes for each group of interviewees.

RESULTS

Of the 60 African American colorectal cancer survivors, twenty-four (40%) had participated in the CanCORS survey, and 36 were recruited directly from the ASCR. Thirty-one participants were classified as adherent and 29 as non-adherent with guidelines on surveillance following CRC treatment. Survivors were from 4 to 6 years post diagnosis and were almost equally distributed across stage I to III disease (see Table 1). Fifty-seven percent of the respondents were women, 60% older than 65 years, 57% from rural Alabama, 30% with stage 1, 32% with stage 2, and 38% with stage 3 disease (see Table 1). Adherent respondents were more likely to be younger than age 65 than non-adherent patients (48% vs. 31%, respectively). While about 30% of all respondents had stage I disease, adherent respondents were more likely to have stage III disease (45.2%) than non-adherent (31%). Differences in these variables between adherent and non-adherent respondents were not statistically significant.

Family social support

Table 2 presents the social and religious support themes among study respondents. Family support, both material and emotional, was a recurrent theme for adherent and non-adherent survivors. Family material support specifically was also prevalent in both adherent and non-adherent survivors. However, adherent survivors reported this theme somewhat less frequently (84% vs. 90%) than those who were non-adherent with post-CRC treatment surveillance. Participants reporting family material support often spoke of how their families were “always there to see if [they] needed anything [and when their family members] thought [they] couldn’t do [something for themselves]”. One survivor shared how it was his family members that “helped carry [him] to the doctor... helped [him] out with some of [his] finances going to the doctor and [how it was his family members that] motivated [him] to go to the doctor.” Survivors also illustrated family emotional support:

“... knowing that my family might call me at any time and they might say do you need this or need that. All these things give you the drive to do something. It motivates you to know you’re worthwhile. You can’t just sit around and feel sorry for yourself. You get up and start doing whatever you can do for that day.”

Religious social support

Religious support, especially material support, was less prevalent than family support across both groups. As compared to those who were classified as being non-adherent with post-treatment surveillance recommendations, those classified as adherent reported religious material support more frequently (45% vs. 21%). These individuals reported things such as:

“We have missionary people that call you once a week, once a month and check on you and see how you’re doing, if there’s anything you need, if you need something from the store, if you need anything. Then we have ministry tapes and I would get the tape once a week. If I wasn’t able to go to church they would send me one.”

Adherent participants also reported religious non-material support somewhat more frequently (77% vs. 69%), expressing sentiments such as:

“I talked to anybody that would listen to me. I wanted them to know the experience I went through. I wanted them to know how they helped me when they was praying for me, visiting me, even just a phone call or a card, how it just strengthened me.”

Individuals classified as adherent with post-treatment surveillance recommendations also reported faith and coping just as frequently as individuals that were considered non-adherent (97%). This theme was present in the majority of the interviews where participants expressed sentiments such as:

“My faith in the Lord and my family. Just being able to have those relationships gives me the strength to carry on and do whatever I need to do.”

Reiterating the themes of faith and coping, other participants also responded with comments such as:

“Well, they were all sad about it, but I told them I felt like I could pull through it. I had faith. They were all wall-eyed, going on and crying, and stuff, but I didn’t give up. I knew when the thing was over with. Then they were all in the hospital with smiles and no tears—such a blessing” and “I have seen people get diagnosed with cancer and they go into despair. I tell them that with me, I was doing so good that they said, ‘I forgot about you even having cancer.’ I tell them put their faith in God and it’ll be all right.”

However, adherent patients responded that doctors are tools of God more frequently than non-adherent patients (36% vs. 17%).

Support from other cancer patients

Support from others with cancer was reported more frequently (48% vs. 28%) among adherent participants than non-adherent, who often responded that they “... got some pretty good relationships going with them [other cancer patients]. They were very supportive and they seem to have gone through similar situations I had. They kept encouraging me to get my follow ups.” When asked to further describe the support they received from other cancer patients, some respondent shared: “... He was good, because he had the same thing I had. I’d go down there and sit and talk with him; it helped out a lot to be around somebody that had the same problem, or been through the same problem that you’ve been through”, and “... yea, I’ve talked to a couple of older fellows who have taken the treatment and they [were] real[ly] impressed. A couple of them told me to go ahead with it and to make sure I keep with it.”

DISCUSSION

This is the first in-depth study to investigate reasons why African American CRC survivors may not receive surveillance according to available guidelines on follow-up after cancer treatment. To better understand why disparities in post-CRC treatment rates exist, the Y So Low study conducted detailed interviews to examine the role of social and religious support in adherence to post-CRC treatment surveillance.

Family social support

Self-reported receipt of social support received from family was high, and did not differ meaningfully between survivors who reported adherence vs. non-adherence with post-treatment surveillance. Family members served an important role and were present in all aspects of the patient care while providing for their needs. Members in the patients' families provided material support including transportation to and from medical appointments or assistance with household activities, as well as emotional support. Family support was reported more frequently than religious support, suggesting that survivors are relying on those in their family networks more frequently for meeting these needs.

Religious social support

More adherent vs. non-adherent survivors reported religious support themes. This suggests an additional and important role of support received from those in one's faith-based network. These differences, though based on a small qualitative convenience sample, are not likely a function of stage of disease in that there were no differences between the survivors groups across the stages.

Religious social support among the study participants was seen in the form of care from congregations, spiritual interventions, and assistance from pastors and hospital chaplains. The study's findings showed higher levels of religious support reported from the adherent CRC survivors than in the non-adherent CRC survivors. This highlights the importance of the faith community in supporting African Americans with serious illnesses such as cancer. Indeed, faith-based organizations such as churches, often take on the significant roles of praying for the sick and providing support to those who are ill (ACS, 2013; Puchalski, 2001; Breitbart, 2002; Kanu et al., 2008; Masters, Spielmans, & Goodson, 2006; Mytko & Knight, 1999).

These findings are consistent with the previous research conducted on social and religious support (Ellison and George, 1994; Taylor, Chatters, Jayakody & Levin, 1996; Musick et al., 2000; Krause et al., 2001; George, Ellison & Larson, 2002; Ellison et al., 2010; Krause, 2011). Not surprisingly, individuals classified as being adherent reported higher rates of religious support and support from others with cancer than individuals classified as being non-adherent. These findings could potentially reflect the influence of an increased feeling of community with other churchgoers as churches often bring together individuals who share common interests and values. Because members may often retain their affiliation over a long period, strong friendships with other churchgoers may develop (Olson, 1989). For example, religious non-material support may serve to lower anxiety through the receipt of intangible help during difficult times. Having a fellow church member to listen to one's concerns may help ease feelings of doubt or fear. These friendships mean that on average, individuals who regularly attend services enjoy larger social networks, more frequent interaction, and more frequent receipt of (and more types of) support than their counterparts who attend less often (Fagan, 2006; Johnson et al., 2005; Jang and Johnson, 2004; Krause et al., 2001; Bradley, 1995; Ellison and George, 1994; Brown & Gary, 1991; Taylor and Chatters, 1988). Regular church attendees also tend to view their networks as more dependable and fulfilling than other people (Fagan, 2006; Johnson et al., 2005; Krause et al., 2001; Ellison and George,

1994; Brown & Gary, 1991). Finally, churches may promote an environment that is conducive to health in a number of other ways. For example, clergy members may pass health-related messages through sermons or letters published in church publications. These health-related messages may also come in the form of prayers or through informal conversations with other churchgoers (Fox et al., 1998; Koenig et al., 2001; Lannin et al., 1998). The Y So Low results are consistent with prior research demonstrating the positive association between religious involvement, social and religious support, and the use of health care services (Koenig et al., 2001; Fox et al., 1998; Lannin et al., 1998).

Support from other cancer patients

Support from others with cancer also emerged as a potential factor in describing the support structures characteristic of individuals reporting adherence with post-treatment surveillance guidelines when compared to those who were non-adherent. Previous studies have reported the benefit of peer support by cancer survivors on psychosocial outcomes (Hoey et al., 2008) and on participation in health care (Gustafson et al., 2001) by breast cancer patients in particular. Y So Low participants, especially individuals reporting adherence with post-treatment surveillance guidelines, appreciated the opportunity to share their experience with others who had gone through the same ordeal, and received support from these survivors, for example to continue their checkups. It may be, however, that compliant survivors were more likely to have the opportunity to meet survivors because of the relationships established in the clinics during chemotherapy, for example. It may also be that those who are exposed to a greater number of other patients either have a larger social network or were treated in particular types of facilities in which receipt of post-treatment surveillance procedures would be more likely (e.g., larger or specialty facilities).

However, participants also mentioned that survivors approached them, or that they approached a neighbor or coworker who was a cancer survivor. Hence, the relationships were not limited to the cancer care context. Perhaps the encouragement from those going through a similar experience, or informational support (House, 1981) from other patients may help explain why this theme emerged more in adherent patients. Engagement with other survivors may have also led to more information sharing about follow-up care, which some of the patients did express. Therefore, our findings suggest that research is warranted on how cancer patients at all stages of disease may be paired with peer survivors to improve the survivorship experience and especially adherence with follow-up care.

Strengths and Limitations

One of the primary strengths of this study is that it focuses on African American adults, a population heavily impacted by health disparities. Our use of qualitative methodology to explore these disparities is also a strength of this study because it is important to explore, in-depth, reasons why African American CRC survivors may not get the recommended surveillance after CRC treatment. Previously identified as relevant to the uptake of health behaviors (Ellison, Hummer, Burdette & Benjamins, 2010), the Y So Low interview guide also included the exploration of various forms of support (e.g., family and religious), in addition to the exploration of the different types of support within those support domains (e.g., informational, instrumental, etc.).

The present findings must not be over-interpreted and should be taken in the context of some study design limitations. Primarily, uptake of post-CRC treatment surveillance tests was self-reported and receipt of post-treatment surveillance procedures could not be verified. Additionally, several years had elapsed between diagnosis and/or treatment and the implementation of the study. Therefore, adherence with post-treatment surveillance guidelines based on the respondents' recall of procedures received may have been compromised. Future studies may consider validation of outcomes such as post-treatment surveillance (e.g., colonoscopy, CT scans, and blood work) with sources such as medical record data. Another related limitation of the present study is that the participants were from Alabama only. Although our group of participants may be reflective of African Americans in the rural and urban southeastern United States, the generalizability of our findings may not hold true for African American CRC survivors in other parts of the US.

Implications/Future Research

Results from this study suggest an important role for social and religious support in African American colorectal cancer survivors' post-treatment surveillance. Findings from this study allowed us to highlight aspects of patients' support system that may affect understanding of the importance of post-treatment surveillance and, thus, the ability to be adherent with guidelines. Specifically, material and emotional support from the family and faith community were frequently reported as being key factors for those coping with CRC and trying to adhere to post-CRC treatment surveillance. Those survivors who adhered to post-CRC treatment surveillance reported higher rates of religious material and non-material support, as well as support from other CRC survivors.

The findings of the Y So Low study lead to a number of future areas of exploration that may provide a more detailed understanding of the role religious and social support has on post-treatment surveillance in the African American community. These findings may have implications for interventions that seek to improve adherence rates to post-treatment surveillance recommendations by fostering emotional support through health ministries and other structured health activities that faith communities offer to their members, such as cancer support groups. Furthermore, finding additional ways to foster relationships and stimulate informed health-related conversations between members of religious organizations may be beneficial for the CRC survivors' well-being. By following these steps, and by including components that emphasize other cancer survivor, familial, and religious support, the faith community may fill a number of support functions that may improve future interventions and ultimately have a beneficial impact on health outcomes of African American CRC survivors.

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Table 1

Demographic characteristics of participants in the in-depth interviews

	All	Adherent	Non-Adherent	P
N	60	31	29	
CanCORS	40.0%	35.5%	44.8%	0.46
ASCR	60.0%	64.5%	55.2%	
Male	43.3%	41.9%	44.8%	0.82
Female	56.7%	58.1%	55.2%	
Age 40–64	40.0%	48.4%	31.0%	0.09
Age 65–74	28.3%	16.1%	41.4%	
Age 75+	31.7%	35.5%	27.6%	
Stage I	30.0%	29.0%	31.0%	0.47
Stage II	31.7%	25.8%	37.9%	
Stage III	38.3%	45.2%	31.0%	
Urban	43.3%	38.7%	48.3%	0.45
Rural	56.7%	61.3%	51.7%	

Table 2 Social and religious support of CanCORS participants in the Y So Low in-depth interviews

Support	All N = 60		Non-adherent N = 29		Adherent N = 31	
	# with code	% with code	# with code	% with code	# with code	% with code
Religious material support	21	35.0%	6	20.7%	14	45.2%
Religious non-material support	45	75.0%	20	69.0%	24	77.4%
Family material support	54	90.0%	26	89.7%	26	83.9%
Family emotional support	58	96.7%	27	93.1%	29	93.5%
Other cancer patient support	23	38.3%	8	27.6%	15	48.4%
Faith						
Faith and coping	60	100.0%	28	96.6%	30	96.8%
Doctors are tools of God	16	26.7%	5	17.2%	11	35.5%