What precipitates depression in African-American cancer patients? Triggers and stressors

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ABSTRACT

Objective: This study examined general and cancer-related stressors of depression that are unique to African-American cancer patients.

Method: The study used cohort design and mixed methods. Seventy-four breast and prostate cancer survivors including 34 depressed and 23 non-depressed African-Americans and 17 depressed whites were interviewed. Qualitative data analysis identified themes. The thematic codes were converted to a SPSS data set numerically. The Fisher's exact test was performed to examine group differences in the experience of stress.

Results: Significantly more depressed African-Americans experienced a dramatic reaction to a cancer diagnosis (p = 0.03) or had concerns about functional decline (p = 0.01), arguments with relatives or friends (p = 0.02), and unemployment status (p = 0.03) than did non-depressed African-Americans, who reacted to the cancer diagnosis as a matter of reality (p = 0.02). Significantly more depressed African-Americans talked about feeling shocked by a cancer diagnosis (p = 0.04) and being unable to do things that they used to do (p = 0.02) than did depressed whites. Qualitative analysis shed light on the extent of such group differences.

Significance of results: Distress from the initial cancer diagnosis and functional decline were likely to have triggered or worsened depression in African-American cancer patients. This study highlighted racial differences in this aspect. It is critical to screen African-American cancer patients for depression at two critical junctures: immediately after the disclosure of a cancer diagnosis and at the onset of functional decline. This will enhance the chance of prompt diagnosis and treatment of depression in this underserved population.

KEYWORDS: Depression, Stress, Cancer, African-Americans, Health disparity

INTRODUCTION

The literature suggests that depression is significantly associated with cancer death (Satin et al., 2009; Pinquart & Duberstein, 2010). Pre-cancer diagnosis of depression was associated with high cancer mortality because of poor treatment compliance (Goodwin et al., 2004). Post-cancer depression has, in part, been considered a product of immunological response to cancer (Dantzer et al., 1999; Spiegel & Giese-Davis, 2003). The concerted effort of the scientific community in recent decades, however, has produced a more comprehensive explanation of cancerrelated depression. A variety of stressors were reported to significantly predict depression in cancer patients, including socioeconomic, physical (Kurtz et al., 2002), psychological (Deimling et al., 2006), social (Talley et al., 2010), and behavioral factors such as making treatment and care decisions (Zhang et al., 2010).

African-Americans have the highest cancer death rates and the shortest cancer survival among all racial and ethnic groups in the United States (American Cancer Society, 2009). There is an urgent need to identify unique stressors that incur or worsen depression in this underserved population. It has

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been hypothesized that, in addition to the identified stressors, African-American cancer patients experience stress from race-related stressors (e.g., residential or occupational risks, racism, economic disadvantages), cancer appraisals, and coping mechanisms (e.g., adaptation) that are related to a lack of social resources such as social support (Garofalo et al., 2006); yet supporting evidence is lacking. Agarwal et al. (2010) reported that African-Americans who were young (≤ 65), unemployed, living alone, or experiencing multiple cancer symptoms were more likely to be depressed after receiving a cancer diagnosis. Others attributed an elevated level of depression in these patients to the effects of low socioeconomic status (Nelson et al., 2010).

Current knowledge of physical, psychosocial, and economic stressors in the general cancer population is inadequate for reducing depression and cancer mortality in African- Americans for several reasons. Most studies of cancer patients' stress have collected data from predominantly white participants, and their findings cannot be generalized to the specific stressors encountered by African-American cancer patients. Studies that have reported findings on African-American cancer patients are often associated with methodological shortcomings, including the use of skewed populations of African-Americans who do not accurately reflect the African-American community at large, standardized survey methods that lack cultural sensitivity, and standardized instruments, especially depression measures, that have not been adequately validated in African-American populations, and hence do not ensure adequate validity and reliability.

Cultural sensitivity as evinced in the cultural competence of data collectors and culturally appropriate measures are critical to developing an accurate understanding of African-Americans' experience of cancerrelated stress. It is most important that the collected data truly reflect African-Americans' lived experiences. For this reason, we used an open-ended interview to inquire about African-Americans' lived experiences with stressors that they have encountered since receiving a cancer diagnosis. We compared these cancer patients' experiences with other cancer patients of different depression status or race in order to identify both universal and unique stressors. The goals are to identify stressors that are likely to have caused or exacerbated depression, so that we can formulate a strategy to better identify and treat depression in African-American cancer patients.

METHOD

The study was conducted in Cleveland, Ohio between 2006 and 2008. It used a cohort design and mixed

methods to collect data from depressed African-Americans and two control groups: non-depressed African-Americans and depressed whites. The hospital tumor registry was used to identify potential participants. Subject eligibility included a diagnosis of early-stage (I–III) breast or prostate cancer within the past 3 years, having completed cancer treatments for at least 6 months, and not having a psychotic disorder such as schizophrenia. Patients having an existing depression diagnosis or taking an antidepressant at the time were eligible because their experience was valid. Recruiting cancer survivors between 6 and 36 months post-treatment would allow them to tell stories at a time when they were well enough to dwell on their past experience. With institutional review board approval and physicians' permission, an introductory letter and an informed consent form were mailed to the identified cancer patients. Research staff followed up with a call to introduce the study, and the Center for Epidemiologic Studies-Depression Scale (CES-D) was used to screen for depression. Seventy-five eligible and consenting patients were recruited.

The recruited study participants received an hourlong face-to-face interview at home or, occasionally, at other private locations. An interview guide, although originally designed to collect information about depressive experiences, included a major interview question: "Looking back at what you have been through since cancer diagnosis, have there been times and events when you felt depressed? Can we talk about your experiences with these depressing times and events?" The question aimed to elicit contextual information about times or events identified as cancer-related stressors and the participants' appraisals of these stressors. Participants' responses to this question were analyzed and reported in this study. The interviews were audiotaped and transcribed. Study investigators (authors) listened to 40% of the taped interviews to safeguard against interview deviation. Written informed consent was obtained at the beginning of the interview. Each study participant received a \$30 honorarium for completing the interview.

Because the existing depression measures lack a cultural validation, we decided to identify the depressive status of all participants according to an agreement between the screening instrument CES-D (\geq 16) and another measure of depression. When cases did not meet this condition, for example, if a participant was considered "depressed" by CES-D alone or by measures other than CES-D, study investigators reviewed the transcripts and made a determination based on the consensus. Two standard measures of depression (the Hamilton Rating Scale for Depression and the Beck Depression

Inventory-II) were administered and the interviewer's observational rating (not depressed, mildly depressed, moderately depressed, or severely depressed) was recorded at the end of the interview to aid this determination. The process resulted in a final study sample of 74 participants, including 34 depressed and 23 non-depressed African-Americans and 17 depressed whites. A white participant was considered "not depressed" and excluded from the analysis based on the investigators' consensus.

Three interviewers (two African-Americans and one white) conducted each interview individually. Interviewers were licensed in psychiatric nursing or social work, had a minimum of a Master's degree, and had decade-long clinical experience with the mentally ill. They completed a mandatory training session in advance, which addressed such topics as crisis management, referral resources for individuals in need, and cultural issues that were present in the local African-American community. The interviewers were matched with study participants by racial/ ethnic status to ensure cultural sensitivity during data collection.

An experienced African-American transcriptionist transcribed all audiotapes. Mixed methods data analysis was conducted through a few steps. Two experienced coders (one white, one African-American), led by the principal investigator (the first author), developed a code book based on the five initial transcripts and then coded each transcript independently using Atlas 9.0 software. The team met biweekly to discuss merging codes and to ensure coding consistency. This process allowed for exhaustive grouping of transcripts by themes and produced codes for the identified stressors. Next, the principal investigator read the transcripts of every code, reorganized transcripts when necessary, and finalized the codes. These codes were then converted to an SPSS database with "1" indicating the presences and "0" indicating the absence of a code in each transcript. Finally, the Fisher's exact test was performed to compare the depressed African-American group with the other two study groups on the frequency (occurrence) of each code. The tests were used to compare stressors by race and by depression status to aid the identification of stressors that are unique to depressed African-American cancer patients.

RESULTS

Table 1 presents demographic information on each of the three study groups. The non-depressed African-American group was significantly older than the other two groups, with a mean age of 67 ($p \leq 0.05$). The three groups did not differ significantly in terms of gender, marital status, education,

employment, income, and the type of treatment (surgery, radiation, and chemotherapy), despite the presence of some cross-group variations. The depressed African- American group, however, had had significantly more co-morbidity, medications, and pain in the previous week than the non-depressed African-American group ($p \leq 0.01$). Nine members (27%) of this group had a pre-existing diagnosis of depression as documented in the medical chart, and this was significantly higher ($p \leq 0.05$) than the depressed white (6%) or the non-depressed African-American group (4%). The level of depression was not significantly different between the depressed African-American and white groups on any of the depression measures.

The Fisher's exact test indicated significant differences on stressors by the presence of depression. Compared to non-depressed African-Americans, significantly more depressed African-American cancer patients talked about having had an argument with a family member or friend (p = 0.02), having no job or having difficulty finding a job (p = 0.03), being in pain (p = 0.05), being unable to do things that they used to do (p = 0.04), feeling upset about not being able to do things they used to do (p = 0.01), experiencing functional decline (p = 0.01), and feeling terrified or scared at learning about a cancer diagnosis (p = 0.03). However, significantly more non-depressed African-American cancer patients reported a matter-of-fact reaction to a cancer diagnosis than did depressed African-American cancer patients (p = 0.02).

Further, when compared with the depressed white group, significantly more depressed African-American cancer patients talked about an inability to do things that they once used to do (p = 0.02) and feeling shocked by a cancer diagnosis (p = 0.04), which indicates significant racial differences in the perception of stressors (Table 2).

Additionally, a number of themes that emerged from the data analysis detailed a wide range of stressors (see Appendix). These stressors were either general (e.g., financial, marital, and/or family problems) or cancer specific (e.g., worry about cancer and death, anxiety about or dissatisfaction with treatment process, physical problems, loss of sexual desire or performance ability, and distress about a cancer diagnosis). The frequency of discussing these topics was neither significantly different by race nor by the depressive status. However, a sizable portion (20-30%) of depressed African-American cancer patients experienced stress related to financial problems, burdens of caring for sick family members, fear of death, uncertainty of cancer recurrence, loss of sexual desire that compromised relationships, and emotional turmoil in response to their cancer diagnosis (feeling devastated or crying). A review of transcripts sheds light on the

Table 1. Sample demographics

Variable	Non- depressed African- Americans (n=23): G1		Depressed African- Americans (n=34): G2		Depressed whites (n=17): G3			
	n	%	n	%	n	%	Group difference	
Gender								
Female	11	48%	18	53%	12	71%		
Marital status								
Married	12	52%	10	29%	10	59%		
Single	4	17	10	29	3	18		
Other (divorced etc.)	7	30	14	41	4	24		
Education								
≤High school	7	30%	12	36%	3	18%		
Some college	12	52	17	52	6	35		
≥College	4	17	4	12	8	47		
Employment								
Full time	6	26%	8	25%	9	53%		
Half time	2	9	4	13	2	12		
Unemployed	15	65	20	63	6	35		
Income (optional)								
<\$15000 (household)	7	30%	10	29%	1	6%		
<\$25000	4	17	4	12	0	0		
<\$50,000	5	22	6	18	4	24		
≥\$50,000	6	26	3	9	7	41		
Ūnknown	1	4	11	32	5	29		
Level of depression (observer rating)								
Mild to moderate			13	38%	9	53%		
Severe			21	62	8	47		
Prior depression diagnosis	1	4%	9	27%	1	6%	$G2 > G1^*$	
Had surgery	16	70%	19	56%	14	82%		
Had radiation	11	48%	$\overline{24}$	71%	12	71%		
Had chemotherapy	6	26%	11	32%	7	41%		
	Mean	SD	Mean	SD	Mean	SD		
Age	67	10	60	9	58	10	$G1 > G2, 3^*$	
Number of disease	2.1	2	5.3	3.8	3.4	2.2	$G2 > G1^{**}$	
Number of medication	1.8	1.9	5.9	6.5	3.8	4.9	${ m G2} > { m G1}^{**}$	
Pain in last 7 days (0–10 pt.)	2.1	2	5.6	2.9	4.1	2.9	$G2 > G1^{**}$	

* $p \le .05$; ** $p \le .01$.

Table 2. Thematic difference b	by depressi	ion and by race
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Merging Themes	Depressed African Americans	Non-Depressed African Americans	р
Comparison by depression	n (%)	n (%)	
Argued with family or friends	8 (24%)	0	0.02
Had no job (unemployed and could not find a job)	7(21%)	0	0.03
Complained of having pain at the time	9 (27%)	1 (4%)	0.05
Could not do things that one used to do	10 (29%)	1 (4%)	0.04
Felt upset about inability to do things one used to do	9(27%)	0	0.01
Concerned about functional decline	13 (38%)	1 (4%)	0.01
Was scared and terrified by cancer diagnosis	7(21%)	0	0.03
Reacted to the cancer diagnosis in a matter-of-fact fashion	4 (12%)	9 (39%)	0.02
Comparison by race		Depressed whites	
Could not do things that one used to do	10 (29%)	0	0.02
Was shocked by cancer diagnosis	19 (56%)	4 (24%)	0.04

following areas in which depressed African-American cancer patients experienced stress significantly differently from others.

Reaction to Cancer Diagnosis

Of depressed African-Americans, 21% (n = 7) used the words "scared" or "terrified" to describe their initial reaction to a cancer diagnosis. They made comments such as, "I was scared to death;" "I was scared. I did not know what to do. I did not know how to react;" and "just frightening, just thinking, 'I might die." A participant described her initial reaction to a cancer diagnosis as: "I'm shaking. I'm already scared, because she said a lump. So the only thing I could figure that could be just breast cancer."

By contrast, none of the non-depressed African-Americans used the words "scared" or "terrified" to describe their initial reaction. Instead, 39% (n = 9)described their initial reaction with a matter-of-fact response as opposed to 12% (n = 4; p = 0.02) of depressed African- Americans. They explained their calm manner mostly in pragmatic terms. A participant responded to her doctor's diagnosis with, "Why wouldn't I be okay?' I said. 'I'm not afraid of cancer. So what do we do?" Another person said, "I was disappointed that it turned out that I actually had cancer, but I wasn't overwhelmed by it. I said, 'Well, I guess I'm going to have to deal with it.' ... I just decided, 'That is what I've got. It's a fact." Non-depressed African- Americans appeared to be less fearful of a cancer diagnosis. One participant said, "When I was diagnosed with cancer, I never felt like this is the end ... I did feel like I'm going to go through something that I have never been through with before."

Compared to depressed white cancer patients, more depressed African-Americans used the word "shocking" to describe their reaction to a cancer diagnosis (56% vs. 24%, p = 0.04). They explained this feeling of shock with such comments as: "Shocked. I mean, to me that was the last straw, cancer;" "I was very, very shocked because I [had] taken all my mammograms and everything;" "It was just I can't believe it. I just felt like somebody had just hit me upside the head. The tears just started flowing. I was in shock ... I just stood there for a while, with the tears flowing, and I said, 'What do I do now?'' Non-depressed African-Americans also used the word "shocking," but to a lesser extent (56% vs. 30%; p = 0.10).

Functional Decline

Ten depressed (29%) and one non-depressed (4%) African-American cancer patient talked about the inability to do things they used to do (p = 0.04), ranging from daily activities to lifelong hobbies. For example, a depressed African-American breast

cancer patient said, "Everything bothers me because my body will not let me do it, and if I do it then I suffer afterwards. Because I'll pull, I'll lift this arm too much or I'll bend over too much and I'll suffer for it later on ...The only way to get better is to be good and not overexert myself ... and follow doctor's orders." Others mentioned giving up swimming, running, traveling, or simple activities like maintaining the house or mowing the lawn.

Moreover, nine depressed African-Americans (27%) talked about how the inability to carry out routine activities upset them. Resultant distress was obvious in one participant: "It makes me cry because I can't do it. I just can't get everything done." Another participant explained, "I just feel useless and I get sort of angry ... I can't wash, I can't do nothing. I cook every now and then. It's very aggravating and maybe I'm depressed. I don't know." Another participant said, "It might have made me depressed that what I was able to do very effectively prior to the chemo, I no longer could do this."

Distress over losing autonomy and independence was discussed by four depressed (12%) but none of the non-depressed African-Americans. A participant explained, "I never thought that I would be in a position that I had to have someone care for me ... You feel like it's demeaning to other people that you're having to call on them, to always have to ask for help, or have someone there helping you seven days a week." Another person said, "I hate that pity. Don't pity me. Don't patronize me. Just leave me alone ... because I'm independent and I can do what I do, when I want to do it, and how I want to do it." The difference between depressed and non-depressed African-American groups concerning personal independence was not statistically significant (12% vs. 0%, p = 0.14). However, when we combined all three issues discussed above and created a code of "concerns about functional decline," a statistically significant difference between the groups was found (38% vs. 4%, p = 0.01).

By contrast, none of the depressed white cancer patients discussed not being able to do things that they used to do, as if this was taken for granted or assumed (0 vs. 29%, p = 0.02). They discussed upsetting feelings about their inability to perform routine activities at a lower frequency, which, however, was not significantly different from that of depressed African-Americans (18% vs. 27%, p = 0.73). They discussed the fear of losing independence as often as did depressed African-Americans (12% vs. 12%).

Arguments with Relatives or Friends

Of the depressed African-American cancer patients, 24% (n = 8) talked about conflicts with a loved one or a friend. They stressed the role emotional anguish

played in contributing to feelings of depression. A participant said, "What caused the depression during cancer was my sister, who is a nurse. She walked out of my life. She got mad at me [crying] over something ridiculous at Thanksgiving of 2006. It was the last time we saw each other and we still to this day have not reconciled and I needed her more than anybody." In comparison, none of the non-depressed African-Americans discussed this matter (p = 0.03) and only two of the depressed white cancer patients did (12%, p = 0.73).

Unemployment

Seven depressed African-Americans (21%) discussed unemployment. Some had lost their jobs because of cancer and others could not find a job because of cancer-induced disability. As a participant said, "It's hard for me to get a job and, really, if I had a job, I wouldn't have the time to be depressed." On the other hand, none of the non-depressed African-American cancer patients discussed unemployment experiences (p =0.03). Three depressed white cancer patients (18%) had similar experiences with job loss, and the group difference was not significant (p = 1.0).

DISCUSSION

The data analysis revealed a wide range of stressors for cancer patients in this study. In particular, depressed African-Americans experienced more stress than did non-depressed African-Americans from a cancer diagnosis, functional decline, pain, family or personal conflict, and job loss. When compared with white cancer patients who were also depressed, they reported more stress from a cancer diagnosis and from losing the ability to perform routine activities. The findings suggest that two sources of cancerrelated stress — a cancer diagnosis and functional decline — contributed uniquely to African-American cancer patients' depression.

Depressed African-Americans recalled more dramatic reactions to a cancer diagnosis than did non-depressed African-Americans; they frequently described their initial reaction as "scared" or "terrified" rather than matter-of-fact. This recall may be attributable to a biased recollection because of the depression itself. However, when compared with equally depressed whites, depressed African-Americans continued to show more dramatic reactions to a cancer diagnosis; they frequently described the experience as "shocking" whereas only two depressed whites used the word "scary" (12%). Depressed African-Americans' choice of other words supports this finding because they indicated the same trend, though it was not statistically significant across groups. For example, when compared with non-depressed African-Americans or depressed whites, depressed African-Americans frequently used the words "devastated" (21% vs. 13% or 12%, respectively, p = 0.64) and "crying" (24% vs. 4% or 12%, respectively, p = 0.13) at receiving a cancer diagnosis. The causes for a dramatic reaction to cancer diagnoses have yet to be understood, but the findings suggest that initial anguish at a cancer diagnosis enhances the vulnerability of some African-American cancer patients to depression.

Depressed African-Americans viewed functional decline to be more stressful than did non-depressed African-Americans: they discussed the inability to perform routine activities and related distress with a significantly greater frequency. The finding may be explained by more disease burden and poorer health in depressed African-Americans than in non-depressed African-Americans, but it was unlikely to be related to pain, because it remained true for participants who did not complain about pain. The finding may not be explained by the impact of depression in that depressed African-American cancer patients, when compared with depressed whites with comparable co-morbidity, expressed significantly more concerns as such. Hence, the finding suggests an association between the recognition of functional decline and depression in African-American cancer patients. This recognition can be distressing for multiple reasons including the loss of one's independence and dignity, feelings of frustration or uselessness, sense of helplessness related to insufficient resources, or loss of joy in life. Although the depressed African-American and white cancer patients showed no difference in expressing emotional upset at functional decline, the recognition of functional decline perhaps can worsen existing mental conditions or precipitate depression among patients under vulnerable conditions.

Another influential factor is pre-existing depression. In this study, we encountered more African-American (n = 9, 27%) than white (n = 1, 6%) cancer patients who had had a diagnosis of depressive disorders prior to cancer diagnosis, although the level of depression was not significantly different by race. Pre-existing depression can affect a participant's experience of cancer stress, but this influence on the study findings is limited. After removing participants with pre-existing depression from the analyses, depressed African-American cancer patients continued to show more dramatic reactions to a cancer diagnosis and concern about inability to perform routine activities than did the other two groups by 14% to 18%.

The study findings have important implications for the identification of depression in African-American cancer patients. First, the study discerned a wide range of stressors that potentially contributed to depression in African-American cancer patients. Stressors that were experienced frequently by African-Americans (>20% of the time) were identified and reported. Second and more importantly, the initial cancer diagnosis and functional decline appear to be the most upsetting stressors and likely have triggered or worsened depression in African-American cancer patients. Previous studies have indicated a significant association between depression and distress of a cancer diagnosis or functional decline (Cummings et al., 2003; Akechi et al., 2006). Assuming this is true across ethnic groups, this study, for the first time, sheds light on a potential racial difference, suggesting that reaction to a cancer diagnosis and functional decline have a greater impact on and hence a unique contribution to African-American cancer patients' depression. If this finding remains true in a large-scale and more rigorously controlled study, it would be imperative to screen African-American cancer patients for depression at the two critical junctures: immediately after the disclosure of a cancer diagnosis and at the onset of functional decline. Identifying highly stressed patients at these times and closely monitoring these patients and those with a pre-existing diagnosis of depression, will increase the chance of successfully capturing the onset or worsening of depression in this underserved population, and will offer the opportunity of prompt interventions.

The study has some limitations. Early-stage breast and prostate cancers have a good prognosis, but also have significant long-term treatment side effects over a protracted course. The patients in our study may have a different appraisal of cancer stress from those with advanced cancer or other types of cancer. The data were characterized by self-reported recalls and analyzed using mixed methods. Therefore, the study findings are explorative in nature and best used to provide insight or generate hypotheses, rather than treated as conclusive evidence. The depressed white patient group had fewer members and comprised predominantly female participants. This could potentially bias the study results, because women might express depressive feelings differently from men. The study also has a small sample and low power for statistical tests. For example, we used logistic regression to explore significant group differences uncovered by the Fisher's exact test. We found a significant racial difference (p = 0.05) in the initial "shocking" reaction to cancer diagnosis and a marginal difference in the inability to perform routine activities between the two African-American groups (p = 0.07) after controlling for selective demographic covariates. We could not confirm other significant group differences with logistic regression. Nonetheless, the findings suggested a new direction for the assessment of depression in African-Americans who are at a high risk of cancer death. Further investigation along this direction is warranted.

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APPENDIX

Merging Themes That Were Not Significantly Different by Race or Degree of Depression

1. Not Related to Cancer Condition

Have a financial problem* Have a housing problem Have a problem with medical bills Have a problem with stressful job Have a marital problem Caring for a sick family member* Being a single parent General lack of support/help

2. Related to Cancer Condition

Cancer and death

Realization of death Fear of death* Worry of cancer spreading Heightened bodily sensitivity Feelings of uncertainty about possible cancer recurrence*

About treatment and procedures

 $Upset \ with \ treatment \ procedures$

Upset with doctor's manner or incompetence Anxious about laboratory and testing results

• Physical problems

Pain is distressing

Upset with hair loss

Feeling of a loss of independence because of functional decline

• Sexuality

Sexually limited Lost sexual desire* Losing sexual ability is upsetting Losing sexuality affects relationship and is stressful* Have a problem with dating

Reaction to cancer diagnosis

Was devastated by the cancer diagnosis* Cried when learning cancer diagnosis* Felt out of control at learning cancer diagnosis Felt sad or upset at learning cancer diagnosis Felt numb at learning cancer diagnosis Felt overwhelmed at learning cancer diagnosis Angry and asked "Why me?" at learning cancer diagnosis

• Other sources of distress

Self-doubt or regret Talking about cancer is upsetting Media's portrayal of cancer is distressing

 \ast An item that ${>}20\%$ of depressed African American cancer patients talked about.