Published in final edited form as:

Patient Educ Couns. 2011 December ; 85(3): 446–453. doi:10.1016/j.pec.2011.01.023.

Relationships and Emotional Wellbeing among African American and White Advanced Cancer Caregivers

Linda E. Francis, PhD,

Department of Medicine, Case Western Reserve University

Karen F. Bowman, PhD,

Department of Medicine, Case Western Reserve University

George Kypriotakis, MA, and

Department of Medicine, Case Western Reserve University

Julia Hannum Rose, PhD

Department of Medicine, Case Western Reserve University

Abstract

Objective—Advanced cancer family caregivers who have good relationships with other family members and with patient's health care providers (PHCPs) have less emotional distress than caregivers with poor relationships. Given a history of different experiences in medical settings among Whites and African Americans, we examined moderation effects by race.

Method—Baseline data from an ongoing study were collected via telephone interviews with 397 family caregivers of advanced cancer patients at two cancer clinics. Depressed mood and anxiety were measured with the 14-item Profile of Mood States.

Results—Caregivers reporting good relationships with family ($p<.001$) and PHCPs ($p<.001$) had lower anxiety and less depressed mood (family, $p<.01$; PHCP, $p<.001$). Caregiver race moderated relationship quality: Whites with good PHCP relationships felt less depressed mood ($p<.01$) and anxiety ($p<.01$). African Americans with good family relationships showed less depressed mood ($p<.05$), but no association with anxiety.

Conclusion—Good relationships are important for caregivers, but PHCPs may have more influence on the wellbeing of White than of African American caregivers.

Practice implications—Developing relationships with caregivers of advanced cancer patients may improve wellbeing for caregivers. In addition, creating strategies to support family relationships may be a useful intervention, especially for African American advanced cancer caregivers.

1. Introduction

The deleterious psychological and emotional consequences of informal caregiving for family caregivers of advanced cancer patients have been well-documented [1–3]. Numerous studies have shown caregiver emotional wellbeing to vary by the characteristics of the caregiver [1,2,4–6], and caregiving situation [1,5,7]. However, research has only begun to scratch the surface in understanding how caregiver wellbeing is affected by caregiver

Publisher's Disclaimer: This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final citable form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

interactions with others involved in the care of the patient. In particular, the unique sociocultural experiences and expectations for health care among African Americans raises the issue of whether relationships in medical contexts have the same effect for African Americans and Whites [8,9]. The nature and quality of such important connections during a medical crisis such as cancer could explain why some family caregivers suffer more than others from the negative psychological consequences of caregiving [10–12].

1.1 Family caregivers' relationships and emotional distress

In previous research we have established that good relationships between the advanced cancer family caregiver and other family members and between caregiver and patient's health care provider are associated with lower subjective burden during the early treatment phase of late-stage cancer care [13]. This is supported by an extensive body of literature on the relevance of supportive relationships with family [14–18] and health care providers [19–22] for cancer patients and their caregivers.

Yet more important than burden in the early treatment phase of late-stage cancer, however, is caregiver emotional distress, including the feelings of depression and anxiety experienced by the caregiver. Caregivers for people with degenerative diseases, including advanced cancer, are at much higher risk for clinically significant psychological morbidity than the general population [1,12,23]. Caregivers who report feeling depressed and anxious at the time of patient diagnosis report higher levels of depression as the disease progresses [24,25] and more complicated grief after the patient's death [26]. Finally, caregiver depression has been shown to influence patient emotional wellbeing [27], as well as patient care and outcomes [15,28]. Identifying factors that ameliorate caregiver distress early in the patient's cancer treatment would inform efforts to improve both patient and caregiver wellbeing.

Relationship quality has been demonstrated to be one of these factors [13]. Good relationships with health care providers and family are important contributors to positive psychosocial outcomes for seriously ill patients [29–33] and caregivers [34,35]. The importance of both provider and family relationships for caregivers has been documented particularly at end-of-life, when patients and their families grapple with the prospect of the patient's imminent death [26,36,37]. Given the dire prognosis of advanced cancer, however, both family members and health care providers are likely to be heavily involved from the moment of diagnosis forward. Thus these relationships are potentially fruitful targets for intervention regarding caregiver distress.

1.2 Race and caregiver relationships in advanced cancer

Relationship expectations are not uniform across all groups, but can vary due to social, structural and cultural factors [38]. Different expectations and beliefs about medical care between African Americans and Whites, for instance, may influence the role of relationships in cancer care. Historically, African Americans have reported less trust in medicine than have whites [8,9]. This mistrust has been reflected in a desire for more aggressive treatment [39], greater preference for CPR and resuscitation, even at end of life [40,41] and higher use of alternative medicine among African Americans compared to Whites [42,43]. African American families are more likely than Whites to take on informal caregiving roles within the family [44]. They are also much less likely than White families to place impaired or infirm elders in nursing homes [45,46], hire health care aides to care for family members [47] or make use of hospice [48,49].

While there is little evidence of a racial difference in distress, either among caregivers [6,50] or in general [51], most such research accounts for few differences beyond the socioeconomic between Whites and African Americans. However, the potentially different

expectations held by the two groups in medical environments suggest that the association between relationships and distress may be moderated by race. In particular, the relationship with the PHCP may have more influence on distress among Whites than among African Americans, given the greater trust and reliance on medical professionals in the former group.

1.3 Relationships and distress among African American and White cancer caregivers

The association of relationship quality with caregiver emotional distress has not been examined, nor has the effect of race on that association been explored. The purpose of this study, therefore, is to investigate how relationships between advanced cancer caregivers and others – specifically family members and the patient's health care providers – are associated with the emotional distress or wellbeing experienced by caregivers during the early treatment phase of cancer care. A second purpose is to examine moderating effects by race (African American and White) in the association between these relationships and emotional distress. These research questions are depicted in Figure 1:

2. Methods

Study data were baseline assessments from a large randomized controlled trial evaluating effects of a coping and communication support intervention for advanced cancer patients and their caregivers [52–54]. This study was conducted in two cancer clinics that care for disadvantaged and underserved patients. The IRBs of both hospitals approved the study. Beginning in June 2004, recently diagnosed late-stage cancer patients were enrolled and randomized into intervention and control groups. Eligible patients were diagnosed with Stage IV [or Stage III lung, pancreatic or liver] cancer, were 40 years or older, cognitively intact and English speaking.

During enrollment, patients identified the person they most depended upon for assistance with care and gave contact permission. Caregivers were then contacted and each completed a baseline telephone interview, after providing informed consent. Of 514 primary caregivers identified by patient participants, 462 agreed to participate in the study. Of these 42 were non-kin and excluded from the current analysis on family caregivers. Race was conceptualized as African American vs. White. Twenty-three caregivers in the study did not fall clearly into one of these two categories and were dropped from the analysis, leaving a final sample of 397 family caregivers [FCGs]. At the time of these analyses, the only complete data set available for caregivers was the baseline interview, and this is the source of the data for the current study.

2.1 Measures

2.1.1. Measures of emotional distress/wellbeing—The outcome variables were measured by the Short Form of Profile of Mood States [POMS], subscales of Tension-Anxiety [6 items, $\alpha=.80$] and Depression-Dejection [8 items, $\alpha=.91$] [55]. Questions are phrased as: —In the past week have you felt: [unhappy, restless, discouraged, nervous, etc.] and are scored from 0 [Not at all] to 5 [Very much]. Scores are summed, with high scores indexing higher distress. Lacking clinical cut points, these measures are used as measures of distress/wellbeing, rather than diagnosable disorders.

2.1.2. Measures of FCG relationships—Recognizing that different relationships will have dissimilar expectations, we used two separate measures to capture relationship quality for family and for PHCPs. The FCG-family relationship was assessed using the Family Relationship Index [FRI] [26]. This 12-item scale was derived from the Family Environment Scale [FES] [56] using four items drawn from each of three subscales: cohesion, expressiveness and conflict, although the FRI is designed to be used as a single scale. The

scale includes such items as “family members really help and support one another,” and “there is a feeling of togetherness in our family.” Developed for use with families of cancer patients, the FRI has been effective in distinguishing families at risk of maladaptive bereavement adjustment [57]. The items were coded to index more positive family relationships. The scale has satisfactory consistency, stability and predictive and discriminant validity [$\alpha=.89$] [58].

The FCG relationship with the PCHPs was measured by the 20-item Fulfillment of Care Needs subscale of the Family Inventory of Needs in advanced cancer care [FIN] [59]. This subscale measures how well the family member perceived each identified family need as being met by the patient’s health care provider/s, and is predictive of the responding family members health and family functioning during cancer care [21]. As respondents are only asked about need fulfillment for needs that they identified as important, not all needs received a score on the Fulfillment of Needs subscale. Therefore, scores were summed and divided by the number of responses given to obtain an average for each respondent. Questions included the needs to: “have my questions answered honestly,” “know the probable outcome of the patient’s illness,” “to feel accepted by my relative’s doctors,” and “have someone be concerned about my health.” Caregivers reported if the need identified had been met=2, partially met=1, or unmet=0. A high rating of needs being met was considered indicative of a good relationship. Reliability for this scale is .83 [59].

Caregiver sociodemographic characteristics were included as control variables: age [in years], gender, education [in years], annual income [seven ordinal categories ranging from \$0–\$9,999 to \$50,000+], and whether or not the caregiver was living with the patient. The last control variable of living with the patient was included as a measure of caregiver closeness to patient, as in this largely low income sample, caregiver relationship to patient was too diverse to collapse into meaningful categories.

Other than the variable on weeks since diagnosis, no data on patient characteristics were included in these analyses. While we acknowledge that patients may influence the quality of caregiver relationships with other family members and the PHCP, exploring such influence is a separate question for later analysis. The current study is focuses on the fundamental question of whether these caregiver relationships are associated with caregiver distress.

2.2 Analysis

The analysis was conducted using multiple linear regression in SPSS (v17), with R used to assess model fit of interaction terms. We initially performed one regression for each of the two dependent variables [depressed mood, anxiety]. Our moderation regression analyses followed, including interactions, subgroup analyses and chi-square tests of model fit for the interaction terms.

3.0 Results

3.1 Description of sample

As seen in Table 1, most caregivers were female [78.3%]. Median household income was \$35,000, well below the state average of \$48,000 [60]. 47.9% of caregivers were employed. African Americans made up 31.2% of the sample. Median education was 12 years, and median age for caregivers was 51, though there was substantial variability on these measures. Our two variables assessing caregiver involvement show that 57.6% percent of caregivers lived with the patient. Median time past diagnosis of advanced cancer for patients was six weeks [6.00, range 0–53].

Table 1 shows both relationship variables rated above the midpoint. The family relationship [FRI] mean was 8.62 [SD=2.26] on a 12-point scale. On the FRI a score of 9 or above indicates good family functioning, meaning the sample mean falls into the category of “at risk for negative psychological outcomes” [32]. PHCP relationship showed a high mean of 1.55 on a 0–2.5 scale, though with substantial variability [SD=.44].

At baseline, both outcome variables had moderate values on the POMS, but with high variation. Anxiety had a mean of 6.50 [SD = 5.59] on a 24-point subscale, and the mean for depressed mood was 6.37 [SD= 6.54] out of 32 points.

3.2. Associations between Independent Variables and Emotional Distress

Collinearity diagnostics revealed no problems with multicollinearity. In Model 1 (Tables 2 and 3), African Americans had both lower anxiety [−2.585, $p<.001$] and lower depressed mood [−2.246, $p<.01$] than Whites. Both relationships with family and PCHP were associated with caregiver distress. Caregivers felt less anxiety when they had good family relationships [−.431, $p<.001$] and good PHCPs relationships [−2.772, $p<.001$]. They also felt less depressed mood when relationships with family [−.425, $p<.01$] and PCHP [−3.223, $p<.001$] were good.

3.3. Moderation Analyses

Three of the four interaction terms created with the race and relationship variables were significantly associated with caregiver distress. Model 2 in Tables 2 and 3 shows the race and family relationship interaction, and Model 3 shows the race and PHCP interaction.

The race and family relationship interaction was not associated with anxiety, although family relationship as a simple independent variable remained significant. On the other hand, the race and family interaction showed a negative association with depressed mood [−.634, $p<.05$], and the simple family relationship variable became nonsignificant when the interaction term was added to the equation.

In Model 3, the race and PCHP interaction is positively associated with both caregiver anxiety [3.603, $p<.01$] and depressed mood [3.838, $p<.01$]. Thus the associations between both family and PCHP relationships and caregiver distress are moderated by the race of the caregiver.

To clarify the meaning of these moderation effects, we present subgroup analyses by race and relationship type for the three significant interactions. In these models, the relationships between the interaction terms and the dependent variables were evaluated by the significance of the Wald statistic and the 95% confidence interval of the specific regression coefficients of the interaction terms. This test allows us to assess the effects of the interaction term, and any other covariate, on the overall fit of the model, and also the degree that the model improves by the inclusion of the covariate effect (in this case, the interaction term). Subgroup analyses of relationship type and distress by race are graphed in Figures 2–4.

3.3.1. FCG- PHCP Relationship by Subgroup—The first subgroup analysis [Figure 2] illustrated a strong association between the caregiver’s PHCP relationships and anxiety by race. The WALD test supported this, showing that the interaction term added to the model fit [$F=4.42$, $df=1$, $p<.05$]. In Figure 2, among white caregivers, poor PHCP relationships were associated with higher anxiety and good PHCP relationships were associated with low anxiety. However, among African Americans caregivers there was virtually no association between PHCP relationships and anxiety. Figure 3 illustrates the association between PHCP

relationships and depressed mood by race, showing a similar pattern. The slopes appear flatter due to a wider scale on the dependent variable, but the slopes are nonetheless significantly different from zero [$F=4.42$, $df=1$, $p<.05$]. It is apparent that the interaction term added to the model, and that PHCP relationship was associated with distress primarily for White caregivers, and not for African American caregivers.

3.3.2. FCG-Family Relationship by Subgroup—As the interaction term of race and FCG relationship for anxiety was not significant it is not shown. Figure 4 illustrates an association between family relationships and caregiver depressed mood by race ($F=6.41$, $df=1$, $p<.05$). Regardless of race, all caregivers with poor family relationships had higher anxiety than those with good family relationships. However, among African Americans, the decline in anxiety was steeper as family relationships improved, resulting in lower anxiety for African Americans than for whites when family relationships were good.

4.0 Discussion and conclusion

Families and health care providers are nearly always involved in the on-going care of late-stage cancer patients, and for better or for worse, these relationships influence the caregivers' experiences and emotions. In this research, we sought to clarify the importance of these relationships for caregiver wellbeing. We considered the experiences of family caregivers for advanced cancer patients during the early phase of advanced cancer treatment. We began with the question of whether family caregivers with poor family and/or patient's health care provider relationships experience more emotional distress than those with good relationships. Our results affirmed the importance of both types of relationships. Caregivers with good family relationships reported lower anxiety than caregivers who viewed their family relationships as poor. Caregivers with good PHCP relationships had both lower anxiety and depressed mood than those with poor PHCP relationships. These findings confirm earlier research [61] showing cancer patients value support from people connected to their cancer experience.

This study extends the current state of research on both medical and family relationships. While reports on such topics as patient trust, concordance and communication permeate the field [62–64], most address provider-patient relationships, rather than relationships with family caregivers. The recognition of the need for providers to establish good relationships in practice is evident in the growing body of research directed at increasing our understanding of such relationships [65–68]. In this work we have illustrated the effects of good caregiver relationships with PCHPs in the context of a real ongoing medical crisis for the people involved.

Family relationships have been studied extensively in connection with emotional wellbeing. Research reports on the importance of intimacy, expressiveness, emotional support and role performance in marital relationships [18,21,69,70] for the psychological and emotional wellbeing of spouses. Lack of family help and caring burdens caregivers and increases their risk of depression [7,12,25]. The current study clarifies the relative importance of family relationships and relationships with the PHCPs, indicating that, at least in the early treatment phase of cancer, caregivers may look to both types of relationships for support.

Our second research question assessed possible moderations effects on relationships with family and/or PHCPs. Results demonstrated that race moderated the association between relationships and distress, but varied depending on the type of relationship. White caregivers reporting poorer PHCP relationships were substantially more distressed than African Americans with similarly poor provider relationships. Indeed, there was little association between provider relationships and either type of distress for African Americans. It appears

that at least during the early phase of late-stage cancer treatment, PHCP relationships made little difference for the emotional wellbeing of African American caregivers, but was an important factor for White caregivers.

Our findings regarding caregiver's family relationships and distress by race were less consistent. Both Whites and African Americans with good family relationships were less distressed than those with poor relationships. We found that African American caregivers with good family relationships felt less depressed than did comparable White caregivers. Conversely, when their family relationships were poor, African Americans experienced more depressed mood than Whites. However, the association of family relationship with anxiety was not different by race.

With only cross-sectional data we cannot verify direction of these effects. One could argue that caregivers with high anxiety or depressed mood were less likely to form good relationships. However, that argument appears less convincing for analyses showing little or no association. In particular, it would require assuming greater distress among African Americans does not impact their ability to form good relationships with their PHCPs. Therefore it appears more reasonable to suggest the direction we proposed: that among African Americans, their PHCP relationships just were not as relevant to their emotional wellbeing.

These differences in emotional wellbeing for African American and White cancer caregivers resonate with previous research on racial differences in health care system attitudes. White Americans on average tend to revere medical doctors and depend heavily on their authority [71]. African Americans, on the other hand, are often less willing to rely on the perceived "white" medical establishment, given its history of colluding with those who did not have African Americans' best interests at heart [72]. However, given there was no difference in how African American and white caregivers rated their PHCP relationships, perhaps an explanation based entirely on medical trust or mistrust is too simple.

The fact that we saw a moderation effect by race for family relationships bolsters the argument that we have tapped into more than just medical mistrust. While the two kinds of relationships cannot be directly compared to each other due to different measures, it is nonetheless telling that each type of relationship interacted with race in a different way. Family relationships were universally important for caregivers, but more so for African American than White caregivers. This may reflect the extended kin network model identified by social network and family theorists as more common among African American families, rather than the nuclear family model that typifies White families [73–75]. Findings from related research add weight to this idea. More family members of African Americans than Whites are involved in health-related discussions, and extended family attend more decision-making visits with African American patients [76–79]. Given a preference for informal caregiving over hospice and nursing care among African Americans [44–49], the relative importance of family relationships over provider relationships for caregiver wellbeing may reflect cultural views on the role of family as much as attitudes towards the medical care system. By this argument, health care providers using a more family-inclusive model of health care treatment could potentially find their influence on African American patients and caregivers enhanced. Ironically, HIPAA regulations may actually interfere with such a model by emphasizing individual privacy over family support. As Bellah et al [80] point out, modern medical practice is reflective of the ideology of "therapeutic individualism," emphasizing the separation of the person from their environment. Perhaps findings like those in this study indicate a need for further research on race and culture differences in the interaction of family and medical systems, as opposed to a focus on the individual patient.

4.1. Limitations

Our nonprobability sample limits the generalizability of our findings. The sample intentionally had a lower income on average than the general population, so may not represent higher income groups. The study is also limited by its cross-sectional design, so directionality of effects cannot be assured. Nonetheless, the study's strengths, including a sizeable sample among a population difficult to recruit, rigorous data collection and validated measures, all support the fruitfulness of the findings for future research.

4.2. Conclusion

Relationships can be either positive or negative in their impact on emotional wellbeing [81]. Some relationships are beneficial and reduce the effects of stress, while others have little effect, and yet others exacerbate the effects of stress. Considering caregiver relationships with important others, therefore, adds to our understanding of processes that may ameliorate cancer caregiver distress and improve wellbeing, especially during the early phase of treatment.

The findings of this study raise questions for future research. This study was done using cross-sectional data collected during from patients with advanced cancer and their caregivers during the early phase of treatment. The patterns of relationships seen here may change in importance over time as the disease progresses, and this should be investigated. This study could also have benefited from including variables on how much other family members were involved in caregiving, decision-making, and patient support.

4.3 Practice implications

Health care providers working with advanced cancer patients may find they can be effective in improving the quality of life of the family caregivers of their patients by establishing a relationship with the family caregiver as well as the patient particularly among white caregivers of advanced cancer patients. Developing strategies in the practice setting to support family relationships may also be an effective intervention for caregivers, particularly among African American families. Finally, creating a more family-oriented practice model has the potential of improving caregiver psychosocial outcomes in advanced cancer care.

Acknowledgments

The authors would like to gratefully acknowledge the funding sources for this project: National Cancer Institute, R01-CA10282; Veterans Administration Health Services Research & Development Merit, IIR-03-255; American Cancer Society, ROG-04-090-01.

References

1. Nijboer C, Triemstra M, Tempelaar R, Mulder M, Sanderman R, van den Bos GAM. Patterns of caregiver experiences among partners of cancer patients. *The Gerontologist*. 2000; 40:738–746. [PubMed: 11131090]
2. Given B, Wyatt G, Given C, Sherwood P, Gift A, DeVoss D, Rahbar M. Burden and depression among caregivers of patients with cancer at the end of life. *Oncology Nursing Forum*. 2004; 31:1105–1115. [PubMed: 15547633]
3. Northouse LL. Helping families of patients with cancer. *Oncology Nursing Forum*. 2005; 32:743–750. [PubMed: 15990903]
4. Drentea P, Goldner MA. Caregiving outside of the home: The effects of race on depression. *Ethnicity and Health*. 2006; 11:41–57. [PubMed: 16338754]
5. Pinquart M, Sorensen S. Ethnic differences in stressors, resources, and psychological outcomes of family caregiving: a meta-analysis. *The Gerontologist*. 2005; 45:90–106. [PubMed: 15695420]

6. Gaugler JE, Given WC, Linder J, Kataria R, Tucker G, Regine WF. Work, gender, and stress in family cancer caregiving. *Supportive Care in Cancer*. 2008; 16:347–357. [PubMed: 17891502]
7. Kim Y, Baker F, Spillers RL, Wellisch DK. Psychological adjustment of cancer caregivers with multiple roles. *Psycho-Oncology*. 2006; 15:795–804. [PubMed: 16502472]
8. Kennedy BR, Mathis CC, Woods AK. African Americans and their distrust of the health care system: healthcare for diverse populations. *Journal of Cultural Diversity*. 2007; 14:56–60. [PubMed: 19175244]
9. Halbert CH, Weathers B, Delmoor E, Mahler B, Coyne J, Thompson HS, Ten Have T, Vaughn D, Malkowicz SB, Lee D. Racial Differences in Medical Mistrust Among Men Diagnosed With Prostate Cancer. *Cancer*. 2009; 115:2553–2561. [PubMed: 19296516]
10. Gaugler JE, Hanna N, Linder J, Given CW, Tolberta V. Cancer caregiving and subjective stress: A multi-site, multi-dimensional analysis. *Psycho-Oncology*. 2005; 14:771–785. [PubMed: 15750995]
11. Pearlin LI, Mullan JT, Semple SJ, Skaff MM. Caregiving and the stress process: An overview of concepts and their measures. *Gerontologist*. 1990; 30:583–594. [PubMed: 2276631]
12. Given BA, Given CW, Kozachik S. Family support in advanced cancer. *CA Cancer Journal for Clinicians*. 2001; 51:213–231.
13. Francis LE, Worthington J, Kypriotakis G, Rose JH. Relationship quality and burden among caregivers for late-stage cancer patients. *Supportive Care in Cancer*. 2009; 10:00520–009–0765–5
14. Townsend AL, Franks MM. Quality of the relationship between elderly spouses: influence on spouse caregivers' subjective effectiveness. *Fam Relat*. 1997; 46:33–39.
15. Williamson GM, Shaffer DR. Relationship quality and potentially harmful behaviors by spousal caregivers: how we were then, how we are now. *Psychol Aging*. 2001; 16:217–226. [PubMed: 11405310]
16. Yates ME, Tennstedt S, Chang BH. Contributors to and mediators of psychological well-being for informal caregivers. *J Gerontol*. 1999; 54:P12–P22.
17. Northouse LL, Mood D, Templin T, Mellon S, George T. Couples' patterns of adjustment to colon cancer. *Soc Sci Med*. 2000; 50:271–284. [PubMed: 10619695]
18. Northouse L, Templin T, Mood D. Couples' adjustment to breast disease during the first year following diagnosis. *J Behav Med*. 2001; 24:115–136. [PubMed: 11392915]
19. Teno JM, Casey VA, Welch LC, Edgman-Levitan S. Patient-focused, family-centered end-of-life medical care: views of the guidelines and bereaved family members. *J Pain Symptom Management*. 2001; 22:738–751.
20. Rose JH, Bowman KF, O'Toole EE, Abbott K, Love TE, Thomas C, Dawson NV. Caregiver objective burden and assessments of patient-centered, family-focused care for frail elderly veterans. *The Gerontologist*. 2007; 47(1):21–33. [PubMed: 17327537]
21. Kristjanson LJ, Sloan JA, Dudgeon D, Adaskin E. Family members' perceptions of palliative cancer care: predictors of family functioning and family members' health. *J Palliat Care*. 1996; 12:10–20. [PubMed: 9019032]
22. Dibbelt S, Schaidhammer M, et al. Patient-doctor interaction in rehabilitation: The relationship between perceived interaction quality and long-term treatment results. *Patient Education and Counseling*. 2009; 76:328–335. [PubMed: 19683407]
23. Given B, Wyatt G, Given C, Sherwood P, Gift A, DeVoss D, Rahbar M. Burden and depression among caregivers of patients with cancer at the end of life. *Oncology Nursing Forum*. 2006; 31:1105–1117. [PubMed: 15547633]
24. Aneshensel CS, Botticello AL, et al. When caregiving ends: The course of depressive symptoms after bereavement. *Journal of Health and Social Behavior*. 2004; 45:422–440. [PubMed: 15869114]
25. Kim Y, Given BA. Quality of life of family caregivers of cancer survivors: across the trajectory of the illness. *Cancer Supplement*. 2008; 112:2556–2568.
26. Kissane, DW.; Bloch, S. *Family Focused Grief Therapy*. Philadelphia: Open University Press; 2002.

27. Rose JH, Kypriotakis G, Bowman KF, Einstadter D, O'Toole EE, Mechekano R, Dawson NV. Patterns of Adaptation in Patients Living Long Term With Advanced Cancer. 2009; 115(Suppl):4298–4310.
28. Williamson GM, Shaffer DR. Relationship quality and potentially harmful behaviors by spousal caregivers: how we were then, how we are now. *Psychol Aging*. 2001; 16:217–226. [PubMed: 11405310]
29. Step MM, Rose JH, Albert JM, Cheruvu VK, Siminoff LA. Modeling patient-centered communication: Oncologist relational communication and patient communication involvement in breast cancer adjuvant therapy decision-making. *Patient Education and Counseling*. 2009; 77:369–378. [PubMed: 19811883]
30. Ommen O, Janssen C, Neugebauer E, Bouillon B, Rehm K, Rangger C, Erli HJ, Pfaff H. Trust, social support and patient type—Associations between patients perceived trust, supportive communication and patients preferences in regard to paternalism, clarification and participation of severely injured patients. *Patient Education and Counseling*. 2008; 73:196–204. [PubMed: 18450408]
31. Maly RC, Stein JA, Umezawa Y, Leake B, Anglin MD. Racial/ethnic differences in breast cancer outcomes among older patients: effects of physician communication and patient empowerment. *Health Psychology*. 2008; 27:728–736. [PubMed: 19025268]
32. Thorne, Sally E.; Hislop, T Gregory; Armstrong, Elizabeth-Anne; Oglov, Valerie. Cancer care communication: The power to harm and the power to heal? *Patient Education and Counseling*. 2008; 71:34–40. [PubMed: 18096354]
33. Zachariae R, Pedersen CG, et al. Association of perceived physician communication style with patient satisfaction, distress, cancer-related self-efficacy, and perceived control over the disease. *British Journal of Cancer*. 2003; 88:658–665. [PubMed: 12618870]
34. Frick E, Rieg-Appleson C, Tyroller M, Bumeder I. Social support, affectivity, and the quality of life of patients and their support-givers prior to stem cell transplantation. *Journal of Psychosocial Oncology*. 2005; 23:15–34. [PubMed: 16618686]
35. Musil CM, Morris DL, Warner CB, Saeid H. Issues in caregivers' stress and providers' support. *Research on Aging*. 2003; 25:505–526.
36. Cherlin E, Fried T, Prigerson HG, Schulman-Green D, Johnson-Hurzeler R, Bradley EH. Communication between physicians and family caregivers about care at the end of life: When do discussions occur and what is said? *Journal of Palliative Medicine*. 2005; 8:1176–1185. [PubMed: 16351531]
37. Rabow MW, Hauser JM, Adams J. Supporting family Caregivers at the end of life - They don't know what they don't know. *Jama-Journal of the American Medical Association*. 2004; 291:483–491.
38. Merton, RK. *On Theoretical Sociology*. NY: The Free Press; 1967.
39. Fishman J, O'Dwyer P, Lu HL, Henderson H, Asch DA, Casarett DJ. Race, Treatment Preferences, and Hospice Enrollment: Eligibility Criteria May Exclude Patients With the Greatest Needs for Care. *Cancer*. 2009; 115:689–697. [PubMed: 19107761]
40. True G, Phipps EJ, Braitman LE, Harralson T, Harris D, Tester W. Treatment preferences and advance care planning at end of life: The role of ethnicity and spiritual coping in cancer patients. *Annals of Behavioral Medicine*. 2005; 30:174–179. [PubMed: 16173914]
41. Phipps E, True G, Harris D, Chong U, Tester W, Chavin SI, Braitman LE. Approaching the end of life: Attitudes, preferences, and behaviors of African-American and white patients and their family caregivers. *Journal of Clinical Oncology*. 2003; 21:549–554. [PubMed: 12560448]
42. Dessio W, Wade C, Chao M, Kronenberg F, Cushman LE, Kalmuss D. Religion, spirituality, and healthcare choices of African-American women: results of a national survey. *Ethnic Dis*. 2004; 14:189–97.
43. Jones RA, Taylor AG, Bourguignon C, Steeves R, Fraser G, Lippert M, Theodorescu D, Mathews H, Kilbridge K Laing. Complementary and alternative medicine modality use and beliefs among African American prostate cancer survivors. *Oncology Nursing Forum*. 2007; 34:359–64. [PubMed: 17573300]

44. Dilworth-Anderson P, Williams IC, Gibson BE. Issues of race, ethnicity and culture in caregiving research: A twenty year review [1980–2000]. *The Gerontologist*. 2002; 42:237–272. [PubMed: 11914467]
45. Weinland JA. The lived experience of informal African American male caregivers. *American Journal of Men's Health*. 2009; 3:16–24. [PubMed: 19477717]
46. Kosloski K, Schaefer JP, Allwardt D, et al. The role of cultural factors on clients' attitudes toward caregiving, perceptions of service delivery, and service utilization. *Home Health Care Services Quarterly*. 2002; 21:65–88. [PubMed: 12665072]
47. Cagney KA, Agree EM. Racial differences in skilled nursing care and home health use: the mediating effects of family structure and social class. *Journals of Gerontology B*. 1999; 54:S223–36.
48. Washington KT, Bickel-Swenson D, Stephens N. Barriers to hospice use among African Americans: a systematic review. *Health in Social Work*. 2008; 33:267–74.
49. Mitchell BL, Mitchell LC. Review of the literature on cultural competence and end-of-life treatment decisions: the role of the hospitalist. *Journal of the National Medical Association*. 2009; 101:920–6. [PubMed: 19806850]
50. White TM, Townsend AL, Stephens MAP. Comparisons of African American and White women in the parent care role. *The Gerontologist*. 2000; 40:718–28. [PubMed: 11131088]
51. Kessler RC, Neighbors HW. *Journal of Health & Social Behavior*. 1986; 27:107–115. [PubMed: 3734380]
52. Bowman KF, Rose JH, Radziewicz RM, O'Toole EE, Berila R. Family caregiver engagement in a coping and communication support intervention tailored to advanced cancer patients and families. *Cancer Nursing*. 2009; 32:73–81.
53. Rose JH, O'Toole EE, Einstadter D, Love TE, Shenko CA, Dawson NV. Patient age, well-being, perspectives, and care practices in the early treatment phase for late-stage cancer. *The Journals of Gerontology*. 2008; 63A:960–967. [PubMed: 18840801]
54. Radziewicz RM, Rose JH, Bowman KF, Berila RA, O'Toole EE, Given B. Establishing treatment fidelity in a coping and communication support telephone intervention for aging patients with advanced cancer and their family caregivers. *Cancer Nursing*. 2009; 32:193–202. [PubMed: 19295420]
55. Shacham S. A shortened version of the profile of mood states. *Journal of Personality Assessment*. 1983; 47:305–306. [PubMed: 6886962]
56. Moos, RH.; Moos, BS. *Family Environment Scale Manual*. Stanford, CA: Consulting Psychologists Press; 1981.
57. Kissane DW, McKenzie M, Bloch S, Moskowitz C, McKenzie DP, O'Neill I. Family Focused Grief Therapy: A Randomized, Controlled Trial in Palliative Care and Bereavement. *American Journal of Psychiatry*. 2006; 163:1208–1218. [PubMed: 16816226]
58. Holahan CJ, Moos RH. Social support and adjustment: Predictive benefits of social climate indices. *American Journal of Community Psychology*. 1982; 10:403–415. [PubMed: 7137128]
59. Kristjanson LJ, Atwood JR, Degner LF. Validity and reliability of the family inventory of needs of advanced cancer patients. *Journal of Nursing Measure*. 1995; 3:109–126.
60. Kaiser Family Foundation. *State Health Facts.org*. 2007. Retrieved 3/20/09 from <http://www.statehealthfacts.org/profileind.jsp?rgn=37&ind=15&cat=1>
61. Rose JH. Social support and cancer: adult patients' desire for support from family, friends and health professionals. *American Journal of Community Psychology*. 1990; 18:439–463. [PubMed: 2264559]
62. Bezold C. The future of patient-centered care: scenarios, visions and audacious goals. *Journal of Alternative and Complementary Medicine*. 2005; 11:S77–S84.
63. Bissell P, May CR, Noyce PR. From compliance to concordance: barriers to accomplishing a re-framed model of health care interactions. *Social Science & Medicine*. 2004; 58:851–862. [PubMed: 14672598]
64. Blenkinsopp A. From compliance to concordance: How are we doing? *International Journal of Pharmacy Practice*. 2001; 9:65–66.

65. Laidlaw TS, Kaufman DM, Sargeant J, MacLeod H, Blake K, Simpson D. What makes a physician an exemplary communicator with patients? *Patient Education and Counseling*. 2007; 68:2153–160.
66. Schoenmakers B, Buntinx F, Delepeleire J. What is the role of the general practitioner towards the family caregiver of a community-dwelling demented relative? *Scandinavian Journal of Primary Health Care*. 2009; 27:31–40. [PubMed: 19040191]
67. Pedersen R. Empirical research on empathy in medicine-A critical review. *Patient Education and Counseling*. 2009; 76:307–322. [PubMed: 19631488]
68. Adler, NE.; Page, AEK., editors. *Cancer care for the whole patient: meeting psychosocial needs*. Institute of Medicine; Washington, DC: National Academies Press; 2008.
69. Marcussen K. Explaining Differences in Mental Health Between Married and Cohabiting Individuals. *Social Psychology Quarterly*. 2005; 68:239–257.
70. Simon R, Marcussen K. Marital Transitions, Marital Beliefs, and Mental Health. *Journal of Health & Social Behavior*. 1999; 40:111–125. [PubMed: 10467758]
71. Starr, P. *The social transformation of American medicine: The rise of a sovereign profession and the making of a vast industry*. New York: Basic Books; 1982.
72. Gamble VN. Under the shadow of Tuskegee: African Americans and health care. *American Journal of Public Health*. 1997; 87:1773–1778. [PubMed: 9366634]
73. Stewart P. Care Provision for African American Elders: Family Attitudes and Strategies. *Journal of Intergenerational Relationships*. 2008; 6:61–81.
74. Dressler WW. Extended Family Relationships, Social Support, and Mental Health in a Southern Black Community. *Journal of Health & Social Behavior*. 1985; 26:39–48. [PubMed: 3998433]
75. Jarrett RL, Jefferson SR, Kelly JN. Finding Community in Family: Neighborhood Effects and African American Kin Networks. *Journal of Comparative Family Studies*. 2010; 41:299–328.
76. Mazanec PM, Daly BJ, Townsend A. Hospice Utilization and End-of-Life Care Decision Making of African Americans. *American Journal of Hospice & Palliative Medicine*. 2010; 27:560–566. [PubMed: 21071435]
77. Williams SW, Hanson LC, Boyd C, Green M, Goldmon M, Wright G, Corbie-Smith G. Communication, Decision Making, and Cancer: What African Americans Want Physicians to Know. *Journal Of Palliative Medicine*. 2008; 11:1221–1226. [PubMed: 19021485]
78. Shrank WH, Kutner JS, Richardson T, Mularski RA, Fischer S, Kagawa-Singer M. Focus group findings about the influence of culture on communication preferences in end-of-life care. *Journal of General Internal Medicine*. 2005; 20:703–709. [PubMed: 16050878]
79. Haley WE, Allen RS, Reynolds S, Chen HB, Burton A, Gallagher-Thompson D. Family issues in end-of-life decision making and end-of-life care. *American Behavioral Scientist*. 2002; 46:284–298.
80. Thoits PA. Stress, coping, and social support processes - where are we - what next. *Journal of Health and Social Behavior*. 1995; (SI):53–79. [PubMed: 7560850]
81. Bellah, RN.; Sullivan, WM.; Swidler, A.; Tipton, SM. *Habits of the Heart: Individualism and Commitment in American Life*. University of California Press; Berkeley: 1985.

Figure 1.
Model of Associations between Relationships and Distress as Moderated by Race

Figure 2.
Association of Relationship between Caregiver and Patient's Health Care Providers with
Caregiver Depressed Mood by Race

Figure 3.
Association of Relationship between Caregiver and Family Members with Caregiver Depressed Mood by Race

Figure 4.
Association of Relationship between Caregiver and Patients' Health Care Providers with
Caregiver Anxiety by Race

Table 1**Independent and Control Variables**

FCG Characteristics	Median [Range] or N [%]
Gender	
-Female	314 [78.3%]
-Male	83 [20.7%]
Age (years)	51 [18–88]
Education (years)	12 [5–23]
Income	
-\$0–9,999	30 [7.5%]
-\$10,000–14,999	46 [11.5%]
-\$15,000–19,999	31 [7.7%]
-\$20,000–29,999	73 [18.2%]
-\$30,000–39,999	53 [13.2%]
-\$40,000–49,999	31 [7.7%]
-\$50K or more	110 [27.4%]
Employed	
-Yes	192 [47.9%]
-No	205 [51.1%]
Race	
-African American	125 [31.2%]
-White	274 [68.3%]
Live Together	
-No	168 [41.9%]
-Yes	231 [57.6%]
Weeks since Diagnosis	6.00 [0–53]
Relationship Variables	
Variable [Range]	Mean [SD]
Family Relationship [0–12]	8.62 [2.26]
HCP Relationship [0–2.5]	1.55 [0.44]
Outcome Variables	
Variable [Range]	Mean [SD]
Anxiety [0–24]	6.50 [5.59]
Depressed Mood [0–32]	6.37 [6.54]

Table 2
Unstandardized Regression Coefficients and Standard Errors for Caregiver Anxiety⁺

Caregiver Characteristics	Model 1		Model 2		Model 3	
	b	(se)	b	(se)	b	(se)
African American	-2.585***	(.575)	-2.585***	(.575)	-2.428***	(.571)
Family Relationship	-.431***	(.117)	-.376**	(.134)	-.429***	(.115)
PHCP Relationship	-2.772***	(.569)	-2.753***	(.569)	-4.212***	(.722)
Race × Family Relationship			-.213	(.256)		
Race × PHCP Relationship					3.603**	(1.134)
Adj. R2	.13***		.13***		.15***	

⁺ Analysis adjusted for demographics

* p<.05

** p<.01

*** p<.001

Table 3
Unstandardized Regression Coefficients and Standard Errors for Caregiver Depressed Mood⁺

Caregiver Characteristics	Model 2	Model 3	Model 4
	b (se)	b (se)	b (se)
African American	-2.246** (.673)	-2.245*** (.670)	-2.079** (.670)
Family Relationship	-.425** (.137)	-.261 (.156)	-.423** (.135)
HCP Relationship	-3.223*** (.666)	-3.166*** (.664)	-4.758*** (.848)
Race × Family Relationship		-.634* (.298)	
Race × PHCP Relationship			3.838** (1.331)
Adj. R2	.11***	.12***	.12***

⁺ Analysis adjusted for demographics

* p<.05

** p<.01

*** p<.001