

APPRAISAL OF THE CANCER EXPERIENCE BY FAMILY MEMBERS AND SURVIVORS IN LONG-TERM SURVIVORSHIP

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SUMMARY

This study assessed the appraisal of the stressfulness of the cancer experience and its correlates for family members and older survivors living in the long-term survivorship phase of the disease. On average, family members appraised the cancer experience as more stressful than their surviving relatives. Beliefs about the effect of the diagnosis and treatment on family members were important correlates for both family members and survivors in the appraisal process. Cancer characteristics were not related to appraisal for survivors, but stage at diagnosis was associated with a more stressful appraisal for family members. Demographic characteristics were unrelated to appraisal for family members, but being African-American was linked to a less stressful appraisal for survivors. These findings highlight the stressful impact of the cancer experience on family members and can help guide health care interventions which include family members from African-American and White ethnicities. Copyright © 2006 John Wiley & Sons, Ltd.

KEY WORDS: cancer appraisal; long-term survivorship; cancer survivors and families

INTRODUCTION AND BACKGROUND

Studies of long-term cancer survivorship are 'relatively recent and scarce' (Benyamini *et al.*, 2003), but find that the survival experience is often stressful for both patients and their families (Ferrario *et al.*, 2003). In general, studies report that most survivors do well after an initial adjustment period that occurs in the first one to two years following diagnosis and treatment (Kornblith, 1998). Some research finds that, as survivors improve over time, their family members actually get worse (McCorkle *et al.*, 1993; Northouse *et al.*, 2000; Stuber *et al.*, 1996). Little is known about how older long-term survivors or their family members appraise their total cancer experiences (Bowman *et al.*, 2003). Even less is understood about the correlates of those appraisals and how they may be

different for older survivors and family members living in long-term survivorship.

The purpose of this research is to inform these issues by focusing on the concept of cognitive appraisal and its correlates for older adults and their family members in the long-term survivorship phase of cancer. Guided by the Lazarus and Folkman (1984) stress–appraisal–coping theoretical framework, it explores person and situation factors related to a stressful appraisal of the cancer experience separately for older survivors and their family members.

Survivors often express the need to get on with their lives by integrating the cancer experience into the context of their day to day existence (Taylor, 1993, Dow *et al.*, 1999). To accomplish this, survivors appraise the meaning of the experience for their current existence (Taylor, 1993). It has been suggested that the appraisal of the cancer experience changes over time and its meaning not explicit until years following diagnosis and treatment (Pelusi, 1997; Dow *et al.*, 1999; Zebrack, 2000). Those close to patients during diagnosis and treatment are likely to have long lasting effects

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from the cancer experience as well (Benyamini *et al.*, 2003). The director of Office of Cancer Survivorship at the NCI, Julia Rowland, has referred to family members as 'secondary survivors' who are 'often profoundly affected by the cancer diagnosis of a loved one' (Twombly, 2004). Family members who are 'surviving along with patients' (Mellon, 2002, p. 1122) are likely to also be appraising the meaning of the cancer experience for their lives.

The Lazarus and Folkman concept of cognitive appraisal

Cognitive appraisal is a central concept in the stress-appraisal-coping paradigm of Lazarus and Folkman (1984). It is an interpretative and evaluative process that focuses on the meaning and significance that an occurrence has for one's well-being. According to their model, appraisal is influenced by antecedent factors and has consequences for the degree of distress ultimately experienced (Lazarus and Folkman, 1984). Appraisals categorized as stressful are linked to greater psychological distress (Folkman *et al.*, 1986). This research focuses on stress appraisal, defined as family members' and survivors' perceptions in long-term survivorship about the stressfulness of the total cancer experience. The model presented purports that the stress appraisals of family members and survivors are directly affected by their person and situation factors (see Figure 1).

Lazarus and Folkman (1984) link two groups of antecedent variables to cognitive appraisal, person factors and situation or environment factors. Person factors are characteristics of individuals that affect their evaluations of the stressfulness of an encounter. Among the most important person factors are beliefs. Beliefs are 'perceptual lenses' that 'shape perceptions of the environment' (Lazarus and Folkman, 1984, pp. 63–64). In this study, two sets of variables are conceptualized as person factors: the demographic characteristics of family members and survivors (age, race, gender) and family members' and survivors' beliefs about the effect of the cancer diagnosis and treatment on the family (family member distress, family member/survivor communication).

Situation factors are characteristics of situations or the environment that affect individuals' appraisals of stressful encounters. They are

'properties of situations that make them potentially harmful, dangerous, threatening, or challenging' (Lazarus and Folkman, 1984, p. 82). The current research defines characteristics of survivors' cancer (type, stage) as situation factors.

Applying stress appraisal to cancer

Northouse *et al.* (1999) interviewed African-American females who had survived breast cancer on average for nearly five years and found they had low to moderate scores on stress appraisal. Northouse *et al.* (2000) explored colon cancer patients' appraisals of their cancer experience. Appraisal measures included uncertainty about the nature and course of the illness and hopelessness about the future. Patients were found to have low to moderate levels of uncertainty and hopelessness that remained relatively stable from one week after diagnosis to one year after surgery. Older prostate survivors who were about six years from diagnosis reported their cancer to have been moderately stressful and moderately challenging (Bjorck *et al.*, 1999). Bowman *et al.* (2003) studied older individuals who had survived breast, colorectal, or prostate on average for just over ten years. Seventy-five percent of older survivors rated the cancer experience to have been stressful, ranging from a little stressful (25%), quite a bit stressful (23%), to very much stressful (27%).

Appraisal has been associated with a number of outcome measures in studies of cancer. It has been shown to have direct effects on outcomes; that is, more stressful appraisals lead to more negative outcomes. Northouse *et al.* (2000) found that more negative appraisals of cancer were related to greater psychosocial role adjustment problems. Bjorck *et al.* (1999) learned that older prostate survivors' stress appraisals were related to greater depression and anxiety. More recently, Bowman *et al.* (2004) found a more stressful appraisal was associated with greater depression, anxiety, and cancer-related health worry in older survivors.

Appraisal has also been shown to be indirectly linked to outcomes. Northouse *et al.* (2000) reported that although age, concurrent stress, and marital satisfaction had no direct effects on role adjustment problems, they were associated with role adjustment through the appraisal variable. Similarly, Bowman *et al.* (2004) found that age, race, family involvement in treatment choices, family distress, and illness symptoms during

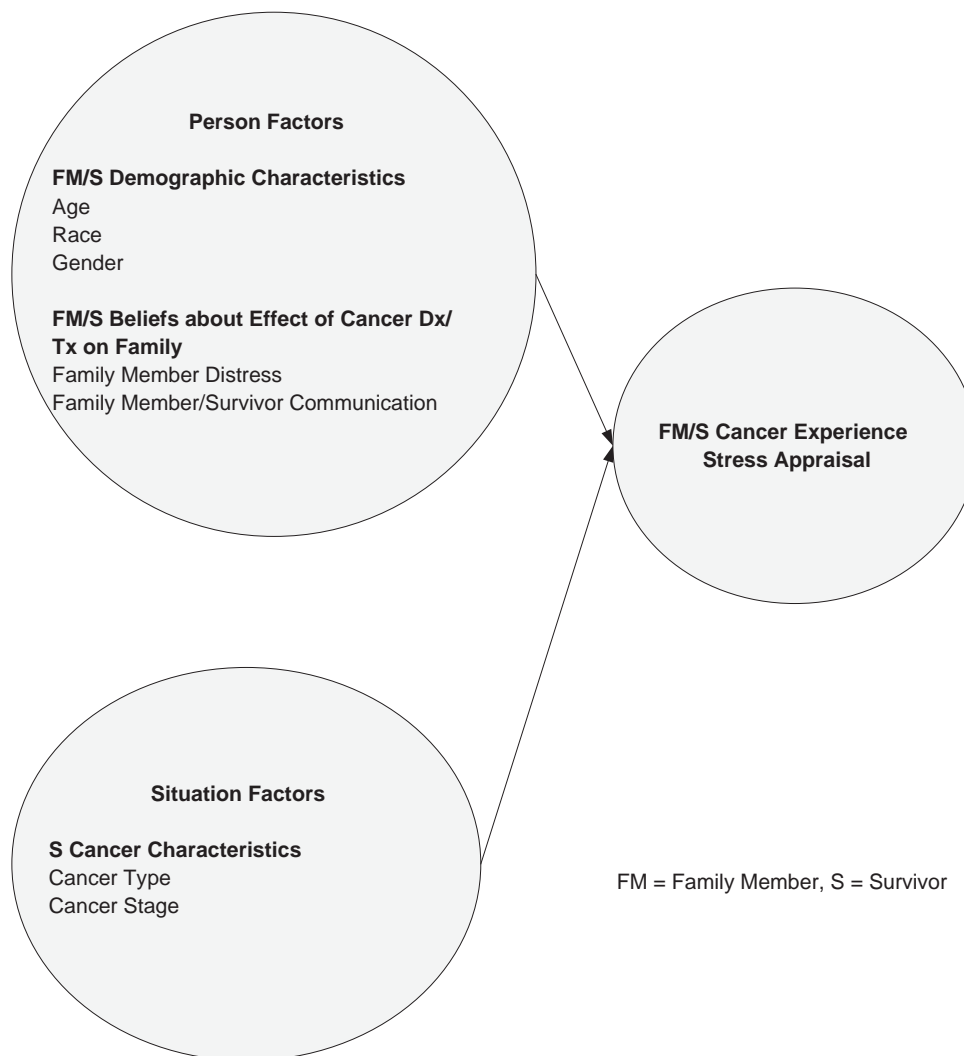


Figure 1. Conceptual model of family appraisal of the cancer experience.

cancer were related to mental health outcomes via the stress appraisal measure.

Correlates of appraisal

Little is known about the relationship between other factors and survivors' appraisals of cancer. Personal characteristics and illness characteristics have been linked to appraisal. Munkres *et al.* (1992) found an appraisal of cancer as stressful was predicted by lower economic status, more symptom distress, and recurrence. African-Amer-

icans were found to have a more despairing view of health in general (Ferraro, 1993) and a more negative appraisal of cancer in particular compared to Whites (Powe, 1995; Powe and Weinrich, 1999). Non-illness related concerns were a major predictor of appraisal in a sample of African-American breast cancer survivors, while cancer-illness variables, such as severity and recurrence, and demographic variables, such as age and education, were unrelated (Northouse *et al.*, 1999). Northouse *et al.* (2000) found that patients' negative appraisals of cancer were positively related to age and concurrent stress but unrelated to gender.

Bowman *et al.* (2004) found older and African-American survivors appraised their cancer experiences as less stressful than Whites. That research also found cancer characteristics unrelated to appraisal with one exception, more illness symptoms during diagnosis and treatment were related to a more stressful appraisal of the cancer experience.

Bowman and colleagues (2003) introduced the concept of survivors' beliefs about the effect of cancer on the family and its relationship to a stressful appraisal of the cancer experience. Their work on stress appraisal in long-term survivorship showed that older survivors' perceptions of greater family distress and more family involvement in treatment choices were associated with more stressful appraisals of the cancer experience.

To synthesize, the long-term survivorship phase of cancer, when survivors and families have lived with the illness for some time, is most likely when older adults and their family members can finally appraise the experience. Past research has confirmed a link between person factors (demographic characteristics, beliefs about the effect of cancer on the family), situation factors (cancer characteristics), and appraisal for older long-term survivors. This has not been investigated in family members of older long-term survivors nor has appraisal of the cancer experience by family members been compared to that of their surviving relative. This study explores both by assessing appraisal of the stressfulness of the cancer experience and its correlates for both family members and survivors who are living in the long-term survivorship phase of the disease.

METHODS

Sample

Data for the current cross-sectional study were derived from a three-year pilot project of family member/older long-term cancer survivor dyads conducted in Cleveland, OH and funded by the National Cancer Institute. Older adults, randomly selected from the tumor registry of the Ireland Cancer Center (ICC) at University Hospital Health Systems (UHHS), were participating in a longitudinal study (three waves of interviews) about quality of life in long-term cancer survivorship. The family member study was initiated

during the third wave of the ongoing survivor study. Of 228 survivors who completed wave three interviews, 149 (65%) identified a spouse or adult child as 'the family member who is most knowledgeable about my cancer experience', granted the project permission to contact him/her, and provided contact information. Of the 79 (35%) remaining survivors, 30 identified family members who were not eligible because they were not a spouse or adult child ($N = 19$) or they lived outside the greater Cleveland study area ($N = 11$). Forty-nine survivors did not want family members contacted about participation in the family study.

Of the 149 spouse and adult child family members identified, the project was unable to reach three individuals for screening. The remaining 146 were phoned and screened for eligibility. At screening, six refused to be interviewed and 140 agreed. However, when interviewers made contact, 31 (22%) of those originally agreeing were not scheduled for interviews (24 refused, one was cognitively unable, and six could not be reached). Thus 109 spouse and adult child family members (78% of those who agreed at screening) actually completed interviews. Interviews were conducted by interviewers who were experienced in talking with older cancer survivors and trained to administer the project's structured survey instrument.

Family member data were subsequently matched and merged with data from corresponding older survivors, thus creating a family survivorship data set of 109 family member/survivor dyads. These dyads are the focus of the current study.

Measures

Table 1 contains a summary of all the measures used in this research. It includes the name of each measure and its component items, coding scheme, and alpha reliability.

The reader is referred to Table 1 throughout the following section describing the study's measures.

Dependent variable

Cancer experience stress appraisal. Seven items were developed by the study to measure appraisal of the cancer experience in long-term survivorship.

Table 1. Summary of study measures for family members (FM) and survivors (S)

Measure	Items	Coding	Alpha reliability
Stress appraisal	Life threatening Traumatic experience Challenge Stressful life event	0-Not at all to 3-Very much	FM = 0.77 S = 0.77
Age	Single item	Number of years	NA
Race	Single item	0-White 1-African-American	NA
Gender	Single item	0-Male 1-Female	NA
FM distress	Distress Disruption of daily routine Relationship strain with survivor Relationship strain with other family members Decline in health Interference with activities at home Interference with social life	0-Not at all to 3-Very much	FM = 0.70 S = 0.73
FM/S communication about the life-threatening aspects of cancer	Cancer might recur Cancer might spread Survivor might die from cancer	0-Not at all to 3-Very much	FM = 0.84 S = 0.84
Breast cancer	Single item	0-No 1-Yes	NA
Colorectal cancer	Single item	0-No 1-Yes	NA
Prostate cancer	Single item	0-No 1-Yes	NA
Cancer stage	<i>In situ</i> Local Regional Distal	1-Least invasive to 3-Most invasive	NA

Family members and survivors were asked the extent to which they now considered the cancer to have been life threatening, just a part of living, a traumatic experience, a challenge, a stressful life event, an opportunity of personal growth, and a learning experience. Principal components factor analysis with varimax rotation revealed a four-item factor describing a *stressful appraisal of the cancer experience* (see Table 1). Although Lazarus and Folkman (1984) described both challenge and threat as stress appraisals, they

considered them 'separate, although often related constructs' (p. 33). In this study, the challenge and threat variables combined with the trauma and stressful variables to form the stress appraisal measure.

Independent variables

Person factors: Demographic characteristics. Demographics included characteristics of both

family members and survivors. These characteristics were *age*, *gender*, and *race* (see Table 1).

Person factors: Beliefs about the effect of cancer on the family. Family members and survivors were asked seven questions about how the cancer diagnosis and treatment affected the family member. These items, based on the work of Ferrell *et al.* (1995) and Schipper *et al.* (1984), created the *family member distress* scale (see Table 1).

Family members and survivors were also asked a series of questions that were developed for the study to assess discussions they had with each other during the time of diagnosis and treatment. Principal components factor analysis with varimax rotation revealed a three-item factor describing conversations about the *life-threatening aspects of cancer* (see Table 1).

Situation factors. Survivor cancer characteristics. The survivor study's selection criteria specified that all participants must have been diagnosed and treated for one of three cancer types: *breast*, *colorectal*, and *prostate* (see Table 1). This information was obtained from the tumor registry and verified with survivors.

Also obtained from tumor registry data was information about cancer staging at diagnosis. The variable, based on SEER conventions, was categorized as *in situ*, local, regional, and distal. In regression analyses, the *cancer stage* was treated as a continuous variable (see Table 1).

Analysis

Descriptive statistics were used to report frequencies with percentages and means with standard deviations. Pearson's zero-order correlation explored the bivariate relationship between appraisal and personal and situation factors.

Given the cross-sectional nature of the data, the multivariate analyses did not attempt to test causality, but rather to investigate the strength of associations between person and situation variables and the stress appraisal outcome measure, while controlling for all other variables in the model. Separate family member and survivor models were tested using ordinary least squares (OLS) regression analyses. In multivariate analyses, when variables have more than two mutually exclusive categories, all but one

of the categories are used as dummy or dichotomous variables and the omitted category functions as a reference group against which comparisons are made (McClendon, 1994). The cancer type variable used breast and prostate in the models and omitted colorectal as the comparison group.

RESULTS

Table 2 presents descriptive statistics for all variables used in the analyses and provides results of tests to detect differences between family members' and survivors' mean scores for the beliefs measures and the appraisal measures. These include personal factors, situation factors, and appraisal of cancer.

Person factors

Demographic characteristics. The demographic characteristics revealed that the age range for family members was 29–86 years, with a mean of 61 years. Survivors ranged from 60 to 90 years of age, with a mean of just over 73 years. The sample was nearly 36% African-American and predominantly female (73.4% family members; 56.0% survivors).

Beliefs about the effect of cancer Dx/Tx on the family. There was no difference between family members' and survivors' perceptions of family member distress. Both reported low levels of family member distress around diagnosis and treatment (mean 4.6 versus mean 3.9, respectively, $p = 0.075$). There was a difference in family members' and survivors' beliefs about communication they had during diagnosis and treatment. On average, family members recounted that the dyad had more extensive conversations about the life threatening aspects of cancer compared to survivors' (mean 3.5 versus mean 2.0, $p = 0.000$).

Situation factors

Survivor cancer characteristics. Just over 40% were survivors of breast cancer, nearly 24% had survived colorectal cancer, and about 36% were prostate survivors. At the time of diagnosis, nearly

Table 2. Descriptive statistics of study variables

	Number (%) or Mean (S.D.)		
	Family member (FM) (<i>N</i> = 109) ^a	Survivor (<i>S</i>) (<i>N</i> = 109) ^a	<i>p</i> -value
Person factors			
<i>FM/S demographic characteristics</i>			
Mean age	61.0 (14.0) (Range 29–86)	73.3 (6.8) (Range 60–90)	NA
Race			
African-American	39 (35.8%)	39 (35.8%)	NA
White	70 (64.2%)	70 (64.2%)	
Gender			
Female	80 (73.4%)	61 (56.0%)	NA
<i>FM/S beliefs about effect of cancer Dx/Tx on family</i>			
FM distress ^b (Range 0–21)	4.6 (3.3)	3.9 (3.1)	0.075
FM/S communication about life threatening aspects of cancer ^c (Range 0–9)	3.5 (2.9)	2.0 (2.3)	0.000
Situation factors			
<i>S cancer characteristics</i>			
Cancer type			
Breast	NA	44 (40.4%)	NA
Colorectal		26 (23.9%)	
Prostate		39 (35.8%)	
Cancer stage			
<i>In Situ</i>	NA	4 (3.9%)	NA
Local		70 (64.2%)	
Regional		25 (25.5%)	
Distal		3 (2.9%)	
Unknown		7 (6.4%)	
FM/S stress appraisal			
Stressfulness of cancer experience ^d (Range 0–12)	7.7 (2.8)	5.8 (2.9)	0.000

^aSample size varies slightly due to missing values.

^bScale measures survivor perception of family member distress, family member perception of own distress.

^cScale measures survivor and family member perception about dyad communication.

^dScale measures survivor and family member perception of the cancer experience.

two-thirds had been staged as local (64.2%) while just over one fourth were staged as regional (25.5%).

Stress appraisal

Cancer experience appraisal. The appraisal outcome measured the perceptions of family members and survivors about the extent to which each considered the cancer experience so far to be stressful. There was a significant difference in these perceptions. On average, family members reported the cancer experience to be more stressful than did survivors (mean 7.7 versus 5.8, $p = 0.000$).

Table 3 displays the bivariate relationship between appraisal and person and situation factors for family members and survivors. For family members, both measures of beliefs about the effect of diagnosis and treatment on family members and one survivor cancer characteristic were significantly related to appraisal. Greater personal (family member) distress around diagnosis/treatment ($r = 0.54$, $p = 0.000$), more extensive family member/survivor dyad communication about the life threatening aspects of cancer ($r = 0.27$, $p = 0.005$), and having a relative with a more invasive stage of cancer ($r = 0.32$, $p = 0.001$) were related to a more stressful appraisal of the cancer experience by

Table 3. Zero order correlation of cancer experience stress appraisal with person and situation factors

	Family member (FM) stress appraisal ($N = 109$) ^a		Survivor (S) stress appraisal ($N = 109$) ^a	
	<i>r</i>	<i>p</i> -value	<i>r</i>	<i>p</i> -value
Person factors				
<i>FM/S demographic characteristics</i>				
Age	-0.01	0.940	-0.24	0.012
Race (African-American = 1)	-0.13	0.178	-0.25	0.008
Gender (Female = 1)	-0.09	0.350	0.13	0.193
<i>FM/S beliefs about effect of cancer Dx/Tx on family</i>				
FM distress ^b	0.54	0.000	0.39	0.000
FM/S communication about life threatening aspects of cancer ^c	0.27	0.005	0.30	0.002
Situation factors				
<i>S cancer characteristics</i>				
Breast cancer	-0.00	0.980	0.16	0.108
Colorectal cancer	0.16	0.090	-0.04	0.721
Prostate cancer	-0.14	0.136	-0.13	0.185
Stage at diagnosis	0.32	0.001	0.01	0.941

^aSample size varies slightly due to missing values.

^bScale measures survivor perception of family member distress, family member perception of own distress.

^cScale measures survivor and family member perception about dyad communication.

family members. Their demographic characteristics were unrelated to appraisal.

For survivors, both belief measures and two demographic characteristics were significantly associated with their appraisal of the cancer experience. Survivors' beliefs that diagnosis/treatment had caused more distress in family members ($r = 0.39$, $p = 0.000$) and that more dyad communication about the life threatening aspects of cancer occurred around diagnosis and treatment ($r = 0.30$, $p = 0.002$) were linked to a more stressful appraisal of the cancer experience by survivors. In addition, being older ($r = -0.24$, $p = 0.012$) and being African-American ($r = -0.25$, $p = 0.008$) were significantly related to a less stressful appraisal for survivors. Cancer characteristics were not correlated with survivors' appraisal of the stressfulness of the cancer experience.

Table 4 presents results of separate regression equations for family members and survivors. Appraisal of the cancer experience was regressed on person and situation factors. The strongest correlate of family member appraisal was their own (family member) distress (beta = 0.45, $p = 0.000$), followed by survivor stage at diagnosis (beta = 0.23, $p = 0.007$). Controlling for all other variables in the model, greater family member distress around diagnosis and treatment and

having a relative with a more invasive cancer stage were associated with a more stressful appraisal of the cancer experience for family members. These two variables accounted for 33% of the variance in family member appraisal (adjusted $R^2 = 0.332$).

Regression results for survivors revealed that three measures were significantly related to stress appraisal, race (beta = -0.25 , $p = 0.005$), family member distress (beta = 0.27, $p = 0.003$), and family member/survivor communication about the life threatening aspects of cancer (beta = 0.25, $p = 0.008$). For survivors, being African-American was related to a less stressful appraisal of the cancer experience, while beliefs about more family member distress and more extensive conversations by the dyad about the life threatening aspects of cancer during diagnosis and treatment were related to a more stressful appraisal of the cancer experience. The survivor model accounted for 23% of the variance in appraisal (adjusted $R^2 = 0.230$).

DISCUSSION

Long-term survivorship is most likely the time when survivors and their families can finally appraise what the cancer experience means to

Table 4. Regression of cancer experience stress appraisal on person and situation factors

	Family member (FM) stress appraisal (<i>N</i> = 109)			Survivor (<i>S</i>) stress appraisal (<i>N</i> = 109)		
	<i>B</i> ^a	Beta ^b	<i>p</i> -value	<i>B</i> ^a	Beta ^b	<i>p</i> -value
Person factors						
<i>FM/S demographic characteristics</i>						
Age	−0.01	−0.06	0.534	−0.04	−0.10	0.302
Race (African-American = 1)	−0.31	−0.05	0.522	−1.53	−0.25	0.005
Gender (Female = 1)	−0.47	−0.07	0.427	0.55	0.09	0.627
<i>FM/S beliefs about effect of cancer Dx/Tx on family</i>						
FM distress ^c	0.39	0.45	0.000	0.27	0.27	0.003
FM/S communication about life threatening aspects of cancer ^d	0.15	0.15	0.076	0.33	0.25	0.008
Situation factors						
<i>S cancer characteristics</i>						
Breast cancer ^e	−0.62	−0.11	0.301	0.43	0.07	0.578
Prostate cancer ^e	−0.67	−0.11	0.283	−0.32	−0.05	0.755
Stage at diagnosis	1.16	0.23	0.007	0.24	−0.05	0.623
<i>F</i>		7.72	0.000	5.03		0.000
<i>R</i> ²		0.382			0.287	
Adjusted <i>R</i> ²		0.332			0.230	

^aUnstandardized regression coefficient.

^bStandardized regression coefficient.

^cScale measures survivor perception of family member distress, family member perception of own distress.

^dScale measures survivor and family member perception about dyad communication.

^eDichotomous variables with colorectal cancer as the comparison group.

them and put it within the context of their daily lives. Stress appraisals by older long-term cancer survivors and the correlates of those appraisals have recently been addressed by research in cancer and aging. This research has not accorded the same attention to these issues for family members in long-term survivorship, even though the diagnosis and treatment of cancer is known to impact the entire family. The current research found that, on average, years following diagnosis and treatment family members appraised the cancer experience as more stressful than their surviving relatives. This may help explain why previous research has found that some family members do worse long term compared to survivors (McCorkle *et al.*, 1993; Northouse *et al.*, 2000; Stuber *et al.*, 1996). It also suggests that older long-term survivors may do a better job of incorporating cancer within the context of their other life experiences compared to family members. Survivors, on average, just over ten years older than family members, may be dealing with other more acute health problems, functional difficulties, or personal losses that make the cancer more peripheral to their lives. This notion is

supported in work by Deimling *et al.* (2004) that found other health problems have a greater impact on functioning and activities of older adult, long-term survivors than cancer-related factors.

Both similar and different measures were found to be correlated with appraisals by family members and survivors. In terms of similarities, it is clear that beliefs about the effect of the diagnosis and treatment on family members were extremely important to both family members and survivors in the appraisal process. The belief of greatest consequence dealt with perceptions of family member distress. Perceptions of more family member distress by survivors (evaluating family members) and family members (evaluating themselves) were related to more stressful appraisals of the experience for both. This finding has been previously documented for older long-term survivors (Bowman *et al.*, 2003), but, to our knowledge, this is the first study to make that link for family members. The belief that the cancer diagnosis and treatment complicated the lives of family members had far reaching and long-term stress effects for family members and survivors alike.

The second belief about the effect of cancer on the family, dyadic communication about the life threatening aspects of cancer, was also related to more stressful appraisals for survivors. Although not significant at conventional levels, this measure pointed to a trend in the same direction for family members. These conversations are more likely to have occurred when the prognosis was perceived by one or both members of the dyad to be less favorable and thus more stressful. It may be that the difficulty related to discussing these issues remains vivid for families for years to come and colors their evaluations of the experience. It is also possible that some conversations took place despite the fact that one member of the dyad was not comfortable with their content. Being forced to confront difficult or emotional topics may have contributed to long lasting stress.

Other than the beliefs measures, the correlates of stress appraisal differed for family members and survivors. Cancer characteristics played a role for family members, but not for survivors. Cancers staged as more invasive at diagnosis were associated with a more stressful appraisal of the experience by family members. Feelings of helplessness in their inability to affect cancer progression or treatment outcomes early on in their loved ones may, in part, explain their more stressful appraisals in long-term survivorship. Family members still may be very concerned about the effects these cancers have for the well being and future of their surviving relatives. Survivors, on the other hand, may have moved on from these cancer concerns to concerns about more pressing current issues.

Another difference in the correlates for family members and survivors was in terms of demographic characteristics. Family members' characteristics were unrelated to appraisal, but race was a factor for survivors. As past research has shown (Bowman *et al.*, 2003), African-American survivors appraised their cancer experience as less stressful than White survivors. That study speculated that a cancer diagnosis may be less stressful for older African-American survivors who have more pessimistic views of general health and more fatalistic views of cancer compared to Whites (Ferraro, 1993; Powe, 1995) and thus, may have lower expectations for good health outcomes. In the current study, the question is why this is not also true for African-American family members. It may be that younger African-American family members (younger family members are adult children in this sample and approximately 48% of adult chil-

dren are African-American) are becoming more health conscious and more savvy health consumers and thus are beginning to anticipate better health outcomes. Health promotion activities of younger African-Americans need to be addressed in future cancer research.

These findings have several implications for planning interventions for cancer patients and their family members. Interventions designed to reduce patient stress around diagnosis and treatment need to focus on the entire family, not just the patient. Beliefs about the effect of the diagnosis and treatment on the family are crucial considerations and need to be evaluated. Addressing ways to manage family members' distress may benefit both patients and families during diagnosis and treatment and as they move into the survivorship phase of the disease. Interventions need to focus on family communication and its relationship to stress. Helping families figure out which topics are deemed appropriate/inappropriate by all members and teaching them how to talk with and listen to one another about the appropriate topics might help lower stress.

Interventions need to pay special attention to the long-term effects of the cancer on family members. Family members in our research were having more negative fallout years following the cancer diagnosis and treatment compared to the older cancer survivors. This may be related to beliefs about coping with cancer. A recent study comparing survivors' and family members' beliefs about ideal ways of coping found family members more likely to endorse fighting spirit coping and survivors more likely to endorse cognitive avoidance coping (Bowman *et al.*, 2005). Family members may still be trying to take charge and defeat cancer, while survivors have successfully put thoughts of cancer out of their minds.

We propose that therapeutic interventions for families should be introduced early in the diagnosis and treatment phase as a preventative measure. Such interventions could foster open communication and understanding of one another's stress and ways of coping with the threat and uncertainty of cancer treatment and prognosis. Early interventions of this type might address differences in coping and feelings of helplessness among family members in the short run and mediate long term appraisals of stressfulness. Helping families to move forward after cancer, especially one perceived as more threatening to the life of the patient, should be a goal. The primary aim of all

interventions that assist cancer patients and their families, either in short-term or long-term survivorship, should be to make life with cancer as manageable as possible.

Cancer interventions must be culturally sensitive. Understanding how families of different racial and cultural backgrounds vary in their views of and reactions to the disease will facilitate the development of interventions that have the greatest capacity to reach those most in need.

This research has several limitations that suggest areas for future research. Data from family members were collected at only one point in time, thus allowing only issues of correlation to be investigated. Any discussion of causation is beyond the scope of these data. The sample size is small and restricted the number of covariates that were used in the models of appraisal. It is possible that variables that would have added to our understanding of the cancer experience appraisal are not included in these models. This may be particularly true for the survivor model, where the amount of explained variance is more modest. The measures of beliefs about the effect of the diagnosis and treatment on the family are based on retrospective reports of family members and survivors. Recall of past experiences may be blurred by the passage of time.

Despite these limitations, the study has several strengths. To our knowledge, this is the first research to explore appraisal of the cancer experience in both older survivors and their family members in long-term survivorship. It allows comparisons between family members and survivors in terms of average levels of appraised stress and of factors related to more stressful appraisals. Unlike most previous work in cancer and aging, the sample has a substantial proportion of African-Americans.

This study expands the Lazarus and Folkman (1984) conceptual domain of beliefs to include beliefs by families about the effect of a cancer diagnosis and treatment on them, including family distress and family communication. It points to the considerable significance that family member distress around diagnosis and treatment has for long-term survivorship. It underscores the lack of agreement between family members and survivors about the extent to which life threatening issues related to the cancer were discussed during diagnosis and treatment and the stressfulness of that communication.

This research points to both positive and negative attributes of long-term survivorship for

families. On the positive side, older long-term survivors appear to be able to put the cancer experience within the context of their other life experiences and move on. This is not to say that cancer is not still a part of who they are, but that it is not a major defining characteristic for them. The more troubling issue is for family members. They appear less able to let go of the distress linked to the diagnosis and treatment phase of the disease and thus, it continues to have consequences for their appraisal of the overall cancer experience. This study undeniably supports the notion that cancer is a disease that affects the entire family, even in long-term survivorship. It also highlights the need for family focused interventions throughout the course of the disease so that these 'secondary survivors' can live effectively with the aftermath of cancer.

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