

Distress about Caregiver Proximity and Availability: Self-Reports from Breast Cancer Survivors

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Abstract

Distress is a common side effect of a cancer diagnosis and treatment, and is often referred to as the sixth vital sign. Prolonged exposure to distress can have adverse effects on physical and mental health; unresolved distress may even increase the risk of metastatic disease. The purpose of this study was to identify and compare the level and source of distress in acute leukemia (n=100) and breast cancer survivors (n=100) during early survivorship; a multi-group, cross-sectional design was used. This paper will discuss data associated with self-reported distress from breast cancer survivors related to caregiver proximity and availability.

The level and sources of self-reported distress were collected from survivors during active cancer treatment, at its end, and at 3-, and 6-month post-treatment follow-up. The National Comprehensive Cancer Network (NCCN) Distress Thermometer (DT) was used to quantify the level of distress (analog score, 0-10). A demographic questionnaire included items about caregivers and support persons. The Charleston Index was used to identify survivors' comorbidities; electronic chart reviews validated disease-related information. Data were analyzed with descriptive statistics to define the sample; analysis of variance (ANOVA) was used to measure differences.

Breast cancer patients reported 'moderate to severe' levels of distress (e.g. ≥ 4) during active treatment (5, sd=2.6), upon completion (4.9, sd=3.6), and 3-months following end of treatment (4.8, sd=2.9). Survivors were concerned when their caregivers were not available, such as living (p=0.02) and working outside the home (p=0.04), and working full-time (p=0.04). Age was a significant factor (p=0.00); younger women reported more difficulties than older women. Survivors uniformly reported concerns with work, transportation, and relationship issues. In summary, identification of distress related to availability or proximity perhaps can not

change caregiver or support person circumstances, although may provide an opportunity to develop interventions for the patient to cope and reduce his/her distress.

Introduction

The American Cancer Society (2012 [ACS]) states that one in eight women in the U.S. will be diagnosed with breast cancer in their lifetime. Although breast cancer is the second leading cause of cancer death in women, there have been improvements in technology, early diagnosis, and treatment that have positively affected patient outcomes. These advancements have led to increased numbers of breast cancer survivors, with an estimated 2.6 million breast cancer survivors in 2008 (ACS, 2012). The five-year survival rate for breast cancer in the United States is currently 89% (Lam, Shing, Bonanno, Mancini, & Fielding, 2012), one of the highest cancer survival rates in females (ACS, 2012). Often health care providers focus their care on treatment of the cancer versus a holistic approach that identifies interrelated issues that may exacerbate the patient's experience with a cancer diagnosis. While treatment of the patient's breast cancer is obviously a priority in the journey to recovery, attention to the level and sources of distress, as well as co-morbidities are likewise important. Prevalent physical, psychosocial, and emotional issues require attention to maximize outcomes and enhance survivorship. Distress related to caregiver and support person proximity and availability may also negatively affect the survivor's recovery.

Review of Literature

Distress Screening

The screening of distress should occur on a routine basis and early in the cancer diagnosis for optimal interventions and outcomes (Petty & Lester, 2013). Many healthcare providers may underestimate the level of distress associated with various psychosocial aspects of cancer and the

importance in screening for, and providing support (Dyson, Thompson, Palmer, Thomas, & Schofield, 2012). Some oncologists fail altogether to recognize distress in their patients, as caused by the cancer experience (Söllner, Masilinger, König, Devries, & Lukas, 2004). The oncology field is rapidly becoming more outpatient-based which may result in a decreased amount of physician to patient interaction, and may provide a basis for distress levels to be increasingly unrecognized (Shimizu, et al., 2010).

In a study of Chinese breast cancer survivors surveyed at six years post diagnosis (N=186), researchers noted that early psychological distress from the diagnosis and early treatment of breast cancer can significantly predict long-term psychological distress (Lam et al., 2010). Psychological screening and related interventions during the acute phase of the illness potentially influenced long-term psychological outcomes (Lam et al., 2010). The earlier distress was identified and confronted, the more significant were the positive outcomes for long-term survivorship (Lam et al., 2010). Screening tools such as the distress thermometer give patients permission to open up to a wider range of issues (Hughes, Sargeant, & Hawkes, 2011) than normally addressed in a routine patient visit. In a study of operators (n=17) in an Australian community-based telephone service, the NCCN distress thermometer was used over a four-month period with cancer patients or caregivers (n=666) (Hughes et al., 2011). Patients alluded that many topics areas had never been addressed prior to the implementation of telephone distress screening (Hughes et al., 2011). Survivors indicated that neither their oncology specialists nor their primary care physicians had adequately addressed their questions (Hughes et al., 2011).

In a study of breast cancer patients receiving postoperative radiotherapy (N=276), a fourth of the patients had unmet needs and desired more psychosocial support during their care

for themselves and personal relationships (Luutonen, Vahlberg, Eloranta, Hyväri, & Salminen, 2011). These stated needs independently correlated with younger age ($p=0.001$) and negative hormone receptor status ($p=0.008$).

Sources of Distress

During diagnosis and treatment, patients with breast cancer may encounter a wide range of stressors related to their disease and the treatment process (Lester et al., 2013; Meraner et al., 2009). Breast cancer is often associated with both physical side effects and psychological symptoms. There are multiple etiologies for the occurrence of distress-related psychological symptoms, such as distress from the cancer diagnosis, fear of recurrence and death, altered body image, and treatment-related side effects (Lester et al., 2013; Meraner et al., 2009). The stigma that can surround breast cancer includes the increasing presence of women affected by breast cancer, uncertainty of the outcome, and the extended treatment process. These issues can all factor into feelings of distress; unresolved issues can affect the woman and create even more distress (Petty & Lester, 2013).

Cancer is a life-threatening disease; thus, the diagnosis is often met with fear of the unknown, uncertainty, suffering, and death. Women who receive a breast cancer diagnosis are prone to high levels of distress (Lester et al., 2013). In a study of breast cancer outpatients (N=115) it was noted that psychological problems and psychosocial distress occurred in 25-40% of survivors (Meraner et al., 2009). Women experienced a high level of distress during and after the end of their active treatment (Lester et al., 2013; Meraner et al., 2009). Multimodality treatment regimens may improve the survival rates but can also add a prolonged period of medical interventions which put the patient at risk for increased development of psychosocial issues (Bogaarts et al. 2011). Cancer therapy takes time, money, and energy, and can

temporarily decrease a patient's physical and psychosocial health status. Surgery, chemotherapy, biotherapy, and radiation, the primary treatment modalities all contribute a unique set of physical and emotional side effects. Distress may be experienced in conjunction with these common symptoms and have a negative effect on how patients handle the experienced side effects. It has been noted that any psychological symptoms encountered by the patient can influence the overall symptom experience during and after active treatment (Skerman, Yates, & Battistutta, 2012).

The physical side effects of cancer treatment tend to occur simultaneously, which can further add to the unpleasant experience for the patient. Studies have demonstrated that patients tend to experience symptom clusters, which may lead to increased distress levels (Dodd, Cho, Cooper, & Miaskowski, 2010). In an examination of distress, sleep, and fatigue in metastatic breast cancer patients (N=219), over 60% of patients reported one or more types of sleep disturbance; worsening depression was associated with the greatest number of negative changes in sleep patterns relative to other predictors, such as pain and life stress (Skerman et al., 2012).

Psychosocial sources of distress may be experienced especially in younger women (Danahauer et al., 2007), who report alterations in body image due to the physical changes experienced during breast cancer treatment. Surgery is a primary treatment modality in breast cancer treatment; the potential physical changes can take a toll on a woman's perception of her self-image. Patients that undergo more invasive surgical procedures such as a mastectomy and extensive reconstruction may suffer from a higher degree of altered body image than those women that undergo breast conserving surgery (Bogaarts et al., 2011). Alopecia, a very common side effect from chemotherapy can also cause a woman to have an altered perceived body image (Bogaarts et al., 2011). In addition, sexual dysfunction and premature menopause as experienced

by the younger breast cancer survivors can negatively affect the emotional impact of the illness (Danhauser et al., 2007).

Caregiver, Support Person, & Patient Relationships

As patients try to cope with their diagnosis, it is important that they receive support from persons close to them (Milbury, Badr, Fossella, Pisters, & Carmack, 2013). The spouse or partner typically fulfills the caregiver and support person role(s), although may not in the situation of marital strife, lack of support, concomitant illness, work-related issues, absence, death, or any other reason that may conflict the patient's care and support. In the event that a spouse or partner does not fulfill these roles, another relative may assist such as a parent, sibling, child (e.g. teenager or adult), or perhaps a friend or confidante. It may be most difficult when a patient is being treated away from their home and must temporarily change their residence and rely on a relative or friend. In turn, the spouse or partner is at home with their work-related responsibilities and children. In that situation, perhaps the patient's most important support person is left behind which may cause increased distress due to their absence and lack of physical presence and availability (Williams & Bakitas, 2012).

Spouses and partners are vital in the care of the cancer-affected patient, although the caregiver and support roles can certainly cause suffering, both psychologically and physically. The burden of caregiving can compromise the quality of life in the spouse or partner and in turn, negatively affect the physical and psychological adjustment of the patient (Milbury et al., 2013). If the caregiving burden becomes too intense for the spouse or partners, changes in their willingness to provide care may occur which can interfere with the patient's recovery or comfort.

Conflict between a spouse or partner and patient during the cancer experience is common, although for some couples, the challenges confirm their feelings for each other and

strengthen their relationships. In others, the opposite occurs with a gap in care for the patient *and* the caregiver; both persons may experience significant distress across the cancer trajectory (Pusa, Persson, & Sundin, 2012). It is common for patients' distress to be poorly understood by the caregiver or support person (Silveria, Given, Given, Rosland, & Piette, 2010), and for the caregiver to have different perspectives of the patients' experiences (De Padova et al., 2011). Shorter hospital stays and improved cancer survival rates can increase the overall cancer burden for the caregiver or support person as he/she tries to assist the patient to understand and accept the disease, side effects of treatment, and anticipated long-term adjustments (Lund & Yarbrough, 2011).

In a longitudinal study of lung cancer patients and their spouse/partner as caregiver (N=158), associations between caregiver burden and distress were examined in patients and spouses or partners. Questionnaires were completed at baseline, three-, and six-months with 108 evaluable dyads. While mean scores were stable for schedule disruption and caregiver esteem at three months, spouses reported that they suffered from a lack of family support ($p<0.0001$), increased health problems ($p<0.05$), and financial strain ($p<0.05$) (Milbury et al., 2013). At six months, financial strain was stable ($p<0.05$), although lack of family support remained a problem ($p<0.01$) as compared to baseline (Milbury et al., 2013). Schedule disruption was significantly associated with later distress in the patient ($t=5.52$, $p<0.05$) (Milbury et al., 2013). Spouses or partners with high caregiving responsibilities may be prone to poorer health and behaviors, such as lack of exercise, limited rest, and poor adherence to their own medications (Milbury et al., 2013).

In a study of Chinese women one-week post surgery for treatment of breast cancer (N=285), questionnaires were completed to assess anxiety and depression, impact of events, and

social adjustment. Distress trajectories were assessed: employment issues predicted cancer-related distress ($p < 0.01$) for working women, women who were seeking work, and obligations to contribute to income (Lam, Shing, Bonanno, Mancini, & Fielding, 2012).

Manne et al. (2005) studied 219 women with early stage breast cancer with evaluation of the effect of patient and partner ratings on increased distress over an 18-month period. Both the patient and partner perceptions of support had a negative effect on unsupportive behavior and avoidance; their thoughts were indicative of the patient's distress and coping. When perceived support was present, the patient was able to cope more effectively and experienced less distress ($p < 0.001$) (Manne et al, 2005). If unsupportive behavior was present, whether it was perceived from the patient related to unsupportive behavior, or for partner avoidance, there was a negative correlation in the patients' levels of anxiety and distress ($p = 0.0006$) (Manne et al., 2005). Younger age and greater physical impairment were two factors that predicted distress ($p > 0.0001$) (Manne et al., 2005).

A cross-sectional survey of cancer patients ($n = 354$) and carers ($n = 336$) were evaluated for levels of global distress and unmet support needs using the Distress Thermometer analog scale (0-10) as an overall measure of distress. When elevated at time of contact, the cancer information service would assess additional socio-demographic variables, anxiety, depression, somatization, unmet supportive care needs, cancer-specific distress, presenting problems, and post-traumatic growth. Adjustment to cancer was commonly reported by patients (31%) and carers (30%), followed by anxiety (19.1%) (Chambers et al., 2011). In examination of the top ten 'moderate to high' unmet supportive care needs, the top five needs that patients identified included: 'uncertainty about the future' (47%), 'concerns about the worries of those close to you' (45%), 'fears about cancer spreading' (44%), 'worry that results of treatment are beyond your

control' (43%), and 'learning to feel in control of your situation' (39%) (Chambers et al., 2011). Care givers reported 'addressing fears about the person with cancer's physical or mental deterioration' (51%), 'reducing stress in the person with cancer's life' (45%), 'accessing information about the person with cancer's prognosis, or likely outcome' (40%), 'accessing information on what the person with cancer's physical needs are likely to be' (39%), and 'the impact that caring for the person with cancer has had on your working life, or usual activities' (37%) (Chambers et al., 2011). For patients, most unmet supportive care needs were psychological in nature (53%), whereas for most carers, the greatest needs were related to health care services and information about the person diagnosed with cancer (45%).

Methods

Study Design

The study utilized a cross-sectional design to assess self-reported distress from patients with leukemia (n=100) and breast cancer (n=100) at four different time points in early survivorship: during active treatment (e.g. surgery, chemotherapy, radiation therapy), at its end, three-, and six months later (Lester et al., 2013). This paper will report findings from the breast cancer patients' responses to items in the demographic form about family, caregivers, and support persons.

Sample and Setting

The study was conducted over a three-month period in 2011-12 at a Midwest, academic, NCI-accredited comprehensive cancer center. Inclusion criteria included patients recently diagnosed with breast cancer and receiving initial therapy, age 18 years or older, able to provide consent, and able to read and write in English. Exclusion criteria included a diagnosis of

inflammatory, Stage IV, or recurrent breast cancer, males with breast cancer, and significant mental health conditions impairing cognition (Lester et al., 2013).

A sample size estimate focused on the primary aims of the overall study, including differences across time, and an interaction between group and time. The sample size was estimated using the results of a simulation study in which simulated data from the proposed study and statistical analyses of those data were used to determine the power of detecting various differences in mean DT results. For each group size, we then determined the smallest difference that was detectable with 90% power (Lester et al., 2013). Based on these calculations, a sample of at least 20 participants per time period was needed; an additional five participants per cell were added to ensure 20 subjects per cell after attrition. Therefore, 25 participants were sought (n=100) for each time period (e.g. during active treatment, at its end, and three- and six-months later) (Lester et al., 2013).

Procedure

The research team reviewed the daily clinic lists and census sheets with their respective oncology health care teams to identify eligible candidates for the study with attention to the time points required for the study. Outpatients were invited to participate in the study as they arrived for their scheduled clinic appointment. Following written informed consent, the survey was given to the patient to complete. The average time for completion was 7-15 minutes (Lester, et al., 2013); the research team picked up the completed questionnaire. If a patient rated their distress level as four or higher (the National Comprehensive Cancer Network rates a score ≥ 4 as 'moderate to high distress'), it was reported to their healthcare provider prior to the patient's appointment (Lester et al., 2013).

Measurement

Several measures were completed by the study participant (Lester, et al., 2013) including a demographic form and NCCN Distress Thermometer with an analog scale of 0-10 (Holland & Bultz, 2007). A chart review documented type and stage of disease, cancer-related treatment, comorbid conditions, and medications.

Demographic information

A standard demographic form was used to collect information potentially relevant to survivorship care, including date of birth, gender, race, ethnicity, county, state, and zip code of residence, level of education, marital status, employment status, current (or previous) occupation, and health insurance status and type. Additional information was added by the researchers to elicit information about dependents in household under and over 18, household income before and after cancer diagnosis, primary support person(s) related to cancer treatment, relationship, age, gender, county, and state of residence, religious preference, and rating of health status.

Distress Thermometer

The NCCN Distress Thermometer (DT) was used to screen patient-reported distress surrounding their cancer diagnosis and its impact on their psychological status. Using the familiar image of a thermometer, patients reported their level of distress with a visual analog vertical scale (0-10 answer options). Patients were asked to rate their distress during the past week; a 0 score indicated 'no distress' and 10 indicated 'extreme distress'. A score of 4 or more was representative of moderate to severe psychological distress (Bogaarts et al., 2011).

Electronic chart review

The electronic chart review was performed by the research team to obtain the participant's diagnosis, stage of disease, past/current cancer treatments, medications pre- and post-cancer

diagnosis, and comorbid conditions (Lester et al., 2013). This information added to the participants' demographic profiles.

Charlson comorbidity index

The Charlson comorbidity index was used to obtain information about the participant's comorbid conditions as documented in the electronic medical record (Lester et al., 2013). Each condition was weighted from 1-6 based on the severity of the condition and its relation to mortality; total scores ranged from 0-37 (deGroot, Beckerman, Lankhortst, & Bouter, 2003). In comparison with other instruments that measure comorbidity, the Charlson index yielded correlation coefficients exceeding 0.40, indicating support of concurrent validity (deGroot et al., 2003) and construct validity (deGroot et al., 2003). Predictive validity was confirmed by the identification of multiple significant relationships of the Charlson index with various criterion outcomes such as mortality, disability, readmissions, and length of stay (deGroot, et al., 2003). Test-retest reliability was reported as 'good' by the author; inter-rater reliability was stated as 'moderate to good' by the author with one outlier (ICC-0.16) (deGroot, et al., 2003).

Statistical Analyses

Data to illustrate survivors' distress about caregiver and support persons' proximity and availability consisted of the demographic variables and DT analog scale (values of 0-10). Categorical data collected from the electronic chart review supplemented the participant's demographic profile as well as scores obtained from the Charlson comorbidity index.

Descriptive analyses

Demographic data (categorical and continuous data) were summarized using descriptive statistics such as frequencies and percentages and visit type. With consideration to the specific

parameter, central tendencies were reported; means and standard deviations were calculated as appropriate. Chi-square and analysis of variance (ANOVA) were used to test differences.

Results

The demographic data of the breast cancer survivors (Table 1) included a mean age of 55 years ($sd=11.66$), with an age range from 30-87 years; nearly all participants were white (89%), residents of Ohio (98%) and married (73%). The survivors' self-reported level of distress demonstrated an average DT score of 4.27 ($sd=3.07$) which indicated persistent and sustained 'moderate to severe' distress' (Figure 1). Most persons (Table 2) were not currently employed for wages (51%), were retired (29%), married (73%) and had private insurance (71%). Number and age of dependents in the household (Table 3) were reported. Husbands were the most common caregiver and support person, although differences were evident in the relationship of caregivers to survivors (Table 4), as well as support persons (Table 5); survivors reported that their caregiver and support person were the same in 74% of cases.

Breast cancer survivors reported data that described the geographic proximity (Table 6) of the caregiver to themselves. While the caregiver may live with the survivor (65%), they are often not geographically close as they work outside the home (60%), and on a full-time (46%) or part-time (10%) basis. Chi-square with a two-sided Monte Carlo and 95% confidence interval was used to compare the zip codes of the survivor to the caregiver; findings were significant: $X^2 = (4810, N=100) = 5816.66, p=0.000$ which indicated that often the caregiver does not necessarily live geographically close to the survivor.

The geographic proximity of the support person to the survivor (Table 7) was similar to that of the caregiver, which was expected given that survivors reported that the caregiver and the support person were the same 77% of the time. Chi-square was used to compare the zip codes of

the survivor to the support person; findings were significant using a two-sided Monte Carlo with 95% confidence interval: $\chi^2 = (5254, N=100) = 6459.56, p=0.000$ which indicated that often the caregiver does not necessarily live in close proximity to the survivor. These data support that the caregivers and support persons are often geographically removed from the survivor for at least part of the day, which may cause increased distress due to lack of assistance and support at home.

Survivors were concerned when their caregivers were not available, such as living outside the home ($p=0.02$), working outside the home ($p=0.04$), working full-time ($p=0.04$). Age was a significant covariate ($p=0.00$); younger women reported more difficulties than older women perhaps based on additional responsibilities of children and their own work schedules as compared to women that were used to being home by themselves for part or all of the day. Zip code differences between survivors and support persons were significant using ANOVA: $F(71, 99) = 1.279, p<0.000$. As previously discussed, factors of the survivors' age and number and age of dependents in household were significant covariates, whereas covariates such as education or psychological issues were not significant. All of these unmet needs are present for the younger breast cancer survivor.

Discussion

In this study, breast cancer survivors exhibited elevated distress scores related to issues of geographical proximity and physical and emotional availability of the caregiver and support person(s). In turn, numerous potential conflicts for the caregiver and support person were identified such as 'living outside the home', 'working outside the home', 'working full-time or part-time', or living in a different zip code than the survivor, which validated a geographic

distance. These findings were consistent across all four time points in the study, e.g. during active treatment, at its end, and three- and six-months following the end of active treatment.

The intersections between the survivor and caregiver and support person are complex with multiple barriers. Communication problems can develop and superimpose the underlying issues that are often beyond the control of either person. Waters et al. (2013) discussed low perceived social support and its potential negative effect on quality of life in breast cancer survivors that may take months to resolve. Dempster et al., (2010) presented issues related to different illness perceptions among carer-survivor dyads that increased psychological distress based on the consequences, cause, control, and understanding of the cancer and related issues.

The time points in the early survivorship period are typically chaotic due to a new cancer diagnosis, treatment regimens, physical and psychological side effects, and frequent clinic appointments. Survivors must often rely on caregivers and support persons to provide transportation, babysit children living at home, run errands, and a multitude of other needs based on the pre-existing support system at home. In this study, 48% of dependents living in the home were age 15 years and under; 11% were 10 years of age and under, and 17% were 5 years of age or under.

The onset of a cancer diagnosis that is coupled with young children at home presents a myriad of challenges related to time, activities, energy, fatigue, and all tasks related to parenting. Most (73%) of the study sample reported their marital status as 'married'. When evaluating age and marital status, it is noted for those women aged 31-40, six were married, none were divorced or separated, and one was widowed. In the 41-50 age range, 33 were married, 3 were divorced or separated, and 2 were widowed. These variations in marital status can create additional challenges for women, their home life, and responsibilities. Conflicts occur for the

survivor and caregiver or support person in regard to employment obligations and alterations in work schedules and income. At the time of diagnosis, 34% of breast cancer survivors were working full-time and 15% on a part-time basis. It is unknown if these curtailed work schedules affected the caregiver's or support person's ability to close the geographical distance and amount of time in physical presence.

Limitations of the Study

The findings of this study included distress measures from acute leukemia (n=100) and breast cancer survivors in early survivorship. This paper focused on breast cancer survivors only although it would be interesting to compare and contrast the groups to see if differences existed, and to observe if any differences emerged from comparisons of females to males in the acute leukemia cohort. In addition, it would be of interest to measure survivors with varying types of cancers to observe if the significant distress found in breast cancer is the same or different, e.g. across age groups, number and age of dependent children, and gender regardless of the type of cancer. It would also be interesting to study if the cancer type and treatment is a moderating variable in the distress trajectory of early survivorship.

Another limitation of this study is that it only provided data about characteristics of two cancer types and their self-reported distress. The data is from a limited data set (N=200) with convenience sampling from only one institution in one geographical setting. Nevertheless, it provided a snapshot of unmet needs and discovered expressed needs related to caregiver and support person availability and proximity related to lack of physical and emotional presence.

Summary

Women with breast cancer can experience increased distress related to issues of social support. The tenuous balance of coping with a breast cancer diagnosis, its related treatment,

career or work modifications, and personal life changes is difficult for most survivors and causes increased distress. The support structure within the patient's family can either aid in the coping process or potentially increase her distress level depending on the amount of support provided versus taken. Distress has been linked to poorer family relationships and a poorer self image (Lam et al., 2012). In the event of diminishing personal relationships, it may be more difficult to garner support. The occurrence of these simultaneous manifestations illustrates how quickly a breast cancer survivor can be affected by multiple sources of distress.

Screening for distress (Petty & Lester, 2013) is essential in cancer patients in order to provide holistic care and identify stress-producing needs. There continues to be an increase in numbers of cancer survivors; it is estimated that 12,000 survivors were alive in 2012 and that number is expected to exponentially increase (ACS, 2012). This expanding number of survivors is paired with the decreasing numbers of oncologists which will ultimately result in decreased physician-to-patient interaction and even fewer discussions about psychosocial needs. This study provides data that supports distress needs to be increasingly recognized by the entire oncology health care team with inclusion of supportive care needs related to geographic availability and physical proximity.

Many healthcare providers may underestimate the level of distress and the importance of screening with referral to other members of the transdisciplinary health care team. The addition of distress screening to standard practice may be useful to alert health care professionals to assess, diagnose, and intervene as appropriate. When distress is identified, interventions may positively affect long-term issues.

Implications for Practice

Providers and institutions will need to identify system-wide methods to screen cancer patients for distress in the nearest future. The IOM report continues to gain momentum, primarily from the private sector and cancer support groups who are also proponents for the use of survivorship care plans at the end of active treatment. The Commission on Cancer, a multidisciplinary program of the American College of Surgeons (ACoS) developed a new standard in 2012 with requirements to phase in distress screening for all cancer patients by 2015; this standard will be used as a measure toward ACoS certification (Wagner, Spiegel, & Pearman, 2012).

Future Research

No doubt it is time to develop effective interventions to ameliorate or prevent the varying types and intensity levels of distress in early cancer survivors. Phase II of this study will compare the effect of comprehensive survivorship care that starts during the time of diagnosis and early treatment as compared to standard care with (or without) a survivorship care plan at the end of active treatment.

Once distress screening for cancer patients is established, providers and their team might consider expansion of the limited caregiver and support person research. Perhaps an intervention that involves all the cancer survivors, e.g. all the persons affected by this pervasive disease will aid in communication and diminish the distress felt by all. There is much work to be done!

Table 1. Demographic data of breast cancer sample (n=100)

AGE	Frequency	Percent
31-40 years	n=7	7%
41-50 years	n=32	32%
51-60 years	n=26	26%
61-70 years	n=21	21%
71-80 years	n=12	12%
81-90 years	n=2	2%
RACE	Frequency	Percent
Asian	2	2%
African American / Black	8	8%
White	89	89%
ETHNICITY	Frequency	Percent
Hispanic	0	0
Non-Hispanic	100	100%
EDUCATION	Frequency	Percent
Junior High	1	1%

Some High School	1	1%
High School Graduate	26	26%
Some College (2-year/technical)	19	19%
Some College (4-year college)	6	6%
Associate or Technical Degree	4	4%
Bachelor's Degree	16	16%
Graduate School or higher	27	27%
MARITAL STATUS	Frequency	Percent
Married	73	73%
Divorced, Separated	11	11%
Widowed	10	10%
Single, Never Married	4	4%
Cohabiting, Never Married	2	2%
STATE OF RESIDENCE	Frequency	Percent
Ohio	98	98%
West Virginia	2	2%

Table 2. Demographic data related to employment status of breast cancer survivors.

STATUS	Frequency	Percent
Full-time	34	34%
Part-time	15	15%
Not currently employed for wages	51	51%
UNEMPLOYMENT STATUS	Frequency	Percent
Retired	29	29%
Medically Disabled	8	8%
Unemployed	4	4%
Homemaker	4	4%
Volunteer	4	4%
Other	4	4%
Not Applicable	48	48%
INSURANCE STATUS	Frequency	Percent
Private	71	71%
Public	29	29%

Table 3. Breast cancer survivors' report of dependents in household.

DEPENDENTS IN HOUSEHOLD	Frequency	Percent
Yes	16	16%
No	84	84%
AGE OF DEPENDENTS IN HOUSE	Frequency	Percent
1-5 years	11	20%
5-10 years	6	11%
11-15 years	9	17%
16-20 years	15	28%
21-25 years	10	18%
26-30 years	2	4%
56-60 years	1	2%

Table 4. Relationship of caregiver to breast cancer survivor.

LIVING ARRANGEMENTS	Frequency	Percent
I live with someone	87	87%
I live alone	13	13%
CAREGIVER RELATIONSHIP	Frequency	Percent
Husband	60	60%
Self	18	18%
Daughter	8	8%
Son	5	5%
Mother	2	2%
Mate (1 female, 1 male)	2	2%
Sister	1	1%
Friend (female)	1	1%
Fiance	1	1%
Father	1	1%
Cousin (female)	1	1%
CAREGIVER AGE		
21-30	2	2%
31-40	12	12%
41-50	18	18%
51-60	26	26%
61-70	15	15%
71-80	11	11%

81-85	1	1%
CAREGIVER SEX	Frequency	Percent
Male	68	68%
Female	16	16%
Not Applicable – Self	16	16%

Table 5. Relationship of support person to breast cancer survivor.

LIVING ARRANGEMENTS	Frequency	Percent
I live with someone	87	87%
I live alone	13	13%
SUPPORT PERSON RELATIONSHIP		
Husband	62	62%
Daughter	11	11%
Self	6	6%
Son	5	5%
Friend (female)	5	5%
Mother	4	4%
Sister	3	3%
Mate (male)	2	2%
Cousin (male)	1	1%
Neighbor (female)	1	1%
SUPPORT PERSON AGE		
21-30	2	2%
31-40	17	17%
41-50	18	18%
51-60	29	29%
61-70	16	16%
71-80	13	13%

81-85	1	1%
SUPPORT PERSON SEX	Frequency	Percent
Male	70	70%
Female	25	25%

Table 6. Geographic proximity of caregivers and support persons to breast cancer survivors.

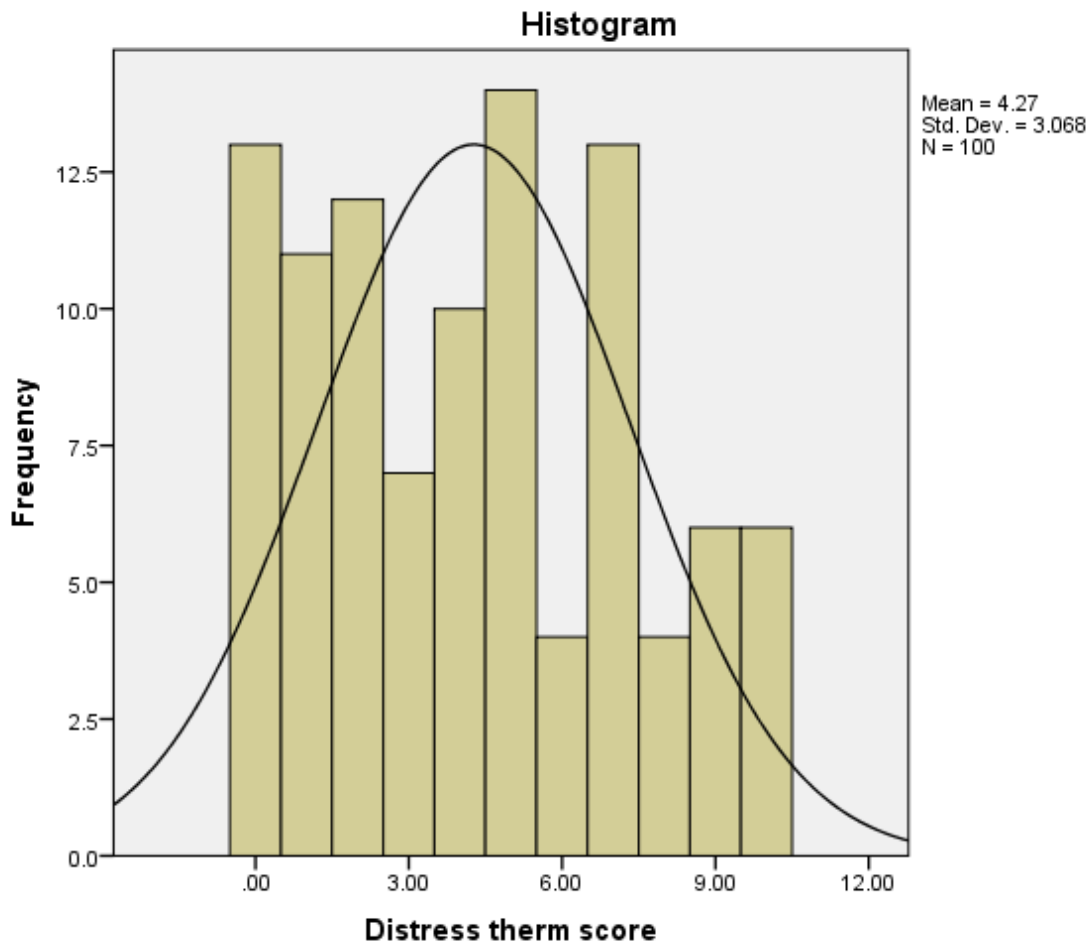
PROXIMITY	Frequency	Percent
Caregiver: Same Zip Code as Survivor (n=83)	78	78%
Caregiver: Different Zip Code than Survivor	5	5%
Caregiver: Same State as Survivor (n=100)	96	96%
Caregiver: Different State as Survivor	4	4%
Support Person: Same Zip Code as Survivor (n=96)	77	77%
Support Person: Different Zip Code than Survivor	13	13%
Support Person: Same State as Survivor (n=95)	95	95%
Support Person: Different State than Survivor	5	5%

Table 7. Availability of caregivers and support persons to breast cancer survivors.

CAREGIVER LIVES WITH SURVIVOR	Frequency	Percent
Yes	65	65%
No	20	20%
Not Applicable – Self	15	15%
CAREGIVER’S EMPLOYMENT STATUS (n=97)		
Full-Time	46	46%
Part-Time	10	10%
Not Applicable – No Current Employment	41	41%
CAREGIVER WORKS OUTSIDE HOME		
Yes	60	60%
No	15	15%
Not Applicable – No Current Employment	23	23%
SUPPORT PERSON LIVES WITH SURVIVOR		
Yes	66	66%
No	24	24%
Not Applicable – Self	9	9%
SUPPORT PERSON’S EMPLOYMENT STATUS		
Full-Time	53	53%
Part-Time	12	12%
Not Applicable – No Current Employment	32	32%
SUPPORT PERSON WORKS OUTSIDE HOME		

Yes	66	66%
No	24	24%
Not Applicable – No Current Employment	10	10%

Figure 1. Average distress scores of breast cancer survivors in early survivorship



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