

Piloting a Needs Assessment to Guide Development of a Survivorship Program for a Community Cancer Center

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Survivorship is recognized as a distinct phase in the continuum of cancer care, but no system exists to guide patients completing treatment through the predictable complexities of recovery. Most community cancer centers in the United States are designed and staffed to focus on meeting the physical needs of patients with cancer and their families. The social, emotional, and spiritual needs of patients with cancer are not consistently evaluated or addressed by healthcare providers, whose primary goals are cancer treatment and physical symptom management. The disparity is more pronounced in patients who have completed treatment, as the focus of the provider narrows to evaluation for disease recurrence. The complex and multidimensional needs of the growing population of cancer survivors must be integrated into their routine assessment, treatment, and follow-up care. Development of a survivorship program to systematically address common and important needs could effectively fill this void. Although interest in addressing the psychosocial needs of patients with cancer has been an issue in the literature since the 1970s, scant progress has been made (Institutes of Medicine [IOM], 2007); this public health concern has been set as a national priority (Aziz & Rowland, 2003; IOM, 2006; Jemal et al., 2004; Rowland et al., 2004). The first step is documentation of the needs of patients with cancer receiving treatment and follow-up care in a community cancer care setting.

The primary purpose of this article is to report the results of a needs assessment of cancer survivors receiving care in a community cancer center. The goals of the research were (a) to construct an instrument to assess cancer survivors' unmet supportive care needs and associated distress; (b) to delineate the physical, social, emotional, spiritual, and other needs of a population of patients in a community cancer center; and (c) to incorporate the identified needs into a developing survivorship program that could be used as a model for other community cancer centers. To achieve these goals, a collaborative research

Purpose/Objectives: To develop and pilot a survey to assess needs and distress of cancer survivors receiving care in a community cancer center.

Design: Descriptive, quantitative.

Setting: A community cancer center in the southeastern United States partnering with a local college of nursing faculty.

Sample: Convenience sample of 307 adult cancer survivors.

Methods: Voluntary completion of a modified survey of needs.

Main Research Variables: Cancer survivor needs and distress according to five subscales (physical effects, social issues, emotional aspects, spiritual issues, and other issues), age, and gender.

Findings: Patients on average reported experiencing more than 25 of 50 possible survivorship needs. Average distress scores associated with individual needs were low. The most frequently experienced needs were fatigue, fear of recurrence, and sleep disturbance. Middle-aged survivors experienced significantly greater need and distress across all subscales.

Conclusions: Need and distress exist among adult cancer survivors receiving treatment and follow-up in community cancer care settings, with the middle-age phase of life creating unique barriers. Survey data may provide documentation of the multidimensional impact of cancer on quality of life and can help direct survivorship program development.

Implications for Nursing: Nurses can address a barrier to survivorship care in community care settings by using the Pearlman-Mayo Survey of Needs to assess outcomes relevant to survivors. Partnership between community hospital RNs and college of nursing faculty may create local or regional solutions and serve as useful models for survivorship care.

effort (Finkelman & Kenner, 2008; Ravert & Merrill, 2008) was undertaken through the partnering of community cancer center RNs with local college of nursing faculty. The intent was to draw on academic resources that were not otherwise available in the community cancer center to develop and ultimately disseminate a community survivorship care model (IOM, 2006). IOM (2007)

noted that such bottom-up efforts may create top-down solutions—local or regional responses that strengthen the capacity to care for patients and serve as useful models for survivorship care.

The term *community cancer center* describes nonacademic centers that provide care to an estimated 85% of patients with cancer in the United States (National Cancer Institute [NCI], 2007; Simone, 2002). As described by the American College of Surgeons Commission on Cancer (2006), community cancer centers are a heterogeneous group of treatment facilities that range from offering one therapeutic modality to fewer than 50 patients a year to caring for more than 650 patients annually by using a full range of diagnostic and treatment services.

Literature Review

Cancer affects an estimated 11 million individuals worldwide each year (IOM, 2006). In the United States, about 1 million patients enter follow-up after active treatment for their cancer annually (IOM, 2006). As of 2009, the 12 million cancer survivors in the United States represented 3.5% of all Americans (American Society of Clinical Oncology, 2007; NCI, 2009).

An estimated 66% of adults currently living with cancer will be alive in 2015 (Jemal et al., 2009). Although a cancer *survivor* has traditionally been defined as an individual who lives beyond five years with no evidence of disease, *survivorship* now is described as an experience stretching from the point of cancer discovery through the balance of the patient's life (Leigh, 2007). The individuals living with, through, and beyond cancer (Leigh, 1996; Mullan, 1985) represent the "relatively neglected phase of the cancer care trajectory" (IOM, 2006, p. 4). Successful cancer care often is laden with significant health issues for patients—the deleterious consequences of cancer and associated treatment are poorly understood (IOM, 2006). Survivors' health and subsequent needs are "a moving target" because of effects of aging, comorbidities, and a limited understanding of late effects associated with continuously changing treatments (IOM, 2006).

The vast majority of cancer care is delivered in community settings (IOM, 2007; McQuellon & Danhauer, 2007). Oncology care in the United States varies significantly by geography and setting (IOM, 2007); Ganz (2002) noted that outcomes associated with cancer care are strongly linked to the care setting and type of care received. Often, patients have little choice over the setting in which they receive care. Variation in cancer care and outcome has been observed by area of residence and other geographic factors, and lack of access may negatively influence cancer survivorship from diagnosis to remission or palliation (Ward et al., 2008).

Of the models proposed for delivery of survivorship care, the shared-care model and community-based care are most likely to succeed in the community setting

(Landier, 2009). In the shared-care model, the patient is followed by the oncologist and the primary care physician, with or without ultimate transition to sole care by the primary care physician. In the community-based model, the primary care team assumes full responsibility for survivorship care at completion of cancer treatment. Both models require thoughtful and effective communication between the two disciplines to achieve optimal post-treatment care. A third model employs a nurse practitioner-run clinic, probably connected to the cancer center and the original cancer-care team (McCabe & Jacobs, 2008). Whichever model is chosen, care should be coordinated to accomplish the goals of survivorship, which include prevention and surveillance of recurrence, recognition and treatment of the late effects of cancer and its treatment, and promotion of risk-reduction behaviors (McCabe & Jacobs, 2008).

Theoretical Framework

The Illness Trajectory Theory was the theoretical framework that supported key survivorship concepts and this survey research (Corbin & Strauss, 1988). The original theory was expanded by Wiener and Dodd (1993) following a study examining family coping and self care of patients with cancer during chemotherapy. The basic premise acknowledges that illness such as cancer disrupts a patient's normal roles and social interactions, creating disequilibrium, loss of control, and uncertainty. Incorporating illness into the patient's psychosocial network requires various types of work in an effort to re-establish equilibrium and a sense of control. In addition to juggling the medical management of cancer and tasks of everyday life and finding the "new normal," the patient must work to abate the uncertainty that invariably accompanies cancer. The focus and content of the work evolve over the course of illness, continuously seeking balance within the physical, social, and psychological domains. In addition to the patient, key players in the theory include family members, friends, and healthcare providers, recognizing that relationships among them impact the course of illness as well as the fate of the patient.

Methods

Design

A descriptive, quantitative design and survey research technique were used with a needs-assessment approach to identify and explore variables of interest (Martella, Nelson, & Marchand-Martella, 1999). Needs assessment among cancer survivors and other consumers of healthcare services offers a rational approach for identification of complex needs existing in rapidly changing environments (Almquist & Bookbinder, 1990; Courtemanche, 1995; Queeney, 1995; Witkin & Altschuld, 1995).

Participant Recruitment and Accrual

Participants were recruited for this convenience sample from a community cancer center in the south-eastern United States. Inclusion criteria were being a cancer survivor receiving treatment or follow-up care at the center, being older than 18 years, and speaking English. Eligible participants were identified by one of the investigators employed at the cancer center, who reviewed daily electronic schedules for patients who met age and language-literacy criteria. A 16-week data collection phase was used to provide a baseline of information on survivor needs.

Instrument

Wen and Gustafson (2004) provided an ample review of needs-assessment instruments used in patients with cancer but failed to identify any tools specific to the survivorship phase of cancer care (Hodgkinson et al., 2007). For this research, the unpiloted *Survey of Needs* (Mayo Clinic Cancer Center, 2007) was identified through networking with oncology colleagues. The developers of the survey, the Cancer Education Center of the Mayo Clinic Cancer Center in Rochester, MN, drew their concepts from the survivorship literature and their experience as cancer educators and care providers. Content validity was established through review by members of the Cancer Patient Education Network. Permission to modify and use the previously unpiloted survey was obtained.

In the modified survey, needs were conceptualized as issues, effects, and aspects associated with the survivorship experience that were linked with patients' healthcare goals and related to optimal management of the survivorship phase (Hack, Degner, & Parker, 2005). The City of Hope Quality of Life Model (Ferrell, Hassey-Dow, & Grant, 1995) was chosen as the framework for needs assessment and categorizes needs into four dimensions: physical, social, psychological, and spiritual. This model complements the Illness Trajectory Theory, echoing the types of work the patient does to maintain a sense of balance and control throughout the course of illness. The original survey was modified to add 17 items, remove 3, and reframe 5 as educational topics of interest, rather than needs. An additional category of *other* was added to encompass needs outside the four dimensions. The modified Pearlman-Mayo Survey of Needs (Pearlman Cancer Center, 2008) consisted of 50 items reflecting physical effects (19), social issues (10), emotional aspects (10), spiritual issues (5), and other issues (6) associated with cancer survivorship. To view the survey, visit www.sgmc.org/pearlman-mayo. Modifications also addressed the psychosocial dimension of distress associated with survivorship needs (Cella, 1987; McQuellon & Danhauer, 2007). A Likert-type scale was added to allow respondents to quantify the degree of distress associated with each need.

Table 1. Survivor Demographic Characteristics

Characteristic	n	%
Age (years)		
X (SD) = 63.26 (12.7)	—	—
25–39	7	2
40–64	148	48
65 or older	146	48
Missing data	6	2
Gender		
Male	98	32
Female	202	66
Missing data	7	2
Diagnosis		
Breast	121	39
Unknown by patient	34	11
Colon or colorectal	29	9
Lymphoma or non-Hodgkin lymphoma	23	7
Lung	22	7
Other	78	25

N = 307

Note. Because of rounding, not all percentages total 100.

To complete the survey, survivors were asked to indicate whether they were experiencing a need and then to rate the level of distress associated with the need (0 = no distress to 5 = extreme distress). Scores were obtained by subscale and summated for need and distress. Higher scores reflected greater numbers of needs and perceptions of greater distress associated with those needs. Reliability was assessed with a Cronbach alpha coefficient of 0.96 calculated across all five subscales. Instrument reading ease was 8.7 with Flesch-Kincaid grade-level criteria.

Procedure

Following institutional review board approval, surveys were distributed to selected patients in the cancer center. Upon check-in, study packets were distributed to potential participants. A cover letter explained the purpose of the project and invited patients to share their survivorship experiences with the investigators. Completion and return of the needs survey was considered respondent consent to participate. To promote data analysis, patient age was collapsed into three groups; similar cancer diagnoses also were collapsed. For baseline comparisons, analyses of variance were used to test the significance of group differences with Bonferroni for pair-wise comparisons. Alpha level was set at 0.05 for analysis.

Results

Survivor Characteristics

Over a 16-week period, about 1,000 patients were seen in follow-up at the cancer center and a total of 826 surveys were distributed to patients. Three hundred seven surveys were returned for a response rate of 37%. Sixty-six percent

Table 2. Descriptive Statistics for Survivor Needs and Distress

Measure	\bar{X}	SD
Needs		
Physical	10.71	5.43
Social	4.6	3.04
Emotional	5.81	3.5
Spiritual	1.57	1.68
Other	3.19	2.28
Average number of needs	25.99	13.67
Distress		
Physical	1.69	–
Social	1.46	–
Emotional	1.74	–
Spiritual	0.89	–
Other	1.63	–
Average distress score	1.48	–

N = 307

Note. The modified Pearlman-Mayo Survey of Needs consisted of 50 items reflecting needs such as physical effects (n = 19), social issues (n = 10), emotional aspects (n = 10), spiritual issues (n = 5), and other issues (n = 6). Respondents rated distress levels associated with needs (0 = no distress to 5 = extreme distress).

of respondents were women, with a mean age of 63 years. Information on survivor diagnoses can be seen in Table 1. No additional demographic information (e.g., race or ethnicity, marital status, religious affiliation, socioeconomic status) was elicited from participants.

Needs and Distress

Patients on average reported experiencing more than 25 of 50 possible physical, social, emotional, spiritual, or other needs listed on the survey. Table 2 displays the mean number of needs by subscale and in total. The most commonly reported individual needs are displayed in rank order (see Table 3). Although average distress scores for individual needs were low, significant proportions of patients reported distress scores of 3 or higher for specific needs. Statistically significant correlations were observed between patients' number of needs and associated distress scores across all subscales, ranging from $r = 0.858$ to $r = 0.895$ ($p < 0.01$).

Notable differences emerged in survivors' needs and associated distress scores according to gender. Significantly higher physical distress scores ($\chi^2 = 89.721$, $df = 70$, $p = 0.05$), average distress scores ($\chi^2 = 170.89$, $df = 133$, $p = 0.01$), and average number of needs ($\chi^2 = 71.88$, $df = 50$, $p = 0.02$) were observed among women, whereas male survivors exhibited significantly greater numbers of other needs ($\chi^2 = 14.992$, $df = 7$, $p = 0.03$). Physical needs included issues such as fatigue, pain, poor appetite, and memory loss; other needs reflected concerns about long-term effects of treatment and having a sense of well-being.

Significant and statistically different reports of number of needs and distress scores also were observed by age,

although effect sizes were small using η^2 as an estimate of strength (Cohen, 1988). Middle-aged survivors (aged 40–64 years) evidenced the highest number of physical needs and associated distress; lower or similar scores were observed among young adult (aged 25–39 years) and older survivors (aged 65 years or older). The same pattern emerged for emotional needs and distress, other needs and distress, and average number of needs and distress (see Table 4). Emotional needs included issues such as living with uncertainty, fear of recurrence, and managing stress.

Middle-aged survivors also evidenced significantly higher numbers of social needs and distress. Social needs included issues such as managing household activities, financial concerns, and returning to work. The lowest numbers of social needs and distress scores were observed among older survivors. Middle-aged survivors also showed significantly higher numbers of spiritual needs and distress scores, although the lowest number of spiritual needs and distress scores were observed among younger survivors. Spiritual needs included issues such as isolation, end-of-life concerns, and loss of faith.

Educational Interest

Patients expressed interest in learning about 6 of 15 cancer survivor educational topics (see Table 5). Statistically significant correlations were observed between number of educational topics of interest and patients' average total need scores ($r = 0.477$, $p < 0.01$) as well as average distress scores ($r = 0.458$, $p < 0.01$). Significant differences by gender appeared in preferences for educational information on survivorship and in information delivery format, with women showing a preference for information on physical issues delivered via video format ($\chi^2 = 3.741$, $df = 1$, $p = 0.05$) and in sessions with healthcare providers ($\chi^2 = 3.79$, $df = 1$, $p = 0.05$) and men preferring

Table 3. Most Frequent and Most Distressing Symptoms in Survivorship

Symptom	Frequency			Distress ^a	
	Rank	n	%	Rank	\bar{X}
Fatigue	1	254	83	1	2.9
Fear of recurrence	2	238	78	2	2.63
Sleep disturbance	3	229	75	3	2.31
Managing stress	4	217	71	5	2.19
Body changes	5	212	69	7	2
Managing difficult emotions	6	208	68	6	2.16
Long-term effects of treatment	6	208	68	4	2.28
Pain	8	204	66	8	1.97
Living with uncertainty	9	198	64	9	1.95

N = 307

^a Scores ranged from 0 (no distress) to 5 (extreme distress).

Table 4. Analysis of Variance for Needs and Distress: Effect of Age

Variable	SS	df	\bar{X}	F	p	η^2
Physical						
Needs	870.89	2	12.46	16.48	< 0.05	0.1
Distress	13,730.65	2	39.22	21	< 0.05	0.12
Social						
Needs	393.08	2	5.8	24.51	< 0.05	0.14
Distress	5,569.68	2	19.08	22.76	< 0.05	0.13
Emotional						
Needs	352.3	2	6.89	15.94	< 0.05	0.09
Distress	6,368.5	2	21.98	19.4	< 0.05	0.11
Spiritual						
Needs	29.13	2	1.89	5.22	0.006	0.03
Distress	366.73	2	5.65	6.13	0.002	0.04
Other						
Needs	81.59	2	3.77	8.21	< 0.05	0.05
Distress	1,336.43	2	12.07	9.09	< 0.05	0.05
Total						
Needs	6,788.8	2	30.97	20.66	< 0.05	0.12
Distress	102,784.3	2	97.52	22.08	< 0.05	0.12

N = 307

information on estate planning ($\chi^2 = 4.236$, $df = 1$, $p = 0.04$) and communicating with healthcare providers ($\chi^2 = 3.591$, $df = 1$, $p = 0.05$). Significant difference also was observed by age related to number of topics of interest, with middle-aged patients desiring greater numbers of educational topics ($F_{2, 293} = 6.397$, $p = 0.002$, $\eta^2 = 0.042$).

Discussion

Needs and Distress

Patients receiving care in this community cancer center clearly experienced survivorship-related need and distress. The needs most frequently identified by this group (e.g., fatigue, fear of recurrence, sleep disturbance) also were identified as most distressing, although the lists differed slightly in rank order, with late effects of cancer treatment rising in the distress ranking. Recent interest in better understanding late effects of cancer treatment among survivors is apparent in the literature. The physical impairments, functional disabilities (Hewitt, Rowland, & Yancik, 2003), and psychosocial issues described by this sample of patients in a community cancer center align with an extensive body of literature (IOM, 2008).

The distress levels self-reported by patients were similar to expected distress symptoms described in oncology practice guidelines for distress management (National Comprehensive Cancer Network [NCCN], 2009). Almost every person with cancer faces distress, anxiety, and depression at the time of diagnosis (IOM, 2007;

NCCN, 2009), and the end of treatment and the survivorship, follow-up, and surveillance phases are recognized as periods of increased vulnerability to distress (NCCN, 2009). However, survivors are reluctant to discuss survivorship-related distress (Earle, 2006) and do not routinely disclose information about symptoms and concerns (Epstein & Street, 2007).

Findings related to female survivors reporting greater numbers of physical needs and total numbers of needs also are supported by existing evidence (Davis, Williams, Redman, White, & King, 2003; Houts, Yasko, Kahn, Schelzel, & Marconi, 1986; Smyth, McCaughan, & Harrison, 1995; Sothill et al., 2001). McBride, Clipp, Peterson, Lipkus, and Demark-Wahnefried (2000) found that the psychological impact of cancer decreases with time from diagnosis in male but not female survivors; therefore, this mechanism may contribute to the current findings of elevated distress levels for women.

NCI data (2008) suggested that 55% of people diagnosed with cancer are aged 65 years or older, and 44% are young and middle-aged adults (aged 20–64). Findings in the current study related to age group suggest that middle-aged survivors experience significantly greater need and distress across

all survey subscales. Finding greater need associated with the midlife phase has been described (Jansen, van Weert, van Dulmen, Heeren, & Bensing, 2007; Sanson-Fisher et al., 2000; Wong et al., 2000) and may be related to personal and social responsibilities associated with the midlife phase (Jansen et al., 2007). Conversely, in the current sample, older adults generally evidenced fewer needs and lower distress scores. Some data suggest older survivors fare better in coping with their disease compared with younger patients (Chouliara,

Table 5. Respondents' Interest in Specific Cancer Survivor Education

Education Topic	%
Physical effects	80
Emotional aspects	69
Social issues	68
Spiritual issues	64
Nutrition	51
Cancer screening	48
Safe exercise	33
Doctor communication	30
Heart screening	29
Disability	21
Community programs	20
Living wills	15
Spouse communication	11
Estate planning	10
Smoking cessation	5

N = 307

Kearney, Stott, Molassiotis, & Miller, 2004; Greene & Adelman, 2003; Jansen et al., 2007). Others suggest that older adults simply attribute poor health and reduced function to the effects of aging or to overexertion, rather than illness (Siegel, Bradley, & Lekas, 2004).

Age has been identified as a risk factor for psychological morbidity and elevated need among survivors (Maunsell, Brisson, & Deschênes, 1992; IOM, 2008). Do these age-related differences represent poor transition from active treatment into survivorship for middle-aged patients in a community cancer center? Time for transition among different age groups in this care setting may be dissimilar on some level. Are healthcare providers failing to capture important information from older survivors because they ask the wrong questions or ask in the wrong ways? Of all age groups, patients older than age 60 have been found to exhibit the most passive behaviors during healthcare encounters, which can hamper information sharing and participatory decision making related to care (Gaston & Mitchell, 2005). Are healthcare providers somehow discouraging survivorship need discussions with older adults—viewing themselves as underprepared to assist survivors in managing these issues (Earle, 2006)?

Educational Interest

Findings in the current study related to educational needs were mixed, which is consistent with prior evidence describing patients' information needs as wide ranging and changing over time as a function of age and gender (Epstein & Street, 2007; Rutten, Arora, Bakos, Aziz, & Rowland, 2005). The current findings align with existing data that suggest patients of both genders and all ages show preference for survivorship information and education in written format (IOM, 2007; Rutten et al., 2005). Ample evidence supports the efficacy of written information for enhancement of recall and knowledge, as well as the utility for nonprint formats for use with underserved and low literacy groups (Coulter & Ellins, 2006; IOM, 2008). Patients' lack of interest in group educational program or class sessions in the current study resembled the findings of Demark-Wahnefried, Peterson, McBride, Lipkus, and Clipp (2000), whose sample preferred distance- or home-based programs over clinic-based programs.

Finding robust relationships in the current study among number of needs, distress scores, and interest in survivorship education among middle-aged patients was consistent with knowledge of this proactive group of healthcare consumers. As baby boomers become older adults entering the higher cancer-risk phase of life, their demand for education and information, as empowered consumers, will escalate (IOM, 2007).

Illness Trajectory Theory

Living with uncertainty was cited as an issue for almost 65% of surveyed survivors and ranked as the ninth most

distressing of the 50 needs. The notion of uncertainty as it influences patients' experiences and affects coping during survivorship has been explored (Shaha, Cox, Talman, & Kelly, 2008). Healthcare professions may ameliorate the negative effects of uncertainty in this population by better understanding patients' specific needs in survivorship (Shaha et al., 2008). The Illness Trajectory Theory (Corbin & Strauss, 1988) recognizes that the disruptions caused by illness impact not only the physical realm but the complex psychosocial interactions that bring meaning and context to an individual's life. The disruptions persist in some form for years following a diagnosis of cancer; therefore, survivors are left to redefine a new sense of self, often referred to in the oncology literature as the "new normal." Finding the new normal is a dynamic process as survivors transition into the post-treatment phase and learn new coping skills. Conducting a needs assessment during the period of transition can promote coping by identification of disruptions (needs and distress) and delivery of appropriate survivorship services.

Limitations

In this study, the potential for response bias among survey respondents may have resulted in a sample of cancer survivors who were very different from patients who did not respond to the survey. The use of volunteer respondents may have resulted in sampling bias (Price, Dake, Murnan, Dimmig, & Akpanudo, 2005), making generalizations from the sample to a larger population of cancer survivors unjustified (Mandal, Eaden, Mayberry, & Mayberry, 2000). In addition, a principled and sequential approach to instrument development would call for pilot testing of the initial version of the survey and represents a limitation in the current study (Haynes, 2003).

Implications

Practice

The current study's findings have at least three implications for practice. First, conducting a needs assessment can be a useful precursor to survivorship care planning efforts. Self-identified needs in this population of patients in a community cancer center can inform the fundamental design of a new program. The Pearlman-Mayo Survey of Needs was valuable in this setting related to available resources, ease of use, and simplicity in analysis. Second, as the survey results suggest, healthcare providers must be alert to significant needs and distress that may be burdening middle-age cancer survivors to promote development of interventions (e.g., providing education and information) that meet the complex needs of this group. Finally, resources to address areas of need and associated distress should be developed, including internal and local referrals, written materials, and a care plan to help bridge the communication gap between oncologists and primary

care physicians. Involvement of veteran survivors willing to share their experiences with new survivors should be a key part of the program, providing newly diagnosed patients a valuable and unique source of information. Because staff nurses and physicians primarily focus on the physical needs of their patients, consideration should be given to assigning the lead role of survivorship program development and perpetuation to an advanced practice nurse or a licensed clinical social worker.

Research

As described by Earle (2006) and Rowland (2007), the current findings will augment the research trend in survivorship of need identification partnered with development of programs designed to improve the experience. The community of survivors will continue to grow as cancer therapies become safer and more effective. As treatment extends longevity, equal efforts should be directed toward studies that focus on improving the quality of life in survivorship. A diagnosis of cancer creates distress in multiple dimensions. Can specific interventions offered by community cancer centers effectively reduce this distress? Can the uncertainty and fear described by cancer survivors be abated by directed educational programs on these topics?

Conclusions

In the relatively unexamined survivorship phase of the cancer trajectory, patients' psychosocial needs have been described as *unique* (IOM, 2006). Using the Pearlman-Mayo Survey of Needs to assess outcomes relevant to the experience of survivors receiving care in community care settings addresses a major barrier that has been identi-

fied in long-term survivorship research (Rowland, 2007). Along with the middle-age phase of life, other variables such as socioeconomic status, ethnicity, race, and setting may create unique needs among survivors. In developing survivorship care models, community healthcare systems may have substantial impact, and their bottom-up efforts may create top-down solutions (IOM, 2007).

Multi-institutional collaborative groups as used in the current study with specific goals and actionable plans may create local or regional solutions that will strengthen the capacity to care for patients and may serve as useful models for survivorship care (IOM, 2007). This observational, cross-sectional survey of patients, the type of inquiry specifically described by IOM (2007), contributes to the research agenda by identifying survivor needs and distress and highlights gaps in cancer care that may be ameliorated by dissemination of a model community-level survivorship program across an array of healthcare settings (IOM, 2006). In addition, the inquiry allows community cancer centers to provide survivorship care appropriate to their settings by using local resources, such as academic institutions, to develop a range of survivorship services (Association of Community Cancer Centers, 2008).

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References

- Almquist, G., & Bookbinder, M. (1990). Developing an educational needs assessment. *Journal of Nursing Staff Development*, 6, 246–249.
- American College of Surgeons. (2006). *Commission on cancer program standards*. Chicago, IL: Author.
- American Society of Clinical Oncology. (2007). *People living with cancer: Survivorship*. Retrieved from <http://www.cancer.net/patient/Survivorship>
- Association of Community Cancer Centers. (2008). *Comprehensive survivorship services: A practical guide for community cancer centers*. Retrieved from <http://acc-cancer.org/education/education-cancersurvivorship-CoSS.asp>
- Aziz, N.M., & Rowland, J.H. (2003). Trends and advances in cancer survivorship research: Challenge and opportunity. *Seminars in Radiation Oncology*, 13, 248–266.
- Cella, D.F. (1987). Cancer survival: Psychosocial and public issues. *Cancer Investigation*, 5, 59–67.
- Chouliara, Z., Kearney, N., Stott, D., Molassiotis, A., & Miller, M. (2004). Perceptions of older people with cancer of information, decision making and treatment: A systematic review of selected literature. *Annals of Oncology*, 15, 1596–1602. doi: 10.1093/annonc/mdh423
- Cohen, J. (1988). *Statistical power analysis for the behavioral sciences* (2nd ed.). Hillsdale, NJ: Lawrence Erlbaum Associates.
- Corbin, J.M., & Strauss, A. (1988). *Unending work and care: Managing chronic illness at home*. San Francisco, CA: Jossey-Bass.
- Coulter, A., & Ellins, J. (2006). *Patient-focused interventions: A review of the evidence*. London, England: Health Foundation and Picker Institute Europe.
- Courtemanche, B.M. (1995). Determining educational needs of staff nurses: An assessment tool for nurse educators. *Journal of Continuing Education in Nursing*, 26, 104–108.
- Davis, C., Williams, P., Redman, S., White, K., & King, E. (2003). Assessing the practical and psychosocial needs of rural women with early breast cancer in Australia. *Social Work in Health Care*, 36(3), 25–36.
- Demark-Wahnefried, W., Peterson, B., McBride, C., Lipkus, I., & Clipp, E. (2000). Current health behaviors and readiness to pursue lifestyle changes among men and women diagnosed with early stage prostate and breast carcinomas. *Cancer*, 88, 674–684.
- Earle, C.C. (2006). Failing to plan is planning to fail: Improving the quality of care with survivorship care plans. *Journal of Clinical Oncology*, 32, 5112–5116. doi: 10.1200/JCO.2006.06.5284
- Epstein, R.M., & Street, R.L. (2007). *Patient-centered communication in cancer care: Promoting healing and reducing suffering*. Bethesda, MD: National Cancer Institute.
- Ferrell, B.R., Hassey-Dow, K., & Grant, M. (1995). Measurement of the quality of life in cancer survivors. *Quality of Life Research*, 4, 523–531.

- Finkelman, A., & Kenner, C. (2008). Educational and service partnerships: An example of global flattening. *Journal of Professional Nursing*, 24, 59–65. doi: 10.1016/j.profnurs.2007.02.002
- Ganz, P.A. (2002). What outcomes matter to patients: A physician-researcher point of view. *Medical Care*, 40(6, Suppl.), iii11–iii19.
- Gaston, C.M., & Mitchell, G. (2005). Information giving and decision-making in patients with advanced cancer: A systematic review. *Social Science and Medicine*, 61, 2252–2264.
- Greene, M.G., & Adelman, R.D. (2003). Physician-older patient communication about cancer. *Patient Education and Counseling*, 50, 55–60.
- Hack, T.F., Degner, L.F., & Parker, P.A. (2005). The communication goals and needs of cancer patients: A review. *Psycho-Oncology*, 14, 831–845. doi: 10.1002/pon.949
- Haynes, S.N. (2003). Clinical applications of analogue behavioral observation: Dimensions of psychometric evaluations. In A.E. Kazdin (Ed.), *Methodological issues and strategies in clinical research* (3rd ed.) (pp. 235–264). Washington, DC: American Psychological Association.
- Hewitt, M., Rowland, J.H., & Yancik, R. (2003). Cancer survivors in the United States: Age, health, and disability. *Journal of Gerontology*, 58, 82–91.
- Hodgkinson, K., Butow, P., Hunt, G.E., Pendlebury, S., Hobbs, K.M., Lo, S.K., & Wain, G. (2007). The development and evaluation of a measure to assess cancer survivors' unmet supportive care needs: The CaSUN (Cancer Survivors' Unmet Needs measure). *Psycho-Oncology*, 16, 796–804. doi: 10.1002/pon.1137
- Houts, P.S., Yasko, J.M., Kahn, S.B., Schelzel, G.W., & Marconi, K.M. (1986). Unmet psychological, social, and economic needs of persons with cancer in Pennsylvania. *Cancer*, 58, 2355–2361.
- Institutes of Medicine. (2006). *From cancer patient to cancer survivor: Lost in transition*. Washington, DC: National Academies Press.
- Institutes of Medicine. (2007). *Implementing cancer survivorship planning: Workshop summary*. Washington, DC: National Academies Press.
- Institutes of Medicine. (2008). *Cancer care for the whole patient: Meeting psychosocial health needs*. Washington, DC: National Academies Press.
- Jansen, J., van Weert, J., van Dulmen, S., Heeren, T., & Bensing, J. (2007). Patient education about treatment in cancer care: An overview of the literature on older patients' needs. *Cancer Nursing*, 30, 251–260.
- Jemal, A., Clegg, L.X., Ward, E., Ries, L.A.G., Wu, X., Jamison, P.M., . . . Edwards, B.K. (2004). Annual report to the nation on the status of cancer 1975–2001, with a special feature regarding survival. *Cancer*, 101, 3–27.
- Jemal, A., Siegel, R., Ward, E., Hao, Y., Xu, J., & Thun, M.J. (2009). Cancer statistics, 2009. *CA: A Cancer Journal for Clinicians*, 59, 225–249.
- Landier, W. (2009). Survivorship care: Essential components and models of delivery. *Oncology (Williston Park)*, 23(4, Suppl.), 46–53.
- Leigh, S. (2007). Cancer survivorship: A nursing perspective. In P.A. Ganz (Ed.), *Cancer survivorship: Today and tomorrow* (pp. 8–13). New York, NY: Springer.
- Leigh, S.A. (1996). Defining our destiny. In B. Hoffman (Ed.), *A cancer survivor's almanac: Charting the journey* (pp. 261–271). Minneapolis, MN: Chronimed Publishers.
- Mandal, A., Eaden, J., Mayberry, J.K., & Mayberry, J.F. (2000). Questionnaire surveys in medical research. *Journal of Evaluation in Clinical Practice*, 6, 395–403.
- Martella, R.C., Nelson, R., & Marchand-Martella, N.E. (1999). *Research methods: Learning to become a critical research consumer*. Boston, MA: Allyn and Bacon.
- Maunsell, E., Brisson, J., & Deschênes, L. (1992). Psychological distress after initial treatment of breast cancer. Assessment of potential risk factors. *Cancer*, 70, 20–25.
- Mayo Clinic Cancer Center. (2007). *Survey of Needs*. Unpublished instrument, Cancer Education Center of the Mayo Clinic Cancer Center, Rochester, MN.
- McBride, C.M., Clipp, E., Peterson, B.L., Lipkus, I.M., & Demark-Wahnefried, W. (2000). Psychological impact of diagnosis and risk reduction among cancer survivors. *Psycho-Oncology*, 9, 418–427.
- McCabe, M.S., & Jacobs, L. (2008). Survivorship care: Models and programs. *Seminars in Oncology Nursing*, 24, 202–207.
- McQuellon, R.P., & Danhauer, S.C. (2007). Psychosocial rehabilitation in cancer care. In P.A. Ganz (Ed.), *Cancer survivorship: Today and tomorrow* (pp. 238–250). New York, NY: Springer.
- Mullan, F. (1985). Seasons of survival: Reflections of a physician with cancer. *New England Journal of Medicine*, 313, 270–273.
- National Cancer Institute. (2007). *Frequently asked questions: NCI Community Cancer Centers Program pilot: 2007–2010*. Retrieved from <http://ncccp.cancer.gov/Media/FactSheet.htm>
- National Cancer Institute. (2008). *Surveillance Epidemiology and End Results (SEER): Stat fact sheets*. Retrieved from <http://seer.cancer.gov/statfacts/html/all.html>
- National Cancer Institute. (2009). Cancer survivors and their doctors have different expectations about care. Retrieved from <http://www.cancer.gov/ncicancerbulletin/040709/page2>
- National Comprehensive Cancer Network. (2009). *NCCN Clinical Practice Guidelines in Oncology™: Distress management [v.2.2009]*. Retrieved from http://www.nccn.org/professionals/physician_gls/PDF/distress.pdf
- Pearlman Cancer Center. (2008). *Pearlman-Mayo Survey of Needs*. Retrieved from <http://www.sgmc.org/pearlman-mayo>
- Price, J.H., Dake, J.A., Murman, J., Dimmig, J., & Akpanudo, S. (2005). Power analysis in survey research: Importance and use for health educators. *American Journal of Health Education*, 36, 202–207.
- Queeney, D.S. (1995). *An essential tool for quality improvement: Assessing needs in continuing education*. San Francisco, CA: Jossey-Bass.
- Ravert, P., & Merrill, K.C. (2008). Hospital nursing research program: Partnership of service and academia. *Journal of Professional Nursing*, 24, 54–58.
- Rowland, J., Mariotto, A., Aziz, N., Tesauro, G., Feuer, E.J., Blackman, D., . . . Pollack, L.A. (2004). Cancer survivorship—United States, 1971–2001. *Morbidity and Mortality Weekly Report*, 53, 526–529.
- Rowland, J.H. (2007). Survivorship research: Past, present, and future. In P.A. Ganz (Ed.), *Cancer survivorship: Today and tomorrow* (pp. 28–42). New York, NY: Springer.
- Rutten, L.J., Arora, N.K., Bakos, A.D., Aziz, N., & Rowland, J. (2005). Information needs and sources of information among cancer patients: A systematic review of research (1980–2003). *Patient Education and Counseling*, 57, 250–261. doi: 10.1016/j.pec.2004.06.006
- Sanson-Fisher, R., Girgis, A., Boyes, A., Bonevski, B., Burton, L., & Cook, P. (2000). The unmet supportive care needs of patients with cancer. *Cancer*, 88, 226–237.
- Shaha, M., Cox, C.L., Talman, K., & Kelly, D. (2008). Uncertainty in breast, prostate, and colorectal cancer: Implications for supportive care. *Journal of Nursing Scholarship*, 40, 60–67.
- Siegel, K., Bradley, C.J., & Lekas, H.M. (2004). Causal attributions for fatigue among late middle-aged and older adults with HIV infections. *Journal of Pain and Symptom Management*, 28, 211–244.
- Simone, J.V. (2002). Understanding cancer centers. *Journal of Clinical Oncology*, 20, 4503–4507.
- Smyth, M.M., McCaughan, E., & Harrison, S. (1995). Women's perceptions of their experiences with breast cancer: Are their needs being addressed? *European Journal of Cancer Care*, 4, 86–92.
- Soothill, K., Morris, S.M., Harman, J., Francis, B., Thomas, C., & McIlmurray, M.B. (2001). The significant unmet needs of cancer patients: Probing psychosocial concerns. *Supportive Care in Cancer*, 9, 597–605.
- Ward, E., Halpern, M., Schrag, N., Cokkinides, V., DeSantis, C., Bandi, P., . . . Jemal, A. (2008). Association of insurance with cancer care utilization and outcomes. *CA: A Cancer Journal for Clinicians*, 58, 9–31.
- Wen, K.Y., & Gustafson, D.H. (2004). Needs assessment for cancer patients and their families. *Health and Quality of Life Outcomes*, 2, 1–12.
- Wiener, C.L., & Dodd, M.J. (1993). Coping amid uncertainty: An illness trajectory perspective. *Scholarly Inquiry for Nursing Practice*, 7, 17–31.
- Witkin, B.R., & Altschuld, J.W. (1995). *Planning and conducting needs assessments: A practical guide*. Thousand Oaks, CA: Sage.
- Wong, F., Stewart, D.E., Dancy, J., Meana, M., McAndrews, M.P., Bunston, T., & Cheung, A.M. (2000). Men with prostate cancer: Influence of psychological factors on informational needs and decision making. *Journal of Psychosomatic Research*, 49, 13–19.