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A closer look at unmet needs at the end of primary treatment for breast cancer: A longitudinal pilot study

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Abstract

This study describes the nature of unmet needs (UN) as women with breast cancer transition from “patient” to “survivor.” Data are from a longitudinal study of 90 women with stage I-III breast cancer. Data were collected 2–3 weeks before, and 10 weeks after, completion of radiation. A modified Cancer Survivors’ Unmet Needs (CaSUN) instrument measured UN. Most participants reported 1 unmet need at baseline (80.00%) and follow-up (69.31%), with UN across physical, healthcare, information, psychosocial, and survivorship domains. Total number of UN declined over time ($t(87)=3.00, p<.01$). UN likely to persist from baseline to follow-up involved cancer recurrence concerns, stress management, household responsibilities, and others not acknowledging/understanding cancer. Younger women ($p=.01$) and those with more severe ($p<.01$), life-interfering ($p=.01$) symptoms had greater burden of UN. This study highlights the dynamics of UN in the weeks before and after primary treatment. Future studies should identify long-term consequences of persistent UN.

Keywords

breast cancer; supportive care needs; unmet needs; cancer survivorship

Due to advances in early detection and treatment of cancer, many individuals with cancer now live far beyond the point of treatment completion ¹. Consequently, a keen focus on cancer survivors’ quality of life is imperative. Consistent with this focus is the assessment, prediction, and fulfillment of “supportive care needs.” As described by Carey and colleagues (2012), “the term supportive care needs is an umbrella term which covers the physical, informational, emotional, practical, social, and spiritual needs of an individual with

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Declarations of Interest

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cancer”^{2(p208)}. Hence, unmet supportive care needs (i.e., “unmet needs”) can be defined as needs that are associated with a problem or concern that requires additional attention, and in some cases, such needs are associated with detriments in quality of life^{3–5}.

Among individuals with cancer, research on unmet needs grew exponentially in recent decades^{for reviews, see 2,6–8}. Based on extant research, it is known that cancer can carry with it significant need for information^{9–11}, psychological support^{5,12–14}, practical assistance^{12,15}, and symptom management^{13,16}. Across studies, however, there is vast heterogeneity in the definition and measurement of unmet needs, and within any given study, there is great diversity in participants’ demographic and clinical characteristics^{7,17}. Furthermore, cross-sectional studies comprise the majority of research in this area⁷ despite unmet needs likely being dynamic. Given these limitations, it is difficult to discern 1) *which*, 2) *when*, and 3) *for whom* unmet needs are most prevalent among cancer patient/survivors. If unmet needs remain an intervention focus^{2,8}, then future studies need to answer more fully the aforementioned questions.

The Institute of Medicine and National Research Council landmark text on cancer survivorship highlights the significance of specific points along the cancer continuum, with particular attention given to the end of primary treatment¹⁸. As the end of treatment is commonly associated with a decline in support from professional and lay caregivers^{18–20}, it presents a unique opportunity in which to examine unmet needs. Thus, the main purpose of this investigation was to describe the nature of unmet needs as women transition from the role of a “patient” to “survivor.” Though definitions for “cancer patient” and “cancer survivor” vary in the literature, for the purpose of this study, we explored unmet needs prior to, and after, primary treatment completion. A secondary aim was to identify demographic and clinical correlates of unmet needs, as there may be individuals “at risk” for a greater burden of unmet needs. Breast cancer is associated with the highest cancer incidence rate among women in the United States²¹, so breast cancer patients/survivors were the focus herein. Overall, this study was designed to extend current knowledge of unmet needs via its focus on a period in which cancer patients are learning about and preparing for the next chapter of their cancer experience.

Method

Participants and Procedure

This study is part of a pilot randomized clinical trial (RCT), which will be presented in detail elsewhere. Briefly, the pilot RCT evaluated a minimal educational intervention designed to prepare breast cancer patients for survivorship. Toward the end of radiation therapy, the intervention group received videotaped and print materials tailored for use with breast cancer patients^{22–25}; the control group received a delayed intervention. Participants were proactively recruited from two South Carolina cancer centers. Eligible to participate were women with a first primary diagnosis of stage I–III breast cancer and plans for radiation therapy. Eligible women were invited provide written informed consent and HIPAA authorization. Participants then completed assessments at *baseline* (2–3 weeks prior to completion of radiation therapy and immediately before intervention delivery) and *follow-up* (10 weeks after completion of radiation therapy). Most data were collected via interview (in-

person or phone) or questionnaire (mail), with some information obtained via chart review. The institutional review board at the Medical University of South Carolina approved study procedures.

Between July 2011 and March 2012, 98 women were approached about the pilot RCT, of whom 92 were eligible, enrolled, and randomized (93.88% accrual rate). Data pertain to 90 participants (one individual was found ineligible *post hoc* and another could not participate for health reasons), of whom 88 completed the follow-up (97.78% retention rate). No differences in any study variable, including unmet needs, were found between the treatment groups at baseline (data not shown).

Measures

Demographic and Clinical Variables—Demographic information was assessed via self-report at baseline. Most clinical information was assessed via electronic medical record review, but the M.D. Anderson Symptom Inventory was administered to assess cancer symptoms²⁶. Presence and severity of 13 symptoms in the past 24 hours were rated on a scale from 0=not present to 10=as bad as you can imagine. Six items assessed the interference of symptoms with one's life in the past 24 hours and were rated on a scale from 0=did not interfere to 11=interfered completely. Symptom severity and symptom interference scores were calculated as the mean of their respective items. Cronbach's α for symptom severity was 0.92 and 0.90 at baseline and follow-up, respectively. Cronbach's α for symptom interference was 0.93 at baseline and follow-up.

Unmet Needs—The 42-item Cancer Survivors' Unmet Needs (CaSUN) instrument assesses unmet needs and positive changes due to cancer²⁷. The CaSUN contains 35 need items that tap multiple domains (e.g., information, relationships) and 1 open-ended need item. Scoring allows calculation of the total number of needs (met and unmet) and strength of any individual unmet need in the prior month. The CaSUN has strong construct validity as its scores correlate with other important survivorship variables (e.g., quality of life) in expected ways²⁷. However, CaSUN administration can be difficult due to the wording of some items and response options. Consequently, modifications were made for this study, with piloting among breast cancer patients in South Carolina. Revisions included 1) excluding items that were confusing or inappropriate (e.g., "Help to find out about financial support and/or government benefits to which I am entitled..."), 2) adding items to address important, but untapped topics (e.g., "Help defining a new sense of normal")²⁸, and 3) making typographic changes. The Modified CaSUN included 30 need items that required participants to report if they had the need in the prior month. Cronbach's α for the Modified CaSUN was 0.92 at baseline and follow-up. Burden of unmet needs was determined by calculating the total number of unmet need items at each assessment.

Data Analysis

Descriptive statistics characterized the sample's demographic/clinical features and unmet needs. A paired t-test assessed change in burden of unmet needs from baseline to follow-up and McNemar tests for paired proportion evaluated change over time in participants' most frequently endorsed unmet needs. For the McNemar tests, participants' responses to the top

10 unmet needs were classified as follows: 1) persistent need—unmet need at baseline and follow-up, 2) resolved need—unmet need at baseline, but not follow-up, 3) emergent need—unmet need at follow-up, but not baseline, or 4) no need—no need at baseline or follow-up. Finally, Pearson's r , Wilcoxon rank sum tests, and Kruskal-Wallis tests were used to evaluate the association between participants' burden of unmet needs and demographic and clinical variables. Although data are from a RCT, intervention versus control group status was not associated with change in unmet needs (data not shown), so study results are presented for the sample. A p -value $\leq .05$ denotes statistical significance.

Results

Table 1 shows participants' ($N=90$) demographic and clinical characteristics. Participants, who were an average of 55.26 years old, included a fair number of African American and single women. Roughly half of participants were employed, most had attained college education, and many had private/HMO insurance. About half of participants were diagnosed with stage I cancer and surgical treatment most often involved a lumpectomy. In addition to radiation therapy, many participants had chemotherapy and/or hormone replacement therapy. Participants experienced modest symptom severity and interference. Most participants had ≤ 1 comorbid condition.

Most participants reported ≤ 1 unmet need prior to (80.00%) and after (69.31%) completion of primary treatment. Furthermore, every unmet need item was endorsed by ≥ 1 participant, with the range being 5.81% (better quality medical care) to 41.86% (up to date information) at baseline and 3.41% (convenient access to healthcare services) to 25.29% (help with stress reduction) at follow-up. The total number of unmet needs was relatively low at baseline ($M, SD=6.49, 6.70$; median=4.00) and follow-up ($M, SD=4.68, 5.97$; median=2.50), reflective of positively skewed data. Despite this, the nature of unmet needs was diverse. Unmet needs were present across *physical* (e.g., help managing treatment side effects), *healthcare* (e.g., assurance that doctors work collaboratively), *information* (e.g., help understanding information about cancer), *psychological* (e.g., assistance with stress management), *social* (e.g., help dealing with the interpersonal impact of cancer) and *survivorship* (e.g., help defining a new sense of normal) domains. The top 10 unmet needs are shown in Table 2, and among them, the most common were related to 1) information, 2) interaction with cancer patients/survivors, 3) explaining the impact of cancer to others, 4) stress management, and 5) treatment complications.

The burden of unmet needs demonstrated a significant decline over time ($t(87)=3.00, p<.01$). Patterns of change in unmet needs are shown in Table 2. Among participants with unmet need, persistent need was not unusual. For instance, 14.94% of participants reported unmet need related to 1) others not acknowledging the impact of cancer, 2) concerns of cancer recurrence, and 3) stress reduction at both baseline and follow-up. More common, however, were instances where unmet need was present only at one assessment. Participants' unmet need was generally more likely to resolve than emerge between baseline and follow-up, a pattern of change that was significant for cancer-related information ($p's=.01$ and $.05$), others not acknowledging the impact of one's cancer ($p=.01$), and emotional support ($p=.04$).

Results of tests of the association between participants' demographic/clinical variables and baseline unmet needs are in Table 3. Younger age ($p=.01$) was associated with a greater burden of unmet need as were greater symptom severity ($p<.01$) and interference ($p=.01$). *Post hoc* analyses that examined these associations for unmet need at follow-up converged with the aforementioned results (data not shown).

Discussion

The end of primary treatment, and the concomitant transition from “cancer patient” to “cancer survivor,” can be a time of both celebration and stress^{29,30}. In this time period individuals with cancer are charged—yet again—to acquire new information, adopt healthier lifestyles, and cope effectively with physical and psychosocial problems due to cancer. As these tasks are sometimes accomplished with limited support, it is conceivable cancer patients might face significant unmet needs near the end of treatment. Despite this possibility, little research investigated the nature of unmet needs during this special period^{for an exception, see 31}. Thus, the principal objective of this study was to characterize unmet needs as women with breast cancer transition from “cancer patient” to “cancer survivor.”

Study results suggest a high prevalence of unmet need at the end of primary treatment for breast cancer. Specifically, 80.00% of participants reported unmet need toward the end of radiation therapy and 69.31% reported unmet need 10 weeks after the end of radiation therapy. Although the overall prevalence of unmet need is not negligible, it provides an incomplete picture of the cancer experience during this clinically significant transition. So, in addition to prevalence rates, this study examined burden and type of unmet needs. Given the possibility of endorsing up to 30 unmet needs, participants reported a fairly modest number of needs, both before and after treatment completion. However, unmet needs were reported across multiple domains with the most common related to 1) information, 2) psychological functioning, 3) practical concerns, and 4) survivorship.

As is often found among cancer patients/survivors^{6,17}, participants frequently reported unmet need related to information about their diagnosis and/or treatment. Far less common were unmet needs related to information about whom to call for medical problems, which is reassuring as it suggests most participants were knowledgeable about their providers' roles and responsibilities. Aggregating the results of several studies, it appears the subject of individuals' requests for information changes as one gets further out from cancer diagnosis. During cancer diagnosis and treatment, unmet informational needs are usually germane to disease characteristics, symptom profiles, treatment plans, and side-effects^{9,32,33}. In the years that follow, however, unmet informational needs likely involve the desire for more information or support services that address health promotion and lifestyle change^{11,17}. The change from a focus on cancer-specific information to more general issues of well-being is commensurate with a transition from the role of “patient” to “survivor” and underscores the importance of providing information that is uniquely relevant to where an individual is along the cancer continuum.

It is well known a cancer diagnosis can be disruptive to psychological functioning³⁴, thus it is neither surprising nor alarming that participants regularly reported unmet needs that pertain to psychological adjustment and support services. Indeed, unmet psychological need is generally at or near the top of the list of problems among heterogeneous groups of cancer patients and survivors^{14,16,32,35}. In this study, the nature of unmet psychological needs was multidimensional. In addition to endorsement of non-specific need for help with stress management and greater emotional support, participants wanted help with “concerns about cancer coming back” and “feelings of uncertainty.” Among those with breast cancer, fear of recurrence and uncertainty are positively associated with psychological distress (e.g., depression)^{36–38}, and may have implications for treatment decision making and satisfaction^{39,40}. Thus, the systematic assessment and subsequent fulfillment of unmet psychological needs among cancer patients/survivors could be a powerful intervention, insofar as a marked reduction in need translates into greater quality of life in the weeks, months, and years to come.

Furthermore, as the “burden of illness” attributable to cancer is far-reaching and remarkable⁴¹, participants’ report of unmet need related to practical concerns about financial and household responsibilities is also understandable. Possible contributing factors to unmet practical needs could relate to income, medical expenses, and health-related limitations, which likely contribute to participants’ concerns about financial and household matters. Despite variation in measurement of unmet needs, other studies have found similar reports of unmet practical needs among cancer survivors^{11,16,31}. For example, in population-based study of individuals who were 3–5 years since cancer diagnosis, 23.70% and 17.90% reported unmet need related to finances and activities of daily living, respectively¹⁶. Although household responsibilities may or may not be as common a source of unmet need as finances in the general population of cancer survivors, there may be subgroups of cancer survivors who require assistance with such tasks. For instance, older cancer survivors, who are at high risk for comorbidities^{42,43}, may need greater assistance with household responsibilities than younger cancer survivors. As cancer burden may differ across groups (e.g., employed versus unemployed, younger versus older), future studies of unmet practical need should utilize measures that allow specificity in the determination of whether financial, insurance, household, transportation, or childcare factors are at play.

A final comment on which unmet needs were most prevalent concerns those closely tied to the cancer experience. Specifically, participants reported unmet need related to their adjustment to changes due to cancer and treatment (e.g., fatigue, pain) as well as the desire to connect with other cancer patients/survivors who could understand “the ins and outs” of their cancer experience. These particular unmet needs may be overlapping, as cancer patients/survivors routinely find solace among those in similar circumstances. Thus, online channels of communication (American Cancer Society’s “Cancer Survivors Network”), in-person support groups, and other activities that bring cancer survivors together (e.g., Light the Night®) remain a viable source of social support for some individuals and potentially offer a means of information and inspiration.

In addition to an account of *which* unmet needs are predominant among breast cancer patients/survivors, this study aimed to provide insight about *when* unmet needs are most

prevalent as few studies in this area have employed longitudinal designs^{9,13,33}. Within-person analyses of change found the burden of unmet needs declined significantly during the transition from treatment to post-treatment. However, a closer look at the top 10 unmet needs show it may not be that simple. For some women with breast cancer, unmet needs persist beyond primary treatment, while others experience resolution during this transition, and yet others report the emergence of new unmet needs after primary treatment—and still others report no unmet needs. Clearly, change in unmet needs is a complex process in need of further study. In regard to treatment implications, one study found most breast cancer survivors who were 1–6 months from the end of primary treatment preferred to have information and supportive care services delivered during or immediately after treatment²⁶. Thus, the weeks that surround end of primary treatment represent a good time to repeatedly assess and intervene upon unmet needs, as some needs will emerge and others will resolve during this time.

Finally, this study aimed to highlight *for whom* the burden of unmet needs is greatest. The rationale for this aim is that in the presence of limited resources it would be advantageous to quickly and accurately identify which cancer patients/survivors are at maximum risk for unmet needs and then target interventions accordingly. Here, demographic and clinical variables were examined to identify subgroups of breast cancer patients who might benefit from intervention. Somewhat unexpectedly, few significant associations among the variables of interest emerged. One possibility for these findings involves difficulty differentiating among individuals at the low end of a given range. As stated above, participants' total number of unmet needs was relatively low, which raises restriction of range as an explanation for null findings. Another possibility for the current findings is that breast cancer patients/survivors, as a group, are at risk for experiencing unmet needs. In support of this possibility, Li and Girgis found breast cancer patients/survivors' burden of unmet needs was 2nd only to lung cancer patients/survivors when comparisons were made across six diagnostic groups³². A third possibility is that most demographic and clinical variables are not strongly associated with unmet needs. This possibility also has support from prior studies, as factors like race, partner status, and treatment type have not consistently shown a significant correlation with cancer patients/survivors' unmet needs^{5,9,12,31,44}. Therefore, to identify cancer patients/survivors "at risk" for a greater burden of unmet need, future investigations should widen the scope of predictive variables to include psychosocial factors (e.g., distress, social support), as they might demonstrate a stronger association with unmet needs than demographic and clinical factors.

In closing, some study limitations deserve comment. As a pilot study, the sample size is small and the limited number of assessments occurred within a circumscribed time frame. Consequently, there are concerns about the ability to measure change in unmet need adequately. Additionally, the context in which participants were recruited and assessed (i.e., RCT), and the inclusion of individuals with breast cancer alone, negatively impacts generalizability. However, treatment group was not associated with unmet need at baseline nor was it associated with change in unmet need over time, and participants' reports generally converge with those in prior studies^{9,11,12,16,32}. Thus, threats to external validity are probably not severe. A final limitation pertains to use of the Modified CaSUN, as it will

not be possible to make 1:1 comparisons between these results and the results of studies that used the “original” CaSUN. Despite limitations, this study shows the weeks before and after the end of primary treatment are associated with a variety of unmet needs among breast cancer patients/survivors. Future studies that link changes in prevalence and/or burden of unmet need to long-term outcomes (e.g., adherence to surveillance guidelines) are still needed, as they will further elucidate the clinical significance of unmet needs among cancer patients/survivors.

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Table 1

Breast Cancer Patients' Demographic and Clinical Characteristics at Baseline (N=90)

Variable	Percent	Mean (SD)	Median
Race			
Caucasian	70.00		
African American	30.00		
Married or partnered	63.33		
Employed full- or part-time	45.56		
Education			
Less than high school degree	7.78		
High school degree or equivalent	21.11		
Some college	30.00		
College degree	41.11		
Insurance			
Private/HMO ± Other ^a	60.00		
Medicare ± Medicaid	21.11		
Medicaid Only	18.89		
Age (years)		55.26 (9.23)	55.00
Cancer stage			
I	52.22		
II	32.22		
III	15.56		
Cancer surgery ^{b, c}			
None	1.11		
Lumpectomy	74.44		
Mastectomy	24.44		
Non-surgical cancer treatment ^{b, d}			
Chemotherapy	54.44		
Hormone replacement therapy	75.56		
Symptom severity		1.88 (1.79)	1.38
Symptom interference		1.74 (2.22)	0.83
Number of comorbidities		2.99 (2.02)	3.00

Note. SD, standard deviation;

^aOptions are mutually exclusive;

^bAll participants had radiation therapy;

^cDue to rounding, percentages do not total 100.00;

^dOptions are not mutually exclusive

Table 2

Breast Cancer Patients/Survivors' Top 10 Unmet Needs (N=88-90)

Item	Unmet Need ^a		Stability Over Time ^b				<i>p</i> ^g
	Baseline	Follow-Up	Persistent Need ^c	Resolved Need ^d	Emergent Need ^e	No Need (Absent) ^f	
In the last month, have you needed...							
Up to date information about your cancer or your treatment?	41.86	24.13	11.63	31.40	12.79	44.19	.01
To talk to others who have experienced cancer?	36.78	25.00	13.64	23.86	11.36	51.14	.07
Help with others not acknowledging the impact cancer has had on your life?	36.78	20.70	14.94	22.99	5.75	56.32	.01
Help understanding information about your cancer? ^h	31.40	18.18	9.20	21.83	9.20	59.77	.05
Help managing your household responsibilities?	31.03	23.86	17.05	13.64	6.82	62.50	.24
Help managing concerns about your cancer coming back?	31.03	21.84	14.94	16.09	6.90	62.07	.12
More emotional support? ^h	31.03	19.32	13.64	17.05	5.67	63.64	.04
Help addressing financial concerns?	28.74	23.86	14.77	13.64	9.09	62.50	.50
Help with feelings of uncertainty?	27.59	19.54	13.79	13.79	5.75	66.67	.15
Help adjusting to changes in your life as a result of your cancer?	26.74	22.72	13.79	12.64	9.20	64.37	.65
Help reducing stress in your life? ⁱ	25.29	25.28	14.94	9.20	10.34	65.51	.81
Help managing the ongoing side effects and complications of your treatment? ⁱ	25.29	24.13	10.34	13.79	13.79	62.07	1.00

Note.

^aPercent of participants who provided affirmative responses.

^bDue to rounding, percentages across categories may not total 100.00.

^cPercent endorsing item at baseline and follow-up.

^dPercent endorsing item at baseline, but not follow-up.

^ePercent endorsing item at follow-up, but not baseline.

^fPercent who did not endorse item at baseline or follow-up.

^gMcNemar test for paired proportion *p*-value.

^hItem was in the Top 10 at baseline, but not follow-up.

i Item was in the Top 10 at follow-up, but not baseline.

Table 3

Associations between Breast Cancer Patients' Demographic and Clinical Characteristics and Burden of Unmet Needs at Baseline (N=90)

Variable	Number of Unmet Needs		<i>p</i>
	Mean (SD)	Median	
Race			.69 ^a
Caucasian	6.40 (6.09)	4.00	
African American	6.70 (8.08)	4.00	
Marital/partner status			.65 ^a
Married or partnered	6.51 (6.48)	4.00	
Single	6.19 (6.48)	4.00	
Employment status			.47 ^a
Employed	6.71 (6.23)	5.00	
Unemployed	6.31 (7.13)	3.00	
Education			.46 ^b
Less than high school degree	13.43 (10.77)	11.00	
High school degree or equivalent	3.95 (6.23)	1.00	
Some college	6.11 (6.14)	4.00	
College degree	6.76 (5.66)	5.00	
Insurance			.25 ^b
Private/HMO ± Other ^d	6.26 (5.99)	4.00	
Medicare ± Medicaid	8.79 (8.73)	6.00	
Medicaid Only	4.65 (5.93)	2.00	
Age (years)			.01 ^c
Cancer stage			.44 ^b
I	6.42 (6.19)	4.00	
II	7.14 (7.40)	4.00	
III	5.36 (7.17)	2.00	
Cancer surgery ^e			.80 ^b
None	1.00 (N/A)	1.00	
Lumpectomy	6.36 (6.63)	4.00	
Mastectomy	7.14 (7.08)	6.00	
Non-surgical cancer treatment ^e			
Chemotherapy			.77 ^a
Yes	6.55 (7.16)	4.00	
No	6.41 (6.20)	4.00	
Hormone replacement therapy			.88 ^a
Yes	6.12 (5.67)	4.50	
No	7.64 (9.28)	3.00	
Symptom severity			< .01 ^c

Variable	Number of Unmet Needs		
	Mean (SD)	Median	<i>p</i>
Symptom interference			< .01 ^c
Number of comorbidities			.84 ^c

Note. SD, standard deviation;

^a Wilcoxon rank sum test *p*-value;

^b Kruskal-Wallis test *p*-value.

^c Pearson's *r* *p*-value;

^d Options are mutually exclusive;

^e All participants had radiation therapy. "None" category excluded from analysis.