Identification and Correlates of Unmet Service Needs in Adult Leukemia and Lymphoma Survivors After Treatment

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Abstract

Purpose: To examine and characterize the psychosocial and health service needs of adult leukemia and lymphoma survivors who had completed active treatment within the past 4 years.

Methods: Self-report surveys were completed by 477 survivors, age 18 to 85 years, to identify areas and correlates of unmet psychosocial, health, and instrumental service needs. Unmet service needs were rank ordered, and nonparametric tests were run to assess relationships.

Results: The rate of unmet need was highest regarding sexual issues, handling medical and living expenses, emotional difficul-

ties, employment, and health insurance. Women were more likely to report unmet child care needs than men; younger individuals were more likely to report needing help with emotional difficulties and family problems; and lower income was related to greater unmet need regarding medical and living expenses. Relationships were also observed among the service needs, suggesting overlapping areas of unmet need.

Conclusion: Adult leukemia and lymphoma survivors demonstrated a diverse range of needs, many of which were related to the psychosocial and physical sequelae of cancer. The findings suggest directions for service provision and development of standards for quality care in this underserved post-treatment population.

Introduction

Advances in the treatment of cancer have resulted in a growing population of cancer survivors.¹ However, as Cella et al² noted, “the successes obtained have not been without cost,”^{2p327} as survival has been accompanied by a host of physical and psychosocial aftereffects that may linger or emerge in longer term survivorship. With growing recognition of the sequelae of cancer and two Institute of Medicine reports highlighting these sequelae and calling for better service provision to the survivorship population, service needs related to physical and psychosocial long-term and late effects of cancer have become salient topics in oncology research and practice.^{3,4}

The 2008 Institute of Medicine report, *Cancer Care for the Whole Patient*, underscores increased recognition of the importance of identifying unmet psychosocial needs of cancer survivors,³⁻⁶ among whom the overall prevalence of distress is estimated to be as high as 35%.⁷ Research has demonstrated high levels of unmet needs in subgroups of survivors, including survivors of breast,^{8,9} prostate,^{10,11} lung,¹² bowel,¹³ childhood/young adult,^{14,15} and skin cancers.¹⁶ In addition to psychosocial needs, survivors report needing support for fatigue,¹⁶ health promotion,^{17,18} infertility,¹⁵ economic burdens, obtaining health and/or life insurance, and employment.³ Research has demonstrated that patients with unmet needs have significantly higher levels of psychologic and symptom-related distress^{3,6,19,20} than those whose needs are being met more fully.

Information regarding the survivorship experiences of adult leukemia and lymphoma survivors is markedly underrepresented in the current cancer survivorship and health services

delivery literatures. The broader literature on cancer survivors suggests that survivors need more information about maintaining good health outcomes after treatment and about follow-up surveillance and testing, symptoms and adverse effects, sexual function and fertility, emotions, and managing daily living after active treatment.^{3,5,6,21}

In terms of leukemia and lymphoma survivors specifically, the literature is sparse with respect to reporting the service needs of adult off-treatment survivors. Moreover, little research exists on the time period spanning the first 4 to 5 years after treatment cessation. One exception to this trend is a key study exploring the service needs of adult hematologic cancer survivors in Australia.²² This study examined informational, emotional, and care coordination needs in the first year after treatment cessation. Younger patients reported more needs in the areas of emotional issues and relationships, and the highest areas of unmet need overall included help with psychosocial concerns, case management, and provider-to-provider communication. Although there is not yet uniform consensus about the post-treatment experience of adult leukemia and lymphoma survivors, the extant literature suggests an array of psychosocial outcomes, with long-term survivors reporting both positive outcomes²³ and long-term difficulties that include impaired quality of life in the areas of cognitive functioning,²⁴ social functioning, pain frequency, fatigue and financial concerns,²⁵ sexual functioning,²⁶⁻²⁹ and infertility.³⁰ In relating these outcomes to service needs, Lim et al³¹ revealed that the use of supportive care services significantly predicted quality of life for long-term cancer survivors. Finally, the work of Mols et al³² suggests a need for

services to address the practical problems reported in their study of non-Hodgkin's lymphoma survivors: problems with work, obtaining health and life insurance, and getting a mortgage. Neither of these studies directly assessed self-reported service needs, which is a different construct from reported problems³² and is still unknown in a US population.

The purpose of this inquiry is to characterize the psychosocial and health service needs of adult leukemia and lymphoma survivors. This study advances our understanding of service needs among adult survivors of hematologic malignancies and contributes to the growing literature on the re-entry phase of cancer survivorship.³

Methods

The sample for this inquiry was derived from a mixed-method study of the quality of life and service needs of adult leukemia and lymphoma survivors. Surveys on quality of life and service needs were mailed to 1,379 adult leukemia and lymphoma survivors between May and December 2007, using the Colorado Central Cancer Registry database. Data collection was completed by March 2008. Eligibility criteria included being age 18 to 80 years at time of diagnosis of leukemia or lymphoma and being 3 to 48 months from the end of active treatment at the time of the survey. Potential participants were mailed a survey packet containing an introductory letter, the survey, an invitation to be interviewed, a refusal postcard, and a postage-paid return envelope. Survey packets were mailed twice, 3 weeks apart, to all individuals except those who responded to the initial mailing with a refusal postcard. Ultimately, 810 individuals responded: 623 participants completed and returned the survey, and 187 individuals returned a refusal postcard, constituting a 45% response rate (623 of 1,379). Of the 623 individuals who returned the survey, 146 were excluded because they did not meet eligibility requirements. The final sample was composed of data from 477 respondents. Data collection and storage procedures conformed with University of Colorado School of Medicine, Colorado Central Cancer Registry, and National Institutes of Health procedures for the ethical treatment of informants.

Medical and demographic data were gathered through the self-report survey questionnaires. These data included respondents' diagnosis, treatment status, treatment modality, presence or absence of comorbid conditions, sex, race, education level, annual household income, health insurance status, and age at time of survey. Self-report data were used exclusively, because registry data on treatment were known to be incomplete, and HIPAA (Health Insurance Portability and Accountability Act) protocols related to use of the registry data prevented validation with medical records data. Service needs and degree of unmet need were assessed using a set of service need items developed by Houts et al³³ through a qualitative and quantitative survey of cancer survivors and subsequently revised by Kornblith et al,³⁴ who modified the response set to assess the degree to which individuals who experienced cancer felt their service needs were met or unmet. The 14 service need items used in this study appear in Appendix Table A1 (online only). At the time of data

collection, this was the most appropriate set of service need items available for the off-treatment survivor population being researched. The Houts et al service need inventory is not a validated instrument but rather a cluster of items with good face validity and item content consistent with survivors' reports of problems and service needs in the qualitative arm of this study.³⁵ Several measures have emerged subsequent to our data collection efforts; these measures demonstrate domains and items parallel to the Houts et al items used in this study (ie, emotional needs, relationships, financial concerns, and information needs).^{36,37} The service need items, listed in Table 1, include financial, instrumental, informational, and psychosocial needs commonly reported by patients with cancer. For each item, respondents were asked to endorse whether their needs were met on a three-point scale: 1 = got as much help as needed; 2 = some help received but less than was needed; 3 = much less help was received than was needed (9 = does not apply). Although the measure was originally designed for a population undergoing active treatment, analysis of the preliminary qualitative data in an earlier stage of the parent study suggested that the items were equally relevant to the leukemia and lymphoma survivors surveyed in this study, and the topic areas in the Houts et al items have been reported in the literature as areas of need in survivor populations.^{3,35}

Descriptive data were generated to explore the prevalence of reported needs by item and to explore which needs were reported as unmet (Table 1). To determine the strength of relationships between patient demographic and medical characteristics and the service needs reported, we used a Kendall's tau-b (correlation) test. This test tells us the strength of association between variables. This test was also used to explore relationships among reported service needs (Table 2). For the purposes of this analysis, which focused on unmet needs, the response categories of the service need items were collapsed into binary outcomes: 0 = got as much help as needed; 1 = got less help than was needed. Data were analyzed using SPSS version 17 (SPSS, Chicago, IL) and SAS version 9.2 (SAS Institute, Cary, NC).

Results

The participants included 257 men (54%) and 219 women (46%) who were age 18 to 85 years (mean, 56 years) when surveyed. The majority of survivors (60%) had a diagnosis of non-Hodgkin's lymphoma; 19% had Hodgkin's lymphoma, and the remainder of respondents had a form of leukemia. The time since active treatment cessation ranged from 3 to 48 months, with the 50th percentile falling in the category of 25 to 36 months. Ninety-five percent of the respondents had completed active treatment and did not receive maintenance treatment. Five percent of the participants reported receiving a maintenance regimen after primary treatment. Eleven percent of patients had experienced a recurrence. Additional medical and demographic information for the sample is listed in Table 3.

Comparison of respondents and nonrespondents was possible on selected demographic and medical variables collected by the Colorado Central Cancer Registry, using Fisher's exact test and χ^2 tests of association. Differences were not found for ur-

Table 1. Participants Reporting an Unmet Need*

Unmet Need	No.	%
Sexual issues	292	41
Handling medical living expenses	379	38
Emotional difficulties	399	37
Employment problems	268	32
Health insurance problems	404	30
Child care needs	116	29
Family problems	320	28
Difficulties with social and leisure activities	366	25
Cancer-related physical needs	375	18
Medical information	468	18
Social support from friends	438	18
Spiritual needs	358	14
Medical staff support	468	8
Transportation needs	393	8

* Of those who deemed the item relevant.

ban versus rural residence, recurrence status, or sex. Higher response rates ($P = .001$) were observed among whites (v non-whites), those with private insurance (v Medicare/Medicaid), those without a comorbid condition (v those reporting $\geq$ one comorbid conditions), and those living in areas with less than 10% poverty ($v > 10\%$ poverty). Although statistically different, comparisons of response patterns across diagnostic groups revealed that return rates for the surveys were relatively consistent across diagnoses, ranging from 30% to 53%, with slightly lower response rates among those with acute myeloid leukemia and chronic lymphocytic leukemia and slightly higher response rates in the lymphomas.

In Table 1, we report the percentage of unmet need for each service need item. For the purpose of this inquiry, the response

categories of the service needs variables were recoded to exclude those who reported a need as not applicable, and thus, they focus on needs that were unmet versus met for those who deemed an item applicable. Variation was observed in endorsement of the not-applicable response category for two items: employment problems and child care. This variation is related to the age distribution of the sample, which is skewed in the direction of older age and thus favors individuals who are less likely to be employed and less likely to have young children in their care. t tests were used to explore whether there were differences in unmet service need endorsement for patients who had experienced a recurrence versus those who had not. A statistically significant difference ($P = .027$) was observed for only one item: family problems, for which individuals who had experienced a recurrence reported more unmet need than patients who had not experienced recurrence. For the remaining 13 service need variables, there were no significant differences on the basis of recurrence status.

Comparisons were made between those who reported they got as much help as needed versus those who reported getting less help than was needed (some help was received, but less than needed, or much less help was received than needed). The service needs with the highest percentage of unmet needs ($\geq 25\%$) were: help with sexual issues, handling medical and living expenses, emotional difficulties, employment problems, health insurance problems, child care needs, family problems, and difficulty with social and leisure activities.

Bivariate correlations were used to determine associations between the service need items and the demographic and medical variables listed in Table 3. To identify those correlations likely to be meaningful in practice, we chose not to rely solely on significant P values alone but instead included only those variables that explained 5% or more of the common variation (achieved by squaring the Kendall's tau-b correlation coefficient).

Table 2. Strength of Relationships Between Service Need Items

Unmet Need	1	2	3	4	5	6	7	8	9	10	11	12	13	14
Sexual issues	—	—	—	—	—	—	—	—	—	—	—	—	—	—
Handling medical and living expenses	0.140	—	—	—	—	—	—	—	—	—	—	—	—	—
Emotional difficulties	0.388	0.392	—	—	—	—	—	—	—	—	—	—	—	—
Employment difficulties	0.281	0.373	0.313	—	—	—	—	—	—	—	—	—	—	—
Health insurance problems	0.161	0.556	0.286	0.269	—	—	—	—	—	—	—	—	—	—
Child care needs	0.313	0.456	0.545	0.419	0.528	—	—	—	—	—	—	—	—	—
Family problems	0.362	0.251	0.490	0.381	0.266	0.424	—	—	—	—	—	—	—	—
Difficulty with social and leisure activities	0.282	0.265	0.493	0.428	0.302	0.597	0.493	—	—	—	—	—	—	—
Cancer-related physical needs	0.234	0.253	0.327	0.262	0.209	0.518	0.420	0.385	—	—	—	—	—	—
Medical information	0.188	0.215	0.283	0.296	0.145	0.289	0.321	0.318	0.307	—	—	—	—	—
Social support from friends	0.219	0.268	0.442	0.373	0.245	0.468	0.415	0.624	0.373	0.269	—	—	—	—
Spiritual needs	0.291	0.220	0.370	0.305	0.211	0.179	0.410	0.434	0.256	0.235	0.458	—	—	—
Medical staff support	0.047	0.067	0.148	0.186	0.178	0.077	0.270	0.279	0.256	0.414	0.273	0.196	—	—
Transportation needs	0.126	0.289	0.294	0.264	0.229	0.455	0.240	0.346	0.405	0.212	0.278	0.320	0.183	—

NOTE. Response categories for all variables: 0 = got as much help as needed (ie, need met); 1 = not as much help was received as needed (ie, need unmet). Correlation coefficients are Kendall's tau-b coefficients. Bold font indicates coefficients for which $\geq 5\%$ of the common variation is explained (achieved by squaring Kendall's tau-b coefficient). This criterion represents the point (statistically) at which there is a higher likelihood of a clinically meaningful relationship between the two items. In practical terms, bold coefficients indicate associations unlikely to have occurred by chance alone and that are likely to be clinically meaningful.

Table 3. Patient Demographic and Clinical Characteristics (N = 477)

Characteristic	No.	%*
Diagnosis		
Non-Hodgkin's lymphoma	284	60
Hodgkin's lymphoma	91	19
Acute myelogenous leukemia	24	5
Acute lymphoblastic leukemia	8	1
Chronic myelogenous leukemia	28	6
Chronic lymphocytic leukemia	37	8
Other	5	1
Treatment status		
Off treatment, months from end of treatment		
3-11	85	18
12-24	124	26
25-36	113	24
37-48	129	27
Maintenance regimen	26	5
Treatment		
Single treatment	325	68
Combined treatment	125	26
Bone marrow transplantation	25	5
Other condition		
None	297	62
Medical condition (in addition to cancer)	176	37
Sex		
Male	257	54
Female	219	46
Race		
White	434	91
Hispanic	25	5
Black	7	2
Asian/Pacific Islander	3	1
Native American	1	0.2
Biracial	4	0.8
Education		
Less than high school	17	4
High school graduate or GED	72	15
Some college	110	23
Associate or technical degree	53	11
College graduate	114	24
Postgraduate education	109	23
Annual household income, \$		
< 25,000	63	13
26,000-50,000	123	26
51,000-75,000	100	21
76,000-100,000	80	17
> 100,000	88	18
Health insurance status		
Yes	429	90
No	41	8

Continued on next column

Table 3. (Continued)

Characteristic	No.	%*
Age at time of survey, years		
Mean		56
Range		18-85

Abbreviation: GED, general equivalency diploma.

* Some percentages do not add up to 100% because of missing data.

cient), indicating a stronger and more clinically meaningful relationship between the variables. This more rigorous and conservative estimate yielded a limited number of relationships between the independent variables (demographic and medical factors) and the service need variables. Four notable relationships were observed. Women were more likely to report unmet child care needs than men (tau b = -0.266 ; $P = .004$; $n = 116$; 7% covariance explained); younger individuals were more likely to report needing help with emotional difficulties and family problems than older individuals (emotional difficulties: tau b = -0.248 ; $P = .000$; $n = 364$; 6% covariance explained and family problems: tau b = -0.276 ; $P = .000$; $n = 318$; 7.6% of covariance explained); and lower income was related to greater unmet need for help handling medical and living expenses (tau b = -0.275 ; $P = .000$; $n = 364$; 7.5% covariance explained).

Bivariate correlations were also conducted to determine relationships among service need items using the 5% or more of common variance criterion (indicated in bold font in Table 2). Emotional difficulties and handling medical and living expenses were most highly correlated with other service needs. Participants who identified an unmet need regarding emotional difficulties also identified unmet needs for sexual issues, employment difficulties, expenses, child care, family problems, and social/leisure activities. Similarly, those who identified an unmet need regarding expenses also identified unmet needs for employment difficulties, child care, health insurance problems, and emotional difficulties. Relationships were also observed between a cluster of social, interpersonal, and emotional needs: sexual issues, employment difficulties, emotional difficulties, and family problems.

Discussion

Using a sample of adult leukemia and lymphoma survivors whose active treatment had ended 3 to 48 months before, the present study aimed to extend the research on service needs of cancer survivors. The results demonstrate that at least one in four survivors reported unmet need in eight of the 14 service need categories outlined in this inquiry. The observed relationships between sex and unmet child care needs and between income and unmet need with handling expenses were expected and consistent with prior literature. Furthermore, younger individuals were more likely to report higher unmet needs in dealing with emotional and family problems, which may be related to the complex needs of negotiating cancer with a young family or a lack of established interpersonal and interfamilial resources to cope with a trauma such as cancer. This finding is

consistent with findings from two studies that showed lower rates of reported care needs for older versus younger adults.^{38,39} Family problems may also be particularly challenging for individuals who have had a recurrence. Together, the findings suggest the need to screen for and address targeted needs in these subgroups. Results are consistent with the study by Lobb et al²³ of Australian hematologic malignancy survivors, suggesting that unmet needs may transcend differences in care delivery between the two countries. The findings reported herein are also consistent with rates of endorsement for unmet psychosocial and instrumental service needs for other cancer types, which ranged from 14% to 17% in a study of breast cancer survivors⁴⁰ and from 20% (information needs) to 36% (care coordination) in a study of colorectal cancer survivors.³⁹ Respondents who identified an unmet need in one service area were likely to report unmet needs in other areas as well. This was especially evident with respect to unmet needs for emotional problems and problems dealing with expenses, both of which were related to a diverse cluster of service needs. The array of intercorrelations among service needs suggests that survivors' unmet needs are diverse and multidimensional in their relationships with one another, crossing boundaries of emotional and instrumental service needs. This finding has important implications for service provision; interventions delivered to this population must be flexible enough to provide a broad range of options and allow for individual tailoring. Moreover, the findings speak to the broader relationship between unmet psychosocial needs and poor psychosocial outcomes,^{3-6,20,21} underscoring the role of service provision.

An important limitation to the generalizability of these findings is that the results reported herein likely under-represent unmet service needs because of the under-representation in the sample of individuals experiencing socioeconomic disadvantage and multiple comorbidities. However, overall, our findings are consistent with the literature reviewed at the outset of this article and the recent Institute of Medicine report,³ suggesting that the service needs of leukemia and lymphoma survivors may not be distinguishably different from those of other cancer survivors during the re-entry period. Thus, the findings of this study may be loosely generalizable to other cancer survivor populations during the re-entry period of survivorship. Although the cross-sectional design of the study limits its ability to compare the reported needs of cancer survivors with age-matched healthy controls, this study was able to accomplish its goal: to provide an understanding of the prevalence, distribution, and nature of service needs in a vulnerable and underserved cancer survivorship population. The literature cited herein demonstrates that reported service needs are congruent with those reported by

survivors of other cancers. In concert with prior research and a sister publication outlining the clinical imperatives and principles for quality service delivery in cancer survivorship,³⁵ these inquiries provide a novel roadmap for follow-up care in psychosocial oncology. Future research should seek to provide comparisons with age-matched healthy controls or individuals with chronic illnesses other than cancer to provide a better understanding of whether these outcomes are unique to cancer. Such inquiries would further inform care delivery in cancer, chronic illness, and the intersecting trajectories of cancer and chronic illness.⁴¹

In conclusion, the preceding analysis strengthens the evidence base used to inform service provision for the growing population of hematologic malignancy survivors. Results suggest the need for intervention models that encompass multiple domains and are able to tailor intervention content to diverse needs. Future research should seek to provide an understanding of the most appropriate and effective channels through which to deliver such tailored interventions across the survivorship trajectory to meet survivors' ongoing reported needs.

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Appendix

Table A1. “Your Needs Related to Cancer”*

Areas	Got as Much Help as I Needed	Some Help Received, but Less Than Was Needed	Much Less Help Was Received Than Was Needed	Does Not Apply
1. Financial responsibilities (eg, paying medical expenses, meeting basic living expenses)	1	2	3	9
2. Employment problems (eg, doing your job, problems with supervisors or coworkers)	1	2	3	9
3. Health insurance problems (eg, inadequate coverage of medical expenses, filling out health insurance forms)	1	2	3	9
4. Transportation needs (eg, transportation going to and from doctors' offices)	1	2	3	9
5. Cancer-related physical needs (eg, physical care needed at home; treatment side effects, fatigue, pain, etc)	1	2	3	9
6. Medical information (eg, informed about my medical condition, treatment side effects, test results, whom to call for help, ways I can help myself get well)	1	2	3	9
7. Medical staff (eg, treated with consideration; available when needed)	1	2	3	9
8. Emotional difficulties (eg, feeling sad, anxious, need help with my emotions so I could cope better; worried about family; worried about cancer spreading; not being able to do the things I used to do)	1	2	3	9
9. Family problems (eg, family has trouble coping with cancer; tensions or arguments among family members about my having cancer)	1	2	3	9
10. Sexual issues (eg, sexual interest, activity, satisfaction)	1	2	3	9
11. Social support from friends	1	2	3	9
12. Social and leisure activities (eg, not able to socialize with family and friends, do leisure activities)	1	2	3	9
13. Spiritual needs (eg, need for spiritual or religious help)	1	2	3	9
14. Child care needs (eg, taking care of my children at home while still sick, coping with children's problems with my having cancer)	1	2	3	9

* Recipients were presented with the following instructions: Cancer patients often face problems or responsibilities for which they may need some help. For which of the following activities do you feel you have enough help, and for which is there less help than you would like?