

**ORIGINAL RESEARCH**

# What are cancer survivors' needs and how well are they being met?

In this large community-based survey of cancer survivors, 7 needs remained unmet for  $\geq 10\%$  of all respondents.

**ABSTRACT**

**Purpose** ► This study sought to identify the needs and unmet needs of the growing number of adult cancer survivors.

**Methods** ► Vermont survivor advocates partnered with academic researchers to create a survivor registry and conduct a cross-sectional survey of cancer-related needs and unmet needs of adult survivors. The mailed survey addressed 53 specific needs in 5 domains based on prior research, contributions from the research partners, and pilot testing. Results were summarized by computing proportions who reported having needs met or unmet.

**Results** ► Survey participants included 1668 of 2005 individuals invited from the survivor registry (83%); 65.7% were ages 60 or older and 61.9% were women. These participants had received their diagnosis 2 to 16 years earlier; 77.5% had been diagnosed  $\geq 5$  years previously; 30.2% had at least one unmet need in the emotional, social, and spiritual (E) domain; just 14.4% had at least one unmet need in the economic and legal domain. The most commonly identified individual unmet needs were in the E and the information (I) domains and included "help reducing stress" (14.8% of all respondents) and "information about possible after effects of treatment" (14.4%).

**Conclusions** ► Most needs of these longer-term survivors were met, but substantial proportions of survivors identified unmet needs. Unmet needs such as information about late

and long-term adverse effects of treatment could be met within clinical care with a cancer survivor care plan, but some survivors may require referral to services focused on stress and coping.

Following a successful course of treatment for cancer, many patients return to or remain in the care of their primary care physician (PCP). What often goes unrecognized, however, are these cancer survivors' unique needs—physical, psychological, social, spiritual, economic, and legal—and the informational and professional services available to address them.<sup>1,2</sup>

■ **Increased cancer survival creates new needs.** There are already >12 million cancer survivors in the United States and >30 million worldwide.<sup>3</sup> As baby boomers age, the number of cancers diagnosed over the next 45 years will double<sup>4</sup> and improved diagnosis and treatments are already prolonging survivors' lives. With the greater number of cancer survivors and longer survival time, a cancer survivorship advocacy community has developed to help identify and address the concerns, needs, and benefits of having lived with, through, and beyond a cancer diagnosis.

■ **The purpose of our study.** Some of these areas of need have been studied extensively with childhood survivors, breast cancer survivors, and, more recently, prostate

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➤ **After effects of treatment, a big concern for most patients, is important to address not only at the outset of treatment but also at its conclusion and with documentation in a survivor care plan.**

cancer survivors. However, few studies have examined adult survivors from all cancer types<sup>5-9</sup> or have had cohorts large enough to yield meaningful information.<sup>5,7-9</sup> The aim of this study was to describe the needs of adult survivors of all cancer types in a general population from Vermont and to determine whether these needs were met. The results of this study can help identify the services needed by cancer survivors.

## **METHODS**

### **Population and sample**

In November 2009, we invited all survivors listed in a cancer survivor registry to complete a 12-page survey. The registry<sup>10</sup> was created as part of the Cancer Survivor Community Study, a community-based participatory research project funded by the National Cancer Institute. The study's Steering Committee was comprised of cancer survivors, cancer registrars, and researchers. We identified and invited cancer survivors from 4 hospital registries in northwest and central Vermont to participate. Registry participants who indicated willingness to enroll in research studies received an invitation letter and informed consent form, the 12-page survey, and an addressed and stamped return envelope. We obtained Institutional Review Board (IRB) approval for these procedures at the University of Vermont and at local hospital IRBs.

### **Instrument development**

A working group from the Steering Committee reviewed a range of available instruments to assess cancer survivors' needs.<sup>9,11-15</sup> We determined that the survey most relevant to our objectives was the Cancer Survivors' Unmet Needs (CaSun) instrument.<sup>13</sup> Because CaSun was developed in Australia, we carefully examined each question for appropriateness to our target audience. We eliminated several questions that we thought less important, added questions from other instruments, and simplified the survey format. Survivors from the Steering Committee pilot tested the draft questionnaire to identify awkward wording or concepts.

We piloted the revised draft using a stan-

dardized feedback form with cancer survivors who were not connected to our project and not enrolled in the survivor registry, and with residents at a senior center. Students and a teacher from an Adult Basic Education program helped to ensure easy readability. Our final instrument had 53 questions about needs in 5 domains. Questions within each domain completed the lead-in, "Since your cancer diagnosis, did you need..." We asked participants to check only 1 of the 3 boxes to the right of each question to indicate that there was no need in that area, that there was a need and it was met, or that there was a need and it was not met. We obtained self-reported demographic data during enrollment in the registry.

### **Data analysis**

We summarized data by computing the percent of survivors who reported having each need (either met or unmet) and the percent for whom the need was unmet. The latter was computed both as a percent of all survivors and as a percent of those who had the need. We also calculated the percentage of survivors that had at least one need and at least one unmet need in each domain, as well as the average number of needs per survivor in each domain. We used SPSS for Unix, Release 6.1 (AIX 3.2)(IBM, Armonk, New York).

## **RESULTS**

Of the 2005 cancer survivors invited into the study, 1668 responded, yielding a participation rate of 83%. **TABLE 1** describes the self-reported demographic and cancer characteristics of participants in this study. Most respondents were female, ≥60 years old, urban dwellers, married or with a partner, well educated, and had household incomes of ≥\$50,000. There were more breast cancer survivors than survivors of other cancers, and 14.6% of all survivors reported being diagnosed with more than one cancer. Cancer was diagnosed at stages 1 or 2 for 78.3% of the participants; 61.9% reported having undergone ≥2 treatment regimens.

The survey addressed needs in 5 domains: access to care and services (A); information (I); emotional, social, and spiritual

TABLE 1

**Demographic and clinical characteristics of study population**

(N=1668)\*

Demographic characteristic	N	%
<b>Age at invitation</b>		
<49	176	10.6
50-59	397	23.8
60-69	553	33.2
70-79	403	24.2
≥80	139	8.3
<b>Gender</b>		
Male	636	38.1
Female	1032	61.9
<b>Residence</b>		
Rural	693	41.5
Urban	975	58.5
<b>Household size</b>		
1	275	16.6
2	1020	61.6
3	184	11.1
≥4	178	10.7
<b>Marital status</b>		
Married/couple	1277	77.1
Divorced or separated	153	9.2
Widowed	132	8.0
Never married	95	5.7
<b>Educational attainment</b>		
Less than high school	46	2.8
High school or GED	295	17.8
Some college	355	21.4
College or graduate school	961	58.0
<b>Employment</b>		
Full-time job	519	32.2
Part-time job	214	13.3
Not working	877	54.5

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(E); physical (P); and economic and legal (L). More than 80% of respondents reported having at least one need in the A, I, and E domains. The E domain had the most survivors with at least one unmet need (N=503),

followed by the I (N=410) and P (N=375) domains.

■ **Identifying unmet needs.** TABLE 2 shows results for the specific questions within the domains in the order they were asked. Most

**TABLE 1**  
**Demographic and clinical characteristics of study population**  
*(cont'd)*

(N=1668)\*

Demographic characteristic	N	%
<b>Household Income</b>		
<\$20,000	117	7.4
\$20,000-\$35,000	246	15.6
>\$35,000-\$50,000	280	17.7
>\$50,000-\$75,000	358	22.7
>\$75,000	579	36.6
<b>Clinical characteristic</b>		
<b>Self-reported cancer type</b>		
Breast	523	31.4
Prostate	300	18.0
Melanoma	111	6.7
Uterine	51	3.1
Colon or rectal	94	5.7
Lymphoma and leukemia	81	4.9
Lung	29	1.7
Other <sup>†</sup>	232	14.0
Multiple cancers	242	14.6
<b>Time since diagnosis</b>		
<5 years	360	22.5
5-10 years	632	39.5
>10 years	609	38.0
<b>Stage</b>		
0	89	5.8
1	646	42.2
2	553	36.1
3	194	12.7
4	49	3.2
<b>Number of types of treatments<sup>‡</sup></b>		
0	73	4.4
1	564	33.8
2	428	25.7
3	390	23.4
4	213	12.8

GED, general equivalency diploma.

\* N does not include missing data. The responses in most categories do not add up to 1668.

† Other self-reported cancer types in order of frequency: other, thyroid, kidney, ovarian, bladder, throat, testicular, cervical, and brain.

‡ Treatment types include: surgery, radiation therapy, chemotherapy, hormonal therapy, immunotherapy, and bone marrow transplant.

participants who had a need also had it met. However, some needs that were not commonly reported were deemed unmet by a large proportion of those who expressed the need. For example, the A need for “A case manager to whom you could go to find out about services whenever they were needed” (A5) was reported by only 29.1% of survivors. But 32.1% of those reporting the need said it was unmet, which corresponds to 9.4% of all study participants having the need unmet. Similarly, the need for “More information about complementary and alternative medicine” (I3) was reported by about a quarter of the study population, 41.4% of whom (9.8% of all participants) reported it as unmet. In the P domain, the need for “Help to address problems with your sex life” (P4) was reported by only 26.5% of the respondents; yet 40.7% of those reporting the need had it unmet. Similarly, in the L domain, “Help with life insurance concerns as a result of your cancer” (L3) was only reported by 10.9% of the participants but was unmet for 46.4% of those who reported the need, or 5% of all study participants.

#### ■ Most commonly expressed needs.

TABLE 2 also identifies 12 needs reported by ≥50% of participants. Three of these needs were in the A domain, 6 in the I domain, and 3 in the E domain. The 2 most common needs related to A: the need “To feel like you were managing your health together with the medical team” (A3) was reported by 68.6% and was viewed as unmet by 5.2% of all respondents; the need for “Access to screening for recurrence or other cancers” (A7) was reported by 63.8% of the survivors but was deemed unmet by only 3.1% of all the respondents. “More information about possible after effects of your treatment” (I5) was a need for 63.2% that went unmet in 22.9% (14.4% of all participants). “Help managing your concerns about the cancer coming back” (E13) was reported as a need by 54.1% and as unmet by 11.8% of all participants.

The rank order of 7 unmet needs reported by ≥10% of the participants is shown in TABLE 3. Four of the 7 unmet needs were in the E domain. The most common unmet need in this domain was “Help reducing stress in your life” (E19).

Only 3 needs were both commonly re-

ported and also unmet for at least 10% of the participants: “More information about possible after effects of your treatment” (I5), “More information about possible side effects of your treatment” (I4), and “Help managing your concerns about the cancer coming back” (E13).

## DISCUSSION

The survey instrument we used to assess the needs of cancer survivors in a large community-based registry included a detailed list of potential needs generated, in part, by representatives of the survivor community. Most cancer survivor needs mentioned in this survey were met. However, some needs were not met for substantial proportions of respondents and should be examined carefully to determine whether services could be improved to better address them. This study was planned and implemented by researchers and cancer survivors using community-based participatory principles to learn about local needs. The results of this study may be generalizable to similar populations of survivors and will inform the survivorship goals for the Vermont State Cancer Plan and future Vermont Cancer Survivor Network activities.

#### ■ Acting on patients' expressed needs.

Over 80% of participants had needs in the A, I, and E domains. The most commonly reported need was in the A domain, “To feel like you were managing your health together with the medical team” (A3). It was also a top need in other studies that asked this question.<sup>16,17</sup> A cancer diagnosis may cause patients to feel out of control. Participation in the management of their health may help them gain a greater sense of control. PCP accommodation of expressed patient preferences may be an important part of a cancer survivor's long-term adaptation to the disease.

Six of the 12 most frequently reported needs and 2 frequently reported unmet needs were in the I domain. Communication of information increases patients' involvement in decision-making and enables them to cope better during diagnosis, treatment, and follow-up.<sup>18</sup> “More information about possible after effects of your treatment” and “More information about possible side ef-



**Concern about cancer recurrence is a prominent patient need that might be addressed most adequately in the course of usual primary care.**

TABLE 2

## Cancer survivors' needs and how often they go unmet

Highlighted needs are those expressed by ≥50% of survey respondents

Since your cancer diagnosis, did you need...		Needs	Unmet needs	
		% reporting a need	% of those who expressed the need	% of the study population
<b>Access to care</b>				
A1	Better access to high quality care?	38.8	4.8	1.9
A2	Better access to complementary and alternative medicine?	15.6	37.9	5.9
A3	To feel like you were managing your health together with the medical team?	68.6	7.5	5.2
A4	Assurance that your doctors talked to each other to coordinate your care (including complementary and alternative medicine services)?	62.0	12.1	7.5
A5	A case manager to whom you could go to find out about services whenever they were needed?	29.1	32.1	9.4
A6	Access to clinical trials/research studies for treatment?	23.6	15.5	3.7
A7	Access to screening for recurrence or other cancers?	63.8	4.9	3.1
<b>Information</b>				
I1	More information about your cancer diagnosis?	60.7	5.3	3.2
I2	More information about your cancer treatment options?	58.0	6.2	3.6
I3	More information about complementary and alternative medicine?	23.6	41.4	9.8
I4	More information about possible side effects of your treatment?	61.8	16.1	10.0
I5	More information about possible after effects of your treatment?	63.2	22.9	14.4
I6	More information about supportive resources such as home health or other A services?	20.7	24.3	5.0
I7	More information about how you can be an active participant in your treatment?	45.5	12.6	5.8
I8	More up-to-date information about your cancer and cancer treatment?	53.1	12.5	6.7
I9	More information for your family and/or partner?	45.5	14.2	6.5
I10	Information provided in a way you can understand?	62.5	5.7	3.5
<b>Emotional, social, and spiritual issues</b>				
E1	Help in figuring out what was most important in your life?	28.4	18.8	5.3
E2	Guidance in coping with mixed advice from family and friends?	20.8	25.9	5.4
E3	Someone to talk with when sadness overcame you?	44.6	20.8	9.3
E4	Opportunities to explore religion and/or spiritual practices?	26.6	11.0	2.9
E5	Opportunities to share your religious and/or spiritual practices with others?	20.5	13.2	2.7
E6	Opportunities to try mind/body/spirit therapies such as yoga, tai chi, or massage?	26.0	35.3	9.2
E7	More contact and support from family members?	49.4	10.2	5.0
E8	More contact and support from non-family?	43.0	10.6	4.6
E9	A group or person with whom you felt safe expressing how you really feel?	50.1	13.6	6.8
E10	Help sorting out your feelings about death?	27.0	28.7	7.7
E11	Help finding ways to reduce your worrying?	40.2	29.5	11.9
E12	Help learning how to cope with your sometimes catastrophic fears?	30.0	30.0	9.0

TABLE 2

**Cancer survivors' needs and how often they go unmet (cont'd)**

Highlighted needs are those expressed by ≥50% of survey respondents

	Since your cancer diagnosis, did you need...	Needs % reporting a need	Unmet needs % of those who expressed the need   % of the study population	
E13	Help managing your concerns about the cancer coming back?	54.1	21.7	11.8
E14	Help knowing how to support your partner or family?	27.9	30.0	8.4
E15	Help dealing with the impact that cancer has on your relationship with your partner or family?	31.7	35.5	11.3
E16	To talk with others who have experienced cancer?	52.0	15.3	8.0
E17	Help handling the topic of cancer in social and/or work situations?	25.2	23.5	5.9
E18	Help trying to make decisions about your life in the context of uncertainty?	26.7	28.7	7.7
E19	Help reducing stress in your life?	43.1	34.4	14.8
<b>Physical issues</b>				
P1	Help managing ongoing side effects or complications of treatment?	48.0	19.2	9.2
P2	Help adjusting to changes in your quality of life?	31.8	26.6	8.5
P3	Help with having a family due to fertility problems?	2.5	38.1	1.0
P4	Help to address problems with your sex life?	26.5	40.7	10.8
P5	Help with pain management?	28.1	13.6	3.8
P6	Help managing changes in bodily functions?	29.7	17.7	5.3
P7	Help managing changes in your ability to participate in activities?	19.7	21.9	4.3
P8	Help adjusting to changes in the way you feel about your body?	25.4	36.1	9.2
<b>Economic and legal issues</b>				
L1	Help with health insurance concerns as a result of your cancer?	25.0	22.8	5.7
L2	Legal assistance as a result of your cancer?	4.6	28.9	1.3
L3	Help with life insurance concerns as a result of your cancer?	10.9	46.4	5.0
L4	Financial assistance in meeting your monthly expenses as a result of your cancer?	14.2	37.1	5.3
L5	Assistance writing advance directives?	19.1	20.8	4.0
L6	Assistance in naming a health care proxy?	17.0	17.7	3.0
L7	Assistance with transportation to health care services?	18.0	11.7	2.1
L8	Assistance with applying for disability benefits?	9.8	23.8	2.3
L9	Assistance with a bankruptcy filing?	1.2	40.0	0.5

fects of your treatment” were reported by a high proportion of participants, and many also reported these needs as unmet. In another study about health-related information needs of survivors, 52% wanted more information about “What late and long-term side effects of cancer treatment are expected”<sup>19</sup>; and in a 2005 review of information needs, 12% of survivors reported similar needs.<sup>20</sup> Two recent articles also noted such needs in adolescent and young adult cancer survi-

vors.<sup>21,22</sup> Based on current evidence, it would be advisable to discuss anticipated effects of treatment with patients not only at the outset but also at the end of treatment, and to write it in a cancer survivor care plan.

Individual needs that were not met for at least 10% of respondents, regardless of how common the need (TABLE 3), provided additional insights. Among these 7 needs, 3 also were reported as a need by more than 50% of respondents (TABLE 2), and 4 by <50%, indi-



TABLE 3

≥10% of cancer survivor respondents reported these needs were not met

Cancer survivor need	Domain (Item)	Ever had need %	Had need, but not met %	Unmet need, % of the study population
Help reducing stress in your life?	Emotional (E19)	43.1	34.4	14.8
More information about possible after effects of your treatment?	Information (I5)	63.2	22.9	14.4
Help finding ways to reduce your worrying?	Emotional (E11)	40.2	29.5	11.9
Help managing your concerns about the cancer coming back?	Emotional (E13)	54.1	21.7	11.8
Help dealing with the impact that cancer has on your relationship with your partner?	Emotional (E15)	31.7	35.5	11.3
Help to address problems with your sex life?	Physical (P4)	26.5	40.7	10.8
More information about possible side effects of your treatment?	Information (I4)	61.8	16.1	10.0

cating that some less common needs are not being met adequately. Among these 7 prominent unmet needs, 4 were E Issues (TABLE 3) and 2 were I Issues.

**Unmet needs are an opportunity to improve care.** In our study and in others, E needs were most likely to be unmet.<sup>17,23-26</sup> Among the 4 common unmet E needs, 2 (E19 and E11) focused on generalized stress and worry, and one (E15) focused on concern about illness impact on family members or partners. Although these issues may be challenging to address successfully in a typical clinical environment, others have confirmed the importance of these needs and proposed ways to meet them.<sup>27</sup> The fourth most common unmet E need focused on concern about cancer recurrence, also a prominent need found in other studies.<sup>15-17</sup> These needs might be addressed more adequately in the course of usual clinical care by PCPs or specialists. In fact, the American College of Surgeons' Commission on Cancer 2012 standards now require psychosocial distress screening and the provision of referral for psychosocial services.<sup>24</sup> Our results are consistent in many respects with prior studies of needs reported by cancer survivors in other countries. The CaSUN survey developed by Hodgkinson et al<sup>13</sup> has been applied to several survivor populations in Australia. In a diverse survivor sample, specific E, I, and A issues were frequently reported as unmet needs.<sup>13</sup> The most promi-

nent unmet needs in a gynecologic cancer sample using CaSUN focused on emotional and social issues such as worry, stress, coping, and relationships with, and expectations of, others.<sup>25</sup>

Barg et al<sup>23</sup> conducted a survey of unmet needs in the United States using a detailed list based on prior survivor research and targeting individuals in a cancer registry. The most prominent area of need expressed was "emotional," similar to the high rank of E needs in our study. In contrast to our study, however, physical and financial issues also were prominent. The latter variances might be explained by differences in access to care, or perhaps the study's low response rate (23.8%). A similar survey reported by Campbell et al<sup>12</sup> identified needs in the emotional domain as the most cited unmet survivor needs based on psychometrically developed subscales of a 152-item survey (29% response rate).

These results from several studies, including ours, call for more detailed exploration of the E needs of long-term cancer survivors. A useful framework developed by Stein et al<sup>28</sup> accounts for factors contributing to cancer stress and burden as well as resources available to survivors (intrapersonal, social, informational, and tangible services), with the interactions between these 2 domains determining how well a survivor will be able to cope. There clearly is a role for development of more effective communication



channels and focused services to meet survivor needs.

The list of most common unmet needs in TABLE 3 also includes a focus on “problems with your sex life” (P4). This is an area that may be difficult to address in a cancer care setting because of the focus on disease management. Primary care providers might be better prepared to address this issue because they likely encounter similar issues among the wide range of patients they serve. However, a recent study reported that only 46% of internists were somewhat or likely to initiate a discussion about sexuality with cancer survivors.<sup>29</sup> Some additional preparation for physicians to address this need might be warranted.

The proportion in this sample reporting needs for access to, or information about, complementary and alternative medicine services fell below the thresholds chosen to designate common needs in this study. Although reported use is relatively common among cancer survivor in several studies,<sup>30-32</sup> it appears that in our survivor sample, those who were interested in these approaches encountered only moderate barriers.

**■ Study limitations.** We invited participants from a registry unlikely to include cancer survivors with lower educational attainment or from rural locations<sup>9</sup>—that is, our participants were less likely to have chal-

lenges in obtaining appropriate services and information. This sample limitation therefore likely underestimates the overall level of needs among cancer survivors.

This was a cross-sectional assessment of perceived needs among a diverse group of survivors, which may have overlooked needs that were met but only after considerable effort on the part of survivors. Longitudinal studies would provide more complete accounts of how readily needs are met and the changes in needs at different times in the continuum of care.

The Vermont population is less diverse racially and ethnically, but not with respect to household income or educational attainment, than the overall US population. Access to health care also is relatively high in Vermont compared with many other states. According to a 2009 Vermont Household Health Insurance Survey, only 7.6% of Vermonters are uninsured.<sup>33</sup>

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Because of the wide range of patients that primary care physicians serve, they might be better prepared to help cancer patients address problems with their sex lives.

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