Differences Between Older and Younger Cancer Survivors in Seeking Cancer Information and Using Complementary/Alternative Medicine

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OBJECTIVE: The purpose of this study was to describe the differences between younger and older cancer survivors in seeking cancer information, using complementary and alternative medical (CAM) services, and using conventional support services.

DESIGN AND METHODS: Participants were 836 survivors of adult cancers (6 months–43 years since completion of primary cancer treatment) in New Zealand who answered a mailed questionnaire between April 2007 and January 2008.

RESULTS: Younger survivors (aged <60 years at diagnosis) were more likely to seek information from sources beyond their physicians and used different sources for that information, compared to older survivors. Older and younger survivors used similar conventional support services, but different CAM services. In logistic regression analyses, information-seekers were 5.9 times more likely to use CAM than those who did not seek cancer information (p=0.02), but the association between information-seeking and CAM use depended on age (p=0.02). Older cancer survivors who did not seek information from sources beyond that provided by physicians were less likely to use CAM.

IMPLICATIONS: Physicians should consider talking to older cancer survivors about their use of information sources or CAM therapies. A conversation between physician and patient may uncover inaccurate information or CAM use that has potential for adverse effects, while allowing the physician to encourage CAM that is potentially useful. Even a brief conversation may be sufficient to encourage older cancer survivors to take action themselves to find services that support their recovery from cancer and cancer treatment.

 $K\!E\!Y$ $W\!O\!R\!D\!S\!:$ cancer; information-seeking; older adults; support services; CAM.

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 $oldsymbol{A}$ pproximately 24.6 million people worldwide have received a cancer diagnosis in the past 5 years, 1 and the

incidence of new cancers is expected to double by the year 2050 as the world population ages.² Many people with cancer, considered "survivors" from the day of diagnosis,³ are treated successfully and become part of a growing population of cancer survivors. There are myriad sources of cancer information and cancer support available to cancer survivors, whether they have been recently diagnosed, are undergoing treatment, or are long-term survivors.

Accessing cancer information can affect the emotional health of cancer survivors by improving understanding of treatments and choices, and aiding in decision-making by patients and families. Individuals who seek more information about cancer, rather than relying solely on their oncologists or primary care physicians, may be more likely to use cancer support services or try complementary or alternative medicine (CAM) services, though the link between information and using support services is largely unexplored. It is likely that older adults will have different needs and preferences for cancer information, and knowing these differences would enable design and delivery of better information and support services for older cancer survivors.

Prior studies about information-seeking have concentrated primarily on use of the internet by cancer survivors of all ages. As yet, few studies have focused on older cancer survivors, though older age has been shown to be one factor associated with less cancer information-seeking over the Internet. 4-7 Some studies of information-seeking among older cancer survivors suggest that they may want different information than do younger adults, 8.9 and possibly prefer less information about their disease. 9

Studies of whether older adults use conventional cancer support services are rare. Preliminary findings suggest that older cancer survivors are less likely to use cancer support groups 10 or psychosocial counseling. 11 More research is available about the use of CAM services by cancer survivors of different ages, $^{12-15}$ and there is evidence that older adults with cancer are less likely than younger adults to use any form of CAM. $^{16-20}$ However, definitions of CAM vary among studies, so there are limited data on the use of specific CAM services by older cancer survivors.

The purpose of this study was to (1) describe the differences between younger and older cancer survivors in seeking cancer information, using conventional support services, and using CAM services, (2) identify which demographic and cancer-related factors, including age, increase the likelihood a cancer survivor will seek cancer information or use CAM, and (3)

determine whether an association exists between informationseeking and use of CAM services and whether the association is the same for older and younger survivors.

DESIGN AND METHODS

Participants

Eligible participants were cancer survivors aged 18 years or older when diagnosed with cancer and at least 6 months beyond the end of primary cancer treatment. Participants were excluded only if they were unable to complete a mailed questionnaire or answer the same questions over the telephone. The inclusion criteria for this study were intentionally broad in order to describe the overall effects of a variety of cancers and cancer treatments in both the early survivorship experience and in long-term survivorship. The wide range of times since diagnosis in the sample also enabled analysis of different historical time periods, which was important for describing information-seeking on the Internet. The study was funded by Genesis Oncology Trust in New Zealand, and procedures were approved by a university ethics committee (equivalent to an institutional review board).

Procedures

Cancer survivors were recruited using community-based methods. New Zealand's tumor registry does not follow survivors, so cancer survivors could only be located through cancer organizations and community media, such as local newspapers, newsletters, radio interviews, and word of mouth. Potential participants telephoned a research assistant who screened for eligibility, or enrolled via the study website, where a series of questions checked eligibility. Eligible persons received consent forms and questionnaires by mail and returned completed documents by prepaid mail. A cover letter was included that described the study and offered to conduct the questionnaire by telephone if needed. When completed, questionnaires were received at the study office, and a research assistant checked for missing data and telephoned participants to get answers to omitted questions.

Life After Cancer Questionnaire

The questionnaire comprised 39 pages with 13 conceptual sections shown to be important to cancer survivors in prior studies. Concepts were measured by validated instruments from prior studies and questions developed specifically for this study. Each section also had space for optional qualitative data with a question "If there is anything else you would like to add about [the topic], please note it here." Questions about information-seeking, conventional support services, and CAM services, described below, were developed by the investigative team.

Information-seeking. Information-seeking was measured by seven questions about information sources (other patients, support groups, friends and/or family, Internet, books, magazines, and newspapers) used "after your cancer diagnosis." For each information source, the participant selected one of four answer choices (did not use, used but

found unhelpful, used and found reasonably helpful, used and found very helpful). To answer our research question of whether cancer survivors sought information from each source, the latter three choices were combined to create a dichotomous variable indicating whether a person did not use/did use each information source.

Complementary/alternative medicine (CAM) services used.

Use of CAM was measured by 14 questions about specific CAM services used "after your cancer diagnosis." For each CAM service, the participant selected one of four choices (did not use, used but found unhelpful, used and found reasonably helpful, used and found very helpful). To indicate whether each service was helpful if used, the answer choices were combined to create a new variable with three levels, not used, used (not helpful), and used (helpful). For logistic regression analyses, answer choices were combined to create a dichotomous variable indicating whether a person did not use any CAM/did use at least one CAM service.

Support services used. Use of conventional support services was measured by eight questions about services (cancer society services, support groups in the community, support groups on the Internet, counseling services, physical therapy, nutrition services, in-home household help, in-home nursing care) used "after your cancer diagnosis." The answer choices were the same as those described for CAM services, and the choices were combined in the same manner to create a new variable with three levels, not used, used (not helpful), and used (helpful).

Analysis

To select a cutoff point for defining "older" survivors, we looked at prior studies of information-seeking in older and younger cancer survivors and found little guidance because the cutoff points varied from age 50 years to age 65 years. 4,8,9,21 We chose age 60 years as our definition of "older" based on New Zealand cancer incidence rates, which showed a clear increase after age 59 years 22 and was within the age ranges used in prior studies.

The use of information sources, support services, and CAM were described using frequencies. Logistic regression models assessed factors that predicted information-seeking and CAM use, and interaction analysis tested the links among information-seeking, CAM use, and age. SPSS 15.0 was used for all analyses (Chicago, IL).

RESULTS

Recruitment began in April 2007, and data collection ended in January 2008. Of 925 participants who enrolled, 836 (90.4%) returned completed surveys. As shown in Table 1, participants were primarily white and female with a mean 9.9 years since the end of cancer treatment. They lived in urban and rural towns throughout New Zealand. The most common cancer reported was breast cancer. There were few missing data because of rigorous follow-up of omitted questions, so imputation of data was not needed.

Table 1. Personal and Clinical Characteristics of Participants (N=836)

	Aged <60 years*, n=610, n(%) or mean(SD)	Aged ≥60 years*, n=226, n(%) or mean (SD)	p value†
Age now (years)	57.7 (11.3), range 23–89	72.9 (6.0) range 61–90	< 0.001
Age at diagnosis (years)	46.3 (9.8), range 18–59	66.9 (5.2) range 60–82	N/A
Years since diagnosis	11.4 (9.5), range 0.5–43	5.9 (4.7) range 0.5–29	< 0.001
Female gender	474 (78)	127 (56)	< 0.001
Ethnicity			0.24
White	566 (93)	217 (96)	
Maori	29 (5)	6 (3)	
Other	15 (2)	3 (1)	
Education			0.001
High school or less	217 (36)	97 (44)	
University	290 (48)	101 (45)	
Postgraduate degree	99 (16)	25 (11)	
Household income (at time of diagnosis)	n=582	n=217	< 0.001
Less than US\$ 30,999	208 (36)	122 (56)	
US\$ 31,000-61,999	234 (40)	70 (32)	
US\$ 62,000-77,999	66 (11)	14 (6)	
More than US\$ 78,000	74 (12)	11 (5)	
Type of cancer			< 0.001
Breast	282 (46)	75 (33)	
Colon, rectum	82 (13)	53 (23)	
Leukemia/lymphoma	59 (10)	15 (7)	
Ovary/cervix	41 (7)	9 (4)	
Prostate	21 (3)	28 (12)	
Other (less than 5% prevalence)	125 (21)	46 (20)	
Surgical treatment only	118 (21), n=567	62 (31), n=202	0.01
Chemo/radiation therapy	449 (78), n=567	138 (68), n=202	0.03

^{*}Age at time of cancer diagnosis; †t-test for means, chi-square for proportions Groups may not total exactly 100% because percentages are rounded

Information-seeking sources used. Table 2 shows the proportion of older and younger cancer survivors who sought cancer information from various sources after a diagnosis during 1963–2000 and during 2001–2007. Because our sample of participants had received cancer diagnoses from 1963 to 2007, their answers to questions about internet use would be valid only after the internet came into broad public use. The world wide web was first freely available in 1993 and the most recent year of explosive growth in internet websites was 1997. We selected 2001 as an estimate of when computers would have been widely available, especially for older adults whose access and uptake might have been slower than for younger adults.

Information-seeking on the Internet was more common in younger cancer survivors. Older survivors were more likely to seek information from friends and family or books than the Internet, but younger survivors used friends, family, and books even more than older survivors and more frequently

than the Internet. In general, younger persons with cancer sought information more frequently than older adults from every source. Individuals diagnosed in 2001–2007 were more likely to seek information than those diagnosed before 2001.

Conventional support services used. Table 3 shows that younger and older cancer survivors used conventional support services in approximately the same proportions and were equally likely to find the services useful. Services connected with the Cancer Society were most frequently used by survivors of all ages. Older adults were less likely to use counseling services and much more likely to use in-home nursing or care services. The reasons for not using support services were similar in both age groups: didn't think it would be of use (selected by a mean 36% of survivors over all support services), didn't know about it (mean 21%), and didn't think it was relevant to cancer (mean 4%).

Table 2. Proportion of Younger vs. Older Adults Who Used Sources to Seek Information Following a Cancer Diagnosis (N=836)

	Diagnosis 1963-2000, n=437			Diagnosis 2001–2007, n=399			
	Age <60*, n=358, n(%)	Age ≥60*, n=79, n(%)	p value†	Age <60*, n=252, n(%)	Age ≥60*, n=147, n(%)	p value†	
Other patients	124 (35)	18 (23)	0.04	126 (51)	48 (34)	0.001	
Support groups	108 (31)	20 (26)	0.41	108 (43)	46 (32)	0.02	
Friends/family	218 (62)	32 (42)	0.001	183 (73)	81 (57)	0.001	
Internet	89 (25)	13 (17)	0.14	162 (65)	54 (37)	< 0.001	
Books	206 (58)	28 (36)	< 0.001	189 (76)	71 (49)	< 0.001	
Magazines	91 (26)	18 (23)	0.66	105 (42)	36 (25)	< 0.001	
Newspapers	56 (16)	12 (16)	0.99	63 (25)	26 (18)	0.10	

^{*}Age in years at time of cancer diagnosis; †chi-square test for proportions Groups may not total exactly 100% because percentages are rounded

Table 3. Comparison of Younger vs. Older Adults Who Used Conventional Support Services Following a Cancer Diagnosis (N=836)

	Age <60 years*, n=610, n(%)			Age ≥60 years*, n=226, n(%)			p value†
	Did not use	Used, not helpful	Used, helpful	Did not use	Used, not helpful	Used, helpful	
Cancer society services	245 (41)	11 (2)	341 (57)	101 (46)	5 (2)	111 (51)	0.21
Support groups in community	418 (70)	15 (2)	165 (27)	169 (76)	6 (3)	47 (21)	0.21
Support groups on internet	555 (92)	13 (2)	36 (6)	214 (95)	2(1)	8 (3)	0.18
Counseling services	438 (72)	26 (4)	143 (24)	190 (85)	9 (4)	25 (11)	0.001
Physical therapy	487 (80)	12 (2)	109 (18)	191 (86)	2 (1)	30 (13)	0.30
Dietician or nutritionist services	463 (76)	20 (3)	124 (20)	177 (79)	4 (2)	43 (19)	0.50
In-home help services (cleaning, shopping, etc.)	489 (81)	6 (1)	112 (18)	178 (80)	3 (1)	40 (18)	0.84
In-home nursing or personal care services	509 (84)	2 (0.3)	94 (16)	170 (76)	1 (0.4)	52 (23)	0.02

^{*}Age at time of cancer diagnosis; †chi-square test for difference among proportions Groups may not total exactly 100% because percentages above 1.0 are rounded

Complementary/alternative medicine (CAM) services used.

Table 4 shows that younger cancer survivors were more likely than older survivors to use all CAM services and to find such services helpful, with the exception of prayer, the most frequently used CAM by both age groups. Dietary supplements and massage therapy were also used quite often by both age groups, but use in young survivors was higher.

Factors affecting information-seeking and use of CAM services.

As shown in Table 5, logistic regression models adjusting for gender, type of cancer, and type of cancer treatment showed that age and higher education levels were significantly associated with both information-seeking and use of CAM services, regardless of physical or emotional health. Survivors who sought information about cancer were 5.9 times more likely to use CAM services than those who had not sought information about cancer. A significant interaction showed that the association between information-seeking and use of CAM services varied by age. To interpret the interaction, two further regression analyses were performed. Among information-

seekers, younger and older survivors were equally likely to use CAM services. In contrast, among those who did not seek cancer information, older survivors were significantly less likely than young survivors to use CAM services.

DISCUSSION

A conversation with a physician about sources of cancer information may be especially important for older survivors in the context of our finding that older adults are less likely to seek information about cancer beyond that provided by a physician. Our finding that older adults are less likely to seek cancer information is similar to results reported by earlier studies. Though some studies have indicated that lower use of the Internet among older adults is a cause for less information-seeking, ^{4,9,21} the older survivors in this study sought less information from all sources than did younger survivors, suggesting that computer literacy is not the only cause of less information-seeking in older survivors. It is encouraging to

Table 4. Comparison of Younger vs. Older Adults Who Used Complementary/Alternative Medicine Services Following a Cancer Diagnosis (N=836)

	Age <60 years*, n=610, n(%)			Age ≥60 years*, n=226, n(%)			p value†
	Did not use	Used, not helpful	Used, helpful	Did not use	Used, not helpful	Used, helpful	
Acupuncture	575 (94)	7 (1)	28 (5)	220 (98)	2 (0.9)	3 (1)	0.15
Acupressure	592 (97)	2 (0.3)	16 (3)	224 (99)	0 (0)	1 (0.4)	0.18
Naturopathy	521 (86)	12 (2)	76 (12)	204 (91)	4 (2)	17 (8)	0.25
Homeopathy	524 (86)	17 (3)	69 (11)	213 (95)	4 (2)	8 (3)	0.005
Herbalism	542 (89)	6 (1)	61 (10)	210 (93)	3 (1)	12 (5)	0.19
Iridology	589 (97)	7 (1)	13 (2)	224 (99)	0 (0)	1 (0.4)	0.13
Aromatherapy	529 (87)	16 (3)	65 (11)	211 (94)	3 (1)	10 (4)	0.01
Massage therapy	463 (76)	4(1)	143 (23)	191 (84)	1 (0.4)	34 (15)	0.06
Therapeutic touch	574 (94)	5 (1)	31 (5)	217 (97)	0 (0)	7 (3)	0.31
Energy healing	557 (91)	6 (1)	47 (8)	218 (97)	1 (0.4)	6 (3)	0.009
Spiritual healing	524 (86)	4(1)	78 (13)	202 (90)	1 (0.4)	21 (9)	0.49
Prayer	411 (67)	14 (2)	185 (30)	155 (69)	1 (0.4)	69 (31)	0.30
Folk remedies	601 (98)	4 (1)	5 (1)	222 (99)	2(1)	0 (0)	0.58
Dietary supplements	405 (67)	26 (4)	175 (29)	169 (75)	6 (3)	49 (22)	0.10

^{*}Age at time of cancer diagnosis; †chi square test for difference among proportions Groups may not total exactly 100% because percentages above 1.0 are rounded

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Table 5. Predictors of Information-seeking	i dila Cawi use amond	Cancel survivors (N=030)

	Information-seeking, Cox and Snell, R ² =0.11			CAM use, Cox and Snell, R ² =0.14		
	OR	95% CI	P	OR	95% CI	p
Age at diagnosis (years)	0.97	0.95-0.99	0.005	1.05	1.01-1.09	0.02
Education						
Less than high school (reference)						
Graduated high school	1.55	0.83 - 2.92	0.17	1.60	0.94 - 2.75	0.09
Graduated technical	1.93	0.95 - 3.93	0.07	1.71	0.95 - 3.04	0.07
Graduated university	3.01	1.52 - 5.96	0.002	1.89	1.09-3.25	0.02
Graduate degree	4.88	1.93-12.37	0.001	2.43	1.30-4.53	0.005
Physical health*	1.02	0.99-1.04	0.11	1.00	0.98 - 1.02	0.82
Emotional health†	0.98	0.95 - 1.00	0.11	0.10	0.98 - 1.02	0.82
Information-seeking (1=yes, 0=no)	-	-	-	5.91	3.39-10.33	< 0.001
Interaction: Age × information-seeking	-	-	-	0.95	0.91-0.99	0.02
Information seekers: Age	-	-	-	0.99	0.98-1.01	0.51
Information non-seekers: Age	-	-	-	1.17	1.02-1.13	0.01

CAM = Complementary and alternative medicine

note that survivors of all ages in our study who were diagnosed more recently were more likely to seek cancer information than those who were diagnosed prior to 2000, suggesting that perhaps patients are more assertive in gathering additional information, that cancer information is more generally available, or that physicians are indeed directing patients to additional sources of information. Information, whatever the source, is likely to empower cancer patients and perhaps relieve some of the psychological stress associated with a cancer diagnosis. Accessing information may also lead to increased knowledge of resources and services available to cancer survivors, including both conventional support services and CAM services.

The strong relationship between access to information and choosing to use services is shown by our finding that cancer survivors of all ages who were information-seekers were 5.9 times more likely to use a CAM service, a relationship that has been shown in only one prior study. 23 In contrast, older adults who did not seek information were much less likely to use CAM than were younger survivors. The importance of age in the association between information-seeking and CAM use may be due to some older survivors having stronger dispositional tendencies to actively seek out both health information and services. However, other unexplored implications could form the basis for future research; for example, having more information may encourage not only the use of CAM, but also other self-care activities that aid in recovery from cancer treatment, such as exercise, diet, and social activities. If so, encouragement to seek information, especially if reliable sources were provided, would be important to the survivorship experience for older cancer survivors, who may not seek helpful services because they lack information about them.

The descriptive findings of this study showed that older and younger cancer survivor groups were similar in their use of conventional support services and most found such services helpful, though older survivors used counseling services less often, a finding similar to that of an earlier study of older prostate cancer patients. ¹¹ In contrast, older adults were generally less likely to use CAM services than were younger survivors. Though other studies have shown that older adults often don't use CAM services, ^{18–20} the reasons for lower use of CAM among older

cancer survivors is not known. The progressively stronger association with CAM as education increased suggests a possible factor for the reduced use of CAM by older adults in our sample, who were generally less educated than the younger adults. Income was highly correlated with education and could not be included in our model, but the correlation suggests that lower income may also be a reason for reduced CAM use in older survivors. It is possible that persons who are older when diagnosed with cancer may have less energy or desire to seek CAM therapies, may have additional transportation or other issues related to accessing CAM therapies, or may have health issues that affect CAM use that are different from the general health measures used in this study.

Our finding that CAM services were almost always helpful to those who used them, regardless of age, is similar to prior studies showing that survivors believed that CAM counteracted the ill effects from cancer and cancer treatment,²⁴ increased the body's ability to fight cancer, 25 and improved well-being. 16,17,26 Since CAM use is generally perceived as helpful by survivors, and CAM is usually used for other benefits, not for cancer treatment, 17,20 there is good rationale for a physician to encourage the use of CAM therapies if they do not interfere with medical treatments for cancer. 14 As in prior studies, our findings about the utility of CAM services are based on the reports of survivors and represent their perceptions, not actual benefits. It is important to acknowledge that some CAM therapies may not be compatible with medical therapies for cancer and may even be harmful, even though the majority of CAM users perceive benefits, making it important that physicians are aware of CAM use. It has been reported that cancer patients, especially males, may fear physicians' disapproval if they raise the subject of CAM. 12 By opening a conversation with cancer patients about CAM, physicians may prevent contraindicated CAM use, yet indicate approval of CAM services that could provide comfort, aid healing, reduce symptoms, or improve the sense of well-being for cancer survivors, while not affecting medical treatment of cancer or other conditions.

Our study was limited by measuring relatively broad descriptions of information-seeking, use of conventional support services, and use of CAM services, because these were part of a

^{*}Physical health measured by short-form 36 v.2, physical component score †Emotional health measured by short-form 36 v.2, mental component score Results are adjusted for gender, type of cancer, and type of cancer treatment

lengthy questionnaire about many survivorship issues. However, our analysis is unique in describing the differences according to age in use of services and seeking information in a large sample of cancer survivors. The findings provide a foundation for future research about the importance of information supplied by physicians vs. information from other sources in whether an individual accesses supportive services, including CAM, and whether CAM or other services improve recovery and well-being in older cancer survivors. As with prior studies of informationseeking or use of support services, findings are based on self-reports from cancer survivors. In this study, which included long-term survivors, recall accuracy may have been limited by the length of time since cancer diagnosis for many participants, though this may have been mitigated by providing a list of support services and CAM services, rather than asking an openended question. We could have limited our sample to recent survivors, but the small number of CAM users in a reduced sample of recent survivors would have reduced our ability to accurately describe CAM use and prevented us from showing higher levels of information-seeking in recent survivors, compared to those diagnosed longer ago.

In summary, survivors of different ages may seek information about cancer and healing from different sources. Some are interested in CAM services. It is therefore appropriate for physicians to ask patients about CAM use and to provide sources of information and services. Office appointments may not provide sufficient time for extensive conversation about survivorship issues, but initiating even brief talk between the physician and patient about cancer information sources and CAM use may raise awareness of potentially helpful CAM therapies, prevent use of contraindicated therapies, and provide an opportunity to correct misinformation or suggest sources of accurate cancer information.

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