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Key Words. *Hairy cell leukemia · Finances · Insurance · Employment*

ABSTRACT

***Background*. While being cured of cancer generally leads to a life expectancy similar to that of the general population, the extent to which other aspects of life are affected is unknown. To address these concerns, patients with hairy cell leukemia, a cancer with a very high cure rate, were queried about employment, insurance, finances, and lifestyle during and following their treatment.**

***Methods*. Study participants (*n* = 31) ranging in age from 24 to 73 years at the time of diagnosis (median, 49 years) were surveyed regarding changes in health and life insurance, employment, out-of-pocket medical costs, exercise, diet, and use of mental and alternative health services that occurred during or following hairy cell leukemia treatment.**

***Results*. Following a diagnosis of hairy cell leukemia, 61.3% of the respondents paid for some aspect of medical care in spite of having health insurance coverage at the time of diagnosis. Four respondents (12.9%) could not obtain health insurance following treatment, and the occupational choices of several individuals or their spouses were based in large part on a desire to obtain or maintain comprehensive health insurance. Of the 13 individuals who attempted to purchase life insurance, 10 had difficulty obtaining a policy or were denied coverage. Lifestyle changes were noted by 40% to 60% of respondents, and included reports of more frequent exercise, adoption of a healthier diet, and having a greater appreciation for life, loved ones, and physical health.**

Conclusions*. While hairy cell leukemia is a highly curable malignancy, cancer survivors' lives and lifestyles are altered substantially after receiving treatment for the illness. *The Oncologist *2001;6:435-440*

INTRODUCTION

Continuing advances in cancer detection, screening, and treatment have led to increased survivorship for cancer patients. Despite these improvements, the non-medical aspects of cancer survivors' lives, including insurance, employment, and lifestyle, may be substantially changed following a cancer diagnosis. Many of the over eight million cancer survivors living in the United States today reportedly experience difficulty obtaining or maintaining private health or life insurance [1], face difficulties with job mobility, and become increasingly concerned about diet and exercise. One survey estimates that about 10% of cancer survivors have been denied health or life insurance coverage because of their cancer, 7% of those with private insurance had to change their coverage following the diagnosis, 5% experienced insurance premium increases, and 2% were asked to waive coverage of their cancer in order to obtain health insurance [2]. Insurance problems are especially difficult for younger cancer survivors, many of whom have been denied health insurance, had policies that excluded care for pre-existing medical conditions, experienced barriers to obtaining health insurance coverage, paid higher health insurance premiums, and had difficulty obtaining life insurance [3-5]. However, empirical data about changes in occupation and lifestyle among cancer survivors are lacking.

Nonmedical concerns related to insurance, employment, and lifestyle are especially relevant to working-age

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individuals with curable malignancies. One particular example is related to nonmedical effects among survivors of hairy cell leukemia, a rare lymphoproliferative disorder with a high cure rate that predominantly affects individuals who are 65 years of age and younger, and hence, most are not covered by Medicare [6, 7]. Advances in hairy cell leukemia treatment have improved, with 75% to 90% of patients who receive cladribine (2-chlorodeoxyadenosine, [2-CdA], Leustatin) achieving a sustained complete remission and high remission rates for persons who fail other therapies [8-10]. The extent to which a diagnosis of hairy cell leukemia affects an individual's ability to obtain or maintain comprehensive private health and/or life insurance policies, employment, personal finances, and lifestyle choices is not known. The objective of this study was to query hairy cell leukemia patients about these issues.

METHODS

Following study design approval by the Scientific Review Panel of the Robert H. Lurie Comprehensive Cancer Center and the Northwestern University Institutional Review Board, all individuals with a prior diagnosis of hairy cell leukemia, who had been treated by a specialist in the illness (*M.T.*), were mailed an introductory letter describing the study. Questionnaires were mailed to 34 individuals who returned their consent forms and agreed to participate in the study. Thirty-one individuals returned completed surveys (61% response rate). The sociodemographic characteristics of respondents and nonrespondents were similar.

Survey items included questions about sociodemographic characteristics (current age, years since diagnosis, marital status, education level, race/ethnicity, employment status, and income); health insurance provider (changes in premium following diagnosis of hairy cell leukemia, yearly deductible, and co-payments for prescriptions, physician visits, and other medical services); life insurance history (policy holdings prior to and after diagnosis with hairy cell leukemia; difficulties obtaining a policy after diagnosis); and changes in lifestyle habits (exercise, eating habits, use of vitamins or nutritional supplements, use of alternative medical practitioners, and use of psychological counseling; overall impact of hairy cell leukemia experience on lifestyle habits). The instrument represented a modification of an instrument used in costs of AIDS studies that had been shown to be valid and reliable in these studies [11, 12]. Frequencies were calculated for categorical variables. Percentages are reported for each question based on the number of participants who completed that particular question. Qualitative assessments of hairy cell leukemia effects on participants were based on participant comments on how their lives had changed since their experiences with hairy cell leukemia. Participant comments on insurance, employment, and lifestyle since their hairy cell leukemia experience were grouped, following review of participant comments, by two of the investigators (*J.H.* and *K.K.*) into the following categories: effects on insurance and employment, on relationships, on life perspective, and on physical well-being.

RESULTS

The 31 hairy cell leukemia respondents had a mean age of 56.5 and median age of 56.5 years at the time of the survey (range from 27 to 82 years) (Table 1). The age of diagnosis

Table 1. Sociodemographics of participating hairy cell leukemia survivors (*n* = 31)

Sociodemographics	***n***	**(%)**	**Mean**
Age at time of survey, in years			56.5
<45	2	(6.4)	
45-55	12	(38.7)	
55-65	11	(35.5)	
>65	6	(19.4)	
Time since diagnosis, in years			7.8
<5	8	(25.8)	
5-10	16	(51.6)	
>10	7	(22.6)	
Age at diagnosis, in years			48.7
<45	8	(25.8)	
45-55	16	(51.6)	
55-65	6	(19.4)	
>65	1	(3.2)	
Ethnicity			NA
African American/Black	0		
Asian	0		
Caucasian/White	30	(100.0)	
Latino/Hispanic	0		
Other	0		
Highest education level			NA
Less than a high school diploma	0		
High school diploma or GED	5	(16.1)	
Technical certification	4	(12.9)	
Associate of arts	2	(6.5)	
Bachelor's degree	8	(25.8)	
Graduate degree	12	(38.7)	
Marital status			NA
Married	27	(87.1)	
Widowed	0		
Divorced/Separated	2	(6.5)	
Never married	2	(6.5)	
Employment status at time of survey			NA
Employed	15	(50.0)	
Retired	11	(36.7)	
Unemployed	4	(13.3)	
Annual income from all sources at time of survey			NA
0-$30,000	1	(3.6)	
$30,001-$40,000	4	(14.3)	
$40,001-$50,000	1	(3.6)	
$50,001-$60,000	4	(14.3)	
$60,001 and above	18	(64.3)	

for the respondents ranged from 24 to 73 with a mean and median age of 48.7 years (Table 1). All of the participants who indicated their ethnicity on the survey were white; one participant did not identify his ethnicity. The participants were highly educated: 25.8% had a bachelor's degree and 38.7% had a graduate degree. Almost 90% of the respondents were married at the time of the survey, with an average marriage duration of 27 years. An annual income of $50,000 or more was reported by 78.6%. Half were employed, 36.7% were retired, and 13.3% were unemployed. Over one-fifth had taken a leave of absence from work for an extended period of time because of their experience with hairy cell leukemia. Seven respondents reported receiving treatment for other serious illnesses following their recovery from hairy cell leukemia, including three with a diagnosis of prostate cancer, one with colon cancer, one with melanoma, and two patients who developed severe infections (one with pneumonia and septicemia and a second patient with tuberculosis).

Following treatment, respondents had fee-for-service insurance (*n* = 8), health maintenance organization (*n* = 6), preferred provider organization (*n* = 10), Medicare (*n* = 7), and one patient no longer had health insurance (Table 2). Four study participants (12.9%) reported that their health insurance benefits had been discontinued or that they had been refused a new health insurance policy because of a history of hairy cell leukemia, 24.1% reported that their insurance premium increased, and 3% reported that their deductibles had increased since being diagnosed with hairy cell leukemia. Similarly, several participants reported that their co-payments increased for prescriptions, physician office visits, and other medical services (19.0%, 16.7%, and 33.3%, respectively). Over sixty percent (63.3%) had incurred out-of-pocket costs for medical care following their hairy cell leukemia diagnosis, and four participants (12.9%) had an insurance plan refuse to pay for some health care services. While 83.9% of participants had carried a life insurance policy prior to diagnosis with hairy cell leukemia, of the 13 who attempted to purchase life insurance after treatment for hairy cell leukemia, 10 had difficulty obtaining or were turned down for a policy after the diagnosis of hairy cell leukemia. Following their experience with hairy cell leukemia, many respondents reported incorporating positive lifestyle changes, including increased exercise (61.3%) and healthier diets (51.6%) (Table 3). When asked about the effect of their experience with hairy cell leukemia, 48.4% indicated that the experience had a large impact, 32.3% reported a little impact, and 19.4% reported no impact. Participants reported having a greater appreciation for life, loved ones, and physical health, and many reported having made significant employment and/or lifestyle adjustments as a result of hairy cell leukemia (Tables 3 and 4). In addition to

Table 2. Effects of hairy cell leukemia experience on health insurance, life insurance, and employment status of survivors

Employment status	***n***	**(%)**
Stopped working because of hairy cell leukemia (*n* = 31)	7	(22.6)
Type of health insurance at time of survey*	***n***	
Private insurance	8	
Veterans administration	0	
HMO	6	
PPO	10	
Medicare	7	
No health insurance	1	
Changes in health insurance since illness		
Premium increased	7	(24.1)
Premium did not change	22	(75.9)
Total number of responses	29	
Deductible increased	3	(13.6)
Deductible decreased	0	
Total number who have deductibles	22	
Prescription co-payment increased	4	(19.0)
Prescription co-payment decreased	1	(4.8)
Total number who have prescription co-pay	21	
Physician co-payment increased	3	(16.7)
Physician co-payment decreased	0	
Total number who have physician co-pay	18	
Other medical co-payment increased	3	(33.3)
Other medical co-payment decreased	0	
Total number who have other medical co-pay	9	
Benefits stopped or coverage refused because of hairy cell leukemia	4	(12.9)
Total responses	31	
Insurance plan refused to pay for a health care expenditure	4	(12.9)
Total responses	31	
Health insurance adequacy since hairy cell leukemia diagnosis		
Insurance pays for all needed health care	11	(36.7)
There are minor out-of-pocket costs	13	(43.3)
There are many out-of-pocket costs	4	(13.3)
Many needed medical services are not covered	2	(6.7)
Total responses	31	
Life insurance		
Owned a life insurance policy prior to hairy cell leukemia diagnosis	26	(83.9)
Total responses	31	
Faced difficulty obtaining policy or were turned down for a policy after hairy cell leukemia diagnosis	10	(76.9)
Total responses	13	
Use of vitamins or herbal nutritional supplements		
Prior to illness	8	(25.8)
Since illness	26	(83.9)
Total responses	31	
Use of alternative medicine practitioner		
Prior to illness	2	(6.5)
Since illness	5	(16.1)
Total responses	31	
Use of psychological counseling		
Prior to illness	2	(6.5)
Since illness	5	(16.1)
Total responses	31	

*Multiple types of health insurance were counted in each relevant category.

Table 3. Effects of hairy cell leukemia experience on lifestyle habits of survivors: quantitative findings

Lifestyle habits (*n* = 31)	**%**
Exercise more since hairy cell leukemia experience	61.3
Adopted a healthier diet since hairy cell leukemia experience	51.6
Impact of hairy cell leukemia experience on lifestyle habits (exercise, nutrition, etc.)	
No impact	19.4
A little impact	32.3
A great impact	48.4

Table 4. Qualitative responses from hairy cell leukemia survivors

Hairy cell leukemia survivors reported effects on: (based on 25 responses)	***n* of comments***
Insurance and employment	28%
Relationships	16%
Life perspectives	60%
Physical well-being/lifestyle habits	40%

*Comments pertaining to multiple categories were counted in each relevant category.

lifestyle changes, following the diagnosis of hairy cell leukemia, there was an increase in the frequency of use of vitamins or herbal nutritional supplements (83.9% following diagnosis versus 25.8% prior to the diagnosis), psychiatric counseling (16.1% versus 6.5%), and alternative medicine counselors (16.1% versus 6.5%) (Table 2).

DISCUSSION

In this study, we found that following a diagnosis of hairy cell leukemia, individuals who were in remission and who responded to our survey reported many changes in financial and nonfinancial aspects of their life. The respondents reported that their life choices were influenced by insurance- and job-related considerations that resulted from having a diagnosis of cancer. Many also paid for medical care that was not reimbursed by private health insurance policies. Several respondents or spouses chose employment opportunities primarily because of associated health insurance benefits. However, lifestyle changes were also noted, including initiating mental health counseling, adopting healthier diets, and exercising more often. In interpreting our findings, several factors should be considered.

First, others have previously reported that cancer survivors experienced difficulty obtaining health insurance (Table 6). In a 1999 review, *Hoffman et al*. reported that 25% to 30% of cancer survivors faced insurance discrimination or barriers to obtaining health insurance, including refusal of new applications, waivers or exclusions of preexisting conditions, higher premiums, extended waiting periods, and policy cancellations or reductions [13]. *Guidry et al*. found that 25% to 50% of cancer survivors lost health insurance coverage, had been denied health insurance coverage when changing jobs, and/or were personally responsible for a greater percentage of medical charges [14]. However, clinical and socioeconomic differences in the characteristics of the respondents may account in part for the finding of twofold to fourfold higher rates of difficulty obtaining health insurance in the prior studies of cancer survivors in comparison with our report. Most of the hairy cell leukemia respondents in our study had annual incomes greater than $50,000, almost all were white, 90% were married, all but one had private health insurance, and the chances of hairy cell leukemia relapse following treatment were very low, while in the other studies, many respondents had lower incomes, were from more diverse sociodemographic settings, often lacked health insurance, and had higher chances of recurrence.

Second, this study represents a pilot effort to evaluate if previously developed methods that have been used in studies of AIDS patients in the early 1990s could be modified to cancer survivors in the current era. All but three of the individuals who received questionnaires mailed back completed forms, and the majority of respondents also included qualitative statements about life changes that had occurred following the diagnosis of hairy cell leukemia. Our prior pilot studies for AIDS included similar numbers of respondents and served as the foundation for subsequent large-scale cost studies [11, 12]. Policymakers could consider initiating similar large-scale studies in oncology in order to provide relevant information on the medical and nonmedical costs of cancer.

Third, prior cancer survivor studies have not evaluated lifestyle changes. Many of these responses were obtained through the qualitative part of the survey. It is likely that future efforts would require additional input from patients and survey researchers in order to develop a quantitative set of survey questions that is both reliable and valid. In the prior studies of HIV costs, these issues were often addressed during open-ended questions that were asked in in-person interviews. This methodology, while more complete, is also several times more expensive than the mailed survey method used for this study.

There are limitations to this study. First, the responses were based on patient recall several years after the diagnosis of hairy cell leukemia was made. However, it was reassuring that many study participants had kept logs about financial, insurance, and job-related matters that had occurred since the diagnosis of hairy cell leukemia. In our current costs-of-care studies, we are interviewing patients in person and paying participants a nominal fee if they choose to keep a prospective log book about relevant medical, nonmedical, and lifestyle factors. Second, as a

Table 5. Selected participants comment on how their lives changed due to their hairy cell leukemia experience

Effects on:	Comment
Insurance and employment	• I had difficulty getting long-term care insurance as a result of the hairy cell leukemia. Maybe they knew something I didn't. • Didn't retire early, in order to keep medical insurance coverage. • I found a job, but consider myself lucky as other opportunities vanished when I revealed having had hairy cell leukemia. • I live more for today. My previous emphasis on my job and making money is far less. In fact I've decided to retire five years earlier than I'd planned. • Am afraid to look for other employment. • I was unable to effectively do the duties of a pastor and it was evident that I resign, which I did. I sought other minister positions and I believe there was a sense of caution on the part of other congregations to consider me as their next pastor so I had to seek employment elsewhere. • I retired as soon as I was eligible because of fear of illness returning and wanted to enjoy retirement ASAP.
Lifestyle:	
Relationships	• Greater interest in religion, closer with family, and [greater] appreciation for life. • It was very significant for me, helping fuel my fear of commitment (marriage). • I value my family relationships more than before. I value my work/business relationships less than before.
Life perspective	• I try to eliminate as much stress in my life as possible. • I have a new appreciation for life and loved ones and I feel I've slowed down to enjoy things more. It's been so long ago that it sometimes feels like it was a movie watched. • I am not afraid to take chances and do what makes me happy in my personal and professional life. I am happier. • I enjoy each day more. I appreciate small benefits that were taken for granted before. I am able to relate to people who are dealing with serious illness. I don't "sweat the small stuff," and [I] keep things in perspective • It is worth mentioning that it has made me a more compassionate person toward all cancer patients, with a greater awareness of the entire medical system. • It gave me a new perspective on life. I look at life less seriously now. • My life is richer. • I'll summarize by saying how I appreciate life and its fragile nature and the value of science-based medicine. • After diagnosis and treatment I became a lot less concerned with insignificant things in my life. The psychological experience of cancer was difficult but in a very strange way, I am truly a better person after diagnosis and treatment than before. I now accept my vulnerability and am daily aware of how important each day is.
Physical well-being	• Physically feel very good. Feel blessed to have received treatment and for the good years since and hopefully in the future. • I take better care of myself, overall. • I try to eat properly and take care of myself. I have yearly blood work done to make sure I'm still well. • I'm much more inclined to take better care of my health. • This year I have devoted much more energy to my physical fitness—all part of my relatively new conviction that I have a long life ahead of me.

result of the phasing in of patient confidentiality concerns included in the recently enacted Health Insurance Portability and Accountability Act, we mailed questionnaires only to hairy cell leukemia survivors who, after receiving a mailed request from their oncologist, returned a signed study consent form. This two-step consent process limited our ability to obtain questionnaires from a larger number of cancer survivors. Third, while hairy cell leukemia is a rare malignancy and therefore accounts for the diagnosis associated with only a small fraction of cancer survivors today, our study was designed to address survivorship issues among a cohort of individuals who would not be expected to develop recurrent hairy cell leukemia. Fourth, our sample size was not large enough to determine if the presence of comorbidities was an important factor in the patients' experience with health care and life insurance policies. Preliminary data suggest that changes in life experiences and finances after a hairy cell leukemia diagnosis were similar for those patients who had developed another serious illness and those who had not. Finally, the sociodemographic characteristics of the population included in this study differ markedly from that of the United States as a whole, where 44 million individuals lack health insurance and racial/ethnic diversity is evident throughout the country.

Table 6. Studies of health insurance problems faced by adult cancer survivors

Year of study	Study	% of survivors experiencing difficulties	Specific difficulty reported
1987	*Crothers*; Mayo Clinic Rehabilitation Program [15]	25%	Survivors reported experiencing "insurance discrimination."
1982	*Burton* and *Zones* [16]	30%	Employable cancer survivors faced barriers to health insurance.
1998	*Guidry et al.** [14]	21.4%-54.8%	Lost insurance coverage and/or denied insurance when changed jobs and/or experienced co-payment increase.
2000	Hairy cell leukemia study [this report]	12.9%	Benefits stopped or health insurance coverage refused.

*Percentages reported represent the range experienced by different ethnic groups in the study

CONCLUSION

It is hoped that the findings of this survey can provide some insights into cancer survivorship today. Having a diagnosis of hairy cell leukemia, a cancer with a high cure rate, has a considerable effect on a cancer survivor's life as well as lifestyle choices. Concern over the potential for discontinuity or even loss of health insurance was a major consideration in employment decisions made by hairy cell leukemia survivors. Our findings may be of interest to policymakers who are considering the pros and cons of national health insurance initiatives.

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