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Population-based survivorship research using cancer registries: a study of non-Hodgkin's Lymphoma survivors

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Abstract
Introduction Several recent reports have recommended use of population-based cancer registries for evaluating the long-term health outcomes of cancer survivors. Drawing upon experiences from a study of survivors of non-Hodgkin's Lymphoma (NHL), we discuss conceptual and methodological challenges to and opportunities for conducting population-based survivorship research using cancer registries.
Materials and methods Survivors of aggressive NHL diagnosed between June 1998 and August 2001, 2–5 years prior to the study, were sampled from the Los Angeles Surveillance Epidemiology and End Results (SEER) registry. A conceptual framework was developed to systematically evaluate the association of sociodemographic, clinical, social, psychological, and behavioral factors with survivors' health-related quality of life. Data were collected primarily by a mailed questionnaire; medical records were also abstracted.
Results Of 744 eligible survivors identified from the registry, 181 (24.3%) were lost to follow-up; 408 responded to the questionnaire (54.8%); 155 (20.8%) refused. Those lost to follow-up included a significantly higher proportion of younger, male, and Hispanic survivors compared to the other two groups ($P \leq 0.01$). There were no sociodemographic or clinical differences among the questionnaire respondents and survivors who refused study participation. Medical records were abstracted for 59.8% of the respondents. A high percentage of agreement was seen between survivors' self-report and medical record documentation of key treatments and disease status (≥95% for survivors with complete records).
Conclusions The cancer registry served as a valuable resource for recruiting one of the largest population-based samples of NHL survivors. The methodology and example of a conceptual framework utilized in this study provide a model for future population-based cancer survivorship research.

Keywords Cancer registry · Population-based research · Cancer survivorship · Non-Hodgkin's Lymphoma · Health-related quality of life

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Introduction

The number of cancer survivors in the United States has increased steadily over the past three decades and is currently estimated to be 10.5 million.[53] While individuals diagnosed with cancer are living longer, they are at risk of experiencing adverse physical and psychosocial late and long-term effects of their cancer and its treatment.[7, 25] Population-based assessments of cancer survivors that systematically examine their long-term health-related quality of life (HRQOL) are essential for comprehensively

understanding the individual and societal burden of cancer. Such studies, however, are limited and those that exist have largely focused on the more common cancers such as breast [19] and prostate cancer.[42]

One understudied cancer for which both incidence and survival rates are increasing is non-Hodgkin's Lymphoma (NHL). It is the sixth most common cancer among men and fifth among women in the US.[2] Between 1973 and the mid 1990s incidence rates of NHL increased by 3–4% per year, making it one of the fastest rising cancers in the US.[15] Moreover, NHL is only one of six cancers in men and one of four in women that have shown large absolute gains over time in 5-year survival rates.[26] Based on histology, adult NHLs are divided into two main groups with fairly similar rates of incidence: indolent lymphomas (low grade), which grow slowly, and aggressive lymphomas (intermediate and high grade), which grow more quickly and are often fatal within months without appropriate treatment.[28, 47]

Multi-agent chemotherapy regimens with or without radiation, and potentially bone marrow/stem cell transplantation (BMT/SCT) are the most frequently utilized treatment strategies for aggressive NHL.[47] While such aggressive therapy has resulted in complete remission for 66% of patients and in 5-year disease-free survival for 52%,[57] survivors are likely to experience significant adverse effects of their treatment over a period of several months and sometimes years following treatment.[4, 9, 14] Thus, survivors of aggressive NHL who have completed initial therapy may require regular follow-up care to diagnose and manage potential adverse sequelae of their disease.

Previous studies of NHL survivors' HRQOL have been limited to the first year post diagnosis,[27] to survivors selected from a single institution,[30] or to samples of elderly survivors.[13, 56] In contrast to such studies, a study of longer-term NHL survivors sampled from a population-based cancer registry would permit an assessment of NHL's burden in a much more heterogeneous survivor population diagnosed within a defined geographical area. Recognizing the limitations of existing studies, the Leukemia, Lymphoma, and Myeloma Progress Review Group (LLM PRG) commissioned by the National Cancer Institute (NCI) in 2001, identified as a priority the need for population-based studies of long-term health outcomes of survivors of hematologic malignancies.[37] The present study was conducted in response to the recommendations of the LLM PRG.

Using the Los Angeles County Cancer Surveillance Program's SEER registry as the source of NHL survivors, we conducted a detailed assessment of the follow-up care experiences and health outcomes such as HRQOL among survivors of aggressive NHL who were 2–5 years post diagnosis; the study was titled "Experience of Care and Health Outcomes of Survivors of non-Hodgkin's Lymphoma (ECHOS-NHL) Study." We were interested in examining outcomes among survivors who were 2–5 year post-diagnosis as this appears to be a unique time frame wherein interactions between cancer survivors and the health care system tend to begin to drop off. Importantly, this is also the period when survivors are likely to begin experiencing late sequelae of their treatments. Data were collected primarily by a cross-sectional mailed questionnaire; medical record data were also abstracted.

With an aim to stimulate and inform future population-based survivorship studies, in this paper, we discuss the study design for the ECHOS-NHL study, describe the conceptual framework that guided the development of specific hypotheses and the study questionnaire, examine factors associated with study participation, and highlight opportunities and challenges in conducting such studies using population-based cancer registries.

Materials and methods

Study design

Eligibility: case definition

Survivors were eligible for the study if they (1) were diagnosed with aggressive NHL between June 1, 1998 and August 31, 2001 and were thus between 2–5 years post-diagnosis at the time of the study; (2) were diagnosed as adults (age at diagnosis: 20 years or older); (3) were Los Angeles county residents at the time of diagnosis; (4) were alive at the time of the study; and (5) had not been diagnosed with NHL before. Survivors who had been diagnosed with other cancers more than a year prior to their NHL diagnosis were included as were survivors who experienced a subsequent recurrence of their NHL. We, however, excluded survivors who were diagnosed with a prior cancer within a year of their NHL diagnosis and those who were diagnosed with another cancer subsequent to their NHL diagnosis but prior to the study. Given the limited number of Asian, Pacific Islander, and Native American survivors in the LA SEER registry, the sample was limited to individuals who were identified in the registry as either Hispanic, non-Hispanic white, or non-Hispanic black. Identification of aggressive NHL was based on the ICD-O-2 codes from the NHL Working Formulation: intermediate grade (9,593, 9,672–76, 9,680–9,683, 9,697–9,698); high grade (9,684–9,687).[58]

Recruitment

The study protocol was approved by the Institutional Review Board (IRB) at the University of Southern California. According to standard registry procedures, prior

to contacting the survivors, a courtesy letter was sent to one physician per survivor (usually the treating oncologist) informing these physicians that their patient had been selected for this study. The letter further informed them that their patient would be mailed the study materials unless they contacted the SEER study staff with objections within 2 weeks of receipt of the letter; we received objections from only two physicians whose patients were hence not contacted.

Each survivor received an introductory letter explaining the study along with a 52-page questionnaire, a $20 gift certificate that could be used as cash at local grocery stores, a form on which to identify the doctors and hospitals from whom they had received care following their NHL diagnosis, and a Health Insurance Portability and Accountability Act (HIPAA)-compliant medical record consent form giving permission to obtain medical record data. A postage-paid business reply envelope was included for returning the questionnaire and the two forms. The letter also included an explanation for survivors on how their name was obtained for this study.

Questionnaires were mailed between April and August of 2003. Trained telephone interviewers at the SEER registry conducted telephone follow-up if the questionnaire was not returned within 3 weeks. Non-respondents were mailed a second copy of the questionnaire if they never received or no longer had one. The follow-up effort, conducted over a period of approximately 3 months, consisted of up to five calls made on different days and at different times of the day. A second series of up to five calls was made to non-respondents who were reached initially but still had not returned the questionnaire. Extensive tracing efforts (e.g., reviewing voting and tax records, driver license files, and engaging credit agencies) were used to locate the current address for non-respondents whose questionnaire was returned undeliverable or who could not be reached by telephone. For a subgroup of survivors who expressed interest in the study but were unwilling or unable to complete the questionnaire by mail, we reduced their respondent burden by conducting a telephone interview as a last resort with a subset of the questionnaire items that accounted for approximately 30 of the 52 pages of the mailed questionnaire. Finally, between April and July 2005, we conducted a small second wave of data collection by engaging a new tracing service that the registry had recently utilized to reach lost survivors and non-respondents who were still eligible for the study; while we had hoped to enroll at least 30 more survivors, only nine additional questionnaires were obtained as a result of this exercise.

Conceptual framework

To systematically study the HRQOL of NHL survivors, we developed a conceptual framework that identified several sociodemographic, clinical, social, psychological, and behavioral factors that are likely to be associated with survivors' HRQOL (see Fig. 1). This framework was adapted from Andersen's 1995 version of the "Behavioral Model of Health Services Utilization"[3] and Wilson and Cleary's "Conceptual Model of Health-related Quality of Life."[62] Below, we discuss the various components of the framework. Specific instruments used to operationalize the constructs in the framework are referenced later.

Health-related quality of life (HRQOL)

Drawing from Wilson and Cleary's model of HRQOL,[62] we classified patient reports of their HRQOL into three interrelated categories: symptoms, functional status, and overall health perceptions.

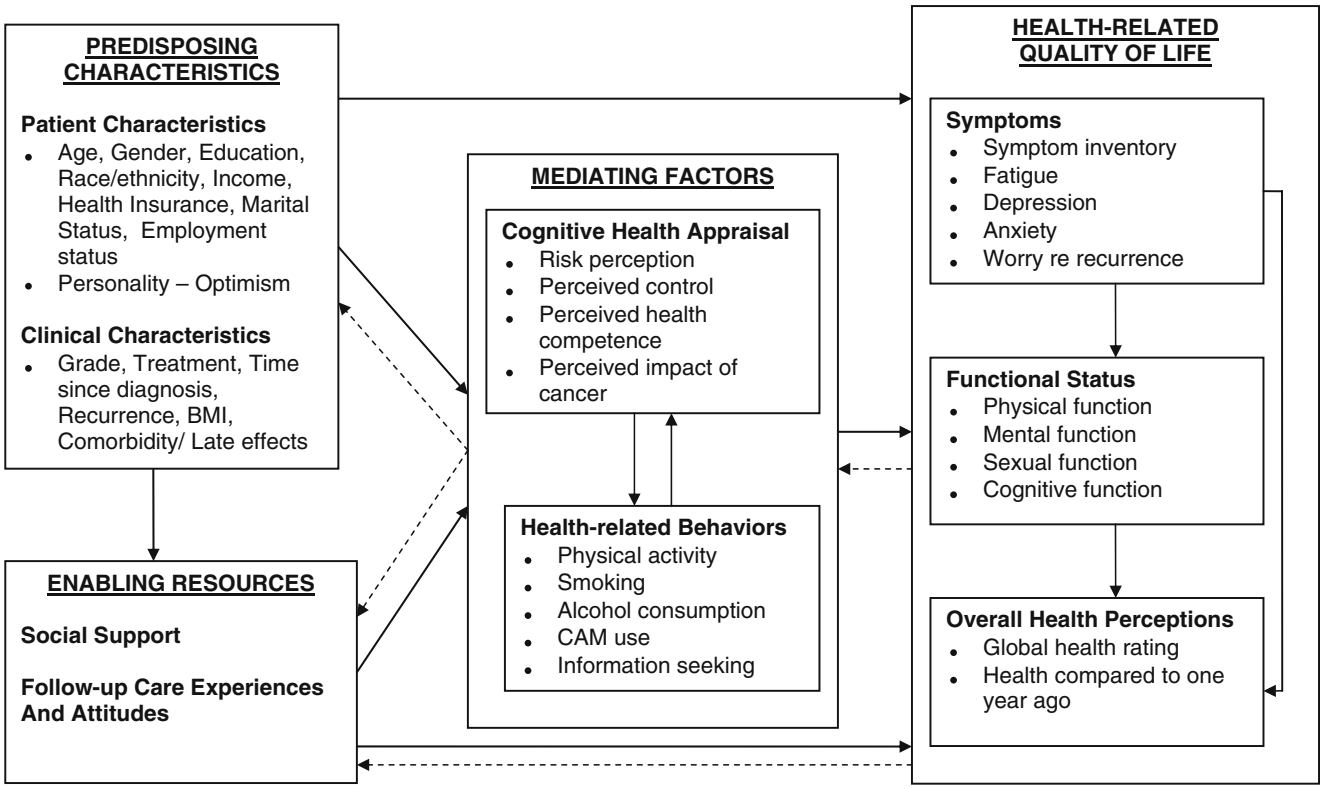
Symptoms Wilson and Cleary define a symptom as a patient's perception of an abnormal physical, emotional, or cognitive state.[62] We evaluated NHL survivors' symptom status across multiple domains, including a detailed symptom inventory of potential physical ailments, as well as assessment of the impact of fatigue on multiple aspects of their lives, symptoms of anxiety and depression, and psychological distress based on worry about a recurrence.

Functional status Wilson and Cleary define functional status as the ability of an individual to perform particular defined tasks related to physical function, social function, role function, and psychological function.[62] We assessed NHL survivors' functional status across several domains, including physical, mental/emotional, sexual, and cognitive functioning.

Overall health perceptions While an individual's global assessment of his/her health is arguably more subjective in nature compared to symptoms and functional status, it has been shown to be a significant predictor of health services utilization as well as mortality.[62] We assessed survivors' overall perception of their current health in absolute terms as well as relative to their health a year ago.

Factors associated with survivors' HRQOL

We adapted Andersen's model [3] as it allowed us to simultaneously examine several different correlates of survivors' HRQOL and helped us organize them into distinct categories. The model resulted in the generation of theoretically driven, apriori hypotheses for future analyses which are often not apparent in many cross-sectional cancer survivorship studies. Based on Andersen's model,[3] we classified potential correlates of survivors'



Adapted from Andersen's (1995) version of the Behavioral Model for Health Services Utilization [3] and Wilson and Cleary's (1995) Conceptual Model of Health-related Quality of Life [62]
Dotted lines represent potential feedback loops

Figure 1 Conceptual framework for the ECHOS-NHL study.

HRQOL into three categories: predisposing characteristics, enabling resources, and mediating factors.

Predisposing characteristics These are characteristics specific to each individual that are likely to be associated with their health outcomes but have a low level of mutability and hence would not be the focus of interventions. These characteristics serve as exogenous variables in our framework. As shown in Fig. 1, the predisposing characteristics in our study included sociodemographic, personality (optimism), and clinical (e.g., NHL grade, treatments received, comorbidities, late effects) characteristics of the survivor.

Enabling resources These are resources which when available to survivors can enable more positive adjustment and hence are likely to be positively associated with their HRQOL. Enabling resources generally are highly mutable and are often the focus of intervention studies.[20, 51] We focused on two types of enabling resources: social support and follow-up care experiences. As shown in Fig. 1, enabling resources are also likely to be predicted by predisposing characteristics.

Mediating factors We identified two types of factors that might mediate the relationship of predisposing and enabling factors with survivors' HRQOL: cognitive health appraisal and health-related behaviors. Cognitive health appraisal, the process by which survivors evaluate their cancer experience for meaning and impact, is likely to be significantly associated with HRQOL.[29, 31] We measured several indicators of cognitive health appraisal including survivors' perception of risk of a recurrence, perception of control over different aspects of their health and health care, level of competence/self-efficacy in taking care of their health, and their perception of whether and how their cancer experience impacted different aspects of their personal lives.

We also measured several health-related behaviors that are likely to be associated with HRQOL, including physical activity, tobacco and alcohol consumption, use of complementary and alternative medicines, and need for different types of cancer-related information. A reciprocal relationship between cognitive health appraisal and health behaviors was hypothesized. Both cognitive appraisal and health behaviors are highly mutable and have been the subject of intervention studies.[11, 32]

Feedback loops

In addition to the hypothesized direction of associations in our framework (see dark arrows in Fig. 1), we also posit potential feedback loops and alternative explanations to our hypothesized relationships that could be tested in future prospective longitudinal studies (see dotted arrows in Fig. 1). For example, our framework posits that survivors with greater levels of social support, higher perceptions of control, and who engage in physical activity may experience more positive HRQOL; however, longitudinal studies could examine a reverse causal pathway, i.e., survivors who report poor HROQL at baseline may, at subsequent follow-up assessments, have lower perceptions of control, they may be less likely to engage in physical activity, and may report greater difficulty in receiving social support from their social network.

Data collection methods

Questionnaire development and testing

Components of the conceptual framework were operationalized by several measures that were included in a 52-page questionnaire (see Table 1 for details on the content of the questionnaire, including citations for source of items; items included on the abbreviated telephone interview are also identified). The questionnaire was created in English only. To facilitate comparison between the ECHOS-NHL findings and those of other studies, where possible, we either used previously validated items and scales verbatim or modified them for enhanced relevance to the NHL survivor population. In areas where significant gaps in measurement existed, the research team consisting of experts in the varied content areas relevant to the study developed new items. These were extensively tested prior to their inclusion in the final questionnaire. Specifically, all new items and those that were adapted from existing instruments were subjected to two rounds of in-depth cognitive testing to ensure that they were clearly understood and reliably interpreted by NHL survivors; nine NHL survivors participated in each round.

Feedback from the cognitive tests resulted in a modified version of the questionnaire that was then pilot tested with 32 survivors of aggressive NHL randomly sampled from the registry. Thirteen of the 32 survivors returned questionnaires (of the remaining 19 survivors, six were determined to be ineligible as we found out during telephone follow-up that four were deceased and two did not speak English and hence could not respond to the questionnaire; four questionnaires were returned by the post-office due to incorrect address; three survivors promised to return the questionnaire but never did; five had invalid telephone numbers that precluded any follow-up; and one survivor did not answer our follow-up telephone calls). Thus, among the 26 eligible NHL survivors we achieved a response rate of 50% on the pilot test. The final field version of the questionnaire was created based on a detailed review of responses from the pilot test.

Medical record abstraction

We abstracted medical records pertinent to survivors' NHL in order to complement and validate survivors' self-reports of key clinical variables such as treatments received and history of disease recurrence/progression. All physicians and hospitals listed by a survivor were sent a letter requesting copies of medical records along with a copy of the consent form. If required, a trained abstractor from the registry visited the physician's office or hospital to obtain the information directly.

Statistical analyses

Bivariate analyses using t-tests and chi-square statistics were conducted to compare the characteristics of several subgroups of NHL survivors including (1) respondents who completed the questionnaire by mail and those who answered the abbreviated telephone interview and (2) respondents for whom medical record data were abstracted and respondents for whom medical records were unavailable. Bivariate analyses were also conducted to compare the characteristics of the questionnaire respondents with survivors who were lost to follow-up and those who declined study participation. A statistically significant (i.e., $P \leq 0.05$) overall effect across these three groups was followed up by conducting multiple comparisons among the groups. If multiple significant independent variables were identified in any of the above bivariate analyses, we conducted multivariate logistic regression analyses to identify factors that independently predicted the outcomes of interest.

Results

Sample recruitment

Figure 2 presents a detailed flow chart of the recruitment process. All potentially eligible survivors not known to be deceased were selected and mailed questionnaires (N= 1,025). These survivors comprised 58.1% of the total number of incident cases (N=1,767) who would have met the eligibility criteria (had they all been alive). Seven hundred and forty four of the selected survivors were retained as eligible and 281 were deemed ineligible after contact due to several reasons as outlined in Fig. 2. The top

Table 1 ECHOS-NHL questionnaire content

Domain	Variables	Number of items	Source	Comment
I. Predisposing characteristics				
A. Survivor characteristics				
	Age[a]	1	Ganz et al. breast cancer survivorship study [18]; Cancer Care Outcomes Research and Surveillance (CanCORS) patient survey [33]	
	Gender[a]	1		
	Race/ethnicity[a]	2		
	Education[a]	1		
	Income[a]	1		
	Marital status[a]	1		
	Employment status[a]	1		
	Health insurance[a]	1		
	Personality-optimism	6	LOT-R [46]	Four filler items were excluded
B. Clinical characteristics (Note: data on date of diagnosis and tumor grade were obtained from the SEER registry)	Types of treatment and dates[a]	14	ECHOS team	
	Recurrence (no. and dates) [a]	3	ECHOS team	
	Body Mass Index[a]	2	Ganz et al. [18]	
	Comorbidity and late effects[a]	42	ECHOS team: New items created and several items from the Childhood Cancer Survivorship Study (CCSS) [45] and the Prostate Cancer Outcomes Study (PCOS) [43] surveys were included in a 42-item checklist	Comorbidities and late effects were distinguished by asking respondents to indicate whether they had been diagnosed with any of the 42 conditions before or after their NHL diagnosis
	Women's health[a]	6	ECHOS team	Assessed impact of treatment on menstruation
II. Enabling resources				
A. Social support				
	Social support scale	12	Ganz et al. [18]	Ganz et al. used a 12-item short form of the original 19-item MOS Social Support Survey [48]
B. Follow-up care experiences and attitudes				
	Content & setting of f/up care visits[a]	2	ECHOS team	
	Frequency & recency of f/up care visits[a]	2	CAHPS survey [23]	
	Specialty & gender of f/up care doctor[a]	2	ECHOS team	
	Duration of doctor–patient relationship[a]	1	CAHPS survey [23]	
	Doctor–patient communication[a]	11	ECHOS team; CAHPS survey [23]	CAHPS communication scale (4 items); 7 items were new
	Ratings of f/up care[a]	2	CAHPS [23] & CanCORS [33] surveys	
	Attitudes towards f/up care	9	Cancer Patients' Attitudes Towards Follow-up survey [54]	Reassurance and nervous anticipation subscales included
	Care received from all other doctors in the past 12 months	5	ECHOS team	No. of additional doctors seen; reason; specialty of doctors; quality of care rating
	Preference for discussing HRQOL-related problems with f/up care doctor[a]	10	ECHOS team: adapted and built upon items used in a study by Detmar et al. [12]	Assessed survivors' willingness to discuss problems in the areas of physical, emotional, role, social, and sexual functioning

Table 1 (continued)

Domain	Variables	Number of items	Source	Comment
III. Mediating Factors				
A. Cognitive Health Appraisal				
	Risk perception[a]	1	HINTS 2003 version [39]	Modified item to assess risk of recurrence in the next 10 years
	Perceived control	4	ECHOS team: Adapted items from existing control scales [1, 34]	
	Perceived health competence	4	Perceived Health Competence scale [50]	Created a four-item short form of the original eight-item PHC scale
	Perceived impact of cancer	20	ECHOS team: Created new items; adapted existing items from a similar checklist by Ganz et al. [18]	Assessed positive or negative life change due to cancer on relationships, finances, health behaviors, and spirituality
B. Health-related behaviors				
	Physical activity	7	Hawkins et al. Physical activity study [24]	Recall period was changed from "the last year" to "last 4 weeks"
	Smoking	5	Adapted from the NHIS [38]	Created discrete response options
	Alcohol consumption	3	Adapted from the NHIS [38]	Recall period was changed from "the last year" to "last 14 days"
	CAM use	28	ECHOS team; Hamilton et al. CAM study; [21] CanCORS survey [33]	Types of CAM (Hamilton et al.); reasons for CAM use (adapted from CanCORS); discussion of CAM with cancer doctor (new)
	Information seeking[a]	17	ECHOS team: Created new items; adapted others from a checklist by Marrow et al. [49]	Assessed current need for information on different cancer-related topics
IV. Health-related quality of life outcomes				
A. Symptoms				
	Symptom inventory	26	ECHOS team: created new items and included others from existing symptom checklists [10, 17, 41]	Assessed symptom experience in last 6 months and whether survivor had discussed it with a doctor
	Fatigue	10	Fatigue Symptom Inventory (FSI) [22]	Three items assessing degree of fatigue and the seven-item fatigue disruption scale were included
	Anxiety and depression	14	Hospital Anxiety and Depression Scale (HADS) [64]	Seven items assessed anxiety; seven assessed depression
	Worry[a]	1	HINTS 2003 version [39]	Modified item to assess worry about recurrence
B. Functional status				
	Physical and mental function	34	SF-36 v2 [60, 61]	34/36 SF-36 items result in eight subscales; these eight subscales also combine to provide overall physical and mental component summary scores
	Sexual function	15	Sexual Activity Questionnaire (SAQ);[59] PCOS survey;[52] Sexual Functioning Questionnaire (SFQ)[55]	Frequency and satisfaction with sexual activity (SAQ and PCOS); problems and limitations with sexual functioning (SFQ)
	Cognitive function	4	MOS HIV health survey [44, 63]	Response options modified to be consistent with SF-36v2
C. Overall health perceptions				
	Global health status and current health relative to past year[a]	2	SF-36 v2 [60, 61]	

[a] Indicates that these questions were asked on the abbreviated telephone interview

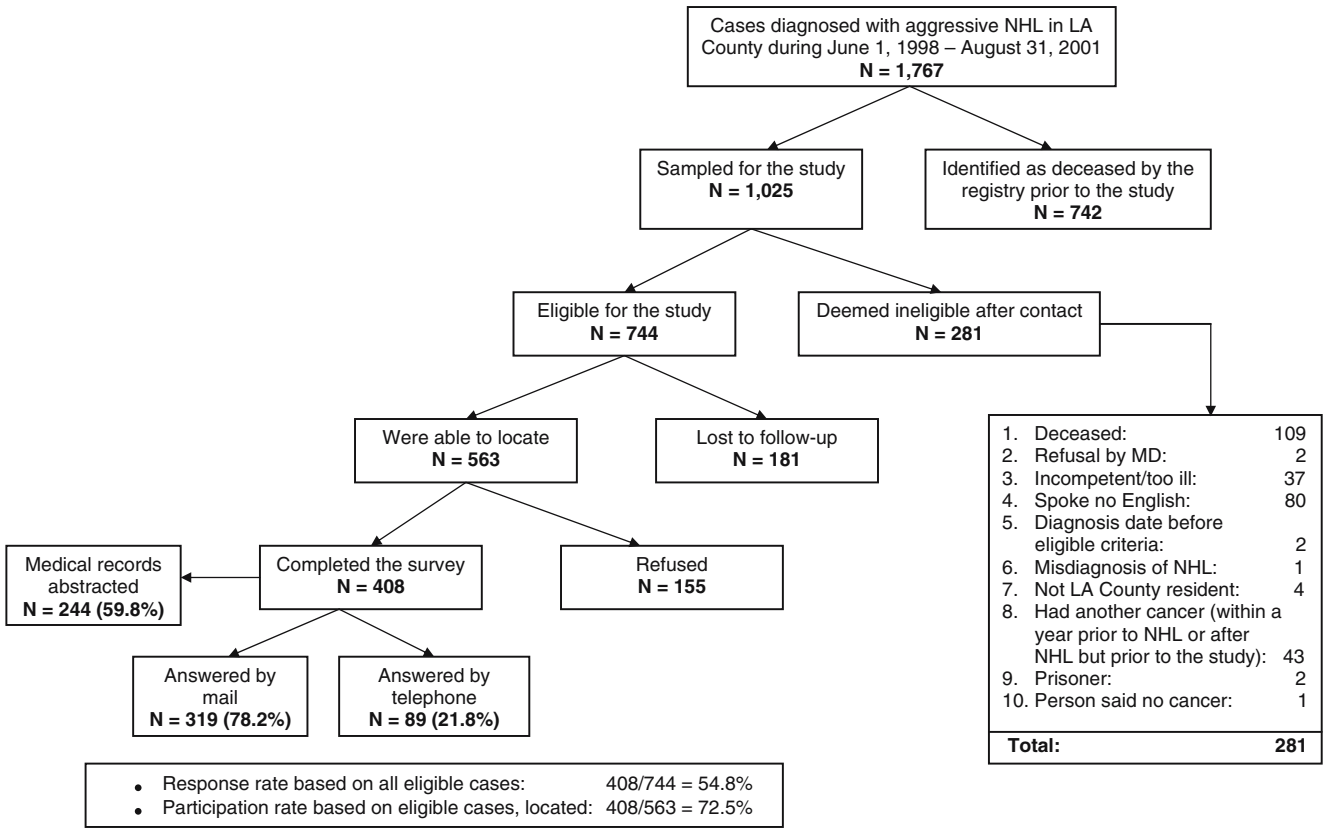


Figure 2 Flowchart describing recruitment of NHL survivors for the ECHOS-NHL study.

two reasons for ineligibility were: (1) the individual was no longer alive (N=109); (2) the individual did not understand English (N=80).

Despite extensive tracing efforts, 181 of the 744 eligible survivors (24.3%) could not be located; 72.5% of the 563 NHL survivors whom we did locate participated in the study (N=408) resulting in an overall response rate of 54.8%. The length of the questionnaire and lack of stamina were cited as the most common reasons for non-response, despite the financial incentive provided. A further indication of the challenge posed in completing the mailed questionnaire is reflected by the fact that 21.8% of the respondents (N=89) agreed to only complete the abbreviated version of the questionnaire by telephone. The average time reported for completion of the mailed questionnaire was 95 min (median: 75 min); it required an average of 29 min (median: 28 min) to complete the telephone interview.

Sample description

Sociodemographic and clinical characteristics of the 408 survivors who participated in the study are presented in Table 2 (see column A). We were successful in recruiting a fairly heterogeneous group of NHL survivors: men and women were almost equally represented, mean age was 59.7 years (about a fifth were younger than 45 years in age and another fifth were 75 years or older), and almost a fourth were Hispanics. Respondents also varied on income and education. For example, while a fifth reported less than $20,000 as their annual household income, almost another fifth reported an income of $100,000 or more. An overwhelming majority of the respondents had intermediate grade NHL (89.7%), were in remission (91.0%), and had not experienced recurrence or disease progression (81.4%). Ten percent had been diagnosed with another cancer prior to their NHL (mean number of years between the prior cancer and NHL was 10.5, median: 8.8; range: 1.8–29.3). Two-thirds of the respondents also reported being diagnosed with at least one additional comorbid condition.

The subgroup of survivors who had experienced a recurrence/progression (N=76), compared to those who did not (N=332), were older (mean age at the time of the study: 63.7 years v/s 58.5 years, P=0.01), were more likely to have received a BMT/SCT (27.6% v/s 5.4%, P<0.001), and were less likely to report being in remission (69.4% v/s 95.7%, P<0.001). NHL survivors who had been diagnosed with another cancer prior to their NHL (N=41), compared to survivors for whom NHL was their first primary cancer diagnosis, were older (mean age at the time of the study: 70.7 years v/s 58.5 years, P<0.01), were diagnosed with NHL closer to the study (mean years since diagnosis: 3.2 v/s

Table 2 Sociodemographic and clinical characteristics of study participants

Sample characteristics	Total respondents (*N*=408) (A)	Responded by mail (*N*=319) (B)	Responded by telephone (*N*=89) (C)	*P* value* B v/s C	Medical records abstracted (*N*=244) (D)	Medical records missing (*N*=164) (E)	*P* value D v/s E
Sociodemographics							
Age at the time of the study							
Mean years (sd)	59.7 (15.0)	59.9 (14.9)	59.1 (15.6)	N.S.	60.4 (14.9)	58.7 (15.2)	N.S.
Gender							
% Male	51.7	51.1	53.9	N.S.	50.0	54.3	N.S.
% Female	48.3	48.9	46.1		50.0	45.7	
Race/ethnicity							
% Non-Hispanic White	67.2	69.9	57.3	N.S.	72.5	59.1	<0.01
% Hispanics	23.5	21.3	31.5		20.9	27.4	
% Non-Hispanic Black	6.9	6.9	6.7		5.7	8.5	
% Non-Hispanic Other	2.5	1.9	4.5		0.8	4.9	
Education[a]							
% < High school	11.6	10.4	15.7	N.S.	8.6	16.0	<0.05
% High school graduate	19.8	19.0	22.5		17.3	23.5	
% Some college	32.1	33.5	27.0		37.0	24.7	
% College graduate	18.3	18.4	18.0		17.7	19.1	
% Attended graduate school	18.3	18.7	16.9		19.3	16.7	
Annual Household Income[b]							
% < $20,000	22.5	20.4	30.3	N.S.	19.3	27.4	N.S.
% $20,000–$39,999	16.4	15.7	19.1		16.0	17.1	
% $40,000–$59,999	15.4	16.0	13.5		18.0	11.6	
% $60,000–$99,999	17.9	19.1	13.5		18.9	16.5	
% $100,000 or more	18.9	20.1	14.6		20.1	17.1	
% Missing	8.8	8.8	9.0		7.8	10.4	
Marital status[a]							
% Married/living as married	63.3	65.1	56.8	N.S.	67.5	56.9	<0.05
% Other	36.7	34.9	43.2		32.5	43.1	
Health Insurance[a]							
% Private insurance	69.7	68.6	73.3	N.S.	70.8	67.9	N.S.
% Public/no insurance	30.3	31.4	26.7		29.2	32.1	
Clinical characteristics							
NHL grade							
% Intermediate	89.7	88.7	93.3	N.S.	88.5	91.5	N.S.
% High	10.3	11.3	6.7		11.5	8.5	
Time since diagnosis							
Mean years (sd)	3.6 (0.9)	3.5 (0.8)	3.8 (0.9)	<0.01	3.5 (0.8)	3.7 (1.0)	<0.05
Health status[a]							
% Poor	4.0	3.8	4.5	N.S.	3.3	4.9	N.S.
% Fair	17.0	17.4	15.7		17.4	16.6	
% Good	35.3	36.1	32.6		34.3	26.8	

Table 2 (continued)

Sample characteristics	Total respondents (*N*=408) (A)	Responded by mail (*N*=319) (B)	Responded by telephone (*N*=89) (C)	*P* value* B v/s C	Medical records abstracted (*N*=244) (D)	Medical records missing (*N*=164) (E)	*P* value D v/s E
% Very good	27.4	27.8	25.8		29.8	23.9	
% Excellent	16.3	14.9	21.3		15.3	17.8	
Currently in remission[a]							
% Yes	91.0	90.8	91.8	N.S.	91.3	90.6	N.S.
% No	9.0	9.2	8.2		8.8	9.4	
NHL recurrence/progression							
% Yes	18.6	19.4	15.7	N.S.	21.7	14.0	0.05
% No	81.4	80.6	84.3		78.3	86.0	
Treatment[b]							
% Chemotherapy only	50.2	48.9	55.1	N.S.	50.8	49.4	N.S.
% Chemo + radiation	33.3	33.9	31.5		32.8	34.1	
% BMT/SCT	9.6	10.7	5.6		11.1	7.3	
% Missing	6.9	6.6	7.9		5.3	9.1	
Another cancer prior to NHL							
% Yes	10.0	11.0	6.7	N.S.	9.4	11.0	N.S.
% No	90.0	89.0	93.3		90.6	89.0	
Number of Comorbidities[a]							
% None	33.0	31.4	38.8	N.S.	29.5	38.2	N.S.
% 1 or 2 comorbidities	46.5	48.0	41.2		49.1	42.7	
% 3 or more comorbidities	20.5	20.6	20.0		21.4	19.1	

The questionnaire was the source of data on age, gender, race/ethnicity, education, income, marital status, health insurance, health status, remission, and comorbidities; the SEER registry provided data on date of diagnosis and NHL grade; the questionnaire and medical records were both used for data on type of treatment and history of disease recurrence/progression.

**P* values are based on bivariate *t*-tests for age and time since diagnosis and on the chi-square statistic for all other variables. A *P* value of ≤0.05 is considered statistically significant. N.S. implies not significant.

[a] Education, marital status, health insurance, health status, remission, recurrence, and comorbidity variables had less than 5% missing data; percentages shown for these variables are based on all available data and exclude the cases for whom the data were missing.

[b] Income and treatment had more than 5% missing data hence a missing category was created for these two variables. There were no missing data for the remaining variables.

3.6, $P<0.01$), and were less likely to report their health as excellent or very good (24.4% v/s 45.9%, $P<0.05$). The two subgroups of survivors who had a recurrence and those who had a prior cancer were independent of each other (correlation among the groups was 0.01, $P=0.9$).

Survivors who completed the abbreviated telephone interview did not differ from those who responded to the mailed questionnaire on any of the sociodemographic or clinical variables (see columns B and C in Table 2). The only exception was that the telephone responders were more likely to be diagnosed with NHL slightly earlier than those who completed the mailed questionnaire (mean years between diagnosis and the study: 3.8 v/s 3.5, $P<0.01$). Table 2 also shows comparisons between respondents for whom medical records were abstracted and those who were missing medical records data; these are discussed later.

One advantage of using the cancer registry was that basic information was available on all non-respondents; this facilitated a comparison between the respondents ($N=408$) and the two groups of non-respondents: those who were lost to follow-up ($N=181$) and those who declined participation ($N=155$). Bivariate analyses (see Table 3) showed that the lost to follow-up group had a significantly greater proportion of younger, male, and Hispanic survivors compared to the other two groups. Multivariate logistic regression analyses confirmed these results (data not shown in tables); for example, in comparing the respondents and lost to follow-up groups, the elderly (65+ years old) were less likely to be lost to follow-up compared to survivors who were 20–44 years old (adjusted OR=0.5, 95% CI: 0.3–0.8, $P<0.01$). In contrast, Hispanics compared non-Hispanic whites and men compared to women were more likely to be lost to follow-up (adjusted OR for Hispanics=2.3, 95% CI: 1.5–3.4, $P<0.001$ and adjusted OR for males=1.8, 95% CI: 1.2–2.6, $p<0.01$). However, as shown in Table 3, among the survivors whom we were able to contact, no

Table 3 Comparison of study respondents and non-respondents based on data available in the SEER registry

Selected characteristics	Respondents (A)	Refused (B)	Lost to follow-up (C)	*P* value* (overall)	*P* value A vs B	*P* value A vs C	*P* value B vs C
Total *N*	408	155	181				
Age at diagnosis							
% 20–44	25.8	25.8	37.6	<0.01	N.S.	<0.001	<0.01
% 45–64	39.3	38.7	42.5				
% 65+	34.9	35.5	19.9				
Gender							
% Male	51.8	52.9	66.3	<0.01	N.S.	0.001	0.01
% Female	48.2	47.1	33.7				
Race/ethnicity							
% Non-Hispanic White	71.0	66.4	52.5	<0.001	N.S.	<0.0001	0.01
% Hispanic	21.9	23.9	39.2				
% Non-Hispanic Black	7.1	9.7	8.3				
NHL grade							
% Intermediate	89.7	92.3	85.1	N.S.[a]			
% High	10.3	7.7	14.9				
Year of diagnosis							
% 1998	14.2	14.2	15.5	N.S.[a]			
% 1999	30.2	20.6	30.4				
% 2000	31.9	43.9	33.2				
% 2001	23.6	21.3	21.0				

N.S. implies not significant.
* *P* values are based on the bivariate chi-square statistic. A *P* value of ≤ 0.05 is considered statistically significant.
[a] Follow-up subgroup comparisons (A v/s B, A v/s C, B v/s C) were not conducted if the overall effect was not significant.

significant differences were found between those who responded to the questionnaire and those who did not.

Medical records

We received forms listing physicians and hospitals seen by survivors since their NHL diagnosis along with the signed medical release from 268 of the 408 respondents (66.3%). There was sufficient information to mail requests to physicians and/or hospitals for 261 survivors. An average of 2.6 physicians/hospitals (range 1–7) were listed per survivor resulting in the mailing of 677 letters requesting medical records. We obtained complete or partial records for 244 of the 268 survivors (93.5%) who gave permission; complete records from all physicians/facilities were obtained for only 154 of these 244 survivors (63.1%). Among the 319 survivors who completed the mailed questionnaire, 264 (82.8%) gave permission to obtain records, whereas only four of the 89 survivors (4.5%) who completed the telephone interview did so.

Table 2 presents a comparison, based on bivariate analyses, of the sociodemographic and clinical characteristics of the 244 respondents for whom medical records were abstracted with those of the 164 respondents for whom records were unavailable (see columns D and E). Significant differences were noted for race/ethnicity, marital status, and education such that survivors for whom records were obtained were more likely to be non-Hispanic white, married/partnered, and had more than a high school education compared to survivors for whom records were missing. The two groups were clinically similar on most indicators; they reported similar distributions for NHL grade, health status, remission, type of treatment, and comorbidities. The only statistically significant differences were that survivors for whom records were obtained were diagnosed slightly later but were more likely to have a history of disease recurrence/progression compared to survivors missing medical records (mean years between diagnosis and the study: 3.5 v/s 3.7, $P<0.05$; % reported recurrence/progression: 21.7 v/s 14.0, $P=0.05$).

In a multivariate logistic regression model, marital status was no longer significant but race/ethnicity, education, time since diagnosis, and history of recurrence/progression remained significantly associated with availability of medical records (data not shown in tables). We were more successful in obtaining medical records for non-Hispanic whites than Hispanics (adjusted OR=1.7, 95% CI: 1.0–2.9, $P=0.05$) and for survivors with some college education compared to survivors with a high school education or less (adjusted OR=2.7, 95% CI: 1.5–4.6, $P<0.001$); interest-

ingly, there were no significant differences between survivors who had a college degree and those who only had a high school or lesser education. We were also more successful in obtaining records for survivors who reported a history of disease recurrence/progression (adjusted OR=2.0, 95% CI: 1.2–3.6, $P<0.05$). Finally, odds for obtaining medical records significantly decreased with increase in time since diagnosis (O.R.=0.7, 95% CI:0.6–0.9, $P<0.05$).

Concordance between self-reports and medical records

We evaluated the validity of self-report of key clinical variables such as types of treatment received and history of disease recurrence/progression by assessing the concordance between medical records and questionnaire data. Among the 244 survivors for whom records were abstracted, the percent agreement between medical records and questionnaire data was sufficiently high for treatment modalities typically used to treat NHL (chemotherapy: 88%, radiotherapy: 94%, and BMT/SCT: 99%) to justify the use of self-reports. Further confirmation of the validity of self-reports was reflected in the increase in percent agreement (95% for chemotherapy and 97% for radiotherapy) when analyses were restricted to those 154 survivors for whom the most complete set of medical records were obtained. Similarly, percent agreement between survivors' self-reports and medical records for disease recurrence/progression was high (95%).

Discussion

Use of the SEER registry allowed us to enroll one of the largest cohorts of NHL survivors to be studied to date. While there are no existing population-based studies of NHL survivors with whom we could compare response rates, our overall response rate of 54.8% among all eligible survivors and participation rate of 72.5% among survivors whom we were able to locate compares favorably with those reported in existing population-based studies of survivors of other cancers. For example, response rates of 55.9, 26.2, and 47.9% were achieved in three recent studies of survivors of breast cancer,[40] cervical cancer,[36] and a cohort of mixed cancer survivors,[8] respectively.

Conceptual framework for evaluating survivors' HRQOL

We illustrated the use of a conceptual framework to better organize the generation of specific hypotheses and related measurement effort. While the conceptual framework itself is not unique to this study as it was adapted from existing models, it can provide future studies with the foundation for systematically evaluating the interrelationships among several sociodemographic, clinical, social, psychological, and behavioral factors that are likely to influence cancer survivors' HRQOL. As noted by others, there are few survivorship studies that go beyond the assessment of the association between sociodemographic/clinical factors and survivors' HRQOL and begin to identify modifiable mechanisms and factors associated with HRQOL.[5] We hope that planned analyses for this study, driven by the conceptual framework, will identify such modifiable determinants of HRQOL and generate hypotheses that can be examined in prospective studies, thereby informing the development of future interventions for facilitating the HRQOL of cancer survivors.

The conceptual framework led to the creation of a comprehensive 52-page questionnaire; other survivorship studies have utilized questionnaires of similar length.[19, 40] While several respondents appreciated the breadth and depth of coverage of issues relevant to their survivorship, the length of the questionnaire was, nonetheless, one of the key reasons cited for non-response by survivors who did not participate in the study. The need for shorter surveys is further evidenced from the fact that we were successful in collecting data on the telephone on an abbreviated version of the questionnaire (approximately 30 pages) from 89 survivors who would have otherwise not participated in the study. Future studies will have to wrestle with the right balance between conducting theoretically driven, comprehensive evaluations of issues salient to cancer survivors and minimizing respondent burden.

Medical records abstraction

SEER registries do not routinely record disease recurrence/progression nor do they accurately track receipt of initial treatments that are typically provided in outpatient settings such as chemotherapy. Hence, we collected data on receipt of different treatment modalities and disease recurrence on the questionnaire. To verify the validity of survivors' self-reports, we also abstracted data from medical records. However, getting access to medical records from multiple physicians and facilities that the survivors had visited since their NHL diagnosis and abstracting data from them proved to be a challenging, time consuming, and costly endeavor, especially for longer-term survivors. Given the difficulties faced in collecting these data, it was encouraging to find a high level of concordance between survivors' self-reports and medical records on key treatments received and NHL recurrence/progression. Our efforts in confirming the validity of self-reported data may thus be helpful in determining the need to obtain records for future survivorship studies.

We do acknowledge that since all but four medical records were obtained for survivors who responded to the

mailed questionnaire, our findings are limited to establishing the validity of self-reported treatment data collected via mailed questionnaires; we cannot address the validity of self-reported clinical data obtained via telephone surveys. It is reassuring to note, however, that a recent study of breast cancer survivors who were approximately three years post-diagnosis did report high concordance between survivors' self-report of cancer treatments obtained via telephone and medical record data.[35]

Challenges in using cancer registries

The biggest challenge in conducting this study was the high percentage of survivors who were lost to follow-up. SEER registries do not have a uniform process for updating the address of cancer survivors in their database. For a majority of the survivors eligible for the study, we only had access to their address at the time of their diagnosis. Despite extensive efforts to update survivors' addresses, we were unable to locate almost one-fourth of all eligible NHL survivors. Survivors lost to follow-up were more likely to be of younger age, male gender, and Hispanic ethnicity; these subgroups represent some of the more mobile populations in the LA county region. High rates of loss to follow-up have been reported by other survivorship studies as well.[40] Future studies that utilize cancer registries for survivorship research, especially those focusing on longer-term survivors, should take into account the potential for significant loss to follow-up in planning the sample sizes for their study and should budget for sufficient resources needed to track and follow-up the survivors in their sampling frame.

Despite the challenges in locating eligible survivors, utilizing the registry as a sampling frame resulted in a population-based sample of NHL survivors that was socio-demographically diverse and more likely to be representative of the general NHL survivor population in the community. The finding that the questionnaire respondents were similar on several sociodemographic and clinical characteristics to the survivors who declined participation further enhances our confidence in the representative nature of our sample.

Conclusion

Adverse consequences of cancer and its treatment are being reported to be more persistent and severe among certain cancer survivors than previously expected.[6, 7] Methodologically sound studies, based on representative population-based samples, that conduct a detailed evaluation of the late and long-term health issues faced by cancer survivors and identify intervenable factors associated with them are urgently needed. Several recent reports have called for expanding the use of population-based cancer registries that traditionally have been utilized for understanding the etiology of cancer and monitoring the patterns of its treatment, to study the quality of life including symptom burden and quality of care experiences of cancer survivors.[5, 16, 25] To maximize their utility in facilitating survivorship research, cancer registries will, however, need to develop a systematic way to track cancer survivors as they are now living longer and becoming more geographically dispersed.

As demonstrated in this study, cancer registries can serve as an important source for enrolling large cohorts of survivors diagnosed with relatively less common cancers. The conceptual framework and methodology utilized in the ECHOS-NHL study as discussed here provide a useful model for future population-based survivorship studies that are critical for enhancing our knowledge of the needs of this growing segment of the US population.

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