Original Article

Population-Based Cancer Registries for Quality-of-Life Research

A Work-in-Progress Resource for Survivorship Studies?

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BACKGROUND: With the increasing number and diversity of cancer survivors, studies of survivors' physical, emotional, and social health and well being are of growing importance. Population-based cancer registries, which collect data on incident cases, can play an important role in quality-of-life (QoL) studies. In this review, the authors provide an overview of QoL studies that have used cancer registry data in this emerging area of research. **METHODS:** Publication databases were searched for relevant peer-reviewed original articles published between 2001 and mid-2011. Inclusion criteria were articles published in English that used cancer registries as the sampling frame and/or that used registry data in analyses with QoL data. All included articles were assessed on the quality of information provided, cancer registry procedures, and study design. **RESULTS:** In total, 173 articles from 13 countries were reviewed, and a large proportion were from the United States (n = 72) and Europe (n = 70). Fourteen different malignancies were studied, and the most frequent were breast cancer. Most studies focused on adult survivors, and only 4 focused on the elderly (aged >70 years). Of the reviewed articles, 110 (64%) provided a good amount of information on the cancer registry. Information less frequently reported included mainly follow-up of vital status and characteristics of respondents/nonrespondents. **CONCLUSIONS:** QoL studies increasingly use population-based registries, which provide important clinical variables and an excellent sampling frame for identifying subgroups. Until now, most studies have tended to focus on more prevalent cancers, and surprisingly few studies have focused on QoL of elderly survivors, who remain understudied in clinical trials. ***Cancer* 2013;119(11 suppl):2109-23.** © *2013 American Cancer Society.*

KEYWORDS: cancer survivors; cancer registry; health-related quality of life; population-based; symptoms.

INTRODUCTION

The number of cancer survivors worldwide is increasing because of a combination of rising cancer incidence rates and improving 5-year survival rates. Specifically, as the absolute size and proportion of the world population aged >65 years continues to grow, it is likely that the number of individuals being diagnosed with cancer also will continue to rise. In addition, advances in cancer screening, early detection, and treatment strategies have resulted in significant increases in the 5-year survival rate for all cancers combined in most industrialized countries.[1] However, despite these advances, cancer treatments often are quite debilitating and may put cancer survivors at risk for late/long-term effects, such as fatigue, cardiomyopathy, or second primary cancers.[2] Consequently, the long-term well being of cancer survivors has begun to demand increasing attention.[2,3] Clearly, more research is needed to address these issues. However, the identification and recruitment of post-treatment cancer survivors can be a challenge to conducting such studies.

One potential solution to the challenges of identification and recruitment of cancer survivors for research purposes is the use of national, state, and regional cancer registries. Cancer registries originally were developed to track incidence,

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European-American Dialogues on Cancer Survivorship: Current Perspectives and Emerging Issues

This supplement was guest edited by Vittorio Mattioli, MD (NCRC, Bari, Italy) and Kevin Stein, PhD (American Cancer Society, Atlanta, Georgia) and was produced with the authoritative contribution of 58 authors from the European Union and the United States. The primary aims are to highlight the potential differences between European and American approaches to cancer survivors' issues, increase coordination among oncologists and other primary care providers, and aid the development of a shared care model that can improve the quality of cancer care.

The opinions or views expressed in this supplement are those of the authors and do not necessarily reflect the opinions or recommendations of the journal editors, the American Cancer Society, John Wiley & Sons, Inc., or the National Cancer Research Center Istituto Tumori "Giovanni Paolo II" Bari.

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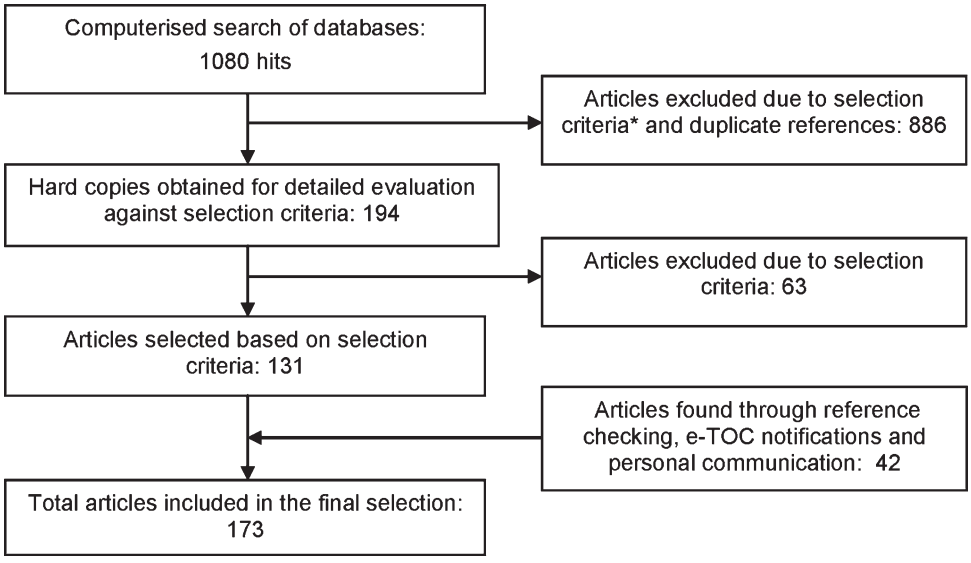

Figure 1. This is a flow diagram of articles that were accepted and rejected during the selection procedure. *The selection criteria were: studies in English, a population-based registry was used for sampling or data linkage, and the articles were published in peer-reviewed journals within the last 10 years from 2001 to mid-June 2011. e-TOC indicates electronic table of contents.

patterns of care, and cancer mortality in well defined populations.[4] Advantages of using national or regional registry data include their wide geographic reach, the inclusion of all patients/survivors regardless of treating facility, the large numbers of cancer patients/survivors they include, and the wealth of information on patients' sociodemographic and clinical characteristics available; thus, registries provide an excellent sampling frame from which to identify cases for survival studies. Because they are population-based, data from cancer registries can attain better external validity and are less likely to have problems with referral biases associated with institutional registries, especially those coming from traditional cancer centers.[5]

Quality of life (QoL) is an umbrella term that covers information on symptoms (eg pain and fatigue), functioning (eg physical functioning), health status, psychological well being, and overall QoL. Patient-reported outcomes (PROs) are the gold standard for QoL assessment and are defined as data provided by the patient without amendments or interpretation from clinicians or others.[6] QoL assessed using PROs is now recognized as an indicator of treatment efficacy, because many new treatments offer only marginal improvements in survival. The US Food and Drug Administration and the European Agency for the Evaluation of Medicinal Products have recently acknowledged the essential role of QoL and PROs in clinical trials.[7,8] The US National Cancer Institute is encouraging the use of QoL and PRO assessment as primary and secondary endpoints in clinical trials when appropriate.[9,10] PRO is also an important tool for measuring long-term outcomes among post-treatment survivors—especially QoL and symptoms—in a patient-centered way.[11]

The stated advantages of using cancer registry data in survival studies are also applicable to QoL studies.[12] These QoL studies can investigate the prevalence of late/long-term effects of cancer and its treatment, identify groups of survivors at increased risk for such effects, and identify the risk factors for developing such effects. By providing externally valid data that describe the prevalence of and risk factors for late/long-term effects, registry-based QoL studies can inform efforts to improve the quality of care of cancer survivors and to design interventions that improve their QoL.[2] Such information could be used to develop interventions to reduce inequities in cancer care and improve patients' well being after diagnosis and treatment.[13] The objectives of this review were to provide a broad overview of QoL studies among cancer survivors that use cancer registry data; to describe the issues, procedures, and regulations that are relevant to these studies in Europe and the United States; and to discuss approaches to optimizing the use of cancer registries in QoL cancer survivor studies.

MATERIALS AND METHODS

Search Strategy

We conducted a computerized literature search in July 2011 for articles published between 2001 and mid-June

TABLE 1. Checklist of Information Provided in Registry-Based, Quality of Life Articles (n = 173)

Criteria	No. of Articles That Met Criterion (%)
Description of cancer registry	
1. Geographic name and location of the registry are provided	158 (91)
2. Coverage of the cancer registry; "population-based" is stated in title, abstract, or text	150 (87)
3. Variables available from the cancer registry are described (eg patient demographics, stage, grade, primary treatment)	107 (62)
4. The registry performs active follow-up of patients' vital status	66 (38)
Study population	
5. Cancer registry used as a sampling frame or linkage of QoL data with clinical and/or demographic data from the cancer registry after sample inclusion	169 (98)
6. Description of the sampling process	165 (95)
7. Description of inclusion/exclusion criteria	170 (98)
8. Participation rates for patient groups are described and are >70%	73 (42)
9. Information on the characteristics of respondents vs nonrespondents	101 (58)
Study design	
10. The study size is at least 100 patients/survivors	165 (95)
11. Data registered by the cancer registry are used in the analyses (eg stage, grade, primary treatment)	105 (61)
12. Validated PRO assessments (health-related quality of life, health status, symptoms, functioning) are used	170 (98)

Abbreviations: PRO, patient-reported outcome; QoL, quality of life.

2011. We restricted our search to this time frame because most of the articles were published in the last decade. Searches on PubMed using the Medical Subject Heading (MeSH) terms ("neoplasms" [MeSH] AND "registries" [MeSH] AND "quality of life" [MeSH]; and ("neoplasms" [MeSH] AND "quality of life" [MeSH] AND "population-based") and searches of the PsycInfo and Medline databases using the combinations of "quality of life" and "cancer" with "registry" or "population-based" were carried out.

Selection Criteria

Only studies that used population-based cancer registries were included; most studies used the registry as a sampling frame and source of clinical data, whereas other "linkage" studies used the registry only as a source of data. Cancer registries could be regional or national or could be specialized registries, like those focused on childhood and hematologic malignancies or gastrointestinal cancer. Studies that used data from a single-site registry or clinical databases (for example, a hospital registry or database) were excluded. The search was limited to original articles in English that were published in peer-reviewed journals.

The search terms produced 1080 initial hits. Of these, a review of the titles or abstracts revealed that 886 articles were either duplicates or did not meet our inclusion criteria. The remaining 194 articles were downloaded for further evaluation. Of these, 131 met eligibility criteria for this study. Reasons for further excluding 63 articles included the use of registries that were not population-based, methodology articles, or qualitative reports. Another 42 articles were identified through reference checking, electronic table-of-contents notification, or personal communication. In total, 173 articles were selected for this review (Fig. 1).

For each of the 173 selected articles, we quantified the amount of information reported regarding the cancer registry, the study population, and the study design. Two authors (M.S.Y.T. and F.M.) conducted the assessment using a 12-point standardized checklist modified from established criteria for systematic reviews (Table 1).[14-16]

First, the articles were assessed independently; then, the results from reviewers were compared. The reviewers agreed on the ratings of most criteria. Four of the criteria (Table 1, criteria 3, 4, 6, and 10) generated disagreement between the 2 reviewers (M.S.Y.T. and F.M.), mainly because of differences in interpretation with criteria 3 and 4 relating to the data recorded by the cancer registry, its use in the analyses, and information on the sampling process. Differences in interpretation were resolved through consensus meetings.

A total score was generated for each article by awarding 1 point for each criterion met. If the information provided in the article did not meet the criterion, was insufficiently described, or was not provided, then that criterion was scored zero. Thus, an article could score a maximum of 12 points. Articles that scored ≥9 points on the description checklist were considered to have "good" descriptions. Articles that scored between 6 and 8 points were rated as "moderate," and those that scored ≤5 points provided "insufficient" descriptions.

RESULTS

Characteristics of the reviewed articles, including references, are outlined in Table 2. Of the 173 reviewed articles, 39% reported on independent samples. The remaining 61% involved 2 to 8 articles per sample, and most came

TABLE 2. Characteristics of Included Studies (n = 173)

Characteristic	No. of Articles	Reference(s)
Sample		
Independent	65	44-108
Repeat	108	109-216
Design		
Longitudinal	55	28, 34, 51, 62, 72-74, 80, 82-128
Cross-sectional	118	44-54, 56-60, 62-77, 79-88, 90-98, 102-106, 108, 109, 118-124, 128-131, 137-139, 145, 146, 148, 150, 153, 155-157, 160, 161, 163, 169-182, 187, 188, 190-194, 198, 200, 201, 203-206, 209-215
Country of article(s)		
North America		
USA	72	18-20, 22, 25, 26, 29-33, 37-39, 41-44, 54, 56-58, 62, 67, 68, 73-75, 79, 80, 82, 83, 90-92, 103, 105, 106, 110, 115-123, 125-148
Canada	10	48, 62, 78, 90, 92, 98, 108, 123, 200, 201
Europe		
Netherlands	23	80, 104, 109, 153, 163, 173-182, 203-206, 209-212
Germany	19	96, 97, 105, 112-117, 140-144, 154, 158, 159, 169, 170, 217
Sweden	13	51, 54, 74-76, 82, 139, 191-194, 213, 214
Norway	7	63, 72, 129-131, 160, 161
France	4	55, 77, 79, 86
Finland	1	88
Denmark	1	91
Italy	1	44
France and Italy	1	67
Australasia		
Australia	13	50, 61, 87, 93, 99, 136-138, 149, 166, 167, 190, 199
China	7	103, 132-135, 164, 165
Japan	1	73
Survivorship		
Short (<5 y)	78	47, 48, 50, 55, 56, 64-66, 69, 76, 81, 83-85, 87, 89, 93, 94, 96, 98-108, 111-116, 118-122, 125, 128, 132, 133, 136-139, 141, 142, 147-149, 155-157, 160, 161, 164-168, 183, 185, 186, 189-192, 196, 197, 199, 213-216
Long (≥5 y)	51	44, 45, 49, 51, 54, 57, 58, 60, 63, 67, 71, 73, 75, 77, 79, 86, 88, 91, 92, 97, 109, 117, 126, 127, 140, 143-145, 151, 152, 162, 163, 173-176, 178-182, 184, 195, 203, 204, 207-212
Short and long	44	46, 52, 53, 59, 61, 62, 68, 70, 72, 74, 78, 80, 82, 90, 95, 110, 123, 124, 129-131, 134, 135, 146, 150, 153, 154, 158, 159, 169-172, 177, 187, 188, 193, 194, 198, 200-202, 205, 206
Special patient samples		
Children and adolescents	1	211
Adult survivors of childhood or adolescent cancer	5	44, 75, 88, 92, 97
Elderly (aged >70 y)	4	55, 151, 162, 175
Rural population	4	29, 74, 187, 188
Types of cancer		
Breast	56	46, 53, 57-59, 64, 66, 74, 76, 79, 83, 87, 91, 95, 104-106, 108, 110, 111, 113, 115-117, 119-121, 125-128, 132-138, 140, 143, 144, 149, 155-157, 159, 164, 165, 168-170, 181, 190, 197, 210, 216
Colorectal	24	55, 67, 72, 73, 90, 100, 107, 112, 114, 129-131, 142, 154, 158, 166, 167, 187, 188, 195, 199, 205, 206, 208
Prostate	20	94, 99, 101, 109, 147, 151, 152, 160, 161, 174, 178, 180, 183-186, 193, 194, 204, 207
Bladder	3	45, 78, 86
Testis	2	63, 77
Thyroid	1	82
Retinoblastoma	2	211, 212
Melanoma	3	96, 153, 177
Laryngeal	1	81
Central nervous system	2	54, 75
Extracranial malignancies	1	88
Gynecologic cancers		
Cervical	6	47, 49, 51, 68, 71, 80
Ovarian	3	93, 200, 201
Endometrial	2	62, 209
All 3 gynecologic cancers	1	50
Upper gastrointestinal		
Esophagus	5	139, 191, 192, 213, 214
Gastric	1	103
Lymphoma		
Non-Hodgkin	3	65, 124, 173
Hodgkin	1	182
Various cancers (≥2 types of cancers)	36	44, 48, 52, 56, 60, 61, 69, 70, 84, 85, 89, 92, 97, 98, 102, 118, 122, 123, 141, 145, 146, 148, 150, 162, 163, 171, 172, 175, 176, 179, 189, 196, 198, 202, 203, 215

TABLE 3. Summary of Current Methods for Sampling Quality-of-Life Studies Using Cancer Registry Data

Sampling Method	Example	Positive	Negative	Considerations
Identify survivors through cancer registry before sending PRO	ACS-SCS, PROFILES	• Population-based • Compare the clinical and demographic characteristics of respondents with nonrespondents • Create samples with specific medical characteristics (eg cancer or treatment type) • Create samples of patients with rare cancers	Bias (survival, response)	• Patient contact procedures (informed consent from patients and physicians) • Coverage of cancer registry; length of time between diagnosis and registration • Amount and quality of collected clinical and demographic data • Follow-up of vital status by cancer registry—allow for tracking of patients
PRO collected before linkage with cancer registry	IWHS; MHOS; ePOC	• Identify incident cancer patients at diagnosis • (Possible) availability of PRO before cancer diagnosis	Bias (survival, response)	• Population-based

Abbreviations: ACS-SCS: American Cancer Society's Studies of Cancer Survivorship[12]; ePOCS, electronic Patient-Reported Outcomes From Cancer Survivors[28,29]; IWHS, Iowa Women's Health Study (available at: http://www.cancer.umn.edu/research/programs/peiowa.html, last accessed 15 March 2013); MHOS, Medicare Health Outcomes Survey (available at: http://outcomes.cancer.gov/surveys/seer-mhos, last accessed 15 March 2013); PRO, patient-reported outcome; PROFILES, Patient-Reported Outcomes Following Initial Treatment and Long-Term Evaluation of Survivorship.[18]

from the Prostate Cancer Outcomes Study. Most studies were either cross-sectional in design, whereas 55 articles reported on longitudinal data.

Countries of Articles

Certain countries were more prolific in QoL research using cancer registries. Of the included articles, 72 were from the United States. A significant number of articles also came from Canada (n = 10). Many articles (n = 70) came from Europe, including 23 from the Netherlands, 19 from Germany, and 13 from Sweden. Seven Norwegian articles and 4 French articles were identified, whereas 1 publication each came from Finland, Denmark, and Italy. One publication reported on results using data from 2 European registries in France and Italy. From the Australasia region, there were 13 Australian publications. Few articles came from Asia, 7 came from China, and 1 came from Japan. We identified no articles from Africa or South America.

Sample Characteristics

Most articles (n = 78) focused on patients who were <5 years from diagnosis ("short-term survivors"). Fifty-one articles focused on long-term survivors (≥5 years since diagnosis), whereas 44 articles included both short-term and long-term survivors.

In general, all articles sampled adult survivors of cancer, except for 1 article on pediatric survivors and 5 articles on adult survivors of childhood or adolescent cancers. Only 4 articles reported on the outcomes of elderly cancer survivors based on the European Society for Medical Oncology definition of elderly oncology patients (aged >70 years at diagnosis).[17] Only a few articles used registry data to report on underserved populations, like those living in rural areas.

Types of Cancer

Studies on breast cancer survivors dominated with 56 articles, and studies of prostate cancers were the next most common (n = 20). Other specific cancers studied included bladder (n = 3), testis (n = 2), thyroid (n = 1), retinoblastoma (n = 2), melanoma (n = 3), laryngeal (n = 1), central nervous system (n = 2), and extracranial malignancies (n = 1). Of the 12 articles on gynecologic cancers, there were 6 on cervical cancer, 3 on ovarian cancer, 2 on endometrial cancer, and 1 on all 3 gynecologic cancers. For upper gastrointestinal cancers, there were 5 articles on esophageal cancer and 1 on gastric cancer. Four articles focused on patients with lymphomas, including 3 articles on non-Hodgkin lymphoma and 1 article on Hodgkin lymphoma. The remaining 36 articles included 2 or more cancer types, which were often combinations of high-prevalence cancers of the colon or rectum, breast, prostate, or the lymphomas.

Assessment of Information Provided

Assessment of the amount of information provided on the cancer registry, study population, and design yielded the following results: the summary score, which was a summation of the number of criteria each article met, ranged from 5 to 12. According to this rating system, 110 articles provided a good amount of information (9-12 points), 59 articles provided a moderate amount of information (6-8

points), and 4 articles provided an insufficient amount of information (≤5 points). The most common insufficiencies were a lack of information on the follow-up of vital status (Table 1, criterion 4), a lack of information on the characteristics of respondents and nonrespondents (criterion 9), and a response rate that was either unreported or <70% (criterion 8). These shortcomings also occurred among highly rated articles (Table 1).

Cancer Registry Information

Information on the cancer registry provided in the Methods section of each reviewed article varied in detail and length. Some reports described the mandate, coverage, and tracking system of the cancer registry, whereas others provided only the name of the cancer registry.

Description of cancer registry

Most articles provided the name of the cancer registry from which its sample was selected, thus giving an indication of the geographic coverage of the registry (Table 1, criterion 1). The articles that did not name the registry (9%) often indicated that the data source was a state-wide cancer registry or a group of several registries. Similarly, most authors (87%) explicitly stated that their sample was selected from a population-based registry (Table 1, criterion 2). Otherwise, authors either provided the name of a cancer registry known to be population-based or indicated that the cancer registry used was part of the Surveillance, Epidemiology, and End Results (SEER) registry system in the United States, which is population-based. Over one-third (38%) of the articles did not provide a description of the clinical variables available from the registry (such as stage, grade, or primary treatment) (Table 1, criterion 3). Follow-up of patients' vital status by the registry, which refers to whether the registry actively tracks the vital status (alive or not) of the patients in the registry, either was not reported or was not clearly stated in 38% of the articles (Table 1, criterion 4).

Data used from registry

In 98% of articles, registries were used as a sampling frame or for data linkage (Table 1, criterion 5). Of the 2% of articles that did not meet criterion 5, all reported on follow-up assessments. Although registries were most often used as a sampling frame, there were exceptions. For example, if legislation did not allow registries to be used for sampling or if rapid patient identification for study eligibility was necessary, then clinical data from the participating patients were abstracted from the relevant registry after informed consent and were then merged with PRO data.

In addition to sampling, clinical data from the registry, such as date of diagnosis and cancer stage, were commonly accessed for use in the analyses (Table 1, criterion 11). Although most articles included clinical data in the analyses, only 61% clearly described which variables came from the registry.

Sampling Process

Most articles (95%) described the sampling process (criterion 6). Similarly, nearly all articles (98%) provided inclusion/exclusion criteria used in the study (criterion 7). Those articles that did not provide information regarding these 2 criteria referred to previous publications.

Response Rates and Characteristics of Respondents and Nonrespondents

Only 42% of the articles (n = 71) reported a response rate >70% (criterion 8). Over half of the articles (n = 101) described the sample selected and compared the clinical/demographic characteristics of respondents and nonrespondents (Table 1, criterion 9). The vast majority of articles (95%) had sample sizes greater than 100 survivors (Table 1, criterion 10).

Use of Validated Patient-Reported Outcome Instruments

Almost all articles used validated PRO instruments to assess QoL (Table 1, criterion 12). Only 3 articles did not get a score on this criterion. One article reported that a 21-item questionnaire was used to assess QoL, whereas another used a computer-assisted telephone interview to assess the presence of symptoms that interfered with daily mood or function, and a third reported data collected from a questionnaire that was also used in a normative population.

Given the wide range of instruments used in assessing QoL, only a few of the most commonly used are mentioned here. For the assessment of general QoL, the most commonly used instrument was the Medical Outcome Study 36-item short-form health survey (SF-36). For disease-specific QoL, the European Organization for Research and Treatment of Cancer Quality-of-Life Core Questionnaire (EORTC-QLQ-C30) and the Functional Assessment of Cancer Therapy (FACT) were the most commonly used questionnaires.

DISCUSSION

In overview, we identified 173 articles published between January 2001 and June 2011 that assessed the QoL of

cancer survivors with the assistance of a cancer registry. Most articles scored high on the amount of information provided on the cancer registry, study population, and study design. However, data on the follow-up of vital status provided by the cancer registry was the least often reported element of our assessment in these reports. Response rates for the included articles varied from 91% to 24%, and the majority fell below 70%.

Sampling-Related Issues

Tumor registries vary in their procedures for identifying and following cancer patients,[19] which was also exhibited in this review. A significant proportion of cancer registries do not routinely update contact information (eg address, telephone number) after the patient is entered into registry records. Consequently, locating cancer survivors may be difficult at times, particularly for those who are further out from diagnosis or those who have moved from the original address at which they resided at the time of diagnosis. This is reflected by the reality that longer term survivors are less likely to respond to questionnaires than shorter term survivors.[12] This may explain in part why only 73 studies (42%) reported a response rate >70%. Efforts to update both vital status and contact information should be important considerations in QoL research that uses cancer registry records. Indeed, conducting research using those registries that routinely update contact information and vital status of patients in their databases may offer significant advantages.

Lack of vital status follow-up information in these studies raises the question of how representative the sample was and also the differences in characteristics of respondents, nonrespondents, and those who have died. Vital status follow-up is essential for studies in which death is a primary outcome. For example, loss of patients to death can introduce major bias in case-control studies when a dose-response relation causes patients with greater exposure to die sooner. Although vital status information and loss of patients to death are less important in QoL studies with primary outcomes like as symptoms, functioning, and overall QoL, the provision of vital status information (if routinely collected by the cancer registry) is good practice, because it indicates the representativeness of the sample.

A large proportion of the articles covered common malignancies, such as breast, colorectal, or prostate cancers. It is worth noting that we identified no articles on less common malignancies, such as hepatobiliary or pancreatic cancers; the high mortality rate of these cancers may make it difficult to accrue samples. Also, there are relatively few articles specifically focusing on the QoL of the elderly, although they are more likely to be diagnosed with cancer than younger individuals. Because cancer is more likely to occur among older individuals, study samples are likely to contain significant numbers of elderly survivors; however, articles rarely focused on this group. The use of cancer registry data to study the QoL of elderly survivors will be important, because they often are understudied or are not included in clinical studies. Since the review selection for the current study was completed (July 2011), several articles on the physical and emotional functioning of elderly cancer survivors have been published using data from the American Cancer Society's Studies of Cancer Survivorship (ACS-SCS) project.[20,21]

Only 62% of the articles provided information on the clinical data routinely collected by cancer registries, such as stage and grade of cancer at diagnosis or primary treatment. Although most articles did include clinical data in their analyses, a substantial minority did not specify whether these were registry data. Similar to survival studies, high-quality clinical data from registries also are important for QoL studies, but the quality of data may vary within and across registries. Consistent with the goal of tracking cancer incidence, the quality of registry data on diagnosis is generally excellent. In contrast, the quality of data on stage or receipt of adjuvant treatments may be lower and may be related to patient or cancer center characteristics.[22-25] Researchers should take into account the strengths and weaknesses of the data at the specific registry they are using when designing studies, conducting analyses, or interpreting results.

Although the majority of studies used validated scales to assess QoL, the wide range of measures used makes it difficult to compare results between studies or to encourage collaboration between different research organizations. Incidence and survival data traditionally collected by cancer registries are readily merged across registries or research organizations, because they have broadly accepted, uniform definitions. This facilitates the study of trends in cancer incidence, survival, and treatment effectiveness at national and international levels. However, QoL comparisons among samples from different registries are more challenging not only because of variations of care but also because of differences in the QoL instruments used. With QoL increasingly becoming accepted as a routine endpoint in assessing treatment efficacy, some have suggested that a core set of QoL data should be part of the regular data collected for effectiveness and should be recorded by cancer registries. Naturally, this idea raises questions. What constitutes core

QoL data? How should the cancer registry collect such information? Along these lines, in the United States, the National Institutes of Health have developed a publicly available set of QoL assessment tools referred to as the Patient-Reported Outcome Measurement Information System (PROMIS). Built on the World Health Organization framework, PROMIS includes a core set of items that assess several QoL domains, such as pain, fatigue, depression, and physical function.[26] Among the goals of PROMIS is to increase standardization and data harmonization in QoL assessments. Another initiative is the Grid Enabled Measures (GEM) database by the US National Cancer Institute (www.gem-beta.org). GEM is a dynamic, web-based database that was designed to organize PRO measures by theoretical constructs and to facilitate the exchange of harmonized data.

Models of Registry-Based Quality-of-Life Studies

The vast majority of articles used 1 of the 2 models of registry-based studies (for a summary, see Table 3). Most of the articles reported using a cancer registry as a sampling frame. Those studies used the registry to identify and sample cancer survivors before sending a questionnaire to collect QoL data. Examples of studies using this model are reports from the ACS-SCS project[12] and publications from the PROFILES registry in the Netherlands.[18] The other commonly used model collects sample participants before linking with the registry. The Iowa Women's Health Study (IWHS) is an example of this second common model. In that sample, women ages 55 to 69 years from the Iowa drivers' license register were randomly sampled to complete a self-reported questionnaire on QoL and other factors (http://www.cancer.umn.edu/research/programs/peiowa.html). This cohort is then linked with the SEER cancer registry annually to identify incident cancer cases. Regardless of the strengths of these methods, both methods will have to contend with issues of survival and response bias.

The first model, which uses registry data as a sampling frame, has several advantages. Because these registries are population-based, the studies using this model have the potential to achieve excellent external validity. Because the registry provides a limited set of medical and demographic variables on everyone who was sampled, it enables the investigator to assess bias by comparing respondents with nonrespondents.[19] However, only 58% of the articles in our review provided such information. Given the large number of cancer survivors contained in registries, investigators can assemble samples with specific demographic, disease, and/or treatment characteristics. This is important, because the issues faced by cancer survivors vary widely, depending on these characteristics. Registries also can enable investigators to assemble samples of less common or even rare cancers, which would be difficult at individual hospitals.

An advantage of using the second model, which samples participants before linkage with a cancer registry, is the possibility of including participants and the collection of QoL data *before* the cancer diagnosis. The availability of QoL data before the participant is diagnosed with cancer allows the assessment of changes in QoL as a result of the disease and/or treatment.

Although both models have to contend with issues of survival and response bias, another consideration for the second model is the degree to which the sample collected is sufficiently population-based. Other considerations salient to both models include the geographic coverage of the cancer registry, the amount and quality of data registered by the cancer registry, and whether the registry conducts regular vital status follow-up and updates contact information of the registered patients.

Using Cancer Registries in Quality-of-Life Research

Currently, there is much discussion regarding whether cancer registries should be involved in approaching survivors for collecting QoL data. Unfortunately, such a proposal may not be feasible for most countries in the European Union, because direct contact with cancer survivors for QoL studies is not allowed without first obtaining consent from or providing notification to the attending (and reporting) physician. In the United States, each state has its own regulations for registry operations such as physician and patient contact procedures. For example, some states require physician consent before recruitment of their current or former patient. Investigators conducting the ACS-SCS used data from their study to demonstrate that obtaining written physician consent reduced response rates sufficiently to convince registry staff in 3 states to abandon the requirement of physician consent and to use physician notification instead.[12] Furthermore, research suggests that most patients (87%) do not want physicians to decide whether they will be approached for a study.[27] Researchers may consider suggesting changes to registry policies, especially when they have data to support their request. Because of the (sometimes great) variability in registry laws and regulations, the adoption of national standards around collecting QoL data represents a significant challenge. This barrier likely

could be overcome by pilot projects demonstrating the safety and utility of collecting QoL data.

Common barriers to using cancer registries to conduct QoL research include issues with patient sampling and recruitment that have adequate response rates. In the United States, concerns around privacy and the use of publicly reportable data for patient follow-back studies are sometimes cited as barriers to registry-based QoL research. Although cancer registries often have a mandate to collect clinical data, such as date of diagnosis or cancer characteristics from pathology reports and medical records, this mandate frequently does not extend to initiating the contact with patients necessary for QoL studies. Including the attending physicians with interests in QoL into the study can circumvent the problem and facilitate access to patients. However, this may also vary in relation to the regional organization of the participating physician and may be reflected in the response rate to studies. Another consideration is that physicians may not always be an adequate source of information of survivors' current eligibility or ability to complete a survey. This pertains especially to situations in which data on survivors are sampled years after diagnosis and the registry no longer maintains follow-up with their initial treating physician. Regardless of the methods used, the collection of QoL data are outside the current scope of registry operations, and additional funding would be required for registries to engage in this activity.

Another consideration is the amount and quality of data registered by the cancer registry. In Europe, both the European Network of Cancer Registries (ENCR), now with a common data portal for quality control, and the EUROCARE (EUROpean CAncer REgistry-based study on survival and care of cancer patients) project focus on the standardized reporting of population-based survival data. EUROCARE, which started in 1989 with 13 population-based cancer registries in the European Union, has now expanded to almost 100 registries that, all together, cover 13 million patients with newly diagnosed cancers (www.eurocare.it), whereas ENCR comprises almost 200 registries. Nevertheless, data incompleteness remains an issue, and ENCR has guidelines to ensure completeness of data reporting by the participating registries (www.encr.com.fr). The US equivalents would be the National Program of Cancer Registries (NPCR) and the SEER registry. The NPCR, which is administered by the Centers for Disease Control and Prevention, supports state cancer registries and represents data from 96% of the US population (http://www.cdc.gov/cancer/npcr/). The SEER registry was started in 1973 to collect complete and accurate data on cancer cases and currently covers approximately 28% of the US population (http://seer.cancer.gov/).

The registry-based collection of QoL data also requires specifying the time point after diagnosis or treatment at which to recruit survivors and, for longitudinal studies, the frequency of follow-up. After all, cancer survivors experience changes in QoL over time, depending on where they are on the survivorship trajectory. Another challenge of using cancer registries in QoL studies is the lack of information on patients' status before cancer. However, this problem can be overcome with a design like that of the IWHS, which links data collected through a large population-based cohort with data from of a cancer registry.

Despite these barriers, growing interest in cancer survivorship within the European Union and the United States is pushing the cancer registries in the direction of addressing QoL. In the European Union, the "EUROpe Against Cancer: Optimization of the Use of Registries for Scientific Excellence in research" (EUROCOURSE) project (www.eurocourse.org) was started to optimize the use of cancer registries in outcome research. Under the auspices of EUROCOURSE, European cancer registries discussed the feasibility of collecting QoL data within cancer registries. In September 2011, EUROCOURSE organized a 2-day workshop that was attended by investigators from France, Germany, Ireland, the Netherlands, and the United Kingdom who were active in the field of QoL research using cancer registry data. In the United States, SEER and NPCR registries have begun to explore different mechanisms to integrate registry-based data with QoL data. Specifically, efforts have been made to link SEER registry data with several publicly available data sets to allow for the examination of QoL in the context of cancer cases that are identified through cancer registry databases. For example, SEER data have been linked with Medicare data, providing mechanisms for epidemiologic and health services research with cancer patients and survivors aged >65 years who are enrolled in Medicare (http://healthservices.cancer.gov/seermedicare). In addition, SEER data have been linked with the Medicare Health Outcomes Survey (MHOS), allowing for the investigation of QoL data from cancer patients and survivors who are enrolled in the Medicare Advantage health plans (http://outcomes.cancer.gov/surveys/seer-mhos). These 2 initiatives mark an increasing recognition in the United States of the importance of PROs and the value that cancer registry data can bring to QoL research studies.

Patient-Reported Outcomes Registries

In addition to the possibility of cancer registries collecting patient-reported data, such as QoL, current developments include the setting up of separate psychosocial registries that collect QoL data from cancer survivors. Examples of such registries in Europe include the PROFILES registry from the Netherlands[18] and the electronic Patient-Reported Outcomes from Cancer Survivors (ePOCS) registry from North and West Yorkshire in the United Kingdom.[28,29] These 2 registries collect QoL data, which then are merged with cancer registry data to provide a more in-depth commentary on patients' survivorship trajectory. The sampling process of both registries differs; PROFILES uses the cancer registry as a sampling frame to approach cancer survivors and, thereafter, to link the collected QoL with cancer registry data. For ePOCS, a hospital-based and clinician-led approach is used for patient recruitment, after which, the collected QoL data are linked with clinical data from the cancer registry. The number of QoL publications (n = 13) from the PROFILES registry since mid-2011 attest to the value of linking QoL data with data from a cancer registry.[30-42] Further details of the PROFILES registry and the open-access policy to its data can be obtained at www.profilesregistry.nl. Several such registries also have been developed in the United States. The Psychosocial Data Registry from the Ireland Cancer Center in Cleveland, Ohio has the goal of collecting QoL data from new patients and family caregivers at diagnosis and following them through the entire cancer experience.[43] Another example is the Breast Cancer Mind Affects the Physical (M.A.P.) Project conducted by the Cancer Support Community (http://www.breastcancerregistry.org). To date, over 3500 women with a history of breast cancer from across the United States and over 30 countries have voluntarily enrolled in the registry and have completed self-report surveys on their physical and psychosocial health.

In this overview, we provide important information regarding the use of cancer registries in QoL research. However, there are some limitations that should be addressed. Although main search engines were used to find relevant articles in a systematic manner, this search may not have been exhaustive. Using the PubMed MeSH term "quality of life" may have excluded studies that did not use this term as a keyword. Nevertheless, the proportion of duplicate references eliminated from the initial searches (82%) suggests that the included articles are representative of the publications on this topic. Furthermore, the large number of articles included in this overview limited detailed descriptions of methodology and the scope of topics covered, which should be done in relation to the content of individual articles.

Conclusions

Population-based cancer registries are used in QoL studies covering a range of cancers. Nevertheless, there is room for improvement. Cancer registries are an underused resource for cancer survivorship studies, especially with regard to patients who have rare cancers, patients who have specific disease and treatment profiles, or the elderly, who are understudied in clinical trials. Furthermore, registry-based QoL studies have the advantage of drawing population-based samples with the potential for providing the best possible external validity. Because the majority of the articles identified in our search were conducted in Europe and the United States, future directions might include an international meeting to discuss relevant results, common concerns, and best practices for registry-based QoL research.

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