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Using a Psychosocial Registry as a Data Source for Nurses

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Abstract

Nurses at the bedside strive to base their practice on the best available information derived from evidence. However, issues related to patient care often arise for which evidence is either difficult to attain or not available. This can be particularly true for nurses who care for patients with diverse diagnoses because most studies focus on patients with a single cancer diagnosis. For example, evidence about quality of life (QOL) as perceived by the patient is a concern for clinicians but is of particular importance to nurses at the bedside. A great deal of study has been performed on the QOL of patients with cancer; however, most of these reports focus on narrow or limited samples, typically one specific cancer type. Having access to a registry that enrolls patients with diverse types of cancer and collects QOL data could be very useful to practicing bedside nurses.

A registry is a large database in which patient information is collected using sound measures in a systematic fashion, for use by researchers and clinicians with patient consent. Existing registries have served critical functions, including tracking incidence and prevalence of disease and likely causative factors, providing data for large-scale observations and measurement of outcomes for prevention and treatment, and measuring quality of care (Gliklich & Dreyer, 2010). In the United States, national support of cancer registries began in 1973 with the establishment of the Surveillance, Epidemiology, and End Results (SEER) program at the National Cancer Institute (NCI) (www.seer.cancer.gov). In 1994, the Centers for Disease Control and Prevention began the National Program of Cancer Registries (NPCR) to support and expand the initiatives began by SEER. NPCR registries collect data on cancer cases occurring among 96% of the U.S. population (www.cdc.gov/cancer/npcr). Nurses have used registries as a tool to recruit specific study populations (Foster et al., 2012; Matthews, Tejeda, Johnson, Berbaum, & Manfredi, 2012; Smith, Zimmerman, Williams, & Zebrack, 2009), but no reports exist in the literature of nurses using registry data in clinical practice. This may reflect that most current registries focus on biologic measures, such as laboratory tests and radiologic data. Despite the many uses of registries to investigate the

science of cancer, only one nurse-developed psychosocial data registry, developed at Case Western Reserve University, was identified in the literature (Daly et al., 2007).

As an example of how to use a registry, a nurse who works in an inpatient oncology unit may assume, based on his or her values and work experiences, that patients with higher education and income and an early-stage cancer would have better quality of life (QOL) than those who are not educated, have a low income, and have a late-stage cancer. Based on this, a feasible question for a nurse or nurse researcher to ask would be, “Is there a relationship between demographic and clinical characteristics in patients with diverse cancer diagnoses and QOL?”

A Psychosocial Cancer Registry

Before deciding to use a registry, knowing characteristics about the enrolled patients is important. The data for the psychosocial cancer registry were collected in an outpatient clinic at the NCI– designated Seidman Cancer Center and addressed QOL in patients with diverse cancer diagnoses. To enroll in the registry, individuals met the following criteria: aged older than 18 years, have the ability to comprehend the English language, have a new diagnosis of cancer, and are receiving ongoing care at the cancer center. Exclusion criteria included cognitive impairment or immediate referral for a bone marrow or stem cell transplantation because much of that type of treatment is conducted in the inpatient setting. All cancer diagnoses and stages were included. Demographic and clinical data were gathered at enrollment, and QOL was measured using several questionnaires at enrollment and after three and nine months. During scheduled outpatient visits, patients were given the choice of face-to-face interviews or self-administration of the questionnaires. The project was approved by the hospital’s institutional review board, and data were collected from 2005–2009. Tables 1 and 2 show the characteristics of enrolled patients; gender, education, income level, and other demographic and clinical variables were well represented.

Nurses should know about the instruments used to capture data about various aspects of QOL, including mood state, status, and spiritual well-being. Table 3 provides a summary of validated tools that were used in this study, including tests used to measure QOL. The measurement of several aspects or dimensions of QOL is important when designing a registry useful for a variety of purposes. The Eastern Cooperative Oncology Group (ECOG) questionnaire focuses on functional status. ECOG scores from the authors’ registry ranged from 0 (able to carry out all predisease performance without restriction) to 3 (capable of only limited self-care; confined to bed or chair for more than 50% of waking hours) (Oken et al., 1982). However, overall QOL depends on more than physical well-being. This article focuses on the Functional Assessment of Cancer Therapy–General (FACT-G), an instrument widely used to assess overall QOL in patients with cancer (Brucker, Yost, Cashy, Webster, & Cella, 2005; Lockett et al., 2011). The FACT-G assesses four dimensions of QOL: physical well-being, social and family well-being, emotional well-being, and functional well-being. The test-retest reliability coefficients for the FACT-G range from 0.82–0.92 (Cella et al., 1993); scores above 0.8 are considered to have good-to-excellent reliability. The 27 items are rated on a five-point Likert-type scale ranging from 0 (not at all) to 5 (very

much). A higher score on the subscales and the total score indicates a higher QOL (range of the total score = 0–108).

Answering a Clinical Question

The results to the posed clinical question —Is there a relationship between demographic and clinical characteristics in patients with diverse cancer diagnoses and QOL?—showed that the mean and median scores of the FACT-G were 80.3 (SD = 16.2) and 82, respectively. With the exception of age ($r = 0.238$, $p = 0.00$), no statistically significant associations were found between QOL and patient characteristics; this means that patients who were older reported a higher QOL, which is similar to previous findings about QOL and age (Burfeind et al., 2008; Smith et al., 2009). Although previous studies focused on earlier-stage cancers or specific types of cancer (Brown et al., 2006; Lehto, Ojanen, & Kellokumpu-Lehtinen, 2005; Lu et al., 2007; Strasser-Weippl & Ludwig, 2008), data from the authors' registry confirm that the association of improved QOL with older age holds across all cancer diagnoses and stages of disease.

Implications for Nursing Practice

The data from the registry suggest that nurses cannot assume that patients with a late-stage cancer or with lower income or education levels are at higher risk for impaired QOL. These findings support the importance of addressing QOL in all patients with cancer, regardless of stage or demographic characteristics. Nurse managers who plan to initiate or improve clinical programs designed to contribute to the QOL of patients undergoing cancer therapy should not target predetermined subsets of patients. Instead, screening patients on admission and throughout treatment could be a more reliable method to identify people who might benefit from more intense support.

In addition to the benefits of using registry data, limitations also exist. Despite efforts to collect a broad range of information, registry data may not match a specific research query or clinical question. Incorporating enrollment in a registry and collection of data also requires time and training of personnel. Because biologic registries are so common in cancer centers, collaborating with medical colleagues to add psychosocial data to existing registries may be a feasible approach. Incorporating small data sets in admission interviews, beginning with just one general QOL questionnaire, also can initiate a psychosocial registry. Despite these limitations, registries that include data relevant to the clinical practice of oncology nurses, as well as nurse researchers, can be an important asset to improving care.

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TABLE 1

Patient Characteristics (N = 410)

Characteristic	$\bar{x}$	SD
Age (years) ^a	59.6	12.5
Characteristic	n	%
Gender		
Female	234	57
Male	176	43
Race		
Caucasian	310	76
African American, Hispanic, or other	99	24
Missing data	1	<1
Marital status		
Married	259	63
Not married	146	36
Missing data	5	1
Level of education		
Less than high school	28	7
High school	188	46
College	136	33
Post college	45	11
Missing data	13	3
Employment status		
Employed	155	38
Retired	137	33
Not employed	96	23
Missing data	22	5
Income (\$)		
20,000 or less	78	19
20,001–49,999	130	32
50,000 or greater	171	42
Missing data	31	8

^aMedian = 60; range = 18–90

Note. Because of rounding, not all percentages total 100.

TABLE 2

Cancer Demographics of Patients in a Psychosocial Registry (N = 410)

Characteristic	n	%
Cancer type		
Leukemia, lymphoma, or multiple myeloma	75	18
Lung	69	17
Gynecologic	49	12
Breast	44	11
Head or neck	41	10
Colon or rectal	39	10
Gastrointestinal	39	10
Prostate	14	3
All others	38	9
Missing data	2	<1
Cancer stage		
I	52	13
II	61	15
III	115	28
IV	110	27
Missing data	72	18
Previous history of cancer		
Yes	52	13
No	347	85
Missing data	11	3
Performance status (ECOG)		
0	144	35
1	173	42
2	43	10
3	18	4
Missing data	32	8

ECOG—Eastern Cooperative Oncology Group

Note. Because of rounding, not all percentages total 100.

TABLE 3

Psychosocial Registry Instruments

Instrument	Domain	Number of Items	Range of Scores
Charlson Comorbidity Index	Predicts one-year mortality	19	0–37
Eastern Cooperative Oncology Group	Performance status	1	0–5
Functional Assessment of Cancer Therapy-General scale	Quality of life	27	0–108
Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being scale	Spirituality	12	0–48
Profile of Mood States Short Form	Mood state	30	20–100

Note. Based on information from Brucker et al., 2005; Chaundry et al., 2005; McNair et al., 1992; Oken et al., 1982; Peterman et al., 2002 .