



# Using a Psychosocial Registry as a Data Source for Nurses

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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.

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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](http://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](http://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, University Hospitals Case Medical 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.