

Exploring the Response Shift Phenomenon in Childhood Patients With Cancer and Its Effect on Health-Related Quality of Life

Aeltsje Brinksma, MSN, RN, Wim J.E. Tissing, MD, PhD, Esther Sulkers, MsC, RN, Willem A. Kamps, MD, PhD, Petrie F. Roodbol, PhD, MSN, RN, and Robbert Sanderman, PhD

Health-related quality of life (HRQOL) is important for understanding the impact of cancer on a child's life. HRQOL is defined as "a multi-dimensional construct that includes physical, social, and emotional functioning of the child, measured from the perspective of both the child and his/her family, and sensitive to the changes that occur throughout development" (Bradlyn et al., 1996, pp. 1333–1334). To determine deterioration or improvement in HRQOL during treatment, the reference point for good or poor HRQOL should be the same at all measurement points. However, because the measurement of HRQOL relies on self-report, the rating depends on an individual's perception of HRQOL at the time of measurement. This perception might change over time. Being confronted with cancer, for instance, can change an individual's perception about good and poor HRQOL from adaptation to the diagnosis (Postulart & Adang, 2000). Consequently, individuals may report good levels of HRQOL despite deterioration in their health status and in contrast to what nurses expect. Several studies have demonstrated that patients with cancer reported levels of HRQOL similar to healthy individuals (Breetvelt & Van Dam, 1991). In pediatric patients with cancer, psychosocial HRQOL often was found to be even higher than in healthy children (Russell, Hudson, Long, & Phipps, 2006; Shankar et al., 2005).

The phenomenon of adaptation to a change in health status is called response shift. The response shift phenomenon has been found in adult patients with cancer (Bernhard, Hurny, Maibach, Herrmann, & Laffer, 1999; Jansen, Stiggelbout, Nooij, Noordijk, & Kievit, 2000; Rees et al., 2005; Schwartz, Feinberg, Jilinskaia, & Applegate, 1999; Sprangers et al., 1999; Tavernier, Beck, Clayton, Pett, & Berry, 2011; Visser, Smets, Sprangers, & de Haes, 2000). However, research on the influence of response shift on HRQOL ratings in childhood pa-

Purpose/Objectives: To explore the response shift phenomenon in pediatric patients with cancer and to determine its effects on ratings of health-related quality of life (HRQOL).

Design: Retrospective pre- and post-test design.

Setting: Pediatric oncology department in the northern part of the Netherlands.

Sample: 37 children newly diagnosed with cancer and 80 parents.

Methods: The then-test method was used to determine response shift. HRQOL was assessed within two weeks postdiagnosis (pretest) and three months later (post-test) using both child and parent reports of PedsQL and Cantril's ladder. The post-test and then-test were administered concurrently.

Main Research Variables: Overall and multidimensional HRQOL.

Findings: Scores on Cantril's then-test were lower than the pretest in both child and parent reports, indicating response shift in the assessment of overall HRQOL. Children experienced a greater response shift than parents. No differences were found between the PedsQL then- and pretests.

Conclusions: Both child- and parent-report ratings of overall HRQOL were affected by response shift, resulting in an underestimation of the improvement in overall HRQOL between diagnosis and three months postdiagnosis. No response shift was demonstrated in the more specific domains of HRQOL (PedsQL).

Implications for Nursing: Knowledge of the response shift phenomenon helps nurses to better interpret the outcomes of HRQOL. The use of the PedsQL instrument is recommended in future studies that aim to demonstrate changes in HRQOL.

Key Words: cancer, child, adolescent, parents, quality of life, self-report

tients with cancer is lacking. Response shift is defined as a change in the meaning of one's self-evaluation of a target construct as a result from changes in internal standards (scale recalibration), values (reprioritization),