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

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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