

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

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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),

or a redefinition of the target construct (reconceptualization) (Schwartz & Sprangers, 1999; Sprangers & Schwartz, 1999).

Although response shift is a natural way to cope with and adapt to changes in health status (Ahmed, Mayo, Wood-Dauphinee, Hanley, & Cohen, 2004), it generates a bias in consecutive measurements of HRQOL. As a result, treatment effects on the child's HRQOL can be reduced or inflated. In addition, when studying a nursing intervention aimed at improving HRQOL, the outcome might be underestimated when the endpoint parameter is subject to response shift.

Because the HRQOL of children is preferably measured using both child and parent report (Hinds, 2010), both ratings might be influenced by response shift. Proxy measurement is considered to be less sensitive to response shift because proxy raters do not experience the diagnosis themselves (Postular & Adang, 2000). However, whether this is true for parents of critically ill children is unknown because childhood cancer has a major impact on the parents as well.

In this study, the authors assessed the impact of response shift on the assessment of HRQOL in pediatric patients with cancer at the level of overall impression of HRQOL (because this level is known to be sensitive to response shift in adults) (Schwartz et al., 2006) and at the more specific level of the domains of HRQOL. That level, consisting of the physical, social, and emotional domains of HRQOL, is most commonly used in HRQOL assessment. The study aimed to (a) determine the change in health status and HRQOL during the first three months after diagnosis, (b) examine whether the HRQOL ratings are affected by response shift, and (c) determine similarities and differences with regard to the presence, direction, and magnitude of response shift between child- and parent-report ratings.

Methods

Participants

Data were collected as part of a prospective cohort study of newly diagnosed patients with cancer at the University Medical Center Groningen (UMCG) in the Netherlands. Ethical approval was gained from the medical ethics committee of UMCG. From September 2007 to December 2009, all patients aged 2–17 years admitted to the pediatric oncology department were asked to participate. Exclusion criteria included having insufficient command of the Dutch language or being in a palliative phase of treatment. The response shift study was restricted to children aged 8 years and older and their parents for child and parent report. Parents of children aged 2–7 years were included for parent report only. A total of 121 parents and 61 children were eligible and were invited to participate. Fifty-one children and

100 parents gave informed consent. Response rate was 84% for child report and 83% for parent report. Reasons for declining child report were too burdensome ($n = 6$) and lack of motivation ($n = 4$); reasons for declining parent report were too burdensome ($n = 17$) and lack of motivation ($n = 4$). After inclusion, seven children dropped out (too burdensome [$n = 2$], lack of motivation [$n = 3$], or being too ill [$n = 2$]), and the data of another seven children were incomplete. Fifteen parents dropped out (too burdensome [$n = 5$], lack of motivation [$n = 8$], child is too ill [$n = 2$]), and the data of five parents were incomplete. Thirty-seven child-parent pairs completed all measurements, as did 43 parents of younger children (ages 2–7). Only complete data sets including all measurements were used for analysis.

Procedure

The most widely used method to examine response shift is the then-test method, also known as the retrospective pre- and post-test design method (Howard et al., 1979; Schwartz & Sprangers, 1999, 2010). In this method, individuals were asked to evaluate their HRQOL at the pretest and the post-test. Immediately following the post-test, the then-test is administered, whereby individuals are instructed to reassess their pretest HRQOL. They are not asked to remember their pretest rating, but to retrospectively give a renewed judgment about their HRQOL at the pretest. Because the then-test is completed at the same time as the post-test, respondents would likely use the same internal standards. A difference between the then-test and the pretest provides evidence of recalibration of HRQOL between pre- and post-test measurement. In this study, HRQOL was assessed within two weeks after diagnosis (pretest) and three months later (post-test). For administering the then-test, parents received written instructions to keep the first week after diagnosis in mind when filling out the then-test. The researcher asked children to recall the period shortly after diagnosis and to name special events from that period. When children indicated they could vividly remember this period, the then-test was administered by interview.

Measures

Health status was assessed by the **Play Performance Scale (PPS)** (Lansky, List, Lansky, Ritter-Sterr, & Miller, 1987), a 10-point parent-rated Likert-type scale recording the daily play activity of the child ranging from fully active (100) to completely disabled, not even passive play (10). The PPS has adequate reliability (mother versus father ratings, $r = 0.71$) and content validity (parent versus nurses ratings, $r = 0.75$) (Lansky et al., 1987).

The **Memorial Symptom Assessment Scale (MSAS)** (Collins et al., 2000, 2002) was used for reporting the number of symptoms children experienced. The MSAS

Physical Functioning

1. I had low energy.
2. I hurt or ached.
3. Food did not taste very good to me.
4. I became sick to my stomach when I thought about medical treatments.

Emotional Functioning

5. I felt afraid or scared.
6. I worried about what would happen to me.
7. I felt angry.
8. I felt sad and blue.
9. I got scared about having needle sticks.

Cognitive Functioning

10. It was hard for me to pay attention to things.
11. I forgot things.

Social Functioning

12. I had problems getting along with other kids.

Communication

13. It was hard for me to ask the doctors and nurses questions.
14. It was hard for me to explain my illness to other people.

Note. Items 3, 4, 9, 13, and 14 are from the PedsQL cancer module. All other items are from PedsQL 4.0 Generic Core Scale.

Figure 1. Domains and Items of Adjusted PedsQL

Note. Based on information from Varni et al., 2001, 2002, 2007b.

is a child- and parent-rated instrument consisting of 30 of the most common symptoms experienced during cancer treatment and has demonstrated reliability ($r = 0.83\text{--}0.87$) and validity (high correlations with other symptom instruments and higher symptom number among patients who had recent chemotherapy) in childhood cancer populations (Collins et al., 2000). Cronbach alpha in the sample was $r = 0.8$ and 0.75 for child-reported pre- and post-test, and $r = 0.85$ and 0.83 for parent-reported pre- and post-test, respectively.

HRQOL was assessed by means of **Cantril's ladder** (Cantril, 1965) and the **PedsQL 4.0 Generic Core Scale** (Varni, Limbers, & Burwinkle, 2007b; Varni, Seid, & Kurtin, 2001). Cantril's ladder is a single-item visual analog scale rating the overall impression of quality of life on a scale of 0–10, where 10 represents the best possible quality of life and 0 the worst possible quality of life. Cantril's ladder was used as pre-, post-, and then-test. Although Cantril's ladder has frequently been used in many studies, no data for reliability and validity have been reported.

The PedsQL is a 23-item multidimensional scale designed to measure HRQOL in children and adolescents aged 2–18 years. The PedsQL cancer module (Varni, Burwinkle, Katz, Meeske, & Dickinson, 2002) is a 27-item scale developed to measure pediatric cancer-specific HRQOL. The PedsQL instruments are comprised of parallel child self-report formats (aged 5 years and older) and parent proxy-report formats (aged 2 years and older) and have high levels of internal consistency ranging

from $r = 0.72\text{--}0.88$ for child report and $r = 0.86\text{--}0.9$ for parent report. Validity was demonstrated using the known-groups method; the PedsQL instruments distinguished between healthy children and children with cancer (Varni et al., 2001, 2002; Varni, Limbers, & Burwinkle, 2007a, 2007b). For the then-test, a selection of 14 items from both PedsQL instruments (noted as adjusted PedsQL [aPedsQL]) was used to diminish the burden of filling out the entire HRQOL measures twice at the time of the post-test. Items were selected according to the criteria mentioned by Schwartz and Sprangers (1999). The authors selected items that might be remembered well, like pain or fear of injections. Next, items expected to be prevalent shortly after diagnosis were selected, covering the domains of HRQOL. The sum scores of the aPedsQL were used for the comparison of pre-, post-, and then-test ratings. Because some domains of HRQOL are more sensitive to recalibration response shift than others (Schwartz et al., 2006), the domains of the aPedsQL were analyzed separately. The authors divided the aPedsQL into domains according to the categorization of the original instruments (see Figure 1). For ease of interpretability, the items of the five-point Likert-type scale were reversed and converted to a 0–100 scale, according to standard procedures, so that higher scores indicated better HRQOL. The internal consistency of the aPedsQL was satisfactory (Cronbach alpha, $r = 0.74, 0.77,$ and 0.78 for child report pre-, post-, and then-test; $r = 0.78, 0.87,$ and 0.76 for parent report pre-, post-, and then-test, respectively). The aPedsQL was representative for the PedsQL instruments, with $R^2 = 0.86$ for child report and $R^2 = 0.88$ for parent report.

Analyses

Changes in HRQOL were examined by comparing the pre- and post-test scores (reported change) and

Table 1. Participant Characteristics (N = 117)

Characteristic	Child Report (n = 37)		Parent Report (n = 80 ^a)	
	M	Range	M	Range
Age of children (years)	14	8–17	9	2–17
Characteristic	n		n	
Gender of children				
Female	20		44	
Diagnosis				
Hematologic	12		36	
Solid tumors	18		26	
Brain tumors	7		18	

^aConsisted of the parents of the 37 children aged 8 years or older and of the 43 children aged 2–7 years.

M—median

Table 2. Change in Scores Between Pretests and Post-Tests (Reported Change) and Between Post-Tests and Then-Tests (Adapted Change)

Variable	Pretest		Post-Test		Then-Test		Reported Change		Adapted Change	
	M	IQR	M	IQR	M	IQR	p ^a	Effect Size	p ^a	Effect Size
HRQOL										
Child report										
Cantril	7	2	8	2	5**	3	0.219	-0.2	< 0.001	-0.71
aPedsQL	71.43	19.64	76.79	24.11	73.21	17.86	0.005	-0.46	0.01	-0.43
Parent report										
Cantril	6	2	7	2	5*	3	< 0.001	-0.35	< 0.001	-0.44
aPedsQL	60.71	25.3	73.21	23.96	60.71	19.64	0.028	-0.48	0.001	-0.43
Health Status										
Child report										
MSAS	11	9	7	10	-	-	0.001	0.53	-	-
Parent report										
MSAS	13	9	9	9	-	-	< 0.001	0.5	-	-
PPS	60	30	80	30	-	-	< 0.001	-0.4	-	-

* p < 0.05; ** p < 0.001

^a Wilcoxon signed rank test

aPedsQL—adjusted PedsQL; HRQOL—health-related quality of life; IQR—interquartile range; M—median; MSAS—Memorial Symptom Assessment Scale; PPS—Play Performance Scale

Note. Cantril scores range from 0–10, with higher scores indicating higher HRQOL. Scores for the aPedsQL range from 0–100, with higher scores indicating higher HRQOL. MSAS scores represent the frequency of symptoms and range from 0–30. PPS scores range from 10–100, with higher scores indicating a higher level of play or daily activities.

then- and post-test scores (adapted change). To determine whether response shift had occurred, then-test scores were compared with pretest scores. As the assumptions for normalcy were not met, all comparisons were analyzed using a Wilcoxon signed-rank test with an alpha level of 0.05. To test the relationship between child and parent report, Spearman’s correlation coefficient was used.

Results

Health Status and Quality of Life

Thirty-seven children (aged 8–17 years), their parents, and 43 parents of children aged 2–7 years (80 parents in total) participated in the study (see Table 1). The median parent-reported PPS values increased ($Z = -3.54, p < 0.001$), indicating that the children’s health status improved during the period shortly after diagnosis until three months later. In addition, both children and parents reported fewer symptoms on the MSAS at the post-test than at the pretest (child report, $Z = 3.23, p < 0.001$; parent report, $Z = 4.46, p < 0.001$) (see Table 2).

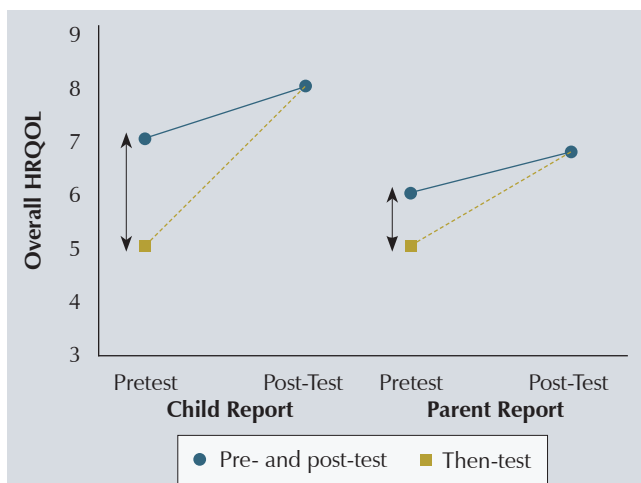
The median child-report ratings of aPedsQL improved ($Z = -2.81, p < 0.001$). However, the increase of the ratings on Cantril’s ladder were not significant ($Z = -1.23, p = 0.219$). The parent-reported scores demonstrated improved HRQOL for aPedsQL ($Z = -4.33, p = 0.028$)

and Cantril’s ladder ($Z = -3.1, p < 0.001$). In keeping with the improved health status, HRQOL ratings improved.

Response Shift

Overall health-related quality of life: To determine the influence of response shift on the child- and parent-report ratings, the scores of the then-tests and pretests were compared. Wilcoxon signed-rank tests indicated that both children and parents rated the overall HRQOL (Cantril’s ladder) retrospectively lower than at the pretest (see Figure 2). The median value of the child-report pretest was 7, and 5 for the then-test ($Z = -4.4, p < 0.001$). The median value of the parent-report pretest was 6, and 5 for the then-test ($Z = -2.52, p = 0.012$). In the response shift literature, this difference is interpreted as an overestimation of overall HRQOL at the pretest. The improvement in overall HRQOL according to the then-test versus post-test design (adapted change) was significantly greater than when based on the pretest versus post-test design both for child and parent report ($Z = -3.9, p < 0.001$; $Z = -4.17, p < 0.001$).

Domains of health-related quality of life: The aPedsQL then-test of both child report and parent report did not differ from the pretest ($Z = -0.57, p = 0.572$ for child report, $Z = -0.08, p = 0.935$ for parent report), indicating no response shift for the aPedsQL. Separate analyses of the domains of the aPedsQL demonstrated the largest difference between pre- and then-test in the domain of



HRQOL—health-related quality of life

Note. Then-test ratings are lower than pretest ratings both for child report ($p < 0.001$) and parent report ($p < 0.05$). The improvement in overall HRQOL according to then- and post-test design is larger than the improvement according to pre- and post-test design ($p < 0.001$ both for child and parent report). Child report response shift is larger than parent report response shift ($p = 0.001$). Median values are presented.

Figure 2. Response Shift of Overall HRQOL of Child-Reported (n = 37) and Parent-Reported (n = 80) Ratings

emotional functioning, namely 75 at pretest and 69.32 at then-test. However, that difference was not significant ($Z = -1.74$, $p = 0.081$). Therefore, no response shift could be confirmed for emotional functioning. Then-test ratings and pretest ratings for the other child-report domains and for all parent-report domains showed no differences.

These results demonstrate that only the ratings of Cantril's ladder were affected by response shift, resulting in an underestimation of the extent of improvement in overall HRQOL between diagnosis and three months postdiagnosis. The aPedsQL ratings were not affected.

Child and Parent Ratings

For this section, the data of 37 child and parent reports were compared pairwise. The pre- and post-test ratings of child and parent report of both Cantril's ladder and aPedsQL were positively related: Spearman's rho varied between 0.48–0.7 (see Table 3). Parent-reported ratings of HRQOL were lower than child-reported ratings both for Cantril's ladder and for aPedsQL at pre- and post-test.

Because no response shift was found for the PedsQL, additional analyses were performed for Cantril's ladder only. The child and parent report then-test and response shift of Cantril's ladder were positively related. Cantril's then-tests did not differ between child and parent report. Although, at the pretest, children and parents rated the overall HRQOL differently, in retro-

spect their perception of overall HRQOL shortly after diagnosis was the same. Comparison of the magnitude of Cantril's response shift revealed a scale recalibration of -2 points in child report and -1 point in parent report. The effect size for child report was -0.74 , and -0.3 for parent report. Children overestimated the pretest more than parents did ($Z = -3.27$, $p = 0.001$).

Discussion

This study is the first to explore response shift in the assessment of HRQOL in childhood patients with cancer. The authors' findings are threefold. First, in keeping with an improved health status, HRQOL improved within three months postdiagnosis. Second, both child and parent report ratings of overall HRQOL were affected by response shift, whereas the more specific domains of HRQOL were insensitive to response shift. Third, children experienced a greater response shift than parents.

Because the health status improved within three months after diagnosis, an improved HRQOL was to be expected. However, one measure did not show a significant change. The change in overall HRQOL (Cantril's ladder) was underestimated because of response shift. After taking response shift into account, the improvement of overall HRQOL was profound for both child and parent report. That the children's health status and HRQOL improved so quickly in the three months after diagnosis is a positive finding, despite the fact that they still were in treatment. Only a few studies have assessed HRQOL in this early phase of treatment and reported either an improvement (Klaassen et al., 2010; Landolt, Vollrath, Niggli, Gnehm, & Sennhauser, 2006; Penn et al., 2008) or no changes in HRQOL (Magal-Vardi et al., 2004). Unfortunately, those studies used different time intervals, which make a comparison with the current article difficult.

The finding of response shift for overall HRQOL is consistent with previous research in adult patients (Adang, Kootstra, Engel, van Hooff, & Merckelbach, 1998; Ahmed et al., 2004; Schwartz et al., 1999; Visser, Oort, & Sprangers, 2005). It corresponds with the then-test hypothesis in the literature, stating that adjustment to an improved health status may lead to lower then-test than pretest ratings (Jansen et al., 2000; Schwartz & Sprangers, 2010). The pretest overestimation of HRQOL might be explained by children's and parents' coping style to be positive despite the severe illness (Miedema, Hamilton, Fortin, Easley, & Matthews, 2010; Phipps, 2007). The fact that the aPedsQL seems to be unresponsive to response shift can be explained by its concreteness. Concrete items are known to be less sensitive to response shift compared to broad domains like overall HRQOL (Ahmed et al., 2004) because a concrete item

offers less room for personal interpretation. Other studies using HRQOL instruments at overall and domain level found comparable results (Jansen et al., 2000; Magal-Vardi et al., 2004). The only exception in the findings was the aPedsQL domain of emotional functioning, which showed the largest difference between pre- and then-test. However, because of the small sample size, statistical significance could not be confirmed. Additional research is needed to demonstrate whether child report of emotional functioning is sensitive to response shift. Because the aPedsQL was very representative for the PedsQL instruments, the authors believe comparable results would have been found when using the total PedsQL. Therefore, for future studies that aim to demonstrate changes in HRQOL, the use of the PedsQL instruments is recommended; whereas the use of a global measure like Cantril's ladder is not advisable.

The finding of response shift in the parent report is congruent with a study examining response shift in children with middle ear infection. Although the health of these children had improved six weeks after surgery, parents rated their child's HRQOL at the then-test more negative than at the pretest (Timmerman, Anteonis, & Meesters, 2003). An improved health status resulted in a shift in internal standards when parents realized that the initial HRQOL was worse than perceived at the moment itself.

Although recall bias might explain the differences between pre- and then-test ratings, some facts argue against recall bias. A study of patients who had suffered a stroke, for instance, examined the influence of memory and found that those with good memory reported the largest response shift (Ahmed et al., 2004). In another study, the memory ratings of the pretest turned out to be very similar to the pretest itself, whereas the then-test ratings differed significantly (Howard et al., 1979). In addition, that recall bias would influence the ratings of only the overall HRQOL and not of both measures of HRQOL is unlikely. The fact that the then- and pretest ratings of the PedsQL were the same indicates that the child and parent were perfectly able to remember the child's condition shortly after diagnosis. Research has demonstrated that children aged 8 years and older could handle a four-week recall period accurately (Rebok et al., 2001). In measures assessing life events, a three-month period resulted in valid and reliable outcomes (Costello, Angold, March, & Fairbank, 1998). In addition, because being diagnosed with cancer is such an overwhelming and daunting ex-

perience, the authors believe children and parents have a vivid memory of this period even after three months, thus diminishing recall bias. However, additional research on the reliability of recalling a period of time three months prior is desirable. Another risk factor that should be taken into consideration when using self-report measures is reporting bias. Children and parents might have rated the then-test lower than the pretest because they feel the situation of the child should have improved as a result of the intensive treatment.

The authors investigated similarities and differences in child and parent reports. Consistent with other studies in pediatric patients with cancer, parents rated the HRQOL of their children lower than the children themselves did (Chang & Yeh, 2005; Eiser & Morse, 2001; Levi & Drotar, 1999; Parsons, Barlow, Levy, Supran, & Kaplan, 1999; Vance, Morse, Jenney, & Eiser, 2001), whereas child and parent ratings were moderately to strongly and positively related (Chang & Yeh, 2005; Eiser & Morse, 2001; Russell et al., 2006; Vance et al., 2001). The effect size of the child- or parent-reported response shift differed considerably. According to Cohen's (1992) criteria, the effect size of parent report was small and comparable with mean effect sizes of overall HRQOL demonstrated in adult patients (Schwartz et al., 2006), whereas the child-report effect size was large. Therefore, the child report of overall HRQOL was more severely biased by response shift than the parent-report ratings. The difference in effect size might be explained by the fact that parents more often have substantial information about the disease and treatment than their child, and are more aware of possible complications and risks. This information and the uncertainty about the prognosis results in lower parent-reported than child-reported ratings of the child's HRQOL at the pretest (Levi & Drotar, 1999). In addition, children

Table 3. Comparing Child- and Parent-Reported Ratings (N = 74)

Variable	Child Report (n = 37)		Parent Report (n = 37)		Difference ^a	Correlation ^b
	M	IQR	M	IQR		
Cantril's ladder						
Pretest	7	2	6	3	< 0.001	0.48*
Post-test	8	2	7	2	< 0.001	0.7*
Then-test	5	3	5	3	0.877	0.55*
Response shift	-2	3	-1	4	0.001	0.55*
PedsQL						
Pretest	71.43	19.64	59.62	26.79	< 0.001	0.64*
Post-test	76.79	24.11	69.64	25	0.001	0.6*

* p < 0.01

^a Wilcoxon signed-rank test

^b Spearman's rho

IQR—interquartile range; M—median

Knowledge Translation

Measurements of overall health-related quality of life (HRQOL) were affected by response shift, resulting in an underestimation of the improvement in overall HRQOL between diagnosis and three months postdiagnosis.

Application of Cantril's ladder to evaluate the effect of nursing interventions on HRQOL, for example, may result in underestimation of the effects, as the measurements of Cantril's ladder are prone to response shift bias.

Application of the PedsQL instruments has to be preferred above a general instrument such as Cantril's ladder in studies that aim to determine deterioration or improvement in HRQOL.

seem to have different response styles than their parents. Children provide more extreme scores and base their judgment on one single example, whereas parents try to give a more balanced rating (Davis et al., 2007).

In contrast to the pretest ratings, the then-test ratings of overall HRQOL of children and parents were the same. They had a similar perception of the past HRQOL, probably because they shared the same experience and because the then-test ratings were not affected by adaptation. Comparable results were found in a study among chronically ill patients in which, contrary to the pretest ratings, the patients' then-test ratings corresponded to the proxy ratings (Postular & Adang, 2000).

Limitations

Some limitations of this study should be noted. First, the final sample consisted of motivated respondents who felt able to participate in the study. Although this phenomenon is not uncommon in survey research, it means that the final sample was not entirely representative of the total population of childhood patients with cancer. Another point to acknowledge is that patients had different diagnoses and, therefore, underwent different treatment regimens. However, the authors believe that neither the heterogeneity of the sample nor the nonresponse affected the magnitude or direction of response shift because response shift concerns differences within participants and not differences between participants. Testing this hypothesis in future research would be interesting. Second, given the large variation in HRQOL scores, the number of included children was too small to demonstrate changes in overall HRQOL or in the separate domains of HRQOL. However, the number was adequate to determine response shift. Third, although the aPedsQL was found to be representative of the PedsQL instruments, it has only been tested in this study. Replication in larger samples is warranted for additional validation.

In this study, the authors found an overestimation of overall HRQOL at the pretest. However, whether overall HRQOL at the post-test was overestimated as well is unknown. As a way of coping with the severe illness, children and parents might tend to present the child's quality of life as more positive than it actually is. Unfortunately, performing a then-test at three months after diagnosis is difficult because this time point is hard to mark. Additional research is needed on coping mechanisms such as repressive adaptation, wishful thinking, and social comparison in pediatric patients with cancer so as to provide more insight in the mechanisms responsible for response shift.

Another important discussion point is which measurement represents HRQOL the best: the actual pre- and post-test, or the retrospective then-test. The authors believe an actual test is preferable. However, researchers should be aware that some self-report measures, including Cantril's ladder, are sensitive to response shift and that measurements of change are biased and may lead to incorrect conclusions. This study demonstrated that the PedsQL instruments, which are frequently used in the assessment of HRQOL in children, were less sensitive to response shift than Cantril's ladder and were able to determine unbiased changes in HRQOL. Because the sample size was relatively small, additional research is warranted to determine how insensitive the PedsQL measures are in larger samples.

In summary, the improvement in overall HRQOL between diagnosis and three months postdiagnosis was underestimated by response shift. No response shift was demonstrated in the more specific domains of HRQOL. Therefore, the use of the PedsQL is recommended in studies that aim to demonstrate changes in HRQOL.

Implications for Nursing Practice

Nurses can learn from the current study that child- and parent-reported ratings of HRQOL can be biased by response shift. As a result, two or more consecutive measurements are not comparable and it becomes difficult to determine, for instance, the impact of treatment or the effect of a nursing intervention. One might wrongly conclude that severity of treatment has no impact on the child's HRQOL or that a nursing intervention does not contribute to HRQOL. Also, other subjective scales measuring pain, fatigue, or nausea could be sensitive to response shift (Schwartz et al., 2006). These measures are frequently used in nursing practice and knowledge of response shift helps nurses to better interpret the outcomes of such measures. In addition, the phenomenon of response shift offers an explanation for the high ratings of HRQOL despite severe illness. To the surprise of nurses and other healthcare professionals, children diagnosed with cancer are very

positive and optimistic, despite the child being severely ill and experiencing many side effects. They rate their HRQOL higher than nurses would expect. Knowledge of the response shift phenomenon will help nurses to understand and interpret these outcomes.

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Digital Object Identifier: 10.1188/14.ONF.41-01AP

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