

The Influence of Patient Reported Outcomes on the Discussion of Psychosocial Issues in Children With Cancer

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Background. This study investigates the effect of using patient reported outcomes (PROs) about health-related quality of life (HRQOL) in clinical practice on the type and amount of psychosocial topics discussed during a paediatric oncology consultation.

Procedure. Children (N = 193) with cancer participated in a sequential cohort intervention study, with a control (no PRO was used) and intervention group (a PRO was used). For each child three consecutive consultations with the paediatric oncologist were audio recorded in order to assess the discussed psychosocial topics. One third of the audio recordings were qualitatively analysed. **Results.** The type of the discussed psychosocial topics in the

control and intervention group did not differ from each other. However, the discussion of psychosocial topics increased in the intervention group compared to the control group. In both groups, topics within the social domain occurred most frequently and topics regarding the emotional domain had the lowest incidence.

Conclusions. PROs do not change the psychosocial content of communication. Paediatric oncologists already address psychosocial issues during the consultation, regardless of the use of a PRO. However, with a PRO available they address these issues more systematically and more often. *Pediatr Blood Cancer* 2012;59:161–166.

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Key words: communication; paediatric oncologists; patient reported outcomes; psychosocial functioning; quality of life

INTRODUCTION

Over the past decade, health-related quality of life (HRQOL) has become an important outcome measure in paediatric oncology research. The World Health Organisation defines quality of life (QOL) as ‘individuals’ perceptions of their position in life, in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns’ [1]. The concept of HRQOL refers to the impact of health and illness on an individual’s QOL [2]. In paediatrics, there are usually four HRQOL domains distinguished: physical, emotional, social and school (or cognitive) functioning, of which the last three can be summarized as psychosocial functioning [3].

Monitoring HRQOL by providing patient reported outcomes (PROs) in clinical practice has been the focus of several studies [4–10]. PROs are based on direct reporting by patients without the intervention of an observer. HRQOL assessment is a form of PRO that often includes both a patient’s functional status (physical and psychosocial) as well as his or her symptoms [11]. PROs can serve as an aid for the physician to systematically identify and discuss psychosocial problems. Positive effects of using PROs have been found for domains such as communication, satisfaction with care and HRQOL [4,5,10]. Still, it remains difficult to prove effectiveness of PROs in clinical practice [12]. Previous research [13] has opted that the integration of PROs in clinical practice can be facilitated by developing stronger theoretical foundations for their use, obtaining buy-in early on from clinicians and patients, and addressing the system-related and methodological barriers that exist. The use of more sophisticated interventions and stronger research designs are needed to move this area of applied research forward.

Children with cancer could also benefit from the use of PROs in clinical practice. Although psychological adjustment of children with cancer is generally good [14], children at risk for psychosocial difficulties in adapting to the disease have been identified [15], e.g. children with brain tumours. Additionally, several studies [16–22] demonstrate that childhood cancer diagnosis is related to poor HRQOL. Physicians are not always aware

of these problems, though [23,24]. In a recent paediatric oncology PRO study (the QLIC-ON study) [25], we illustrated that PROs in clinical practice result in more discussion of emotional and psychosocial functioning without lengthening the consultation. Additionally, more emotional and cognitive problems were identified using a PRO, compared to consultations in which no PRO was used. Based on these findings, we were interested in the content of this difference, firstly to better understand the effect of PROs during a paediatric oncology consultation, and secondly to contribute to PRO research in general. What types of psychosocial issues are discussed during the consultations and does the use of a

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PRO change the content of these psychosocial issues? The aim of the current study, which is a continuation of the QLIC-ON study [25], is to investigate the effect of using a PRO (about HRQOL) in clinical practice on the type and amount of psychosocial topics discussed during a paediatric oncology consultation.

METHODS

Intervention

The intervention consisted of providing a PRO about HRQOL (the QLIC-ON PROfile, Supplemental Fig. 1) to the oncologist. The QLIC-ON PROfile presents four HRQOL domains (physical, emotional, social and cognitive functioning) by summarising the answers of child or parent on two generic HRQOL questionnaires: the PedsQL Generic Core Scale (Pediatric Quality of Life Inventory) [3,26] or the TAPQOL (TNO-AZL Preschool children Quality of Life) [27,28]. The PedsQL self-report form was used for children aged 8–18; parents of children aged 6–7 completed the PedsQL proxy-report. Dutch PedsQL norm scores were available [26]. The PedsQL is brief to administer (approximately 5–10 minutes) and good utility, validity and reliability [3]. The TAPQOL was used for parents of children aged 0–5 years (proxy-report). Dutch TAPQOL norm scores were available as well. Completion time is about 5–10 minutes and psychometric properties are satisfactory [27,28].

Paediatric oncologists were instructed to discuss the items identified as a problem (the red and orange answers on the QLIC-ON PROfile). To optimise the effectiveness of the QLIC-ON PROfile, we developed a training which comprised an individual and a group session for paediatric oncologists, and a patient instruction [29]. The development and implementation of the QLIC-ON intervention (including the training) were extensively described in a previous study [29].

Participants

Participants of the QLIC-ON study were children with cancer (0–18 years) shortly (0–3 months) after completion of treatment, their parents and treating paediatric oncologists. The QLIC-ON study is a large Dutch multi-centre research project in which the Academic Medical Centre/Emma Children's Hospital, Leiden University Medical Centre, Radboud University Medical Centre and the VU University Medical Center joined. The Medical Ethics Committees of all participating centres approved the study.

Procedure

Children and parents were invited by mail to participate as soon as the child had finished treatment. Children with cancer who had undergone stem cell transplantation (SCT) were approached for participation 6 months after SCT. Informed consent was obtained in the out-patient clinic shortly before the first consultation. All measures were completed on paper, except for the QLIC-ON PROfile which was completed digitally on a laptop in the out-patient clinic prior to each of the three consultations.

All consultations were audio recorded utilizing an audio device in order to assess different aspects of communication about HRQOL domains. After the consultation, the audio recording was digitally exported to a computer and saved as the unique child study ID including the date. Only the researchers had access to the key of this code.

Reasons for absent audio recordings were no parental or child consent for audio recording the consultation, drop-out due to relapse of the disease or practical reasons (e.g. technical problems). One third of the audio-tapes were (block) randomly selected and analysed (Table I). If available, each child was included once for analysis.

Study Design

The QLIC-ON PROfile was completed by the child or parent and provided to the oncologist during three consecutive consultations by means of a sequential cohort design. As we described in a previous study [29], randomisation was regarded unsuitable due to the risk of contamination. The study consisted of a control period (QLIC-ON PROfile was completed but not provided) and an intervention period (QLIC-ON PROfile was completed and provided). Oncologists participated in the control as well as the intervention period; children and parents took part in either the control period or the intervention period. To prevent contamination of the control period, oncologists started the intervention period (with the training), only as soon as all children from the control period had finished their three consultations. Both groups were evaluated before (baseline) and during (consultation evaluation) the three consultations.

Measures

Socio-demographic and medical information. Socio-demographic data of participating children and parents were collected at baseline. Child age and gender in the non-participants group were retrieved from medical files. Medical information of participants as well as non-participants was gathered by data managers or oncologists. Socio-demographics of the oncologist were collected at the start of the study: age, gender and years of work experience as an oncologist.

Communication about HRQOL topics. For the current study the (semi-open) audio-assessment form was developed to score the audio recordings of the consultations. The form entailed four HRQOL domains (physical, emotional, social and cognitive functioning), each containing open spaces on which the researcher depicted all topics that came up during the consultation. For example, topics such as 'skin', 'sleeping' and 'walking' were categorised within the physical domain; topics such as 'fear', 'anger' and 'coping' were included within the emotional domain; issues concerning 'friends', 'family' and 'hobbies' were classified within the social domain and finally, topics such as 'school progress', 'teacher' and 'exams' were written down within the cognitive domain. The few topics that could not be covered by the HRQOL domains were classified within the 'Other' category.

TABLE I. Number of (analysed) Audio-Tapes per Consultation

	Control	Intervention	Total
Total audio-taped consultations (N)	216	237	453
Randomised audio-taped consultations (N)	77	78	155
Audio-tapes consultation 1 (N)	26	26	52
Audio-tapes consultation 2 (N)	24	29	53
Audio-tapes consultation 3 (N)	27	23	50

These were mainly issues unrelated to the child and its disease, e.g. the weather, traffic or work of parent. Additionally, the audio-assessment form included some closed questions to rate the consultation, however these data are reported elsewhere [25].

The researcher that scored the consultations on the audio-assessment form remained as close as possible to the phrasing that the persons in the consultations used. Furthermore, the researcher was unaware if the consultation originated from the control or intervention group. To ensure reliable and valid scoring of the consultations a manual containing definitions and rules, regarding which types of topics belong to which of the domains, was applied.

Analysis

Socio-demographic and medical variables. Socio-demographic and medical data were analysed with SPSS 16.0.2. The difference between participants and non-participants, as well as the control and intervention group regarding age group, gender, diagnosis, treatment, country of birth, education and employment was analysed by means of χ^2 tests. Difference in age and treatment duration was examined with *t*-tests.

Communication about HRQOL topics. The software program MaxQDA was used as an aid for analysis. Where possible and appropriate, the principles of framework analysis [30] were applied by the first author to the depicted topics gathered with the audio-assessment forms. Framework analysis was only partly applicable, though, because the collected topics already summarized parts of the conversation; the audio-assessment forms did not provide literal transcripts but a list of topics. Per HRQOL domain these topics were given codes, and if necessary sub codes, for the control and intervention group separately. This resulted in a code tree per HRQOL domain per group.

The number of times that a code occurred was counted per group (control vs. intervention) and not per consultation. It is therefore possible that some codes came up more than once during a consultation, e.g. 'sports'. If a child mentions to play soccer and judo and also goes to swimming class, than all three topics are depicted on the audio-assessment form and thus the frequency of the code 'sports' is 3. Subsequent sub codes are 'soccer', 'judo' and 'swimming'.

Subsequently, codes with a frequency of less than four were excluded from analysis, since their value is limited. The remaining codes (and belonging sub codes) of both groups were then compared per HRQOL domain by the first two authors to decide whether there was a substantive difference. The physical functioning domain was excluded from analysis, because we were especially interested in psychosocial functioning (emotional, social and cognitive functioning).

Eventually the codes are presented (as topics) in tables divided over three categories: (i) topics that were discussed in both groups, (ii) topics that were discussed in both groups, but the frequency of the topics is less than four in one of the groups and (iii) topics discussed in only one group.

RESULTS

Socio-Demographic and Medical Variables

Two hundred and seventy four children with cancer and their parents were approached to participate. Participants were
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significantly younger ($P < 0.01$) and they had undergone significantly less radiotherapy ($P < 0.05$) and SCT ($P < 0.01$) compared to non-participants. For treatment duration, child gender, diagnosis, surgery and chemotherapy no statistically significant differences were observed among the groups [25].

Eventually, 193 (70.4%) participants completed the baseline assessment. Ninety-nine children participated in the control group with a 14.3% drop-out rate; 94 in the intervention group with a 21.3% drop-out rate. Main reasons for drop-out were relapse of the disease and interference of end of data collection with unacceptable long intervals between the consultations, especially between consultation 2 and 3 in the intervention group. There were no statistically significant differences with respect to socio-demographic and medical variables between participants in the control and the intervention group (Table II). A total of 34 paediatric oncologists took part; 47.1% were female, average age was 41.9 (SD 10.1) and mean work experience as an oncologist was 8.7 years (SD 7.6).

Emotional Topics

Emotional topics that were discussed in the control and intervention group are presented in Table III. In the control group the topics 'tension', 'coping' and 'anger' occurred most frequently during the consultations; in the intervention group 'fear', 'sadness' and 'anger' came up most often. 'Emotional functioning' and 'blue' were only discussed in the intervention group.

Social Topics

Table IV demonstrates the social topics that were discussed in the control and intervention group. In the control group as well as the intervention group the topics 'sports' and 'holiday/travel' had the highest frequency. Additionally, in the control group the topic 'playing' was also discussed quite often; in the intervention group the incidence of the topic 'behaviour' was fairly high. The topic 'going out' only came up in the intervention group.

Cognitive Topics

There was no difference in cognitive topics that occurred most frequently when comparing the control and intervention group (Table V). In both groups the topics 'school (unspecified)', 'school attendance' and 'school progress' had the highest incidence. The topic 'fatigue', however, only came up in the intervention group.

Other Topics

With respect to the 'other' category, there was only one topic that had a frequency higher than three, namely 'parental topics unrelated to the child', which was discussed in both groups: control (frequency 25) and intervention (frequency 13).

DISCUSSION

The current study demonstrates that using a PRO (about HRQOL) in clinical paediatric oncology practice increases the amount of psychosocial topics, but it does not influence the type of psychosocial topics discussed during a consultation. The discussion of emotional, social and cognitive functioning

TABLE II. Socio-Demographic and Medical Variables: Control Versus Intervention Group

	Control (N = 99)			Intervention (N = 94)		
	N	M	SD	N	M	SD
Child						
Age (years)	99	9.13	5.07	94	9.41	5.03
Treatment duration (months) ^a	98	13.27	9.37	92	14.02	8.98
Time off treatment (weeks) ^b	98	7.17	4.15	93	8.04	4.88

Child	Control (N = 99)		Intervention (N = 94)	
	N	%	N	%
Age group (years)				
0–4	27	27.3	25	26.6
5–7	20	20.2	16	17.0
8–11	19	19.2	18	19.1
12–18	33	33.3	35	37.2
Gender (female)	46	46.5	46	48.9
Diagnosis ^c				
Leukemia	35	34.4	34	36.2
Lymphoma	12	12.1	12	12.8
Brain tumor	8	8.1	8	8.5
Solid tumor	21	21.2	21	22.3
Bone tumor	16	16.2	13	13.8
Other	7	7.0	6	6.4
Treatment				
Surgery	53	54.1	48	51.6
Radiotherapy	31	31.6	24	25.8
Chemotherapy	97	99.0	87	93.5
SCT	13	13.3	5	5.4

Parent	Control (N = 99)			Intervention (N = 94)		
	N	M	SD	N	M	SD
Age (years)	97	41.05	6.90	93	40.72	7.38

Parent	Control N=99		Intervention N=94	
	N	%	N	%
Gender (female)	77	81.05	73	81.1
Country of birth (Netherlands)	84	85.7	82	88.2
Education ^d				
Low	21	21.4	16	17.4
Middle	50	51.0	46	50.0
High	27	27.6	30	32.6
Employed	65	66.3	60	64.5

N, number; M, mean; SD, standard deviation. ^aTreatment duration: date of end of treatment minus date of diagnosis. ^bTime off treatment: date of completion of the HRQOL questionnaire minus date of end of treatment (only for participants). ^cDiagnosis: *Leukemia*, lymphoid leukemia and acute myeloid leukemia; *Lymphoma*, Hodgkin lymphoma and Non-Hodgkin lymphoma; *Brain tumor*, ependymoma and choroid plexus tumor, astrocytoma and low grade glioma, intracranial and intraspinal embryonal tumor, intracranial and intraspinal germ cell tumor; *Solid tumor*, neuroblastoma and ganglioneuroblastoma, renal tumor, hepatic tumor, rhabdomyosarcoma, fibroblastoma, peripheral nerve sheath tumor, and fibrous neoplasm; *Bone tumor*, osteosarcoma, ewing tumor and related sarcoma of bone. ^dEducation: *Low*, no education, primary school and primary vocational education; *Middle*, secondary school and secondary vocational education; *High*, higher vocational education and university.

TABLE III. Type and Frequency of Discussed Topics Within the Emotional HRQOL Domain: Control Versus Intervention Group

Topic	Emotional domain	
	Control group (n)	Intervention group (n)
Total	63	114
Anger	6	12
Tension	6	11
Coping	6	6
Cheerful	5	7
Fear	4	18
Crying	4	[1]
Sadness	[3]	13
Worries	[3]	6
Emotional functioning	[0]	6
Gloomy	[0]	8

[n], topics with a frequency of less than four were excluded from analysis. ^aTopics discussed in both groups; ^bTopics discussed in both groups but n < 4 in one group; ^cTopics discussed in one group.

increased in the intervention group compared to the control group. In both groups, topics within the social domain occurred most frequently and topics regarding the emotional domain had the lowest incidence. The amount of discussed topics within the ‘other’ category decreased in the intervention group in comparison with the control group. Overall, these findings are in agreement with previous research [4,5]. PROs have a positive impact

TABLE IV. Type and Frequency of Discussed Topics Within the Social HRQOL Domain: Control Versus Intervention Group

Topic	Social domain	
	Control group (n)	Intervention group (n)
Total	288	308
Sports	71	98
Holiday/travel	53	46
Playing	21	12
Friends	17	23
Siblings	16	14
Family	16	7
Trips	14	5
Behaviour	13	25
Parents	12	14
Birthday/party	10	11
Social interaction	7	16
(Creative) Hobby	7	8
‘Make a wish’ activity	5	7
Job	4	[3]
Going out	[0]	5

[n], topics with a frequency of less than four were excluded from analysis. ^aTopics discussed in both groups; ^bTopics discussed in both groups but n < 4 in one group; ^cTopics discussed in one group.

TABLE V. Type and Frequency of Discussed Topics Within the Cognitive HRQOL Domain: Control Versus Intervention Group

	Cognitive domain	
	Control group (n)	Intervention group (n)
Total	165	229
Topic		
School (unspecified)	43	31 ^a
School attendance	13	20
School progress	11	21
Day care/after school care	10	8
Exam/test	9	12
Teacher	8	15
Intelligence/school performance	8	10
Type of education/continued education	7	14
Attention/concentration	5	15
School/class transition	5	5
Additional guidance/remedial teaching	5	15
Writing/drawing	5	7
Reading	5	[2] ^b
Speech (therapy)	[3]	4
Course	[3]	6
Social-emotional functioning	[2]	5
Homework	[1]	9
Forgetting	[1]	6

[n], topics with a frequency of less than four were excluded from analysis. ^aTopics discussed in both groups; ^bTopics discussed in both groups but n < 4 in one group.

on patient–physician communication; they increase systematic attention to psychosocial topics. From previous studies we know that effective patient–physician communication can be of crucial importance to psychosocial outcomes in patients with cancer [31,32].

In general, the same type of topics regarding emotional, social and cognitive functioning came up during a paediatric oncology consultation, regardless of the use of a PRO. This implies that paediatric oncologists already address all the relevant psychosocial topics. In a previous interview study (submitted), we found that paediatric oncologists defined ‘psychosocial functioning’ as emotional (e.g. psychological well-being and coping), social (e.g. family, friends, peers, clubs and sports) and school functioning (e.g. school presence and school performance). This definition validates the results of the present study, since comparable topics were discussed during the consultations and it concerns the same sample of paediatric oncologists. Still, the interview study also taught us that paediatric oncologists sometimes perceive hesitations and uncertainties towards their task in psychosocial functioning, e.g. lack of time or expertise. The current study demonstrates that paediatric oncologists are well aware of and address psychosocial issues in children with cancer. However, these issues are not always consequently discussed during the consultation. Our results illustrate that PROs are a way to make sure that psychosocial functioning is systematically and not occasionally addressed during the consultation. Systematic attention for psychosocial functioning is important in order to identify children at risk for psychosocial difficulties and the paediatric oncologist has a responsibility of identifying psychosocial

difficulties in children with cancer [33,34]. Thus, PROs are helpful, but from practice experience and literature we know that physicians are sometimes reluctant or hesitant towards the use of PROs [35,36]. Therefore, we underline that PROs are intended to help the physician *identify* and not *solve* psychosocial problems. Psychosocial problem solving is mostly beyond the scope of the expertise of a physician. In case of a psychosocial problem, the physician’s task is mainly limited to referring to psychosocial care [37] or giving tailored advice, if he feels competent.

The strength of this study is that it is the first paper that qualitatively reports on communication about psychosocial topics within a paediatric oncology consultation. For paediatric oncologists it is interesting to learn what type of psychosocial issues are usually discussed during a consultation, that these topics concern relevant issues and how PROs can help them discussing these issues more systematically. For PRO researchers this paper provides new qualitative information with respect to the effect of PROs on the content of communication. Results of this study contribute to establishing the effectiveness of PROs, which is still difficult [12]. Another strength of our study is that it is a multi-centre study with a relatively large sample size.

The study limitations need to be considered. The researcher who analysed the consultations with the audio-assessment form was blind to the consultation (control or intervention group). However, it was fairly easy to recognise a consultation from the intervention group, since the QLIC-ON PROfile is sometimes mentioned during the consultation. Nonetheless, we believe we could minimize the bias because analyses were performed according to the instructions in the manual. Furthermore, only one third of the audio-recorded consultations (N = 155) were analysed, due to time constraints. Although analysing all consultations (N = 453) would have provided us with more data, we do not expect this would have changed or added to our current results, because we subtracted the consultations as randomly as possible. Additionally our results may not be representative of other countries, because the organisation and quality of paediatric oncology health care systems can vary. Furthermore, less children with radiotherapy and SCT participated. These children might have more difficulties than children receiving only chemotherapy, because of the burdensome nature of these forms of therapy. Therefore, these children could experience more psychosocial problems, which implies that our findings may not be representative for the more seriously ill children. Another reason that could explain why we did not find any differences between the two groups is a limitation in the applied study design. Although the QLIC-ON PROfile was not used in the control group, participants did complete a HRQOL questionnaire which could trigger them to address these issues during the consultations.

A suggestion for future research is to examine the effect of, e.g. physician’s gender and experience on patient–physician communication with the use of PROs. Physician’s level of training is known to have a confounding effect on doctor–patient interactions [37]. There are probably individual differences between physicians with respect to communication; however, these weren’t investigated in the current study. More knowledge about physician’s characteristics will lead to more knowledge of how to train physicians with different characteristics to use PROs. Furthermore, it is important to note that we only used generic questionnaires (PedsQL and TAPQOL) as PROs. We strongly recommend future studies to include disease specific questionnaires as a PRO

as well, to give the physician more specific information about the child. In addition, we advise the application of more advanced techniques such as PROs via internet [29,38], which will result in increasing the user friendliness of the PRO assessment.

We conclude that PROs do not change the psychosocial content of communication. Paediatric oncologists already address psychosocial issues during the consultation, regardless of the use of a PRO. However, with a PRO available they address these issues more systematically and more often.

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