Monitoring quality of life in paediatric oncology practice

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Chapter 8

General Discussion
1. Aims

This PhD thesis presented the results of the Quality of Life In Childhood Oncology (QLIC-ON) study. Aims of the QLIC-ON study included:

- to investigate the effectiveness of an intervention that provides a patient reported outcome (PRO) tool about health related quality of life (HRQOL) (the QLIC-ON PROfile, p. 173) to the paediatric oncologist (chapter 6);
- to examine the effect of using the QLIC-ON PROfile in clinical practice on the type (and amount) of psychosocial topics discussed during a paediatric oncology consultation (chapter 7).

To provide more insight in the issues around PROs in paediatric oncology additional aims of this thesis included:

- to collect Dutch reference data of an international HRQOL measure (PedsQL) and to assess reliability, socio-demographic within-group differences and construct validity in the Netherlands (chapter 2);
- to determine HRQOL of children with cancer shortly after the end of successful treatment compared with normative values (chapter 3);
- to explore paediatric oncologists’ perception of their role in (1) discussing psychosocial functioning and identifying psychosocial problems and (2) providing emotional support to children with cancer (chapter 4);
- to provide a thorough description of the development and implementation of the QLIC-ON PROfile in clinical paediatric oncology practice (chapter 5).

2. Main findings

An overview of the studies presented in this thesis is provided in Table 1. This paragraph describes the main findings of each study.

In chapter 2 for 496 children from the general Dutch population HRQOL reference data were collected by means of the PedsQL. PedsQL total scores were 84.18 (group 5-7), 82.11 (group 8-12) and 82.24 (group 13-18). Internal consistency coefficients ranged from .53 to .85. With respect to construct validity, healthy children of group 5-7 and 13-18 scored significantly higher than children with a chronic health condition on all subscales, except for emotional functioning. No significant differences were found in group 8-12 regarding health. We conclude that the Dutch version of the PedsQL has adequate psychometric properties and can be used as a HRQOL instrument in paediatric research in the Netherlands.

Chapter 3 demonstrates that HRQOL in children with cancer (N=191, mean age 9.25,
SD 5.06, 47.1% female) shortly after completion of treatment and their parents can be
impaired compared with the norm. Physical well-being was affected for all ages. Compared
to normative values 0- to 7-year-olds with cancer were rated significantly lower on the
majority of the scales. In addition, 12 to 18 year old children with cancer had significantly
better HRQOL than the norm on social scales. Compared to chronically ill norms, children
with cancer aged 8 to 18 years demonstrated no differences, except for 12- to 18-year-
olds who experienced significantly more physical limitations. Additionally, we found
that HRQOL of parents of 0 to 7 year old children with cancer was poorer than the norm.
We conclude that HRQOL in children with cancer can be impaired and that paediatric
oncologists should be aware of these problems.

Twenty-four paediatric oncologists were interviewed for the purpose of chapter 4. In
general, paediatric oncologists believed that it was their task to discuss psychosocial
functioning, to identify psychosocial problems and to provide emotional support to
children with cancer. Provided perceptions with respect to this task were e.g. that it is
‘inherent to being a paediatrician’ and that they apply ‘a holistic view on medicine’ and feel
‘responsible for psychosocial referrals’. Paediatric oncologists also indicated that this task
can be limited due to e.g. their inherent lack of expertise, lack of time or by the physician’s
personality. We conclude that paediatric oncologists felt responsible for providing
psychosocial care to the best of their ability.

The QLIC-ON PROfile is a PRO tool applied in paediatric oncology. Important
considerations regarding the development and implementation of the QLIC-ON PROfile
intervention are reported in chapter 5. These considerations have also resulted in
educational material. Our findings add to current knowledge in PRO research. This chapter
can be used as an initial guide for researchers and other professionals, who are interested
in setting up PRO interventions in clinical practice.

Chapter 6 describes the effectiveness of the QLIC-ON PROfile. The QLIC-ON PROfile
increased discussion of emotional functioning (control M=32.9 vs intervention M=47.4,
p<0.05) and psychosocial functioning (M=56.9 vs M=63.8, p<0.05). Additionally more
emotional problems remained unidentified in the control compared to the intervention
group, e.g. anger (control 26% vs intervention 3%, p<0.01), fear (14% vs 0%, p<0.01) and
sadness (26% vs 0%, p<0.001). The intervention had no effect on satisfaction and referrals,
but did improve HRQOL of patients 5 to 7 years of age with respect to self esteem (p<0.05),
family activities (p<0.05) and psychosocial functioning (p<0.01). We conclude that a
PRO is a helpful tool for systematic monitoring HRQOL of children with cancer, without
lengthening the duration of the consultation.

Finally, chapter 7 demonstrates that the type of the discussed psychosocial topics in
the QLIC-ON 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. We conclude that
paediatric oncologists address psychosocial issues in clinical practice, but with a PRO available they address these issues more often.

3. Key messages

Altogether, the main findings of this thesis lead to three key messages:

- PROs in clinical practice increase identification and discussion of psychosocial problems
- Successful use of the QLIC-ON PROfile in clinical practice: making the right choices
- Paediatric oncologists feel responsible for the identification of psychosocial problems

3.1. Reflections on key messages

3.1.1. PROs in clinical practice increase identification and discussion of psychosocial problems

This thesis demonstrates that the use of PROs in paediatric oncology practice increased the discussion of emotional and psychosocial functioning, increased the time spent on emotional and cognitive domains and enhanced the identification of emotional and cognitive problems, without lengthening the consultation duration (chapter 6).

It is known that effective patient–physician communication is of crucial importance to psycho-social outcomes in patients with cancer [1, 2]. Therefore, we regard the increased identification and discussion of psychosocial problems as the most important effect of our PRO intervention. This is supported by a previous study which demonstrated that if adult cancer patients felt that more attention had been paid to psychosocial aspects of their illness they were more satisfied with their consultations [3]. Additionally, other research concluded that showing compassion by physicians can reduce anxiety in cancer patients [4]. However, oncologists in adult cancer care are not always recognising or dealing with emotional needs. If doctors do not recognise and acknowledge patients’ cues for emotional support, patients will be discouraged from seeking that support [5]. This is in line with a previous study [6] illustrating that the lack of psychosocial questions from oncologists demonstrates how emotional issues remained mostly uninvestigated. With a PRO tool available, psychosocial issues will gain more systematic attention which will eventually benefit secondary outcomes such as HRQOL and overall psychosocial functioning, even though we haven’t been able to prove effectiveness of PROs on these secondary outcomes. However, if psychosocial problems are detected in an early stage, appropriate intervention can prevent the child from having more serious psychological difficulties at a later time. This is supported by a previous study [7] which demonstrated that the beneficial effects of a HRQOL PRO tool intervention in adolescents with diabetes largely disappeared one year after withdrawing the HRQOL monitoring procedure. The authors underscore the importance of integrating a HRQOL PRO tool in routine care for
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<td>Although within limits, paediatric oncologists believe it is their task to discuss psychosocial functioning, to identify psychosocial problems and to provide emotional support in children with cancer</td>
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The QLIC-ON PROfile:
- increased discussion of emotional and psychosocial functioning
- improved identification of emotional problems
- had no effect on consultation duration, satisfaction and referral
- improved HRQOL of 5- to 7-year-olds

Although within limits, paediatric oncologists believe it is their task to discuss psychosocial functioning, to identify psychosocial problems and to provide emotional support in children with cancer.
adolescents with diabetes.

Benefits of PROs in clinical practice have been demonstrated before [8-17], but it remains difficult to prove effectiveness [17-21]. The feedback of PROs to health professionals has, in some studies, had an impact on the process of care, with less evident impact on health outcomes [18]. This was also the case in the QLIC-ON study. Even though we incorporated a PRO and a training that were carefully developed, we did not find a convincing effect of PROs on secondary outcomes HRQOL, satisfaction and referrals. How come? HRQOL was assessed on average two weeks after the third consultation. Perhaps this interval was too short to measure effect of the intervention, but time did not allow more consultations or a follow-up assessment more than two weeks after consultation three. Or maybe the HRQOL instruments we used were not sensitive enough to detect a difference. Another explanation could be that most children finished treatment months ago and that their HRQOL is close to normal again [22], which also makes it difficult to demonstrate a difference. The use of the QLIC-ON PROfile had no effect on satisfaction either, despite a trend towards higher scores for the intervention group. Parents were already satisfied with the consultation, regardless of QLIC-ON PROfile use (ceiling effect [23]). Previous studies demonstrate mixed results with respect to satisfaction [8, 10, 24]. It is possible that the benefits of the QLIC-ON PROfile will be more evident if it is implemented in clinical practice for a longer period of time. Furthermore, our intervention had no effect on psychosocial referrals. This corresponds with earlier studies [8, 9]. According to Greenhalgh et al. [19], PROs were seen as more useful in overall patient management and physician-patient communication and less so in treatment decision making and referrals. Moreover, children had only recently completed treatment, and oncologists may therefore be more likely to adopt wait-and-see policy with fewer referrals as a consequence. Additionally, children with problems during treatment had probably already been referred for psychosocial care.

Nonetheless, the fact remains that PRO tools increase identification and discussion of psychosocial problems in clinical practice, which benefits patient-physician communication. Therefore we recommend implementing PROs in clinical practice.

3.1.2. Successful use of the QLIC-ON PROfile in clinical practice: making the right choices

We believe that various factors contributed to the success of the QLIC-ON PROfile (chapter 5). To begin with, the QLIC-ON study was the first study to report HRQOL outcome on item level with traffic light colours on the PRO tool. This gave the physician the opportunity to immediately focus on the actual problem. With the more traditional PROs, mostly only HRQOL scale scores were presented in graphs. This left the physician sometimes guess what the actual problem was within that HRQOL domain, since graphs are less specific compared to items.

Furthermore, as described in this thesis, the intervention consisted of more than simply
providing the QLIC-ON PROfile to the paediatric oncologist. We developed an individual training and a group training, in which a decision tree (Figure 1) and case studies on video were applied. The decision tree was intended as an aid for interpretation of the QLIC-ON PROfile; it distinguished three steps: (1) identifying a problem, (2) discussing the problem and (3) taking appropriate action towards the problem. Additionally, the case studies on video represented a real consultation of a child and parent visiting a medical specialist, using an actual QLIC-ON PROfile. The cases were implemented in the group training according to the following three steps: before demonstration (1) the QLIC-ON PROfile that occurred in the video was discussed and (2) a watching assignment was given, after demonstration (3) the use of the QLIC-ON PROfile in the video was evaluated. In addition, each case had its own learning goal: case 1) use of the QLIC-ON PROfile in general, case 2) use of the line graphs, and case 3) use of the decision tree.

The visual lay-out of the QLIC-ON PROfile and the developed training can be considered innovative in PRO research. The training was necessary in order to introduce physicians to the PRO tool, to demonstrate them the advantages and to give them examples and instructions of how to use it. An additional purpose of the training was to increase commitment towards the use of PROs. However, to further enhance the chance of successful use of PROs in clinical practice, several other important decisions were made, e.g. with respect to the study design, logistics, the type of PRO questionnaires and the person that uses the PRO.

First of all, it was important to consider which study design was most appropriate for the QLIC-ON study. We applied a sequential cohort design with a control and intervention group. Randomisation was not desirable due to the risk of contamination. Randomising the child was not an option, because in that case the paediatric oncologist had to be trained in advance and be prepared for any child, regardless of control or intervention condition. As soon as paediatric oncologists received the training and gained some experience in using the QLIC-ON PROfile, bias could occur when seeing children in the control condition. Randomising the paediatric oncologists was neither a possibility, because of overlapping responsibilities. Children are frequently discussed in team meetings in which all paediatric oncologists participate and it is not uncommon that paediatric oncologists share the treatment of a child. Finally, randomising the centres would lead to bias as well. Only four centres participated in our study and not all of them contributed equally to the study (the number of participating patients and oncologists differed). Furthermore, from practice experience we knew that there are some differences in hospital policy between the centres (e.g. shared care). Therefore, to prevent bias, a sequential cohort design was considered most suitable for the QLIC-ON study.

Secondly, the logistical organisation of a PRO intervention needs good thought. The QLIC-ON intervention was very labour-intensive. Every child completed the PRO during three consecutive consultations. These assessments took place on a standalone laptop in the outpatient clinic. A researcher was present during every assessment to set up all materials, to guide them through the procedure, to hand a copy of the QLIC-ON PROfile
Figure 1. Decision tree

1. Identify

- No, that’s not right
- There are no problems?
  - Yes, that’s right
  - Item (or domain) is green
  - Start
    - QLIC-ON PROFILE
    - Item (or domain) is red or orange
- Yes, that’s right
- There are problems?
  - No, that’s not right

2. Discuss

- Can you tell more about it?
- When does it bother you?
- How often does it bother you?
- (What is the reason, do you think?)
- How do you feel about it?
- What do you do about it? Does it help?
- Do you feel supported?
- Does it worry you?

3. Take action

- Is there a question for help?
  - Yes
    - Dependent on severity and need
      - Monitor
      - Advice
      - Referral
  - No

QLIC-ON Support: 020 - 516 82 25, vengelen@amc.uva.nl
to the paediatric oncologist and to make sure the consultation was audio taped. To increase the chance of successful implementation of PROs in clinical practice in the future, this logistical barrier can be overcome by making use of the internet [25]. This gives respondents the opportunity to complete the questionnaire at home and physicians to retrieve the PRO on the computer in the consultation room.

Thirdly, one has to determine the type of questionnaires that are used in the PRO tool. In the QLIC-ON study the PedsQL and TAPQOL were employed. These instruments have a generic nature and therefore they also included items not directly relevant to the physician. Some items could have been left out e.g. “I miss school to go to the doctor or hospital” (PedsQL, cognitive domain). The answer to this question is for almost every child yes and there is nothing that the physician can do about it. Moreover, a generic PRO might lack essential information that for example would be provided by a disease specific HRQOL questionnaire, e.g. the PedsQL Cancer Module [26]. However, because participants of the QLIC-ON study had recently finished treatment this disease specific instrument was not suitable for our study sample. The PedsQL Cancer Module would be applicable if HRQOL was monitored during treatment. Overall, we advice that a PRO should be flexible. Besides age appropriate (which was the case in the QLIC-ON study), it should also be tailored to the type of disease and treatment phase. Additionally, the time frame of the questionnaire applied as a PRO should be considered. Most HRQOL questionnaires have a time frame of one month. However, this was problematic for the QLIC-ON study since participants’ HRQOL was monitored during three consecutive consultations and for some children (especially children that had undergone stem cell transplantation) the time interval between the consultations was less than one month. For that reason we chose to use the PedsQL acute version which has a time frame of one week (chapter 2).

Finally, the person that is using the PRO must be taken into account. Before applying a PRO tool in clinical practice one should consider who the most appropriate user of the PRO is. This can be a physician, but also e.g. a nurse or a social worker. It depends on the content and purpose of the PRO. The user must be committed and equipped to work with the PRO. In this thesis, paediatric oncologists were the most suitable PRO users, since it concerned children in the follow-up trajectory after treatment and at that stage paediatric oncologists were the only medical contacts for them. However, if it concerned children during treatment, than e.g. a nurse practitioner would have been an adequate user of the PRO as well. On the whole, it is important to make sure that the PRO user is convinced of the benefits of the PRO tool. If the user lacks enthusiasm regarding the PRO, the willingness to successfully implement the PRO in clinical practice is very difficult. Often, a change in behaviour is required to make the use of PRO tools succeed. Additionally, a ‘user-ambassador’ in the PRO user group could be necessary to convince the group from within. Other ways to increase commitment have been described in chapter 5.

In sum, the use of PROs in clinical practice is all about making tailored choices. Development should take into account e.g. the type of disease, the type of treatment, the
type of PRO user and age of the patient. Every researcher or health professional that aims at successfully implementing a PRO in clinical practice should always bear these multiple choices in mind.

3.1.3. Paediatric oncologists feel responsible for the identification of psychosocial problems

It might seem obvious that most paediatric oncologists feel responsible for the identification of psychosocial problems, after all - they are the child’s primary care taker. However, this is a statement based on assumptions; it was never actually investigated. From practice experience we knew that in general paediatric oncologists acknowledge that psychosocial problems can exist in children confronted with cancer, but - while developing and implementing the QLIC-ON intervention – we also noticed some hesitations regarding this issue: “I am a physician, not a psychologist” and “I want to discuss psychosocial functioning, but what if a cesspool of emotions opens up?” Therefore, it was time to explore the paediatric oncologists’ perception regarding this topic.

This thesis demonstrates that paediatric oncologists believe that it is their task to discuss psychosocial functioning and to identify psychosocial problems in children with cancer. Paediatric oncologists also indicated, however, that fulfilling this task can be limited due to e.g. lack of expertise or time (chapter 4).

In general, our findings agree with previous research that has demonstrated how paediatricians consider themselves responsible in identifying mental health issues [27]. Furthermore, our study showed that paediatric oncologists’ perceptions match preferences of children with cancer and their parents who feel the need for support and empathy, and sufficient time for communication [28]. From previous research we know that effective patient–physician communication is of crucial importance to psycho-social outcomes in patients with cancer [1, 2]. Additionally, paediatric oncologists’ views towards their task in psychosocial functioning met many of the important components of paediatric doctor-patient interactions [29], e.g. general communication skills, patient-parent-centeredness, interpersonal skills and liaisons with other health-care professionals. Still, paediatric oncologists also clearly indicated, that their task in providing psychosocial care is limited. For instance, some of them do not feel qualified for solving psychosocial problems, which is in agreement with other research [30]. Most of them apply a low threshold for referral to psychosocial care. With respect to providing emotional support, some remain distanced from their patients and their patient’s family. Potentially confounding effects on doctor-patient interactions, such as the doctor’s level of training and workload and patient’s age [29] were also mentioned by our respondents. Other reasons for unsuccessful identification of psychosocial problems were dependency on information, undisclosed problems, underestimated problems and lack of structural discussion of problems.

Since paediatric oncologists felt responsible for providing psychosocial care to the best of their abilities, it is important to find ways to overcome these limitations.
Therefore, we suggest considering the use of PROs about psychosocial functioning during the consultation as a possible solution. PROs can serve as an aid for the physician to systematically identify and discuss psychosocial problems, without lengthening the consultation. The benefits of PROs in paediatric oncology practice were demonstrated in the present thesis (chapter 6).

The fact that paediatric oncologists feel responsible does not imply they are the only ones responsible for detecting psychosocial difficulties. We underline that this is a responsibility of the entire medical team involved with the child: nurses, nurse practitioners, social workers, psychologists and - maybe even beyond the hospital - teachers. Still, as the paediatric oncologists indicated themselves, they have the role of being the coordinators of care. Psychosocial care is part of that.

During the implementation of the QLIC-ON intervention we sometimes noticed that there was wavering towards the use of the PRO tool. Paediatric oncologists said e.g. “I don’t need a PRO. I already discuss psychosocial issues in my practice” or “I have a busy practice, the use of a PRO takes too much time”. We understand and acknowledge their arguments; however, their hesitation is based on incorrect assumptions towards the use of PROs. Our suggestion to use a PRO is not a statement against the way in which paediatric oncologists currently provide psychosocial care. Paediatric oncologists already address psychosocial issues during the consultation, which is underlined by the present thesis (chapter 7). PROs can only add to that because it will enable them to monitor psychosocial functioning even more systematically, without increasing the duration of the consultation. To get used to the use of PRO tools we believe it is necessary to introduce PROs during the physicians’ education at university. To further increase commitment towards the use of PRO tools and to enhance the possibility of successful implementation physicians should get more actively involved with the development and implementation of PROs. In that way, physicians (or other users) can apply their preferences regarding the content and presentation of the PRO which will give the PRO a better chance of becoming part of routine practice.

4. Limitations

The findings of the QLIC-ON study must be considered in the light of some limitations. Most of them were already mentioned in paragraph 3 of this Discussion section.

First of all, there is a limitation to the study design we applied. A disadvantage of a sequential cohort design is that the control and intervention group were not assessed simultaneously. Therefore, our study is at risk for a history effect. However, the control and intervention group were contiguous and gradually ongoing over time, and treatment protocols remained comparable within the 3-year time span of the study. It would have been ideal to have a sequential cohort study with three groups (control, attention-control and intervention), but this was not possible because of limited time and limited number of
patients. Nevertheless, the applied sequential cohort design led to a comparable control and intervention group; there were no differences in socio-demographics and medical variables.

Additionally, as stated earlier, the logistical procedure of the QLIC-ON study was very labour-intensive. A PRO internet application would have been more user-friendly and more professional. However, the QLIC-ON study was one of the first PRO studies in paediatrics and at the time of the start of the study (2005), the use of internet for PRO purposes was not common yet. Moreover, current PRO internet applications are based on experiences and advancing insights derived from studies such as QLIC-ON.

Finally, as mentioned before, it is remarkable that the effect of our PRO intervention on HRQOL was limited. Only 5 to 7 year old patients seemed to profit from the QLIC-ON PROFILE with respect to some HRQOL domains. Perhaps the effect of the intervention would have been more evident during treatment, because children are probably experiencing more HRQOL problems [22, 31] than after treatment when the QLIC-ON PROFILE was applied. A general explanation for this overall lack of HRQOL improvement could be the life-threatening nature of cancer, compared to chronic diseases which are not necessarily life-threatening. This may impact on a paediatric oncologist’s chance to apply a holistic approach towards their patients which makes them sensitive to HRQOL problems regardless of the use of a PRO tool. Maybe in paediatric oncology only longitudinal use of a PRO tool, from diagnosis through all treatment stages, will add to the effectiveness.

5. Clinical implications

5.1. Implementation of PROs in clinical practice
Based on the findings of this thesis the main clinical implication is to implement PROs in routine clinical paediatric oncology practice. This thesis can be used as an initial guideline in achieving this goal.

5.1.1. Implementation during all treatment stages
Although the present research focused on children with cancer after end of treatment, we advise to implement a PRO tool during all cancer treatment stages. In that way, psychosocial functioning can be monitored throughout the course of the disease. In the QLIC-ON study only out-patients were involved. However, in-patients will probably profit even more of the benefits of PRO tools, since they have a greater risk of suffering from psychosocial and HRQOL problems [22, 31] because they are still undergoing intense treatment.

We suggest administering the PRO tool once every three months in children with cancer, starting one month after diagnosis, continuing during treatment and follow-up. The user of the PRO should be a professional who has regular contact with the child and its family, who has a complete overview of the care program in which the child is involved.
and who has a coordinating task within the multidisciplinary team.

5.1.2. Implementation in all paediatric populations
The use of PROs in clinical practice should not only be reserved to children with cancer. Children with chronic diseases (e.g. rheumatic arthritis, sickle cell disease, diabetes [24]) may also benefit. The chronic nature of their disease makes them well suited candidates for PRO tools. The condition they suffer from is not immediately life-threatening; still the impact of the disease on their lives can be immense [32]. It is therefore of great importance that their psychosocial functioning is monitored. Additionally, compliance with therapy may benefit from the use of PRO tools. Questions referring to medicine use can be incorporated into the PRO. This information will help the physician to provide the patient with more tailored advice regarding disease management.

5.1.3. Incorporating internet use
The PRO tools applied in research have mainly depended on the work and effort of one or more researchers (e.g. logistics, assessment, evaluation). In the reality of clinical practice, however, there is probably no budget available for this. Internet can provide a step towards a solution, since in the Netherlands 87% of the households has access nowadays [33]. Less staff is needed, if the PRO is directly linked to patient data (e.g. treatments, consultations) and emails with invitations and questionnaires are automatically generated. Recently, a PRO website (www.hetklikt.nu) was developed by our research group and tested in children with rheumatic arthritis [25].

6. Future perspectives

6.1. PRO implementation research
Up to now, PRO studies have mainly aimed at investigating the effectiveness of PROs in clinical practice. Even though it has sometimes been difficult to demonstrate effectiveness on health outcomes, there are quite a few studies that illustrated the effectiveness of PROs on the process of care. The results of the present thesis for example confirm that the use of PROs in clinical practice increases identification of HRQOL problems and improves patient-physician communication. Both factors are important for the short as well as the long term well-being of the patient. Our findings – together with several other benefits of PROs – suggest taking PRO research one step further: future studies should shift from assessing effectiveness to assessing implementation of PROs in clinical practice. But how? We advice to use the Deming circle (plan-do-check-act cycle) as presented by the Netherlands Youth Institute [34]. The cycle is a guide through the process of change, namely the implementation of PROs in clinical practice. It will help the professional to determine the implementation question, to analyse the persons and setting involved, to determine the plan of how to implement and how to create support among users, to
actually facilitate PRO use, to monitor and evaluate, to anchor the use of PROs in clinical practice and subsequently to continuously adjust and improve.

6.2. Parent PROs
Logically, PRO studies have focussed on patients. However, in paediatrics the role of the parent and the impact of childhood disease on the parent may not be overlooked. It is known that parenting children with chronic diseases is highly demanding and has practical and emotional consequences. In a previous study [35] HRQOL of caregivers of children with a chronic disease was determined. Among others, parents of children with end stage renal failure, metabolic diseases, asthma, muscular dystrophy, sickle cell disease and also parents of children treated for paediatric brain tumours were included. Results demonstrated that these parents had a significantly lower HRQOL. Subgroup analysis showed lower HRQOL on sleep, social functioning, daily activities, vitality, positive emotions and depressive emotions in disease-specific groups. On average, 45% of the parents were at risk for HRQOL impairment. This implicates screening of parents at risk in clinical practice, and more attention for family functioning in both research and clinical practice. Additionally, research has indicated that parents of children treated for childhood cancer report significantly more psychological distress than the norm about two months after end of treatment [36]. This is confirmed by the results presented in the current thesis (chapter 3) which demonstrate that parents of 0- to 7-year-old children with cancer have significantly more emotional problems and perceive the general health of their child as less positive shortly after finishing treatment.

Altogether, the psychosocial impact of childhood cancer on parents should not be underestimated and deserves attention. For future research we suggest monitoring psychosocial functioning of parents. This can be done with the use of PRO tools by e.g. a social worker at set moments throughout the course of cancer treatment and follow-up.

6.3. Screening
It is important to note that the QLIC-ON PROfile was not intended as a psychosocial screening device but merely as a psychosocial monitoring tool. Thus no cut-off scores were utilized, and scale scores of the healthy norm population were only presented in the graphs to give the physician a sense of how the child scored compared to healthy peers. The purpose of a PRO monitoring tool in clinical practice is to help physicians and patients discuss and subsequently identify psychosocial problems; it is a communication aid. The purpose of a PRO screening tool in clinical practice is to actually screen for psychopathology with the use of cut-off scores; it is a ‘diagnostic’ aid. Both types of PRO tools differ from each other with respect to the type of questionnaires and also with respect to the type of users. A PRO monitoring tool can be regarded as a low-profile instrument (e.g. HRQOL questionnaires), which can be used by different types of professionals (e.g. physicians, nurses, social workers) with relatively little training. It provides an indication of a problem,
since individual scores cannot actually be compared with norm scores. The scores can facilitate discussion and subsequently the professional can give tailored advice (if he feels competent) or refer to specialised psychosocial care. A PRO screening tool is much stricter (e.g. Strength and Difficulties Questionnaire, SDQ [37]), since individual scores can be compared with the norm population. Therefore, they can only be used by professionals (e.g. psychologists) that are familiar with the screening instrument and that are able to interpret and (if necessary) to provide treatment related to the outcome.

Tools for screening on psychosocial problems in children with cancer are not available in the Netherlands. In order to adequately screen HRQOL problems as well as adequately intervene in children and families who are at greater risk for psychosocial maladjustment, consistent assessment with well validated instruments and evidence based care are required. Structured attention for these problems and identification of children and parents at risk for mental health problems is important. Once these children and parents are identified, tailored psychosocial support can be offered at an early stage, aimed at minimizing long-term mental health problems.

In the United States, a psychosocial screening tool (the Psychosocial Assessment Tool, PAT) that closely fits with these requirements was developed. The PAT systematically screens for psychosocial problems in families after the diagnosis of cancer in their child by assessing distress, problems in beliefs regarding the disease, availability of social support, symptoms of traumatic stress, other psychosocial strains and other kind of severe concerns within the family of children with different kinds of cancer [38, 39]. The PAT is the most frequently used screening instrument in paediatric oncology and it seems practically applicable but its reliability and its validity remains to be proven in the Netherlands. Therefore, we suggest future cancer PRO studies in the Netherlands to incorporate the PAT.

In addition to the three preceding paragraphs, our research group has recently obtained a KWF grant to implement monitoring of HRQOL by paediatric oncologists (as a direct follow-up of the QLIC-ON study) and to screen for psychosocial risks (with the PAT) in children with cancer and their families during treatment by their psychosocial team. The study will start in September 2011.

In conclusion

The QLIC-ON study was the first study to investigate the effectiveness of PROs about HRQOL in clinical paediatric oncology practice. It concerned a multicentre project with a large sample size. The PRO intervention was carefully developed, using innovative methods with respect to the design and the use of the PRO. Positive effects were found for patient-physician communication and identification of psychosocial problems. PROs are recommended to be implemented in clinical paediatric oncology practice.


