Monitoring quality of life in paediatric oncology practice
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Chapter 1
General Introduction
1. Origin of this thesis

The Quality of Life In Childhood Oncology (QLIC-ON) study, presented in this thesis, is the end result of a unique collaboration which officially started in 2005 with a grant from the Dutch cancer Society. The QLIC-ON project team included members from TNO (dr. Symone Detmar), the Leiden University Medical Centre (dr. Hendrik Koopman) and the Emma Children’s Hospital/Academic Medical Centre (dr. Martha Grootenhuis and drs. Vivian Engelen). Symone Detmar had experience in providing patient reported outcomes (PROs) in adult cancer care, Hendrik Koopman was the first to develop a PRO for children with a chronic disease and Martha Grootenhuis was well known for her psychosocial research in paediatric oncology.

At the time of the start of the current study, it was known that some children with cancer experience psychosocial problems and that these problems are not always identified and discussed by physicians. PROs could possibly bridge this ‘gap’ between child and physician. Therefore, the expertise within the project team was combined and the QLIC-ON study was born: introducing PROs in clinical paediatric oncology practice. A unique project in paediatrics and never done before in paediatric oncology.

This general introduction will first elaborate on childhood cancer, health-related quality of life and psychosocial functioning of children with cancer. Secondly, a summary of research findings regarding the effectiveness of PROs in clinical practice is provided. Finally, the set-up of the QLIC-ON study and the outline of the current thesis are described.

2. Childhood cancer

2.1. Diagnosis

In the Netherlands, approximately 500 children each year are diagnosed with cancer [1]. Cancer is defined as the uncontrolled and unrestrained proliferation of cells, which can occur anywhere in the body. The characteristics of childhood cancer differ from those of cancer in adults in type, histology and anatomic location. Leukaemia, central nervous system tumours (CNS tumours) and lymphoma are the most common in children, representing approximately one-third, one-fourth and one-tenth of the incidence of childhood cancer, respectively. The incidence of several cancer diagnoses varies across age groups and gender. The incidence of some childhood cancer diagnoses (e.g. acute lymphocytic leukaemia (ALL), CNS-tumour, neuroblastoma, Wilms’ tumour) decreases with age, while the incidence of other diagnoses (e.g. Hodgkin’s disease and bone tumour) increases with age. With respect to gender, leukaemia and lymphoma are found more frequently in boys than in girls [2].
2.2. Treatment
Children with cancer are treated according to protocols that have been developed through international cooperation and research. Surgery, chemotherapy and radiotherapy are the major modalities of cancer treatment. Standard practice usually involves a combination of these treatment modalities. Length and type of treatment depend on a number of factors, including the type of cancer, location and stage of the disease.

For children with high risk ALL or relapsed malignancies stem cell transplantation (SCT) is a treatment of last resort. The treatment involves high doses of chemotherapy and/or total body irradiation before the stem cells of a donor are infused. SCT is usually performed with bone marrow from a donor (allogeneic) but in some instances takes place with cells from the patient itself (autologous). SCT is a hazardous treatment, associated with high morbidity and mortality, because children become extremely susceptible to infections. It involves a lengthy hospital admission in an isolated, germ-free environment. In the first four to six months post-SCT, children are still prone to develop infections and are forced to live with restrictions [3].

Cancer treatment and related medical procedures cause pain and distress. Although the development of more effective and targeted treatments has reduced the side effects to some extent, they are still present. The severity of the side effects depends on the type and location of cancer, child age and intensity of treatment. Side effects of treatment can occur within days or weeks of initial treatment (early effects) or even months to years after the end of treatment (late effects) [2].

2.3. Survival and late effects
Chances to be cured from childhood cancer have increased over the past several decades; currently, the survival rate is about 75% [4]. Survival rates depend on both diagnostic and prognostic factors. The survival chances for some types of cancer are high. For example the survival chances for Wilms' tumour and Hodgkin's disease are between 80% and 90%. On the other hand, the prognosis for some other cancers (e.g. neuroblastoma) is much lower. Although the majority of the childhood cancer patients can be considered cured five years after diagnosis, 10% of these patients die of disease recurrence or treatment related causes within ten years [2].

Studies indicate that between 60% and 75% of all long-term childhood cancer survivors develop one or more adverse events due to the disease or treatment, and approximately one-third of these events are classified as either moderate or severe. The health problems can be categorised into ten main groups: endocrine, organ toxicity, mobility/orthopaedic, fertility, sensory, cosmetic, fatigue, subsequent neoplasm, psychosocial/cognitive and neurological [2].
3. Health-related quality of life and psychosocial functioning in childhood cancer

3.1. Health-related quality of life

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’ [5]. The concept of health related quality of life (HRQOL) refers to the impact of health and illness on an individual’s QOL [6]. In paediatrics there are usually four HRQOL domains: physical, emotional, social and school functioning, of which the last three can be summarized as psychosocial functioning [7].

HRQOL can be measured in several manners such as with an interview, a diary or a questionnaire. In general, questionnaires are the most frequently used method to assess HRQOL. There is a diversity of paediatric HRQOL instruments available e.g.: TAPQOL [8], TACQOL [9], TAAQOL [10], DUX-25 [11], Kidscreen [12], PedsQL [7] and CHQ [13]. Internationally, the PedsQL is one of the most frequently used HRQOL questionnaires in research. Dutch reference scores are not on hand however. The PedsQL has a broad age range (2-18 years), a short completion time (approximately 5-10 minutes), good feasibility, validity and reliability and it includes self-report as well as proxy-report [7]. Previous research has demonstrated that children aged 5-18 years can reliably and validly self report their HRQOL when an age-appropriate measurement instrument is utilized [14].

Over the years, HRQOL has become an important outcome measure in paediatric oncology research. Several studies [15-23] have demonstrated that childhood cancer diagnosis can lead to poor HRQOL on all domains compared to healthy peers. The studies included patients from several diagnostic groups, ages and treatment stages. For example, children reported more physical complaints, reduced motor functioning and autonomy and impaired positive emotional functioning 6 weeks after cancer diagnosis. Subsequently, HRQOL improved significantly over the year following diagnosis. However, at 1 year after diagnosis, children still showed reduced motor and emotional functioning. Furthermore, at 6 weeks, children with ALL were most affected and at 1 year, children with brain tumours complained about more physical symptoms than the other groups [24]. Another study demonstrated that children treated for high-risk ALL, girls and older children had lower HRQOL. In children treated for standard-risk ALL, those with lower household incomes and unmarried parents experienced lower HRQOL. HRQOL scores were generally constant across phases of ALL therapy, however, children on therapy for ALL have lower HRQOL compared to healthy children [25]. In addition, research has shown that positive expectations of the course of the disease, less frequent parental asking after disease-related emotions of the child and lower levels of family adaptability are psychosocial indicators of a favourable HRQOL [26].

Overall, one can conclude that HRQOL has been the focus of quite a few studies,
however, HRQOL shortly after finishing treatment has only been investigated to a very limited extent. This is remarkable, since especially this transition phase is known to be very stressful.

3.2. Psychosocial functioning
For almost all children and their parents the diagnostic phase and start of treatment is very stressful. It starts with invasive medical procedures necessary to obtain a diagnosis. The child has to endure pain and parents have to witness their child in pain and fear. The next challenge than is to accomplish a realistic, and for the child an age appropriate, understanding of diagnosis and treatment implications. A second stressor at this stage is learning to deal with the effects of medical treatment. Often shortly after the diagnosis chemotherapy starts and the child quickly starts to experience what cancer treatment is about; pain due to medical procedures, sickness because of chemotherapeutic agents and side effects such as hair loss. A third stressor, especially at the beginning of treatment, is to inform the social environment. To ensure social support which keeps the family integrated is important because of the long duration of treatment. Families need ongoing support and stay in touch with everyday life as good as possible.

In the first months after diagnosis, many children show adjustment towards treatment and being ill, but they also start to realize the impact of the cancer experience on their daily lives. Most studies in this field indicate that children with cancer as a group are not very different to control groups in terms of adaptation or adjustment and psychopathology in all stages of the disease and treatment [27]. However, there are children who are at risk for difficulties in adapting to the disease [28], e.g. children who react with withdrawal or social isolation or children with premorbid psychopathology. These children need intensive psychological support during and after treatment.

Children with cancer often feel anger and disappointment because they are restricted to participate in important areas of life, such as going to school or engaging in sports and other social activities. Children who attend school during treatment often feel ‘different’, because of their changed appearance or decline in condition [29]. As a group, however, they hardly seem different from their healthy peers in terms of their classroom behavior and social acceptance [30]. Research shows that children with cancer who receive social support from their teachers, parents and friends report fewer psychosocial problems and a higher self-esteem [31].

The end of treatment in paediatric oncology can be considered a tremendous transition in care and can be experienced as very stressful. Children and parents are supported during the entire treatment by the multidisciplinary team paying attention to all different aspects of functioning. When treatment is finished this multidisciplinary guidance quickly diminishes and families must regain their own lives. Studies in this phase show that children of different ages report problems with physical functioning as a consequence of loss of general condition and strength or ongoing tiredness [23]. Next to
physical functioning adolescents often experience a sense of distance towards their peers which sometimes makes it difficult to reintegrate. Individual counseling can help children and adolescents to express feelings of loneliness or being misunderstood and help them to bridge the gap to ‘normal life’.

Studies in childhood cancer survivors performed during the past 25 years have found little evidence of serious psychological maladjustment. Research on specific areas of psychosocial adjustment, however, has found that between 25% and 30% of survivors and their family members have experienced personal, family or social difficulties that have affected their academic achievement, employment, interpersonal relationships or self-esteem [2].

### 3.3. Psychosocial care and follow-up

In the Netherlands, every academic hospital provides psychosocial care to children with cancer. Psychologists, social workers and/or play therapists are available to support and guide the children and their parents through this difficult time of illness and treatment (if needed). However, the organization of this psychosocial care is different for every hospital with respect to manpower and type of care. Some hospitals refer all newly diagnosed children to a psychologist or social worker for a general psychosocial screening; other hospitals do not have enough manpower to do so and are therefore dependent on the medical team involved around the child to detect psychosocial problems and refer to psychosocial care.

As more children with cancer survive into adulthood the importance of monitoring the late effects, both physical and psychosocial, has gained recognition. In the Netherlands, all survivors are offered regular follow-up by long-term follow-up clinics in the academic hospitals, according to guidelines that have recently been designed [32].

From adult research we know that the majority of patients and physicians want to discuss psychosocial issues during cancer treatment. However, physicians do not always address these issues appropriately [33]. How exactly paediatric oncologists perceive their role towards psychosocial functioning is unknown. Neither is known to what extent these psychosocial issues are addressed in paediatric oncology practice. We believe PROs can serve as an helpful aid in identifying and discussing psychosocial problems.

### 4. Patient reported outcomes in clinical practice

#### 4.1. Definition

The use of PROs in routine clinical practice is becoming increasingly common. PROs are based on direct reporting by patients without the intervention of an observer. They include the self-assessment of functional status, symptoms, and other concerns such as patient needs and satisfaction with care. 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 [34]. PROs in terms of HRQOL can be included in clinical trials, although in paediatric oncology little experience is available yet.

4.2. Effectiveness
Monitoring HRQOL by providing PROs in clinical practice has already been the focus of several studies [35-44]. PRO interventions that monitor HRQOL over time have demonstrated to improve patients’ memory and ability to describe their problems. Further, PROs can identify problems that patients might not have raised and that clinicians would therefore assume were not of concern. Completion of a PRO might also make patients feel cared for, thus improving emotional function [44]. Additionally, incorporating PROs in clinical oncology practice appeared to facilitate discussion of HRQOL issues and increase physician’s awareness of their patients’ HRQOL [35]. PROs also focussed the conversation during the consultation on issues relevant to patient’s experience without extending the visit [40]. Furthermore, there was an impact on physician-patient communication with better HRQOL and emotional functioning for some patients [36]. Moreover, a study in patients with chronic liver disease demonstrated that physicians using a PRO alter their treatment policy significantly more than physicians not using HRQOL feedback [37]. This was also the case for a PRO study involving lung-transplant patients [41]. In addition, it appeared that the introduction of PROs into the daily routine of an out-patient clinic is feasible [42, 43].

Despite these encouraging results, it remains difficult to prove effectiveness of PROs in clinical practice [44-48]. 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 [45]. Researchers often have the desire and purpose to improve health outcomes (e.g. the patient’s HRQOL) by providing PROs in clinical practice, but this is difficult to establish. Several points of consideration to increase the effectiveness of PROs in clinical practice were suggested in a previous study [46]: (1) the applied PRO needs to prioritize the views of the individual in order to adequately reflect the individual’s HRQOL; (2) health care providers other than physicians may also find HRQOL information useful; (3) feedback of HRQOL information should be longitudinally measured and presented over a period of time; (4) a clinically important difference or change in HRQOL data does not always resemble physicians’ perceptions of this difference or change; and finally, (5) commitment and education of the PRO user are needed to address the multiple barriers to the use of PRO in clinical practice. Additionally, another study [44] 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.

In sum, profound development and implementation of a PRO intervention is
necessary to validly assess the effectiveness of a PRO in clinical practice. The current thesis has taken as many of the suggestions above into account in developing and setting up a PRO intervention study (QLIC-ON) in paediatric oncology.

5. The QLIC-ON study

5.1. Background
PRO studies are usually conducted in adult patients, with little attention to paediatrics [48]. A recent exception is a diabetes study [49] which demonstrated positive effects of a PRO tool in adolescents with diabetes. It is remarkable that no other paediatric populations have profited from feeding back HRQOL via PRO tools in clinical practice, since it is known that children with a (chronic) disease are at risk for suffering from HRQOL problems [50] and that physicians are not always aware of these problems [51].

As stated above, children with cancer can also experience HRQOL problems, which can continue after completion of treatment [23]. It is generally recognized that the fulfilling of age-specific developmental tasks in childhood is of great importance to adjustment in adult life; the burden of cancer interferes with this process [52] and may cause HRQOL problems. PRO tools could possibly bridge the gap between child and paediatric oncologist and serve as an aid in identifying and discussing HRQOL problems, also to prevent developmental delay. Additionally, PRO tools could contribute to effective patient–physician communication, which is of crucial importance to psycho-social outcomes in patients with cancer [53, 54].

5.2. Aims
This PhD thesis presents the results of the QLIC-ON study. Aims of the QLIC-ON study included:

- to investigate the effectiveness of an intervention that provides a PRO tool about HRQOL (the QLIC-ON PROfile, p.173) to the paediatric oncologist;
- 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.

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 psychometric properties in the Netherlands;
- to determine HRQOL of children with cancer shortly after the end of successful treatment compared with normative values;
- 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;

• to provide a thorough description of the development and implementation of the QLIC-ON PROfile in clinical pediatric oncology practice.

5.3. Study design
A sequential cohort design was regarded most suitable for the purpose of the QLIC-ON study (Figure 1). Pediatric oncologists participated in the control as well as the intervention period; children and parents participated in either the control period or the intervention period, but not both. First, a control period (Figure 1A) was introduced, in which children or parents (N=99) completed the HRQOL questionnaire while waiting for their consultation in the outpatient clinic. Answers on the HRQOL questionnaire were summarized in the QLIC-ON PROfile. In the control period the QLIC-ON PROfile was not provided to the pediatric oncologist, the child and the parent. The pediatric oncologist started the intervention period (Figure 1C) – with a training (Figure 1B) - only as soon as he had seen all patients participating in the control period during three consecutive consultations. The intervention period consisted of a group of 94 children or parents filling out the HRQOL questionnaire in the waiting room. This time however, the QLIC-ON PROfile was provided to the pediatric oncologist, the child and the parent, to be discussed during the three consultations.

5.4. Intervention: the QLIC-ON PROfile
The QLIC-ON PROfile is a PRO about HRQOL (p. 173), which concerns a monitoring tool (as opposed to a screening tool). The left top provides information regarding the child: name, date of birth, person that completed the questionnaire and period of time. The main part represents the four HRQOL domains, each marked with a coloured line for easy recognition: physical (blue), emotional (green), social (yellow) and school functioning (pink). The items are depicted for every domain, with the answers summarized in a column behind linked to the completion (=consultation) date. An answer accentuated green (‘never’, ‘almost never’) indicates that the child had no problems regarding the subject, orange (‘sometimes’) points out that there were some problems, and a red answer (‘often’, ‘almost always’) illustrates that a child frequently experienced problems. Most recent answers are printed bold to focus the attention of the pediatric oncologist. At the bottom, scale scores are reflected in line graphs presented with the corresponding colours of each domain. In every line graph the scale score of the child is indicated with the completion date. Scores can be compared with previous scale scores as well as with the scale score of the healthy norm population (red dotted line).

To optimize effectiveness of the QLIC-ON PROfile, we provided a training which comprised both an individual and a group session for oncologists, and a patient instruction. The training was also part of the intervention.
Figure 1. QLIC-ON study: sequential cohort design

Control period
March 2006 - January 2008

Baseline
Consultation 1 N=99
Consultation 2 N=86
Consultation 3 N=84

Follow-up
Consultation 1 N=94
Consultation 2 N=93
Consultation 3 N=74

A

Lay-out
Content
Educational/supporting material:
- Decision tree
- QLIC-ON Pocket Card

B

Individual training (po)
Group training (po)
Individual patient instruction (p,c)

In-depth use of QLIC-ON PROFILE:
Theory: background information
Practice: cases on DVD
Group discussion

QLIC-ON PROFILE introduction:
Lay-out
Content
Educational/supporting material:
- Syllabus

C

Baseline
Consultation 1 N=99
Consultation 2 N=93
Consultation 3 N=74

Follow-up
Consultation 1 N=94
Consultation 2 N=93
Consultation 3 N=74

Socio-demographics (po, p, c)
HRQOL (p or c)

Satisfaction (po, p, c)
HRQOL topics (p)

Communication Consultation duration
Sound recording:

Socio-demographics (po, p, c)
HRQOL (p or c)

Satisfaction (po, p, c)
HRQOL topics (p)

Communication Consultation duration
Sound recording:

Socio-demographics (po, p, c)
HRQOL (p or c)

Satisfaction (po, p, c)
HRQOL topics (p)

Communication Consultation duration
Sound recording:

Socio-demographics (po, p, c)
HRQOL (p or c)

Satisfaction (po, p, c)
HRQOL topics (p)

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Socio-demographics (po, p, c)
HRQOL (p or c)

Satisfaction (po, p, c)
HRQOL topics (p)

Communication Consultation duration
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Socio-demographics (po, p, c)
HRQOL (p or c)

Satisfaction (po, p, c)
HRQOL topics (p)

Communication Consultation duration
Sound recording:

Socio-demographics (po, p, c)
HRQOL (p or c)

Satisfaction (po, p, c)
HRQOL topics (p)

Communication Consultation duration
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Socio-demographics (po, p, c)
HRQOL (p or c)

Satisfaction (po, p, c)
HRQOL topics (p)

Communication Consultation duration
Sound recording:

Socio-demographics (po, p, c)
HRQOL (p or c)

Satisfaction (po, p, c)
HRQOL topics (p)

Communication Consultation duration
Sound recording:

Socio-demographics (po, p, c)
HRQOL (p or c)

Satisfaction (po, p, c)
HRQOL topics (p)

Communication Consultation duration
Sound recording:

Socio-demographics (po, p, c)
HRQOL (p or c)

Satisfaction (po, p, c)
HRQOL topics (p)

Communication Consultation duration
Sound recording:

Socio-demographics (po, p, c)
HRQOL (p or c)

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Communication Consultation duration
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Socio-demographics (po, p, c)
HRQOL (p or c)

Satisfaction (po, p, c)
HRQOL topics (p)

Communication Consultation duration
Sound recording:

Socio-demographics (po, p, c)
HRQOL (p or c)

Satisfaction (po, p, c)
HRQOL topics (p)

Communication Consultation duration
Sound recording:

Socio-demographics (po, p, c)
HRQOL (p or c)

Satisfaction (po, p, c)
HRQOL topics (p)

Communication Consultation duration
Sound recording:

Socio-demographics (po, p, c)
HRQOL (p or c)

Satisfaction (po, p, c)
HRQOL topics (p)

Communication Consultation duration
Sound recording:

Socio-demographics (po, p, c)
HRQOL (p or c)

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HRQOL topics (p)

Communication Consultation duration
Sound recording:

Socio-demographics (po, p, c)
HRQOL (p or c)

Satisfaction (po, p, c)
HRQOL topics (p)

Communication Consultation duration
Sound recording:

Socio-demographics (po, p, c)
HRQOL (p or c)

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Communication Consultation duration
Sound recording:

Socio-demographics (po, p, c)
HRQOL (p or c)

Satisfaction (po, p, c)
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Socio-demographics (po, p, c)
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Satisfaction (po, p, c)
HRQOL topics (p)

Communication Consultation duration
Sound recording:

Socio-demographics (po, p, c)
HRQOL (p or c)

Satisfaction (po, p, c)
HRQOL topics (p)

Communication Consultation duration
Sound recording:

Socio-demographics (po, p, c)
HRQOL (p or c)

Satisfaction (po, p, c)
HRQOL topics (p)

Communication Consultation duration
Sound recording:

QLIC-ON Pocket Card

Extension
March 2006 - January 2008
Intervention period
January 2008 - November 2009

<± 1-14 days> <± 4-12 weeks> <± 4-12 weeks> <± 1-14 days>

<± 1-14 days> <± 4-12 weeks> <± 4-12 weeks> <± 1-14 days>

<± 1-14 days> <± 4-12 weeks> <± 4-12 weeks> <± 1-14 days>

po: paediatric oncologist, p: parent, c: child
5.5. Outcome measures
The majority of the outcome measures applied in the QLIC-ON study are known from previous PRO research: communication, referral, satisfaction and HRQOL [48]. According to an earlier study [46], evidence was found for ‘changes to doctor-patient communication’ when using HRQOL in clinical practice. This thesis assesses communication during the consultation in two (partly innovative) ways: 1) communication about HRQOL domains and 2) identification of HRQOL problems. The first communication outcome was examined with audio recordings of the consultations, which were scored with a self-constructed audio-assessment form. For the second communication outcome, two measures were combined: the QLIC-ON PROfile and the HRQOL topics checklist (after each consultation the parent indicated if a topic was discussed during the consultation). Unidentified HRQOL problems were retrieved by matching the answers on the QLIC-ON PROfile with the results of the HRQOL topics checklist. With these two communication outcomes we hope to gain more insight in the effect of applying a PRO tool in clinical practice, since these outcomes are possibly more sensitive to changes than the more traditional ones e.g. referral, satisfaction and HRQOL on which changes are more difficult to find [46]. Still, we have incorporated these traditional outcomes in the QLIC-ON study as well, because they are well known and important as an outcome. Moreover, as can be concluded from previous research, it is not impossible to find change via some of these measures [36, 49].

6. Outline of the thesis
The general introduction of this thesis is covered in Chapter 1. In chapter 2 Dutch reference data of the PedsQL Generic Core Scales are presented. Results regarding reliability, socio-demographic within-group differences and construct validity are also described. Chapter 3 focuses on HRQOL of children with cancer shortly after the end of successful treatment compared with the healthy norm. Chapter 4 elaborates on the paediatric oncologists’ perception regarding their task in discussing psychosocial functioning, identifying psychosocial problems and providing emotional support. A thorough description of the development and implementation of the QLIC-ON PROfile in clinical paediatric oncology practice is provided in chapter 5. The main findings of the QLIC-ON study are depicted in chapter 6, which investigates the effectiveness of the QLIC-ON PROfile in paediatric oncology practice. Finally, the effect of using the QLIC-ON PROfile on the type (and amount) of psychosocial topics discussed during a paediatric oncology consultation is presented in chapter 7. This thesis ends with a general discussion including main findings, key messages, clinical implications and future perspectives (chapter 8) and a summary of the results.
Reference List


