Monitoring quality of life in paediatric oncology practice

Engelen, V.

Citation for published version (APA):
Chapter 4

Psychosocial issues addressed by paediatric oncologists

V. Engelen
M.C.B. Van Zwieten
S.B. Detmar
H.M. Koopman
A.Y.N Schouten – van Meeteren
M.A. Grootenhuis

1 Paediatric Psychosocial Department, Academic Medical Center/ Emma Children’s Hospital, Amsterdam
2 Department of General Practice/ Medical Ethics, Division Clinical Methods and Public Health, Academic Medical Centre, University of Amsterdam, Amsterdam
3 TNO Prevention and Health, Leiden
4 Medical Psychology, Leiden University Medical Center, Leiden
5 Paediatric Oncology Department, Academic Medical Center/ Emma Children’s Hospital, Amsterdam

SUBMITTED FOR PUBLICATION
Abstract

**Purpose.** To examine paediatric oncologists’ perception of their role in (1) discussing psychosocial functioning and identifying psychosocial problems and (2) providing emotional support to children with cancer.

**Methods.** Twenty-four paediatric oncologists were interviewed. Data were qualitatively analysed using a framework approach.

**Results.** Paediatric oncologists believed it was their task to discuss psychosocial functioning, to identify psychosocial problems and to provide emotional support to children with cancer. Paediatric oncologists also indicated that this task can be limited due to inherent lack of expertise or time or by the physician’s personality.

**Conclusions.** Paediatric oncologists felt responsible for providing psychosocial care to the best of their ability.
Introduction

Fulfilling age-specific developmental tasks in childhood is important for successful adjustment in adult life. The burden of having cancer and cancer treatment can interfere with this process [1]. Although the psychological adjustment of most children with cancer is good [2], some children are at risk for psychosocial difficulties [3]. Because paediatric oncologists are the primary caregivers of children with cancer, they should be able to identify psychosocial problems so that they can prevent deterioration. Overall, paediatricians believe that they are responsible for the identification of mental health issues [4]; however, many physicians may not be aware of such problems [5, 6].

In this study, we examine the paediatric oncologist’s role with respect to psychosocial functioning, psychosocial problems and emotional support in children with cancer. While no one has previously investigated these topics in paediatric oncology, related studies in adult oncology will be discussed below.

The identification of psychosocial problems by oncologists has received some attention in literature. Bultz & Carlson [7] for instance, stressed the importance of routinely evaluating levels of distress in adult oncology. According to previous research, oncologists’ sensitivity in recognising moderate distress in patients is relatively high but their ability to detect severe distress is low [8]. Furthermore, the ability to detect distress varies between different oncologists, and oncologists often underrate distress in their patients [9].

With respect to emotional support, research has shown that compassion expressed by physicians can reduce anxiety in adult cancer patients [10], and physician attentiveness and empathy have been associated with increased self-efficacy and reduced emotional distress [11]. Additionally, cancer patients who felt that more attention had been paid to the psychosocial aspects of their illness were more satisfied with their consultations [12]. Butow et al [13], however, stated that oncologists are not recognizing or dealing with the emotional needs of their patients. If doctors do not recognise and acknowledge patients’ cues for emotional support, patients will be discouraged from seeking support. This finding is in agreement with those reported by Ford et al [14], who concluded that the lack of psychosocial questions from oncologists demonstrates how emotional issues are rarely investigated.

The studies described above were all conducted in adult oncology with no research available for paediatrics in general and paediatric oncology more specifically. Crossley and Davies [15], however, described several key components of doctor-patient interactions involving children and their parents. Their research is useful for the current study, because it also includes aspects of the consultation process that are essential for exploring psychosocial functioning, psychosocial problems and providing emotional support in children with cancer. Examples of these aspects are general communication skills, patient-parent-centeredness, interpersonal skills, appropriate family plans, liaisons with other health-care professionals and health-related problems.
In sum, the importance of exploring psychosocial functioning, identifying psychosocial problems and providing emotional support in cancer patients is documented, but how these aspects are perceived by paediatric oncologists has not been reported. Therefore, the aim of the current study is to examine paediatric oncologists’ perceptions regarding their role in (1) discussing psychosocial functioning and identifying psychosocial problems and (2) in providing emotional support to children with cancer.

**Methods**

**Participants and context**

Twenty four paediatric oncologists were interviewed for the purpose of the current paper, which presents a descriptive and explorative study.

The interviews were performed in the context of a larger project: the multi-centre QLIC-ON study (Quality of Life in Childhood Oncology) [16, 17]. The QLIC-ON study provided a patient reported outcome (PRO) about health related quality of life (HRQOL) (the QLIC-ON PROfi le, p. 173) to paediatric oncologists and investigated whether the QLIC-ON PROfi le was an effective tool for systematically identifying and discussing HRQOL problems in children with cancer. A sequential cohort study design was applied in the QLIC-ON study. Paediatric oncologists participated in the control (March 2006 to January 2008) as well as the intervention period (January 2008 to November 2009); children with cancer and their parents participated in either the control period or the intervention period. The QLIC-ON PROfi le was only presented to the paediatric oncologists during the intervention period. Further information and results regarding the QLIC-ON study can be found in previously published papers [16, 17].

The QLIC-ON study is embedded in the HRQOL theme. In paediatrics, there are usually four HRQOL domains: physical, emotional, social and school functioning, of which the last three can be summarised as psychosocial functioning [18]. We were interested in the paediatric oncologists’ perception of psychosocial functioning and therefore, the interview schedule was restricted to the concept of psychosocial functioning (and emotional support) and not HRQOL.

The QLIC-ON study was approved by the Medical Ethics Committees for all participating centres: the Academic Medical Centre/ Emma Children’s Hospital, Leiden University Medical Centre, Radboud University Medical Centre and the VU University Medical Centre in the Netherlands.

**Data collection**

Paediatric oncologists met the following criteria to be interviewed: 1) none of their patients were still participating in the control period of the QLIC-ON study and 2) their first patient was about to start in the intervention period of the QLIC-ON study.

Eligible paediatric oncologists were invited for the interview by email. Because of the
paediatric oncologists’ connection to the QLIC-ON study, the response rate was 100%.

The paediatric oncologists were interviewed between January 2008 and January 2009. All interviews were conducted by the first author and took place in a private room in the centre in which the paediatric oncologist was employed. The interviews were audio-taped by means of a voice recorder and verbatim transcribed to a text file. Audio and text files were saved and confidentially processed.

At the start of the QLIC-ON study, paediatric oncologists completed a brief sociodemographic questionnaire about themselves.

**Interview schedule**
The questions in the interview schedule (Table 1) were used as a guide for each interview. The findings with respect to the questions between brackets are not reported in this paper.

The current paper discusses the themes psychosocial functioning, psychosocial problems (questions 1-5) and emotional support (questions 6-7). To have a notion of what the paediatric oncologists are referring to in the rest of the interview when talking about these themes, we asked the paediatric oncologists to define the themes. To be complete, these definitions are reported in this paper as well; however, it was not the primary aim of this study.

**Data analysis**
Data were qualitatively analysed using the framework approach [19]. The interview schedule was applied as a framework for data analysis. The software program MaxQDA was used as an aid for analysis.

First, to get familiar with the data set as a whole, 10 interviews were randomly read by the first author. Subsequently, for each question from the interview schedule, open codes were (deductively) created for all 24 interviews. Then, axial codes were generated by (inductively) interpreting, redefining and/or merging the open codes, resulting in a code tree (Appendix 1). The findings presented in the current paper are derived from the codes that occurred most frequently.

To ensure that our findings were valid, the analyses were checked by the second author – a senior qualitative researcher - who read 10 interviews and verified the code tree. The remaining authors read 3 interviews and agreed on the content of the code tree. The findings were discussed and approved by all authors. Additionally, the findings were checked for their validity by explicitly asking the fifth author - a paediatric oncologist who was also interviewed for the purpose of the current study - whether she could recognize the findings and judge these as correct (member’s check) [20].

The paediatric oncologists’ answers concerning questions 2 and 3 from the interview schedule were in close agreement; therefore, we integrated both questions for the analysis.

Eventually, the findings were reported in this paper as quotes, presented in boxes. Each quote was made by one paediatric oncologist.
<table>
<thead>
<tr>
<th>Question</th>
<th>(Box Number)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. How would you define psychosocial functioning?</td>
<td>1</td>
</tr>
<tr>
<td>2. To what extent do you regard discussing psychosocial functioning with children and parents as your task?</td>
<td>2a + b</td>
</tr>
<tr>
<td>- (How much attention do you pay to psychosocial functioning during the stage of diagnosis?)</td>
<td></td>
</tr>
<tr>
<td>- (How much attention do you pay to psychosocial functioning during the stage of treatment?)</td>
<td></td>
</tr>
<tr>
<td>- (How much attention do you pay to psychosocial functioning during the stage of follow-up?)</td>
<td></td>
</tr>
<tr>
<td>3. To what extent do you regard identifying psychosocial problems with children and parents as your task?</td>
<td>2a + b</td>
</tr>
<tr>
<td>4. To what extent do you succeed in identifying psychosocial problems?</td>
<td>3a + b</td>
</tr>
<tr>
<td>5. What is your strategy of identifying psychosocial problems?</td>
<td>4</td>
</tr>
<tr>
<td>- (Which criteria do you employ for referral of a child with psychosocial problems to another discipline, for psychosocial care?)</td>
<td></td>
</tr>
<tr>
<td>- (What do you do when you identify psychosocial problems specifically in parents, and thus not in the child?)</td>
<td></td>
</tr>
<tr>
<td>6. How would you define emotional support by the paediatric oncologist?</td>
<td>5</td>
</tr>
<tr>
<td>7. To what extent do you regard providing emotional support (by the paediatric oncologist) to a child as your task?</td>
<td>6a + b</td>
</tr>
</tbody>
</table>

Note: The findings with respect to the questions in parentheses are not reported in this paper.
Results

Participants
The study group consisted of 24 paediatric oncologists from four paediatric oncology centres. Thirteen (54.2%) of the participants were male, their mean age was 43.83 years (SD 7.34), and they had been paediatric oncologists for an average of 8.96 years (SD 7.99). The average duration of the interviews was 26 minutes (range 12 – 58 minutes).

Psychosocial functioning and psychosocial problems

Definition of psychosocial functioning
Paediatric oncologists defined psychosocial functioning as emotional, social and school functioning. Emotional functioning was referred to as psychological or emotional well-being, and the way of coping with (the consequences of) disease and treatment. Aspects of social functioning included the family situation, contact with friends and peers, and participation in clubs and sports. School functioning was primarily addressed with school presence and global school performance. Some paediatric oncologists also defined psychosocial functioning as normal or good psychosocial functioning when the child was able to ‘live a normal life, despite the disease’. Quotes of paediatric oncologists regarding these findings are reported in Box 1.

Perceived task in discussing psychosocial functioning and in identifying psychosocial problems
Paediatric oncologists agreed that it was their task to discuss psychosocial functioning and to identify psychosocial problems. They provided various arguments for this. Many paediatric oncologists indicated to have a holistic view on medicine; the disease must be treated within the context of the child and its environment, also because psychosocial problems may interfere with treatment. Others thought that this task was an inherent duty to being a paediatrician; exploring psychosocial functioning is a part of the job. Being the child’s primary contact or coordinator during and after treatment was another argument they gave. The responsibility of being the primary contact or coordinator includes exploring functioning and identifying problems so that they could refer their patient to specialised psychosocial care (e.g., psychologist, social worker) (Box 2a).

Perceived task in discussing psychosocial functioning and in identifying psychosocial problems - limitations
The majority of the paediatric oncologists we interviewed also believed that their task to discuss psychosocial functioning and identify psychosocial problems was limited. The most frequently mentioned limitation was their lack of expertise in dealing with psychosocial functioning and problems. Some of the respondents reported that they do not solve or extensively discuss certain problems and that they employ a low threshold in referring to
specialised psychosocial care. Furthermore, a number of paediatric oncologists indicated that the time they have available to pay attention to psychosocial functioning is limited, also due to work pressure. Additionally, some respondents reported that it was not exclusively their responsibility to identify psychosocial problems, but the responsibility of the entire medical team involved with the child (Box 2b).

**Practice experience: identification of psychosocial problems**
The majority of paediatric oncologists think that they are mostly capable of successfully identifying psychosocial problems because they are familiar with the children and the children's families, and because the medical team is aware of psychosocial difficulties (Box 3a).

**Practice experience: identification of psychosocial problems - limitations**
Some paediatric oncologists pointed out that their ability to identify psychosocial problems successfully is dependent on the amount and type of information provided by the children or parents. Children and parents do not always want to disclose problems or

---

**Box 1. Definition of psychosocial functioning**

**Emotional, social and school functioning**
“**It is about good and broad functioning in the family, at school, at clubs. That what a normal child would do to lead a normal life within its own social context**” (24)

“I think it refers to total well-being, to the total emotional experience of everything actually, of how you are in life” (1)

“The way the child copes with the disease, the way the child functions in the family, how he is doing at school” (8)

“How the child deals with its environment, thus family as well as everything that surrounds it, such as friends” (19)

**Living a normal life**
“That the child is still comparable to peers without the disease, despite the cancer diagnosis” (2)

“That the child feels well, that it resumes normal things in life. And continues being a child and slowly returns to the normal setting. To school, playing with friends and does not feel patient anymore” (7)

“Yes, the way the child is, the way it would be without the disease. How it would be when playing and learning in its environment” (17)

Note: For each quote, the respondent number of the paediatric oncologist that made the quote is in parentheses.
Box 2a. Perceived task in discussing psychosocial functioning and in identifying psychosocial problems

| Having a holistic view                                                                                     |
| “The child is of course not only a cell, a piece of tumour with a child around it” (17)                      |
| “It is integrated actually; you treat a child and you are treating the disease. But you are also treating the person and the parents” (12) |
| “Well, yes, with a beautiful word: holistic medicine” (4)                                                  |
| “Giving chemotherapy is simple. You need to get a bigger bond. It is about day-to-day contact. Building trust” (16) |

| Interference with treatment                                                                                 |
| “I think it is a necessity for treating the child, to make sure that he or she feels well. To be able to stick to treatment at all” (14) |
| “Yes, absolutely. It interferes with treatment and guidance” (7)                                              |
| “If the child dysfunctions psychosocially, it influences compliance with therapy and cooperation” (10)       |

| Inherent to being a paediatrician                                                                         |
| “I find identifying psychosocial problems an important part of our profession, especially in paediatric oncology” (21) |
| “It is simply inherent to being a paediatrician, because a paediatrician deals with growth and development. This is a primary aim. It is a characteristic of paediatrics. Identifying psychosocial problems belongs to that” (23) |
| “That is why you become a paediatric oncologist, I think” (3)                                               |

| Being the primary contact or coordinator                                                                  |
| “Well, because I am the primary person in charge of treating the child, and I think it is therefore important that I am responsible for the well-being of the child” (13) |
| “They are not seeing anyone else. Normally, you are their only contact” (18)                              |
| “Yes, because the paediatric oncologist is the coordinator of health care” (21)                           |

| Referring to specialised care                                                                               |
| “If I notice there are serious problems, then I will refer quickly” (20)                                    |
| “You have to know when to refer” (23)                                                                     |
| “Because I am the one who has to refer, if I think extra care is needed” (6)                               |
Box 2b. Perceived limitations in task discussing psychosocial functioning and identifying psychosocial problems

**Lack of expertise**
“But I think you have to be aware of the fact that you only have very limited abilities to do that” (23)

“Yes, but we are less trained and schooled in this. We do it on own experience really” (1)

“Because we do not have a psychosocial background, I think we might overlook certain psychosocial problems” (22)

**Not solving psychosocial problems**
“But solving those problems is often not within my expertise” (18)

“I do not regard it as my task to solve problems; I refer them to a psychologist or social worker” (14)

**Not having detailed discussions**
“It concerns restricted questions; I will not extensively explore the child’s mood” (9)

“I would not question very deeply” (24)

“But not necessarily into detail. If there are any problems then I would like to know what those problems are, how serious they are and the impact it has on child and family. But solving those problems is not my expertise, so to what extent will you discuss?” (18)

**Low threshold referral specialised care**
“There is a weekly signal to the psychologist with the request to telephone certain people and ask them if they need any support” (15)

“When I get the feeling that I don’t have the expertise, I try to pass it on” (18)

**Limited time and work pressure**
“However, sometimes, because of lack of time, discussing psychosocial functioning gets an inferior role, maybe” (12)

“And then of course the work pressure at the out-patient clinic plays a part in this” (7)

**Responsibility of whole medical team**
“…as part of the team, I think. So I am one of the people of the medical team who can identify psychosocial problems” (12)

“Yes, but it is not only my task. I think that other people also have to identify” (9)
they may conceal information, which could lead to an underestimation of psychosocial problems. Furthermore, a lack of expertise and time were mentioned as limitations in identifying psychosocial problems successfully. In addition, psychosocial functioning is usually not systematically or structurally discussed during consultation (Box 3b).

### Strategies for identifying psychosocial problems

Many paediatric oncologists questioned children and parents to identify psychosocial problems. If they suspected that certain problems existed, they explicitly addressed these issues to learn more about the situation. In addition, some paediatric oncologists explored the child’s daily activities or observed nonverbal signs and the parent-child interaction during the consultation (Box 4).

### Emotional support

#### Definition of emotional support

Emotional support provided by the paediatric oncologist was often defined as showing empathy, understanding and interest for the child and the family’s situation and feelings (Box 5).

#### Perceived task in providing emotional support

Nearly all of the paediatric oncologists reported that it was their task to provide emotional support for the children and their families. Many respondents achieved this emotional support by showing interest and talking with the child and family. Some respondents provided emotional support by performing ones job well, giving information, referring to psychosocial care or being straightforward and clear about the prognosis and treatment to diminish uncertainty. Moreover, some paediatric oncologists indicated that it was important to be accessible, to maintain a positive attitude towards the child and family, and to offer physical comfort if appropriate (e.g., a hug when the child is sad) (Box 6a).
**Perceived task in providing emotional support – limitations**

Although paediatric oncologists generally acknowledged that providing emotional support is one of their tasks, they also stated that there are some limitations in doing this. Several respondents declared that they keep a certain amount of distance from the child and family’s emotions; crying along will not help their patients. In addition, some paediatric oncologists indicated that offering emotional support depends on the personality and age of the child, and on the personality of the doctor (Box 6b).

**Box 3b. Practice experience: unsuccessful identification of psychosocial problems**

- **Dependent on information**
  "So I am very dependent on what I hear from parents or nursing. Nurses sometimes know different sides of the story than the doctor" (10)

  "What I have noticed quite a few times is that the signals are sometimes relatively weak, or that it does not come through very well. In those cases you identify the problems late or too late" (21)

- **Undisclosed problems or concealed information**
  "Because not all children and parents are explicit if something is going on" (8)

  "I also think, that sometimes parents believe ‘well, this is not something to discuss with the doctor’” (4)

- **Underestimated problems**
  "Oh well, let’s hold on for a while and then it will be okay…’ which is often true. But if it is not, you sometimes think maybe we have been too hopeful that it would resolve by itself” (11)

  "It is possible that I will underestimate how big a problem is” (20)

- **Lack of expertise**
  "My knowledge is too limited” (13)

  "Maybe I have not fully learned how to identify problems” (4)

- **Lack of time**
  "Not always I think, since there is only limited time for each patient” (14)

  "Sometimes you are completely focussed on a certain thing, and then you will skip it. There is no time and no energy left for other things” (19)

- **Lack of structural discussion**
  "What I would want is more structure. Because now I make it up myself…There are no standard questions I ask” (13)

  “No, especially if you do not structurally explore it” (19)
Box 4. Strategies for identifying psychosocial problems

Discussing, questioning and addressing problems
“That is simply asking questions, plainly exploring” (5)

“You need to dare to discuss and you also need to dare to tell it like it is” (1)

“If I hear things I step right up to it and call the parents with me, like a paterfamilias” (21)

“I address what I see” (22)

Exploring daily activities
“I ask additional questions, like what do you do all day?” (19)

“To get an impression of the child’s day” (7)

Observing nonverbal signs
“I think like an intake or interview, but I also find non-verbal signs very important” (6)

“Or just by looking. If children are gloomy, you can obvious see this very well” (15)

Observing parent-child interactions
“Use your eyes, use your ears and simply look what is happening. A child in interaction with the parent” (17)

“What, I think, is very important is the interaction in your consultation room” (2)

Box 5. Definition of emotional support

Showing empathy
“Showing empathy is most important, I think” (23)

“Being a doctor that is empathic and thinks along” (18)

“Showing some empathy” (4)

Showing understanding
“In any case, show that you understand what people are going through” (21)

“That you do not only understand the kind of disease the child suffers from, but also the impact it has” (11)

Showing interest
“Emotional support by the doctor is a bit of empathy, a bit of interest and identifying problems” (13)

“Daily attention. Showing that your attention is sincere” (20)
### Box 6a. Perceived task in providing emotional support

**Showing interest and talking to the children and their families**
- “To keep on communicating, to be aware of each others’ thoughts and feelings” (18)

- “By simply exploring what happens per individual and how things are going in the family. So I think that you provide emotional support by talking about it” (21)

**Performing your job well**
- “First of all, performing your work well” (9)

- “This means providing good substantive work” (18)

**Giving information**
- “I think that you can play a part in it by providing patients with information about the disease” (14)

- “I think, taking enough time to explain things” (12)

**Referring to psychosocial care**
- “There are a number of things you can do yourself, but if you can not, you say ‘I can not do this anymore, I need someone else to do this’” (11)

- “And when necessary, if you think it is not sufficient, you call in the help of other professionals” (21)

**Being straightforward**
- “The most important supporting role of a doctor is that he is honest, I think. That he tells it straightforward and performs his work well” (24)

- “First of all, you have to be very clear to people in your medical message. I believe when you are clear you can take away a lot of uncertainty. This gives people a lot more rest” (5)

**Being available**
- “There is a point of controversy between my colleagues and me, because I always give patients my email address. I find that a very pleasant way of communication” (13)

- “Being available in case of emergency; you say ‘if things do not work, then please call me’” (12)

**Maintaining a positive attitude**
- “For me the most important thing is to give a child hope… Not always being dramatic or pessimistic about the disease. It must be bearable and there must be bright spots” (7)

- “… basically radiate something positive about chances of recovery” (14)

**Offering physical comfort**
- “And then we put our arms around each other and said ‘it is all so shit’” (17)

- “It goes as far as putting a hand on someone’s shoulder. Just being physical for a minute” (23)
Box 6b. Perceived limitations in task providing emotional support

Keeping ones distance
“Let me put it this way: without crying along with the family. I do not think that will help them” (24)

“By showing that you understand their grief, without crying along” (20)

Personality and age of the child
“I think providing emotional support depends very much on the patient” (1)

“That is something which is very age-dependent” (8)

Personality of the doctor
“I believe that everyone acknowledges that every doctor has a personal style. We respect each others’ style” (20)

“I see great differences within our group when it comes to providing emotional support. I would not dare to say which way is best” (18)

Discussion

This study indicates that paediatric oncologists believe that it is their task to discuss psychosocial functioning, to identify psychosocial problems and to provide emotional support to children with cancer. However, paediatric oncologists also mentioned that fulfilling this task can be limited due to e.g. lack of expertise or time.

In general, our findings agree with previous research that has demonstrated how paediatricians consider themselves responsible in identifying mental health issues [4]. Paediatric oncologists’ perceptions towards this responsibility are shown in Box 2a (it is ‘inherent to being a paediatrician’ that you are ‘the primary contact’). Our findings are also in line with several key components of doctor-patient interactions involving children and their parents identified by Crossley and Davies [15]. For instance the key component of patient-parent-centeredness regarding sensitivity to unresolved issues and problem identification can be found in Box 2a, 3a and 4 (‘discussing, questioning and addressing problems’ and having an ‘alert medical team’). The key component of interpersonal skills, such as sensitivity to nonverbal cues, was mentioned by paediatric oncologists as well (Box 4, ‘observing non-verbal signs’). Additionally, the key components health-related problems (e.g., relief of distress), psychosocial problems and problems with cognitive difficulty are applicable to our findings in a more general sense. Some paediatric oncologists defined psychosocial functioning as ‘living a normal life, despite having the disease’ (Box 1). Because they also believe that it is their task to identify psychosocial problems (Box 2a), it likely that they will try to achieve an outcome in which distress and psychosocial and cognitive problems are relieved. Liaisons with relevant health-care professionals (e.g., full
use of the child’s health team, communication with health-care professionals) is another key component. This was mentioned by paediatric oncologists in terms of the alertness of the child’s medical team (Box 2b and 3a) and referrals to psychosocial care (Box 2a and 2b). Finally, Crossley and Davies [15] stated that making appropriate family plans (e.g., addressing the patient’s needs and problems) is important in paediatric doctor-patient interactions as well; paediatric oncologists also regarded this as their task (Box 4, ‘discussing, questioning and addressing problems’).

With respect to emotional support our study illustrates that paediatric oncologists’ perceptions match the preferences of their patients who indicated to need support and empathy (Box 5 and 6a; ‘showing empathy’ and ‘being available’), and sufficient time for communication (Box 6a; ‘giving information’, second quote) [21]. Additionally, our findings regarding emotional support agree with some of the key components described by Crossley and Davies [15]. For instance, interpersonal skills ‘empathy and support’ can be found in Box 5 and 6a, and general communications skills ‘listening, clarity of communication and information-giving’ are presented in Box 6a (‘giving information’ and ‘being straightforward’). Finally, the key component making appropriate family plans, e.g. providing psychological support is reflected in Box 5 and 6a (‘referring to psychosocial care’).

Overall, paediatric oncologists’ views towards their task in psychosocial functioning and emotional support met many of the important components of doctor-patient interactions involving children [15]. However, paediatric oncologists also clearly indicated, that this is a task within boundaries. For instance, some of them do not feel responsible or qualified for solving psychosocial problems (Box 2b), which is in agreement with other research [22]. With respect to providing emotional support, some remain distanced from their patients and their patient’s family (Box 6b). Potentially confounding effects on doctor-patient interactions, such as the doctor’s level of training and workload and patient’s age were identified by Crossley and Davies [15]. These limitations were also mentioned by our respondents (Box 2b, 3b and 6b). Other reasons for unsuccessful identification of psychosocial problems were dependency on information, undisclosed problems, underestimated problems and lack of structural discussion of problems (Box 3b). Since paediatric oncologists felt responsible for discussing and identifying psychosocial problems, it is important to find ways to overcome these limitations. In the light of the QLIC-ON study, we therefore suggest considering the use of psychosocial PROs during the consultation as a possible solution. PROs are answers to questionnaires based on direct reporting by patients without the intervention of an observer. PROs can serve as an aid for the physician to systematically identify and discuss psychosocial problems. In a very recent study [17] we demonstrated that the use of PROs in paediatric oncology practice increased the discussion of emotional and psychosocial functioning and enhanced the identification of emotional and cognitive problems, without lengthening the consultation duration.
Strength of the current study is that a substantial amount (44%) of the total population of paediatric oncologists working in the Netherlands participated in our study. Therefore, our findings are likely to be representative of all paediatric oncologists working in the Netherlands. Because the organisation and quality of paediatric oncology health care systems can vary, however, our findings may not be representative of other countries.

Our study was limited in that the paediatric oncologists knew that the interviewer was employed at the Psychosocial Department of the Academic Medical Centre/Emma Children’s Hospital, and they were aware of the purpose of the QLIC-ON study. These circumstances may have biased some of the respondent’s answers (social desirability). Furthermore, it is a study limitation that the paediatric oncologists had no opportunity to refuse participation because the interviews were part of the QLIC-ON study, in which the paediatric oncologists were enrolled. This may have caused bias in our findings as well. However, because the responses were varied and revealed their perceived limitations, we believe that the paediatric oncologists in this study remained sincere and professional and thus provided us with valid information.

We recommend future studies to investigate whether paediatric oncologists are truly successful in discussing psychosocial functioning, identifying psychosocial problems and providing emotional support. This evaluation could be accomplished by comparing paediatric oncologists’ perceptions with the perceptions of the parents and children. Furthermore, it is important to explore the paediatric oncologists’ view regarding their responsibility in parental psychosocial functioning, since parents of children with cancer can also experience psychosocial impairment [23, 24]. Psychosocial problems of parents were included in our interview schedule; however, analysing these data was beyond the scope of this paper.

We conclude that paediatric oncologists are aware of the psychosocial consequences of childhood cancer and that they provide psychosocial care to the best of abilities.
### Definition of psychosocial functioning

<table>
<thead>
<tr>
<th>Summary psychosocial functioning</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attitude of parent/ child towards psychosocial care</td>
<td>1</td>
</tr>
<tr>
<td>Behaviour</td>
<td>2</td>
</tr>
<tr>
<td>Being able to communicate</td>
<td>1</td>
</tr>
<tr>
<td>Clubs/ societies/ sports/ hobbies</td>
<td>7</td>
</tr>
<tr>
<td>Coping with consequences disease/ treatment</td>
<td>8</td>
</tr>
<tr>
<td>Family/ home/ parents/ brothers/ sisters</td>
<td>26</td>
</tr>
<tr>
<td>Friends/ peers/ boy-girlfriend</td>
<td>18</td>
</tr>
<tr>
<td>Independent functioning</td>
<td>1</td>
</tr>
<tr>
<td>Individuality/ being able to be themself</td>
<td>3</td>
</tr>
<tr>
<td>Interaction with medical team</td>
<td>1</td>
</tr>
<tr>
<td>Normal life</td>
<td>9</td>
</tr>
<tr>
<td>Psychological/ emotional well-being</td>
<td>22</td>
</tr>
<tr>
<td>Quality of life</td>
<td>1</td>
</tr>
<tr>
<td>School/ daycare</td>
<td>23</td>
</tr>
<tr>
<td>Self perception</td>
<td>1</td>
</tr>
<tr>
<td>Sleeping</td>
<td>1</td>
</tr>
<tr>
<td>Support</td>
<td>2</td>
</tr>
</tbody>
</table>

### Task to discuss/ identify psychosocial functioning/ problems

<table>
<thead>
<tr>
<th>Yes</th>
<th>24</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children should live a normal live</td>
<td>3</td>
</tr>
<tr>
<td>Fun/ interesting</td>
<td>2</td>
</tr>
<tr>
<td>Holistic view on treating children</td>
<td>15</td>
</tr>
<tr>
<td>Inherent to being paediatrician</td>
<td>7</td>
</tr>
<tr>
<td>Interference with physical functioning/ compliance with therapy</td>
<td>8</td>
</tr>
<tr>
<td>Parents/ children disclose problems</td>
<td>3</td>
</tr>
<tr>
<td>Parents/ children don’t see problems</td>
<td>2</td>
</tr>
<tr>
<td>Preventing delays in development</td>
<td>1</td>
</tr>
<tr>
<td>Preventing parental problems (work, finances)</td>
<td>1</td>
</tr>
<tr>
<td>Primary contact/ coordinator/ coach</td>
<td>9</td>
</tr>
<tr>
<td>Responsible for identifying problems</td>
<td>11</td>
</tr>
<tr>
<td>Responsible for exploring problems</td>
<td>8</td>
</tr>
<tr>
<td>Responsible for providing psychosocial care by paediatrician</td>
<td>6</td>
</tr>
<tr>
<td>Responsible for referral to psychosocial care</td>
<td>19</td>
</tr>
<tr>
<td>Psychosocial side effects of treatment</td>
<td>2</td>
</tr>
<tr>
<td>However, limited by</td>
<td>1</td>
</tr>
<tr>
<td>Frequent contact</td>
<td>1</td>
</tr>
<tr>
<td>Frequency</td>
<td></td>
</tr>
<tr>
<td>-----------</td>
<td></td>
</tr>
<tr>
<td>Limited contact</td>
<td>1</td>
</tr>
<tr>
<td>Restricted discussion/no details</td>
<td>6</td>
</tr>
<tr>
<td>Restricted responsibility/expertise/training</td>
<td>16</td>
</tr>
<tr>
<td>Restricted time/work pressure</td>
<td>6</td>
</tr>
<tr>
<td>Medical team also responsible for identifying problems</td>
<td>5</td>
</tr>
<tr>
<td>Not responsible for solving problems</td>
<td>2</td>
</tr>
<tr>
<td>Parents/children don’t disclose problems</td>
<td>2</td>
</tr>
<tr>
<td>Type of problem (only disease related)</td>
<td>1</td>
</tr>
</tbody>
</table>

**Successfully identify psychosocial problems**

**Yes/mostly**

- Medical team is alert | 3 |
- Personality paediatrician | 1 |
- Well acquainted with parent/child | 2 |

**Not always/sometimes**

- Blind spot/not alert enough | 2 |
- Depending on info from parents/child/medical team | 5 |
- Difference of opinion in medical team: what is a problem? | 1 |
- It takes time to successfully identify | 2 |
- Restricted expertise/training/knowledge | 3 |
- Restricted time | 3 |
- No structural discussion | 4 |
- Parents/children conceal problems/refuse help | 7 |
- Underestimation of problems | 4 |

**Hopefully**

- Dependent on consultation frequency | 1 |

**Strategy of identifying psychosocial problems**

- Acknowledging problems | 1 |
- Being open/interested | 1 |
- Cooperation with medical team | 3 |
- Depending on age and type of child/parents | 3 |
- Exploring activities/daily functioning | 6 |
- Exploring body image | 1 |
- Exploring crucial moments | 2 |
- Intuition | 1 |
- Listening | 2 |
- Observing | 4 |
- Questioning/communicating/discussing | 23 |
- Standard checklist | 2 |
### Definition of emotional support

**Summary emotional support**

<table>
<thead>
<tr>
<th>Showing empathy/ interest/ understanding/ acknowledging emotions</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>24</td>
</tr>
</tbody>
</table>

### Task to provide emotional support

#### Yes

<table>
<thead>
<tr>
<th>Task</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asking about things not related to disease</td>
<td>1</td>
</tr>
<tr>
<td>Being available</td>
<td>4</td>
</tr>
<tr>
<td>Being honest/ clear</td>
<td>5</td>
</tr>
<tr>
<td>Being objective</td>
<td>1</td>
</tr>
<tr>
<td>Bonding with child/ parents</td>
<td>1</td>
</tr>
<tr>
<td>Getting through treatment</td>
<td>1</td>
</tr>
<tr>
<td>Identifying problems</td>
<td>2</td>
</tr>
<tr>
<td>Listening</td>
<td>3</td>
</tr>
<tr>
<td>Making sure the child can be him/ herself</td>
<td>2</td>
</tr>
<tr>
<td>Part of being a paediatrician</td>
<td>1</td>
</tr>
<tr>
<td>Performing work well</td>
<td>6</td>
</tr>
<tr>
<td>Physical comfort</td>
<td>4</td>
</tr>
<tr>
<td>Positive/ optimistic attitude</td>
<td>5</td>
</tr>
<tr>
<td>Providing info (to prevent uncertainty)</td>
<td>5</td>
</tr>
<tr>
<td>Questioning/ communicating/ discussing</td>
<td>10</td>
</tr>
<tr>
<td>Referral</td>
<td>4</td>
</tr>
<tr>
<td>Regular contact/ continuity of care</td>
<td>3</td>
</tr>
<tr>
<td>Relaxing consultation/ joking</td>
<td>3</td>
</tr>
<tr>
<td>Showing empathy/ interest/ understanding/ acknowledging emotions</td>
<td>24</td>
</tr>
<tr>
<td>Taking action</td>
<td>2</td>
</tr>
<tr>
<td>Working together (parent/ child/ doctor)</td>
<td>2</td>
</tr>
</tbody>
</table>

#### However, limited by

- Age or type of child                                              | 3         |
- Restricted expertise/ skills/ training                            | 1         |
- Not crying along/ keeping distance/ self protection               | 7         |
- Personality of doctor                                             | 5         |
- Time                                                               | 2         |
- Restricted discussion                                             | 2         |

#### No

| Limited time                                                       | 1         |
Reference List


