High-quality care for all children with cancer


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Background: Providing high-quality care for children with cancer could improve treatment outcomes, survival and quality of life of the children and parents. The aim of this study is to select high-quality care recommendations for all children with cancer based on literature and consensus for future development of quality indicators.

Materials and methods: We performed an extensive search in databases for scientific literature and in websites of international health care and guideline development organizations to create an inventory of recommendations for the care for all children with cancer. The RAND modified Delphi method was used to grade and select recommendations for high-quality care.

Results: Our search resulted in a list of 131 recommendations on care for all children with cancer. The expert panel graded, discussed and prioritized these recommendations. Analysis of these ratings resulted ultimately in a list of 109 high-quality care recommendations for all children with cancer, including 31 prioritized recommendations.

Conclusions: This study defines a set of high-quality care recommendations based on literature and consensus. These recommendations provide a basis for the development of a comprehensive set of quality indicators to evaluate care in paediatric oncology.

Key words: childhood cancer, quality improvement, quality of care

introduction

Childhood cancer is the leading cause of death from illness in children in high-income countries, although the improvement of therapy for children with cancer has led to a considerable rise of survival rates [1]. In Western countries, the overall 5-year survival rate for children diagnosed with cancer has risen from 44% in the 1970s to 81% in the early 2000s [2, 3].

The care for patients with cancer is complex [4]. An important factor that contributes to this complexity is the enormous impact of childhood cancer on the emotional and social well-being of the developing child and its family. In addition, childhood cancer is a rare disease with a wide variety of tumour types and thus a wide variety of treatment modalities. Thirdly, the diagnostic, treatment and follow-up phase of a child with cancer requires input from numerous professionals with different backgrounds. Therefore, paediatric oncology faces major challenges in optimizing the quality of health care and patient safety.

Important aspects that should be addressed when providing high-quality care for children with cancer include communication and delivery of information in an honest, understandable and cultural appropriate manner. This is essential for supporting the emotional and social well-being of the child with cancer and its family [5, 6]. The wide variety of treatment modalities requires high-quality professional care, with a minimum of complications, performed in a technically excellent manner [7]. Finally, the care delivered should be embedded in a well-organized setting that provides close collaboration with the numerous involved professionals.

Providing high-quality care for children with cancer may lead to improved patient event-free survival and overall survival [8]. In addition, providing high-quality care may result in reduced treatment-related complications and could improve the quality of life for children with cancer and their parents. Consequently, optimizing and providing high-quality care, key responsibilities of all physicians, is of utmost importance [9]. An essential first step in providing high-quality care is to define such care. The American Academy of Pediatrics (AAP) has been a major contributor in providing and improving the care for children with cancer by publishing guidelines for paediatric cancer centres [10]. These guidelines concentrate on the organization (personnel, facilities and capabilities) of paediatric cancer centres and pay less attention to other...
important aspects of high-quality care, such as communication and professional care. The aim of this study is to complete and extend the recommendations of these guidelines by selecting high-quality care recommendations on all major aspects of high-quality care for all children with cancer. This set of high-quality care recommendations will provide a basis for future development of quality indicators.

**Methods**

**(inter)national literature search**

To create an inventory of recommendations for the care for all children with cancer, we performed an extensive search in databases for scientific literature and in websites of international health care and guideline development organizations.

We searched the databases of Medline-Ovid and the Cochrane Library to identify studies about the development or evaluation of quality indicators for the care for all children with cancer. Quality indicators are measurable items of care, based on recommendations from scientific literature, referring to the structures, processes or outcomes of care [11]. The search strategies, inclusion and exclusion criteria are listed in supplemental Appendices 1–3 (available at *Annals of Oncology* online).

The search in websites of international health care and guideline development organizations to identify recommendations, guidelines and quality indicators for the care for all children with cancer was based on the guideline for Quality Indicator Development of the Dutch Institute for Healthcare Improvement (CBO) [12] and field experts.

**Questionnaire round**

The recommendations that resulted from our literature search were categorized according to the three major aspects of high-quality care for children with cancer as stated above: ‘Patient communication & Information’, ‘Professional care’ and ‘Organization & Collaboration’. These three lists of recommendations were transformed into questionnaires. To each recommendation, a Likert scale rating for relevancy in defining high-quality care (score 1, ‘not at all relevant’ to 9, ‘very relevant’) was added. An expert panel of different stakeholders in the field of paediatric oncology was assembled who graded each recommendation of each list for relevancy. This expert panel was composed of 41 members and consisted of at least two paediatric oncologists of each of the five paediatric oncology centres and the two centres for paediatric allogenic bone marrow transplantation in The Netherlands. Moreover, the panel included the following professionals working in the field of paediatric oncology: nurses, general paediatricians, surgeons, neurosurgeons, radiotherapists, psychologists, an orthopaedic surgeon, an intensivist, radiologists, a neurologist, an infectiologist, a pharmacist, health care managers and a patient representative. Each panellist was asked to make a ranking of five recommendations that they thought were the most relevant per questionnaire. The panellists also had the opportunity to suggest new recommendations that were lacking in our questionnaires and would complete our set of recommendations for high-quality care for all children with cancer.

High-quality care recommendations were selected according to relevancy (median scores of 8 or 9). We made a further selection to single out the most important high-quality care recommendations. This selection of prioritized recommendations was based on relevancy and agreement as stated in the RAND Modified Delphi procedure [13]. We added ‘ranking’ as a third item for prioritization. All prioritized recommendations met the following criteria:

- relevancy (median scores of 8 or 9);
- agreement (>70% of the scores in the same three-point area, with no disagreement; disagreement means that >30% of the scores are in both the highest and lowest three-point area);
- ranking (>10% of members expert panel ranked the recommendation as being among the most relevant per questionnaire).

**Expert panel meeting**

The results of the analysis of the questionnaires were presented in a meeting to which all panellists were invited. The purpose of this expert panel meeting was to give each expert the opportunity to have face-to-face discussions with other experts about the clarity, comprehensibility and measurability of the selected recommendations. During this expert panel meeting, the panellists were divided into subgroups of three to four persons where each subgroup could discuss a set of the recommendations. The comments of each subgroup were presented and discussed in plenary session until consensus was reached about the contents.

**Second questionnaire round**

The comments that derived from the expert panel meeting were used to rephrase and combine some of the high-quality care recommendations for children with cancer. These adapted high-quality care recommendations were included in a second questionnaire, which was presented to the expert panel for final remarks and approval.

**Results**

**(inter)national literature search**

The Medline-Ovid and the Cochrane Library database search yielded 403 abstracts. Two reviewers checked whether the abstracts fulfilled the inclusion criteria of our study. Four abstracts met the inclusion criteria for full-text appraisal [14–17]. Data extraction of these four publications revealed quality indicators for specific tumour treatment and detailed aspects of pain management in childhood cancer but provided neither recommendations nor quality indicators directed at the care for all children with cancer. The search for recommendations, guidelines and quality indicators for the care for all children with cancer, performed in 43 websites of international health care organizations, resulted in 34 guidelines and documents with recommendations regarding paediatric oncology (supplemental Appendix 4, available at *Annals of Oncology* online). No quality indicators were identified. From the assembled data, a list of 131 recommendations for the care for all children with cancer was composed.

**Questionnaire round**

These 131 recommendations for the care for all children with cancer were categorized into three questionnaires:

- ‘Patient communication & Information’: 34 recommendations
- ‘Professional care’: 36 recommendations
- ‘Organization & Collaboration’: 61 recommendations

The questionnaires were completed by 36 members (88%) of the expert panel.

The expert panel graded 115 (88%) of the total 131 recommendations with a median relevancy score of 8 or 9 as high-quality care recommendations (Table 1). The expert panel
graded 25 recommendations (74%) selected from ‘Patient communication & Information’ with a median relevancy score of 8 or 9. These high-quality care recommendations addressed mainly psychological aspects of how a caregiver should communicate with his or her patients. The emphasis of the 31 high-quality care recommendations (86%) on ‘Professional care’ was on collaboration of the main caregiver with other physicians and the importance of documenting decisions concerning findings and/or treatment. Among the ‘Organization & Collaboration’ recommendations, 59 (97%) were graded as high-quality care recommendations. These recommendations reflected issues concerning the organization of multidisciplinary teams in paediatric oncology centres and patient safety aspects.

Because of the unequal division of the number of recommendations per questionnaire, we asked the expert panel to extend their ranking of the most relevant recommendations of the ‘Organization & Collaboration’ questionnaire to 10 instead of the five recommendations they ranked for relevancy for the ‘Patient communication & Information’ and ‘Professional care’ questionnaires.

The expert panel prioritized (based on relevancy, agreement and ranking) 34 of the 115 high-quality care recommendations. The 34 prioritized recommendations had a mean relevancy score of 8.7 and were ranked by an average of 23% of the panellists as being the most relevant for high-quality care recommendations. These recommendations reflected issues concerning the organization of multidisciplinary teams in paediatric oncology centres and patient safety aspects.

Table 1. Distribution of median scores for relevancy of each recommendation per category (score 1, not at all relevant to 9, very relevant)

<table>
<thead>
<tr>
<th>Category</th>
<th>N</th>
<th>Median score</th>
<th>Ranking (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>1 2 3 4 5 6 7 8 9</td>
<td>Mean Range</td>
</tr>
<tr>
<td>Patient communication &amp; information</td>
<td>34</td>
<td>0 0 0 0 1 0 8 21 4</td>
<td></td>
</tr>
<tr>
<td>Professional care</td>
<td>36</td>
<td>0 0 0 0 0 1 4 22 9</td>
<td></td>
</tr>
<tr>
<td>Organization &amp; collaboration</td>
<td>61</td>
<td>0 0 0 0 0 0 2 33 26</td>
<td></td>
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</table>

The expert panel consisted primarily of health care professionals working in the field of paediatric oncology, with only one patient representative participating. By dividing the recommendations into three different questionnaires, reflecting three different aspects of care, we attempted to achieve an ultimate selection of high-quality care recommendations that would cover the whole field of care for all children with cancer. Nevertheless, the high-quality care recommendations developed in this study are mainly from the caregiver’s

second questionnaire round

In the second questionnaire round, this final set of high-quality care recommendations, including the prioritized recommendations, was sent to the entire expert panel. The expert panel had no final remarks and the contents were unanimously adopted. Finally, we regrouped the high-quality care recommendations into five categories to get a better overview. These categories are ‘Medical care’, ‘Communication’, ‘Educations & Training’, ‘General quality measures’ and ‘Structure and facilities of care’. The 31 prioritized recommendations are shown in Table 3. The other 78 high-quality care recommendations for the care for all children with cancer are depicted in supplemental Appendix 5 (available at Annals of Oncology online).

discussion

This study defines a set of literature- and consensus-based high-quality care recommendations for all children with cancer and is a valuable extension of the AAP guidelines for paediatric cancer centres. These recommendations highlight the importance of qualified professionals who communicate in an appropriate manner and provide high-quality care in a well-organized multidisciplinary setting. All these aspects of care are needed in paediatric oncology and also apply to many, if not all, paediatric subspecialties who provide care for complex patients. Our set of 109 high-quality care recommendations, including 31 prioritized recommendations, is a valuable tool to evaluate and improve quality of care for all children with cancer and will be used to develop quality indicators.

For this study, we used the RAND modified Delphi method, which combines scientific evidence and collective judgement of experts to grade recommendations. This method has proven to be successful in numerous occasions [18–22]. In our study, we deliberately deviated from this procedure. An expert panel is, according to the RAND/UCLA Appropriateness Method User’s Manual, ideally composed of nine members. Experience has shown that this number is large enough for providing diversity in the panel group and small enough for providing involvement of every member in the group discussion [13]. However, our expert panel was composed of 41 members. By using this high number of panellists with different professional backgrounds, we provided a broad multidisciplinary support for our set of high-quality care recommendations for all children with cancer. Our procedure with subgroup and plenary discussions provided involvement of each member of the expert panel.

The expert panel consisted primarily of health care professionals working in the field of paediatric oncology, with only one patient representative participating. By dividing the recommendations into three different questionnaires, reflecting three different aspects of care, we attempted to achieve an ultimate selection of high-quality care recommendations that would cover the whole field of care for all children with cancer. Nevertheless, the high-quality care recommendations developed in this study are mainly from the caregiver’s
Table 3. Prioritized High-Quality Care Recommendations for all Children with Cancer

A. Medical care

1. A paediatric oncology centre has so-called ‘Treatment Multidisciplinary Teams’ (TMDT) at its disposal for the treatment of children with cancer directed at the following tumour types: central nervous system (CNS) tumours, solid tumours (outside the CNS), retinoblastoma, lymphomas and leukaemias (including allogenic bone marrow transplantation). The TMDTs are in charge of the care for the patient and consist of representatives of all relevant care providers.

2. A paediatric oncology centre has a functioning supportive Multidisciplinary Team at its disposal directed at the psychosocial care for paediatric oncology patients and their families. This psychosocial MDT consists at least of child psychologists, play therapists, social workers, paediatric oncology nurses, educational service workers, paediatric oncologists and if desired other specialists of the TMDT.

3. A paediatric oncology centre has a functioning supportive Multidisciplinary Team at its disposal directed at palliative care. This palliative care MDT consists at least of a case manager, general practitioner, district nurse, specialized paediatrician and nurse for palliative care, child psychologist and paediatric oncologist. The palliative care MDT is involved with every patient for whom cure is not feasible.

4. A paediatric oncology centre has a functioning supportive Multidisciplinary Team at its disposal directed at the management of pain in children. This pain MDT consists at least of a paediatric oncologist, paediatric nurse, play therapist, paediatric neurologist and a paediatric anaesthesiologist for complex pain management.

5. The paediatric oncology MDT designates a practitioner-in-charge and its substitute who act on behalf of the paediatric oncology MDT. The practitioner-in-charge and its substitute are documented in the (digital) medical file and are known to the patient, parents and/or guardians.

6. The physician-in-charge composes for the total process of care a scheme for diagnostics, treatment and follow-up in close collaboration with other medical disciplines, the patient, parents and/or guardians. This scheme is up-to-date and traceable in the (digital) medical file.

7. The physician-in-charge offers to children, who are eligible, participation in clinical trials. If children do not participate in a clinical trial and if there is no (inter)national guideline available, an individual treatment scheme will be developed based on maximal scientific proof and expertise.

8. The physician-in-charge of the paediatric oncology MDT makes sure that the patient and parents or guardians are being introduced, within 1 week after start treatment, with a member of the psychosocial MDT and take knowledge of their possibilities of support.

9. The physician-in-charge offers to children, who are eligible, participation in clinical trials. If children do not participate in a clinical trial and if there is no (inter)national guideline available, an individual treatment scheme will be developed based on maximal scientific proof and expertise.

10. A shared care centre is a centre where less complex well-circumscribed parts of treatment can take place under supervision of a paediatric oncology centre. A shared care centre has guidelines about when to confer with a paediatric oncology centre about a paediatric oncology patient.

11. The physician-in-charge documents the decisions and conclusions in the medical file which is available and accessible to all caregivers involved in the treatment scheme.

12. The physician-in-charge documents makes summaries about the individual patient (diagnosis, prognosis and treatment) for other caregivers.

B. Communication

13. The physician-in-charge or another relevant member of the MDT has conversations with the patient and parents or guardians on critical and on standard moments in the treatment scheme.

14. A conversation between the patient, parents/guardians and caregiver takes place in a space where privacy is guaranteed.

15. The caregiver takes, according to the patient and parents or guardians, enough time for the conversations with the patient and parents or guardians.

16. The caregiver repeats important information and summarizes this when he/she communicates with the patient and parents or guardians.

17. The caregiver gives information adjusted to the stage of disease of the patient.

18. The caregiver explains medical terms in plain language.

19. The caregiver gives patients and parents or guardians the opportunity to express their feelings during conversations.

20. The caregiver checks with the patient and parents or guardians whether they understood the given information.

21. The caregiver informs the patient and parents or guardians about the possibilities of treatment. This information is adjusted to the situation of the patient.

22. A paediatric oncology centre has (online) information available for patients, parents or guardians and family members.

C. Education and training

23. All caregivers that are a member of an MDT in a paediatric oncology centre have been trained and have proven experience in the treatment of children with cancer.

D. General quality measures

24. A paediatric oncology centre has written guidelines about diagnostics and treatment of all paediatric cancer types, supportive care (including pain management), follow-up care after the end of treatment and palliative care.

25. The caregiver uses evidence-based guidelines.

E. Structure and facilities of care

26. A paediatric oncology centre sees a child suspected for cancer within one working day to start examination of the problem.

27. A paediatric oncology centre admits children with cancer with critical medical grounds on the same day as referral and without delay.

28. In a paediatric oncology centre, the following caregivers are present on working days between 8.00 and 18.00 o’clock, outside these hours, they are available for consultation and can be present within 60 min:

Paediatric oncologist
Paediatric surgeon
Paediatric neurosurgeon
Paediatric intensivist

Continued
perspective. In future studies, we will investigate whether a patient expert panel gives similar results.

The number of recommendations graded with a median relevancy score of 8 or 9 (88%) was remarkably high. The RAND/UCLA Appropriateness Method User’s Manual states that a rating of 7 and higher for a criterion suffices for being appropriate [13]. By raising the bar to 8, we emphasize the significance of the selected recommendations. The high percentage of recommendations with a median score of 8 or 9 illustrates that there are many important aspects to be reckoned with when providing care for children with cancer.

The members of the expert panel had the opportunity to suggest new recommendations. However, none of them brought forward new items. We do not claim that our set of high-quality care recommendations is complete but probably due to the large number of recommendations the expert panel did not detect any omissions. We will submit this set of high-quality care recommendations for children with cancer for cyclical re-evaluation and adjustments after implementation.

To date, no quality indicators have been developed for the care for all children with cancer. Quality indicators can be used to assess the quality of care provided [11]. Our set of prioritized recommendations provides the basis for the development of such quality indicators. The value of our set of prioritized recommendations as a tool to evaluate the care for all children with cancer has to be demonstrated after implementation and should be the focus of future studies.

In health care, most attention is paid to the outcome of delivered care. However, our set of high-quality care recommendations contain only recommendations referring to the ‘process’ and ‘structure’ of medical care and does not hold any recommendations regarding ‘outcome’. The reason why no outcome recommendations are represented in our set is that our extensive search in databases for scientific literature and in websites of international health care and guideline

| Paediatric radiotherapist |
| Paediatric neurologist    |
| Paediatric anaesthesiologist |
| Paediatric cardiologist   |
| Paediatric nephrologist   |
| Paediatric gastroenterologist |
| Paediatric radiologist    |
| Paediatric pulmonologist  |
| Ear–nose–throat specialist |
| Ophthalmologist           |

29. In a paediatric oncology centre, the following caregivers are available on working days between 8.00 and 18.00 o’clock, outside these hours, they are available for consultation and can be present within 60 min:

- Paediatric immunologist/infectiologist
- Paediatric haematologist
- Paediatric endocrinologist
- Nuclear medicine physician
- Members of psychosocial MDT
- Paediatric pathologist
- Paediatric psychiatrist
- Orthopaedic surgeon
- Paediatric urologist
- Plastic surgeon
- Rehabilitation medicine consultant
- Clinical geneticist
- Oral surgeon
- Physical therapist
- Dietician

30. In a paediatric oncology centre, the following facilities are 24 h/day available:

- Paediatric intensive care unit, reachable within 10 min
- Extensive possibilities for imaging, like conventional X-rays, ultra sound, CT-scan/magnetic resonance imaging with the possibility for anaesthetics
- Anaesthetics for diagnostic procedures or therapeutic interventions
- Clinical chemistry laboratory
- Specialized haematology laboratory for morphological analysis, genotyping and immunophenotyping
- Transfusion medicine and laboratory
- Kidney dialysis

31. In a paediatric oncology centre, the following facilities are daily, including weekends, available between 8.00 and 18.00 o’clock:

- Pharmacy with central preparation of cytostatics
- Microbiology laboratory
- Pathology laboratory (for morphologic, immunohistochemic and genetic tumour diagnostics)
- Hospital catering
development organizations did not reveal any quality indicators or recommendations regarding outcome. Nor did the expert panel suggest new recommendations on this matter. We will address the development of outcome indicators in the future.

A limitation of this study could be that this set of high-quality care recommendations for all children with cancer is developed in a Dutch setting and is therefore difficult to translate to other settings. Because our results are based on international scientific literature and websites of international health care organizations and because the collaboration between the Dutch paediatric oncology centres is well established and internationally oriented, we are convinced that these recommendations could be useful for other countries as well.

In conclusion, this study defines a set of literature- and consensus-based high-quality care recommendations for all children with cancer. These recommendations provide a basis for the development of a comprehensive set of quality indicators to evaluate care. This study provides a valuable tool in improving and reaching optimal care for all children with cancer.

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disclosure

The authors declare no conflict of interest.

references