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Individualised advance care planning in children with life-limiting conditions

Erik A H Loeffen,1 Wim J E Tissing,1 Meggi A Schuiling-Otten,2 Chris C de Kruijf,3 Leontien C M Kremer,4 A A Eduard Verhagen,5 Pediatric Palliative Care—Individualized Care Plan Working Group

ABSTRACT

Introduction In 2013, the Pediatric Association of the Netherlands launched an evidence-based guideline ‘Palliative care for children’. To promote implementation in daily practice and hereby improve quality of paediatric palliative care, we aimed to develop a functional individualised paediatric palliative care plan (IPPCP) that covers physical, psychological, spiritual and social functioning, with great emphasis on the guideline’s recommendations, advance care planning and patients’ and parents’ preferences and desires.

Methods A Dutch working group (28 individuals) with a strong multidisciplinary character developed a draft IPPCP, which was piloted retrospectively and prospectively. In the pilots we completed, the IPPCPs for patients who were recently diagnosed with a life-threatening or life-limiting condition and evaluated completeness, usability and user-friendliness.

Results The final IPPCP comprised five domains: (1) IPPCP data, (2) basics, (3) social, (4) psychosocial and spiritual and (5) physical care. Each domain covered various components. In both pilots, the IPPCP was considered a comprehensive document that covered all areas of paediatric palliative care and was experienced as an improvement to the present situation. However, the current form was regarded to lack user-friendliness.

Conclusion We propose a set of essential components of a comprehensive IPPCP for paediatric palliative care with extra attention for advance care planning and anticipatory action. Patients’ and parents’ preferences and desires are included next to the recommendations of the evidence-based guideline ‘Palliative care for children’.

INTRODUCTION

In the Netherlands, every year, nearly a thousand children (aged 0–15 years) die and an estimated fivefold of this number are confronted with a life-threatening or life-limiting condition.1 2 These children deserve high-quality palliative care, which according to the WHO comprises ‘the active total care of the child’s body, mind and spirit, and also involves giving support to the family’.3 4 Palliative care can be misinterpreted as care in the palliative–terminal phase. For instance, children with profound multiple disabilities have a vulnerable health and sometimes extensive underlying suffering. Palliative care in these children should be provided well before the terminal (end-of-life) phase.

What is already known on this topic?

► Paediatric palliative care is a specialised field of medicine, in which advance care planning (ACP) plays an important role.

► Implementation of evidence-based guidelines and ACP can contribute to high-quality paediatric palliative care.

What this study adds?

► This individualised paediatric palliative care plan puts emphasis on several aspects that contribute to quality of care, that is, ACP, evidence-based medicine and patients’ and parents’ preferences and desires.

► Although we focused on paediatric palliative care, we encourage the concept of ACP and individualised care plan-driven guideline implementation to be mimicked in other fields.

Recently in paediatric palliative care, there has been growing interest in advance care planning (ACP), which is a multidisciplinary, structured process that puts great emphasis on patient and family preferences, and encourages discussion of possible scenarios with the child and his/her parents in an early stage.4 Perceived benefits of ACP include better quality of care, respect of patient autonomy and a sense of security and control.5 In a randomised trial in elderly patients, use of ACP improved end-of-life care and satisfaction of patient and family and reduced stress, anxiety and depression in surviving relatives.6 Important aspects of effective implementation of ACP include, for example, timely planning and continuous discussions, taking into account all aspects of palliative and end-of-life care (without losing focus on everyday aspects of life as well), involvement of all relevant professionals and structural education.5

In recently published international guidelines, the need for ACP is acknowledged. For instance, in the American Academy of Pediatrics endorsed 2013 guideline entitled ‘Clinical Practice Guidelines for Quality Palliative Care’, ACP is stated explicitly as preferred practice. Also, specifically in children, detailed documentation of the child’s views and preferences is encouraged. These sentiments are mimicked in (paediatric) palliative care guidance...
documents in other parts of the world, for instance in the UK (National Institute for Health and Care Excellence, 2016) and in New Zealand (National Child & Youth Clinical Network, 2015).8 9

In 2013, the Paediatric Association of the Netherlands was among the first to launch a multidisciplinary, evidence-based guideline focusing solely on paediatric palliative care.2 10 Despite previous efforts, it is our experience that this guideline is not yet optimally implemented.11 We ambition better implementation, since evidence-based guideline compliant care has been repeatedly shown to improve patient outcomes and efficient care delivery.12 11

Naturally, a limitation of all guidelines is the fact that they are not tailored to a specific patient but merely advise on the average patient. An individualised care plan (ICP) contains information, agreements, advices for symptom management, including personal wishes, tailored to a specific patient. It is therefore a highly suitable instrument to translate a guideline into practice. When compared with usual care, the use of an ICP has shown to improve indicators of health status and promotes the capability of patients to self-manage their condition.14

An individualised care approach for children with a life-threatening or life-limiting condition has the potential to contribute to consistent high-quality paediatric palliative care in which all essential areas are explored. In this study, we aimed to develop and test a functional and comprehensive individualised paediatric palliative care plan (IPPCP). This IPPCP is based on both the recommendations of the guideline ‘Palliative care for children’ and on expert knowledge, is in line with the WHO principles for paediatric palliative care and puts great emphasis on ACP and patients’ and parents’ preferences and desires. In addition, it guides the healthcare provider, along with the patient and his/her family, in a structured manner to address all aspects important to paediatric palliative care (planning).

**METHODS**

**Developmental process**

For a detailed flow diagram of the developmental process, see **figure 1**. Initially a project group was created that comprised professionals involved in paediatric palliative care and parents of different children who had received palliative care (see **table 1**). Group members were recruited via existing Dutch paediatric palliative care teams and patient/parent organisations. Several meetings for the entire project group were organised to discuss characteristics and components of the IPPCP.

![Flow diagram portraying the development of the individualised paediatric palliative care plan (IPPCP).](image-url)

**Table 1** Involved professionals

<table>
<thead>
<tr>
<th>Core group</th>
<th>Working groups</th>
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</thead>
<tbody>
<tr>
<td>Paediatrician specialised in palliative care</td>
<td>PHY/PSY</td>
</tr>
<tr>
<td>Paediatric oncologist</td>
<td>PHY</td>
</tr>
<tr>
<td>Paediatrician trained in epidemiology</td>
<td>PHY</td>
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<tr>
<td>Paediatric oncologist</td>
<td>PHY/PSY</td>
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<tr>
<td>Director non-profit paediatric palliative care organisation</td>
<td>PSY</td>
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<tr>
<td>Director paediatric home care organisation</td>
<td>PHY</td>
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<tr>
<td>Board member paediatric nurse organisation</td>
<td>PHY</td>
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<td>PhD student paediatric oncology</td>
<td>PHY/PSY</td>
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<tr>
<td>Project group</td>
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<tr>
<td>Parent of a deceased girl</td>
<td>PHY</td>
</tr>
<tr>
<td>Parent of a deceased boy</td>
<td>PSY</td>
</tr>
<tr>
<td>Paediatric oncologist</td>
<td>PHY</td>
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<tr>
<td>Paediatric oncologist</td>
<td>PHY/PSY</td>
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<tr>
<td>Paediatrician specialised in hereditary and congenital diseases</td>
<td>PHY</td>
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<tr>
<td>Paediatric intensive care unit nurse</td>
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<tr>
<td>General practitioner</td>
<td>PHY/PSY</td>
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<tr>
<td>Paediatric nurse</td>
<td>PHY</td>
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<tr>
<td>General paediatrician</td>
<td>PHY</td>
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<tr>
<td>Staff member non-profit paediatric oncology organisation</td>
<td>PSY</td>
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<tr>
<td>Staff member non-profit paediatric palliative care organisation</td>
<td>PSY</td>
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<tr>
<td>Child life specialist</td>
<td>PSY</td>
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<tr>
<td>Spiritual caretaker</td>
<td>PSY</td>
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<td>Proofreaders</td>
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<td>Paediatric oncologist</td>
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<td>Hospital pharmacist</td>
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<td>Paediatric neurologist</td>
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<td>Paediatric critical care specialist</td>
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<td>Paediatric pulmonologist</td>
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<tr>
<td>Paediatric anaesthetist</td>
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<tr>
<td>Physician assistant specialised in paediatric pain</td>
<td></td>
</tr>
</tbody>
</table>

PHY, working group focusing on physical aspects of paediatric palliative care, PSY, working group focusing on psychosocial aspects of paediatric palliative care.
Supporting manual

We decided to create a comprehensive IPPCP form including personalised recommendations based on the guideline and a separate supporting manual including all recommendations and explanatory information. The manual was drafted by one researcher (EAHL), whereafter it was proofread repeatedly by the entire project group and adjusted according to their comments. Recommendations were categorised as guideline or expert opinion and as do, consider or don’t. Before finalisation, the manual was checked by one external reviewer for agreement with the recommendations of the guideline ‘Palliative care for children’.

Retrospective pilot

To pilot the IPPCP’s usability and completeness, we tested the form retrospectively. We asked three paediatricians with extensive experience in palliative care and who were the responsible physician of a recently deceased child to complete an IPPCP as if it was at the start of the palliative course. We then asked them to recall the palliative course and evaluate if there were things missing, unusable or superfluous in the present form. We discussed this 1-on-1 in a telephone meeting where a researcher (EAHL) took notes and discussed these with the project group. This yielded several valuable small additions (eg, addition of ‘via nasogastric tube’ in way of administration of anti-emetic drugs), changes (eg, pain ladder divided and arranged into more clinically logical steps) and deletions (eg, duplicate items in different locations).

Prospective pilot

Second, we did a prospective pilot that lasted 2 months and was commenced in five Dutch paediatric hospitals: Emma Children’s Hospital (Amsterdam), Beatrix Children’s Hospital (Groningen), Willem-Alexander Children’s Hospital (Leiden), Sophia Children’s Hospital (Rotterdam) and Princess Maxima Centre for Paediatric Oncology (Utrecht). Paediatricians with experience in palliative care were invited to complete an IPPCP for a patient and his/her family with a recently diagnosed life-threatening or life-limiting condition. The IPPCP was completed together with the patient and his/her family prior to discharge to home. After completion, we asked the paediatricians to anonymise the IPPCP and send it to us.

We also invited them to complete an online survey, developed by a consensus-based approach in the core group, that explored section-wise ease of use and completeness, overall completeness, usability and change as compared with the current situation and invited them to give overall comments and suggestions for the current IPPCP (see online supplementary data). Scores were given on a 5-point Likert scale, for example, ‘completeness’ was rated from 1 (very incomplete) to 5 (very complete). Group scores were categorised as ‘low’ (median 1–2), ‘average’ (median 2.5–3.5) or ‘high’ (median 4–5). For analysis purposes, we asked respondents to state their profession and the patient’s age, diagnosis and estimated life expectancy (classified as weeks, months, years or unclear).

Identification of essential components

After incorporation of the feedback from both pilots, the core group evaluated the IPPCP and identified the components and domains for individualised care planning in paediatric palliative care.

RESULTS

This project lasted from October 2014 to December 2015. We chose to develop first an editable Word file (Microsoft Word
Contents of the individualised paediatric palliative care plan. ICP, individualised care plan.

**Physical aspects**
For all symptoms, a section was created with questions that the care provider and patient/parents could complete (eg, ‘What is the goal regarding pain management?’ and ‘First step pharmacological anti-emetic management’), supported by a short manual incorporating recommendations from the guideline and practical matters such as first-choice medication. Also, there were separate sections for medication, nutrition and for complementary therapies and relaxation/wellness.

**Psychosocial aspect**
This working group developed a five-phase model of paediatric palliative care, based on the health report regarding palliative care published in 2013 by the Dutch government. These phases are (1) breaking bad news, (2) life continues—despite the bad news—relatively ‘normally’, (3) increase in symptoms (preterminal), (4) palliative-terminal phase and (5) (bereavement) follow-up care. For all applicable phases, this working group developed separate recommendations for the patient, siblings, parents, close family and relatives, school, sports club, treating physician, general practitioner, paediatric home care nurses and other involved care professionals.

**Supporting manual**
The 42-page manual guides the reader step by step through the various sections of the IPPCP, while providing concise background information, recommendations and other tips/advices.

**Prospective pilot**
Nine patients were included; diagnoses were brain tumour (n=3), DNA repair-deficiency disorder (n=2), peroxisomal disorder (n=2), congenital heart disease (n=1), or unknown (n=1). Median age was 10 years (range: 0–17 years); estimated life expectancy was unclear in five patients, ‘years’ in two patients and ‘weeks’ in two patients.

For the IPPCP in general, median scores were high for ‘completeness’ and ‘change compared to current situation’ and average for ‘ease of use’ and ‘usability in daily practice’ (see table 2). The manual scored high for ‘completeness’, ‘change compared with use of guideline’ and ‘worthwhile addition to IPPCP’ and average for ‘amount of information’. All separate IPPCP sections had average to high scores for both ‘ease of use’ and ‘completeness’.

Professionals showed differences in comments and attitudes towards the IPPCP and manual. Generally, in the overall comments, it was emphasised that the IPPCP was very complete and useful, promoted collaboration and forced the user to anticipatory planning and action. However, multiple professionals felt that the present form lacked user-friendliness and suggested this could be improved by creating a fully digital and responsive version of the IPPCP.

**Identification of essential components**
After incorporating the feedback from the prospective pilot, which leads to similar small additions, changes and deletions as the retrospective pilot did, the project core group discussed and finalised the IPPCP. The final IPPCP consisted of five domains: (1) IPPCP data, (2) basics, (3) social, (4) psychosocial and spiritual and (5) physical (figure 2). These domains included a total of 32 components that were integrated in the IPPCP in 10 sections.

**Example IPPCP**
An example of a partially completed IPPCP for a fictional patient can be found in the online supplementary material.
DISCUSSION

With this study, care providers and parents have identified a set of components that are essential for an IPPCP that facilitates high-quality care (and transition of care from hospital to home). In this IPPCP, we integrated recommendations from the Dutch evidence-based guideline ‘Palliative care for children’ and recommendations from experts on physical, psychological, spiritual and social functioning. With the emphasis on the facilitation of ACP and the patients’ and parents’ preferences and desires, we believe this IPPCP is the pivotal next step in high-quality paediatric palliative care.

The IPPCP together with the manual will help to implement the aforementioned Dutch guideline ‘Palliative care for children’. Care in line with evidence-based guidelines has repeatedly been shown to improve outcomes, which we also suspect it will do in paediatric palliative care. Therefore, putting the available scientific knowledge and recommendations in the hands of the practitioner and the patients and parents should be one of the cornerstones of contemporary medicine.

Implementation of an evidence-based guideline should not be limited to simple dissemination. In fact, a systematic review focusing on implementation strategies found this to be consistently ineffective. Among other things, multifaceted interventions, patient-specific interventions and clinical reminders/decision support systems were found to be effective implementation strategies. An ICP exploits these processes to put a guideline into daily practice. Currently, the IPPCP is already used in several hospitals and specialised paediatric palliative home care teams, and parent support groups have started to actively promote its use among their members. Hereby more first-line professionals (eg, general practitioners and home care teams) will be familiarised with the IPPCP and thus the guideline, making it an important driver of implementation. This implementation strategy is not limited to the field of palliative care per se. We believe that also in, for example, complex chronic diseases an ICP can function as a guideline implementation tool.

In a recent study in the UK, authors found that in one in four children with a life-threatening or life-limiting condition, there was no advanced care plan, and almost half of all patients and their families were not offered a choice regarding location of care in the last months of life and location of death. The lack of this advanced care plan implies important decisions might be made later, on an ad hoc basis and the risk of time and/or emotional pressure. This underlines the importance of timely and structured ACP.

The IPPCP that we developed is comprehensive and was perceived by professionals as an improvement to the current situation especially due to its completeness; nevertheless, users complained it lacks user-friendliness in the current form. This study can be considered as an essential first step. In a subsequent project, we will develop a fully digital and responsive version of the IPPCP (with integrated manual). We believe this will improve user-friendliness substantially without compromising on the current strong points.

In the current project, we merely evaluated postdevelopment, which sometimes resulted in the identification of errors/impracticalities we could have identified beforehand. Thus, prior to developing the next version, we plan to conduct a more thorough pre-evaluation of preferences and experiences of people involved in the field of paediatric palliative care using semistructured interviews. With this, we expect to better map the barriers and facilitators of both healthcare providers and parents and patients when using the IPPCP. Combining these findings with a longer and more systematic pilot phase of the next IPPCP has the potential to substantially increase its value in daily practice.

In conclusion, with this study, we have identified a set of essential components of a comprehensive IPPCP that (1) covers all aspects of paediatric palliative care, (2) puts great emphasis on ACP and anticipatory action, (3) actively seeks and integrates patients’ and parents’ preferences and desires and (4) incorporates recommendations of the Dutch evidence-based guideline ‘Palliative care for children’. In addition, we demonstrated that an ICP is a promising method for nationwide implementation of an evidence-based guideline and management of complex care, which can be mimicked in other fields. Because although we are focusing on paediatric palliative care, the concept of ACP relates very well to the care for all children with chronic complex illnesses.

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Contributors EAH designed and adjusted the IPPCP, coordinated the pilots, carried out the initial analyses, drafted the initial manuscript, revised the manuscript and approved the final manuscript as submitted. WJET and CCdK provided comments for the initial IPPCP, took part in both the retrospective and prospective pilot, critically reviewed the manuscript and approved the final manuscript as submitted. M–O provided comments for the initial IPPCP, critically reviewed the manuscript and approved the final manuscript as submitted. LCMK and EV conceptualised and designed the study, provided comments for the initial IPPCP, critically reviewed the manuscript and approved the final manuscript as submitted. All members of the Pediatric Palliative Care – Individualized Care Plan Working Group provided comments for the initial IPPCP and critically reviewed the manuscript. Some members took part in the prospective pilot. All members approved the final manuscript as submitted.

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Competing interests None declared.

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