

Palliative Medicine

<http://pmj.sagepub.com/>

Pediatric advance care planning from the perspective of health care professionals: A qualitative interview study

Julia D Lotz, Ralf J Jox, Gian Domenico Borasio and Monika Führer

Palliat Med published online 11 November 2014

DOI: 10.1177/0269216314552091

The online version of this article can be found at:

<http://pmj.sagepub.com/content/early/2014/11/08/0269216314552091>

Published by:



<http://www.sagepublications.com>

Additional services and information for *Palliative Medicine* can be found at:

Open Access: Immediate free access via SAGE Choice

Email Alerts: <http://pmj.sagepub.com/cgi/alerts>

Subscriptions: <http://pmj.sagepub.com/subscriptions>

Reprints: <http://www.sagepub.com/journalsReprints.nav>

Permissions: <http://www.sagepub.com/journalsPermissions.nav>

>> [OnlineFirst Version of Record](#) - Nov 11, 2014

[What is This?](#)

Pediatric advance care planning from the perspective of health care professionals: A qualitative interview study

Palliative Medicine
1–11
© The Author(s) 2014
Reprints and permissions:
sagepub.co.uk/journalsPermissions.nav
DOI: 10.1177/0269216314552091
pmj.sagepub.com


Julia D Lotz¹, Ralf J Jox², Gian Domenico Borasio³
and Monika Führer¹

Abstract

Background: Pediatric advance care planning differs from the adult setting in several aspects, including patients' diagnoses, minor age, and questionable capacity to consent. So far, research has largely neglected the professionals' perspective.

Aim: We aimed to investigate the attitudes and needs of health care professionals with regard to pediatric advance care planning.

Design: This is a qualitative interview study with experts in pediatric end-of-life care. A qualitative content analysis was performed.

Setting/participants: We conducted 17 semi-structured interviews with health care professionals caring for severely ill children/adolescents, from different professions, care settings, and institutions.

Results: Perceived problems with pediatric advance care planning relate to professionals' discomfort and uncertainty regarding end-of-life decisions and advance directives. Conflicts may arise between physicians and non-medical care providers because both avoid taking responsibility for treatment limitations according to a minor's advance directive. Nevertheless, pediatric advance care planning is perceived as helpful by providing an action plan for everyone and ensuring that patient/parent wishes are respected. Important requirements for pediatric advance care planning were identified as follows: repeated discussions and shared decision-making with the family, a qualified facilitator who ensures continuity throughout the whole process, multi-professional conferences, as well as professional education on advance care planning.

Conclusion: Despite a perceived need for pediatric advance care planning, several barriers to its implementation were identified. The results remain to be verified in a larger cohort of health care professionals. Future research should focus on developing and testing strategies for overcoming the existing barriers.

Keywords

Advance care planning, advance directives, resuscitation orders, shared decision-making, terminal care, pediatrics

What is already known about the topic?

- Advance care planning (ACP) has been validated in adult care.
- ACP is also recommended for children and adolescents, but there is little research on pediatric ACP.
- Particularly, the professionals' perspective has been largely neglected in research on pediatric ACP.

What this paper adds?

- This study indicates that ACP is perceived as beneficial by health care professionals (HCPs) caring for severely ill children/adolescents.
- Many uncertainties exist among HCP with regard to end-of-life decision-making in minors.
- Important requirements for effective ACP in pediatrics include timely and continuous discussions, involvement of all relevant care providers, attention to a wide range of care and end-of-life issues, as well as professional education.

¹Coordination Center for Pediatric Palliative Care, University Children's Hospital, Ludwig-Maximilians University, Munich, Germany

²Institute of Ethics, History and Theory of Medicine, Ludwig-Maximilians University, Munich, Germany

³Service de Soins Palliatifs, Centre Hospitalier Universitaire Vaudois, Lausanne, Switzerland

Corresponding author:

Julia D Lotz, Coordination Center for Pediatric Palliative Care, University Children's Hospital, Ludwig-Maximilians University Munich, Pettenkoferstr. 8a, Munich 80336, Germany.

Email: Julia.Lotz@med.uni-muenchen.de

Implications for practice, theory, or policy

- The results of this study may inform the development of practicable ACP concepts for a wide range of pediatric patients.
- The identified uncertainties among HCPs stress the need for special support and education on pediatric ACP.

Introduction

Severe chronic or progressive diseases call for advance care planning (ACP) to increase quality of life and promote patient autonomy. While ACP has been practiced and empirically validated in adult palliative care,^{1,2} there is little research on pediatric advance care planning (pACP).³ A few pACP initiatives and tools have been developed, mostly in the United States and the United Kingdom.^{3–11} The planning and effective communication of future care has been hitherto somewhat neglected in pediatric palliative care research. However, international guidelines and medical societies strongly recommend ACP also for children/adolescents.^{12,13} Additionally, health care facilities, insurances, and US state legislations increasingly require ACP documents for pediatric patients. Available data also indicate that parents wish to have ACP discussions that facilitate shared decision-making and ensure care conforming to their wishes.^{14–19} However, this is often disregarded in the current practice.¹¹

Formal ACP procedures, practical tools, and education of health care professionals (HCPs) may help to increase the significance and acceptance of pACP documents.¹¹ However, adult ACP concepts have to be thoroughly adapted to the peculiarities of the pediatric setting.^{10,19} In pediatrics, shared decision-making and planning of future care around the end of life (EOL) may be challenged by prognostic uncertainty, the high emotional impact of EOL decisions in children, the involvement of many different parties in the care of children (parents, school), the importance for children to maintain age-appropriate daily activities as well as the incapacity to consent of many patients and the uncertain legal status of ACP documents by (or on behalf of) minors. In this context, the term “minors” refers to persons under the age of 18 years. With some exceptions, pediatric patients are minors. They may be able to consent if they understand the meaning and scope of a specific decision.²⁰ Usually, decision-making capacity is assessed by the physician.

For minors, two types of ACP documents can be distinguished ethically and legally:²¹ (1) an advance directive (AD) completed by a legally competent minor and (2) an AD issued by a person having legal custody of an incompetent child (usually the parents). The latter has particular relevance in pediatrics because many children have never been able to consent and to document their care preferences. In the following, we refer to both types of ACP documents as ADs.

Pediatric ACP programs need to address the young patients, the parents, and other family members; to find regulations on when and how to involve the child; to include education for HCPs; and to provide child- and adolescent-adjusted ACP documents. The development of such frameworks should be evidence-based. So far, the perspective of HCPs has largely been neglected in the literature.³ Our aim was therefore to investigate the attitudes, barriers, and benefits as well as requirements for pACP from the view of HCPs and to generate hypotheses on pACP that can be tested in a larger cohort.

Methods

This study is a descriptive qualitative study that aims at the development of hypotheses about HCPs' views on pACP. The research methods and their reporting follow the *Consolidated criteria for reporting qualitative research (COREQ)*.²² Any research material related to the study is available from the corresponding author.

Sampling

In total, 17 HCPs from various medical and non-medical professions and care settings were invited and agreed to participate. Our participants were selected by purposeful sampling. Sampling decisions were made a priori based on reasonable criteria rather than theoretical saturation (selective sampling). Based on our research question and our own experience in the field, we identified the following factors to be varied: professional group, pediatric discipline, and care setting (Table 1). The relevant professional groups, disciplines, and care settings were identified by one of the authors with wide knowledge in the empirical field (M.F.). We included at least one representative for each selected profession, discipline, and care setting. Criteria for inclusion were as follows: (1) representative of one of the defined professional groups, disciplines, and care settings; (2) in a leading position with major responsibilities (e.g. senior physician, medical director, head of department, division manager); and (3) special interest in the research question. This corresponds to common definitions of persons with special expertise.^{23,24} Exclusion criteria were as follows: (1) no interest in the research question and (2) insufficient German language skills.

Table 1. Sample characteristics (n = 17).

Professional groups	Represented pediatric disciplines	Care setting ^a	Age (in years)	Professional experience (in years)	Gender
Physicians: n = 9	Pediatric intensive care and emergency medicine	Hospital care: n = 7	M = 46	M = 21	m = 6
Nurses: n = 6	Pediatric cardiology	Outpatient care: n = 8	SD = 14.4	SD = 9.5	f = 11
Social professionals: n = 2	Neuro-pediatrics	Care facility: n = 4			
	Pediatric hematology and oncology				
	Pediatric palliative care medicine				
	Neonatology				
	Pediatric primary care medicine				
	Anesthesiology				
	Adult emergency medicine				

M: mean; SD: standard deviation; m: male; f: female.

^aSetting: Some participants were working in more than one care setting.

Recruitment

Eligible persons were identified through gatekeepers from the pediatric palliative care team and personal knowledge according to the above-mentioned criteria. All participants came from Munich and surroundings. None of the participants was acquainted with the interviewer.

Data collection

Participants were contacted personally by the last author (M.F.). They received an information letter on the study background, methods, and data protection and gave written consent to their participation. Personal interviews were conducted, following a semi-structured interview guide (Appendix 1). The interview questions had been developed and structured according to the recommendations by Helfferich.²⁵ The resulting interview guide was discussed in various research groups with clinical and bioethics expertise and was piloted with an assistant physician of the pediatric palliative care team, resulting in no major revisions. The interviews were conducted from April 2012 to April 2013 by the first author (J.D.L.), a psychologist, and psychotherapist for children and adolescents in training. The interviewer was trained to conduct interviews in a working group on qualitative research methods and received an additional training from a psychotherapist experienced in palliative care research and interviewing. All interviews were audiotaped and transcribed verbatim. Words or phrases stressed by the interviewees were transcribed in capital letters. The transcripts were not returned to the participants in order to avoid censoring and corrections for reasons of social desirability. The study protocol and materials have been reviewed and approved by the ethics committee of the Munich University Hospital (No: 049-12).

At the beginning of each interview, the concept of pACP was explained to the participant as “planning ahead for the further course of disease, difficult situations and

treatment decisions that the patient/family will face over time, and discussing the patient’s/family’s wishes and fears.” Participants were then asked three open questions: (1) *What are your experiences with any forms of advance care planning for severely ill children and adolescents?* (2) *What are your experiences with written ADs that patients/parents bring with them and that have been completed prior to your first encounter with the patient?* and (3) *How should an approach to pACP ideally look like?* At the end of the interview, participants could add anything else they found important relating to pACP. Personal information was collected on the participants’ age, sex, and years of professional experience since graduation, their profession, and additional qualifications. The interviews took between 20 and 60 min.

Data analysis

The interview transcripts were analyzed by the interviewer using qualitative content analysis²⁶ and the software MAXQDA-10. We extracted all information that referred to our research question and summarized them into categories, checking back with the original data. The resulting categories were then organized into three main categories (benefits, barriers, requirements of pACP). For each category, content, coding rules, and prototype examples were defined to increase transparency and reliability. Following suggestions for expert interviews, we first performed a case-by-case analysis and then compared and summarized the results across all interviews.²⁷ The resulting categories and codings were reviewed by the last author (M.F.) as well as discussed and validated in a multidisciplinary research meeting. This resulted in the merging of a few sub-categories.

Results

All 17 HCPs contacted agreed to participate. We included nine physicians and six nurses from different medical

Table 2. Benefits of pACP according to the view of professional stakeholders.

Benefits	Description	Profession groups	Care settings
Sense of security and control	Helps to clarify goals of care and gives a clear direction Provides clear operation instructions Prepares for future situations and the dying process	All professional groups ^a ($n = 13$)	All care settings ^b
Better quality of care	Avoids treatments that are not in the child's best interests Makes families feeling more cared for	Physicians ($n = 4$), nurses ($n = 2$)	All care settings ^b except emergency care, curative education institutions, and children's hospice
Respect of patient autonomy	ADs ensure respect of patient's/parents' wishes	Physicians ($n = 2$), nurse ($n = 1$)	Outpatient and inpatient care

pACP: pediatric advance care planning; AD: advance directive.

^aAll professional groups include physicians, nurses, and social professionals.

^bAll care settings include pediatric palliative care, pediatric intensive care, pediatric cardiology, neuro-pediatrics, pediatric oncology, emergency care (pediatric, adult), primary care practice, outpatient nursing service, children's hospice, special nursing facility, and curative education institutions.

specialties as well as two social workers in our sample. Participants were working in hospitals ($n = 7$), outpatient care ($n = 8$), schools, and long-term care facilities for severely ill children/adolescents ($n = 4$). In average, they had 21 years of professional experience in their field (range: 9–35 years). Table 1 lists participants' demographic characteristics.

Benefits of pACP

All professional stakeholders perceived pACP as helpful. They identified several benefits of pACP, summarized in Table 2.

The interviewees perceived pACP as helpful in the following ways:

1. *Providing a sense of security and control:* 13 participants from all professional groups talked about how pACP gives HCPs and parents peace of mind. It reassures HCPs by providing a clear direction and defining clear emergency procedures in a written document. It is also considered to be relieving for parents because it mentally prepares them for difficult situation so that they know what may happen and how they may help their child:

So, that they then know exactly what has been discussed, what was decided. To have it in black and white [...] it also conveys, I believe, additional security, so you know: It is all right if I do NOT dial the emergency/critical care number now so somebody gets here because it's getting critical. It's all right the way it is. (Nurse in a special nursing facility)

It's important to establish at least a little bit of clarity for the staff, for the parents, just what common goal is pursued and

also which measures ARE taken and which are simply omitted. Insofar, I just think it is really IMPORTANT and makes a whole lot of sense for everyone involved with the child. Therapists included, doctors, nurses, parents. Just to always provide clarity and to just fix one GUIDELINE. Otherwise everyone is always very INSECURE in their doing and acting, and this just provides clarity and thus security. (Nurse in a special nursing facility)

2. *Improving quality of care:* four physicians and two nurses stated that pACP could help reducing unnecessary suffering for the child. They anticipated that pACP discussions and documents would lead to a decreased number of emergency and intensive care interventions in children/adolescents with life-limiting illnesses. The interviewees also considered it a quality improvement that pACP makes families feeling more cared for:

I rather see the realistic situation in a way that you have a patient in the critical care unit where you have to painfully realize: this was somehow wrong, this won't work, ok? And THEN you say: Ok, now he is already here but we tie our own hands and say this and that we WILL NOT DO anymore. (Intensive care physician)

3. *Ensuring respect of patients' and parents' wishes:* two physicians and one nurse noted that pACP makes parents feel that they are being taken seriously and ensures that their own or their child's wishes are respected in situations when they are not present and by physicians unfamiliar with the child:

I think it can take the burden off the parents to a certain degree, and this having-to-be present all the time as well. This family for example would really love to go on vacation for a

Table 3. Barriers to pACP according to the view of professional stakeholders.

Barriers	Description	Profession groups	Care settings
Discomfort with pACP documents for children and unclear responsibilities	Physicians' difficulties with following an AD versus social professionals' need for medical support in verifying an AD Discomfort with signing an AD for a child	All professional groups ^a (n = 11)	All care settings ^b except pediatric palliative care service
Uncertain prognoses	Physicians' difficulties to make precise predictions	All professional groups ^a (n = 8)	All care settings ^b except outpatient care and emergency care
Physicians' difficulties in initiating pACP	Reluctance to talk about treatment limitations Perceived taboos in other cultures Scapegoating by parents concerning the physician who has conveyed the diagnosis	Physicians (n = 5), nurses (n = 3)	All care settings ^b except emergency care and curative education institutions
Difficulties in identifying the child's wishes	Communication impairment in many children and interpretations of non-verbal behavior Lacking capacity to consent Refusal to talk about death	All professional groups ^a (n = 9)	All care settings ^b
Burden for parents	Difficulties to give up hope Burden of responsibility for parents when signing an AD for their child	All professional groups ^a (n = 10)	All care settings ^b
Limitations of pACP documents	Limited applicability of pACP documents Persisting uncertainty during the pACP process Parents' right to revoke an AD	Physicians (n = 13), nurse (n = 1)	Inpatient care, emergency care, special nursing facility
Lack of coordinated communication	Complicated communication patterns Insufficient information-sharing between HCPs and lack of round tables Lack of a continuous contact person	All professional groups ^a (n = 5)	All care settings ^b except pediatric palliative care service
Insufficient implementation in health care system	Neglect of pACP in current practice Shortage of time Lack of funds for pACP	All professional groups ^a (n = 12)	All care settings ^b

pACP: pediatric advance care planning; AD: advance directive; HCP: health care provider.

^aAll professional groups include physicians, nurses, and social professionals.

^bAll care settings include pediatric palliative care, pediatric intensive care, pediatric cardiology, neuro-pediatrics, pediatric oncology, emergency care (pediatric, adult), primary care practice, outpatient nursing service, children's hospice, special nursing facility, and curative education institutions.

week. But then they say, in fact they don't dare to, because surely he will be hospitalized then [...] So there is this fear: the moment I turn my back on the nurses, they do what in fact we don't want. (Primary care physician)

Barriers to pACP

Barriers to pACP perceived by the interviewees are listed in Table 3.

The barriers reported by the professionals highlight their fear and discomfort regarding pACP and ADs. For different reasons, both medical and psychosocial professionals in our sample found that they lack the competence to make EOL decisions in children and were worried about making wrong decisions based on a child's AD. Since psychosocial professionals do not feel competent to assess the child's

medical condition, in a crisis they will call an emergency physician in order to have him decide whether the child's AD applies to the current situation. However, emergency physicians feel uncomfortable with making EOL decisions for a child they do not know, and without adequate time to evaluate the situation. They particularly fear later accusations by the family and legal consequences. This conflict is well illustrated by the following two quotes:

And then, our practice is that we have to say: [...] in such a case, we call the emergency physician and we can give this letter to him, ok? And then, it is again the physician's decision. (Social worker in a non-medical care facility)

When the emergency physician comes, he will always do everything. [...] You can't call him and present him a piece of

paper and tell him: “don’t do anything,” ok? (Intensive care physician)

HCPs also expressed their own reluctance to address EOL issues with the patient/parents because they tend to *close their eyes to the facts* and *don’t want to picture the worst case scenario* (Intensive care physician). They are afraid of taking away hope, forcing and overburdening both the parents and the patient as well as destroying the trusting relationship with the family. Furthermore, HCPs fear to make false-negative predictions and thus refrain from initiating pACP discussions with the patient/parents before the negative prognosis is completely certain. This is well illustrated by the following quote:

On the other side, it is the experience that one can also misassess the situation, also in the negative sense. So, the situations where one would have thought, based on experience, that this cannot turn out well, they have stabilized once again [...] Therefore, one is very cautious. You first have to come to the point for yourself when you say: o.k., I really don’t see, to the very best of my knowledge and belief, any chances left. (Intensive care physician)

Finally, HCPs are worried about not acting according to the child’s wishes because the child’s will is often unknown and can only be presumed.

Requirements for pACP

All interviewees asked for professional education to reduce the many uncertainties with regard to pACP. Their education needs cover medical and non-medical issues. Participants particularly stressed their need for education about the legal situation and for communication trainings. The interviewees found it difficult to define the right degree of standardization and flexibility of pACP procedures and documents. They proposed various solutions for written documents differing in their degree of standardization: an individual letter format, a standardized form, or a standardized but flexible checklist with a free comment section.

Participants identified several requirements for a successful pACP approach. Table 4 lists features viewed as important in pACP by the professional stakeholders.

Most participants called for early initiation of pACP shortly after diagnosing an incurable condition, but considered this unrealistic in many cases, because the parents often need more time to process the bad news. Therefore, they gave priority to the family’s readiness for pACP discussions when deciding about when to initiate pACP. Some also focused on important occasions for initiating pACP in the course of the disease, such as discharge at home or a severe deterioration of the child’s condition. Once initiated, pACP should be conceived as an ongoing process, adapted to the individual family. Decisions should be made known in the community and be regularly reviewed. Written documents

should also be distributed to emergency services and local hospitals to prepare them for potential emergency situations. Besides concrete emergency planning, HCPs working in outpatient care or non-medical care facilities stressed the need to discuss daily life issues and plan for the EOL. This included planning of future support options in everyday life, dying, and bereavement.

Most interviewees viewed pACP as a multi-professional process that should include all relevant HCPs in the community. Specific persons that were viewed as important in pACP are listed in Table 4. The relevant persons differ depending on the child’s condition and the family’s situation and may become relevant at different time points throughout the pACP process. The majority of the interviewees viewed close cooperation and information-sharing between the different care providers as indispensable for pACP. They requested round tables with all relevant HCPs in the community, and a continuous pACP facilitator and primary contact person for HCPs and the family, particularly in acute crises.

The majority of participants found that any child able to communicate should be involved in pACP, regardless of its age. They argued that children should be given the opportunity to discuss their fears, EOL needs, and treatment preferences themselves with an HCP. Their treatment preferences should be considered:

If the patient himself says he wants this and this and that, no matter how old the child or adolescent is, when he can express it I think it has to be considered. (Outpatient nurse)

The interviewees also stressed the importance to use child-appropriate communication (e.g. using children stories). All children should be informed in an age-appropriate way about the decisions made. Most participants found that only adolescents should be offered to complete an AD themselves. Some HCPs also reflected on the possibility of having the competent child signing its AD itself.

Several interviewees claimed that all persons who have attended the discussions and are relevant to the individual case should confirm the decisions by their signature. Most HCPs particularly stressed the importance of a physician signing the AD in order to validate it medically, while some considered it sufficient to certify that the principles of informed consent have been respected, that is, that the patient/parents have been fully informed and were given enough time to reflect their values and preferences in order to come to an informed decision. The interviewees also disagreed on whether the parents should always sign an AD or whether they should only be given the option to do so (given the high burden of responsibility).

Discussion

This qualitative study provides information about the views and needs of the relevant HCPs with regard to pACP.

Table 4. Requirements for pACP according to the view of professional stakeholders.

Parameters	Characteristics and requirements
Time points/reasons for initiating pACP	The patient's/family's readiness for EOL discussions After diagnosis of an incurable disease (as early as possible) Changes in the care setting (e.g. discharge), child left in the care of others Considerable deterioration in the child's condition, severe crises Before admission to the pediatric intensive care unit
Process characteristics	Repeated discussions with the patient/parents Gradual and sensitive process, adjusted to parents' coping Distribution of the AD to all relevant care providers in the community Regular review of decisions; revocation of decisions always possible
Participants in pACP	Pediatric palliative care provider as continuity person/pACP facilitator Any physician in charge for the child (e.g. primary care, local hospital) A second independent physician Nurses in charge for the child Psychosocial professionals in charge for the child (psychologist, social worker, chaplain, representatives of non-medical care institutions such as the school) A non-medical "supervisor" of the pACP process (lawyer, ethicist, chaplain)
Topics of discussions	Information giving (disease, prognosis, treatment options, dying process) Goals of care and future treatments Emergency planning Comprehensive care planning and daily life issues (e.g. school attendance, additional support options) EOL and bereavement planning
Content of ADs	Medical background (diagnosis, prognosis), medical rationale why the child has an AD Confirmation that the parents have been fully informed and engaged in repeated discussions The patient's/parents' treatment preferences for specific situations: what they want/do not want to be done Concrete instructions for emergencies, contact person with phone number Future care/support options discussed (e.g. outpatient care service, disability home) Persons that have attended the discussions Specific date or conditions for re-examination of the AD
Professional education	Education about pACP and pACP documents Legal issues (e.g. legal status of pACP documents, involvement of the child) Overview of available care/support services in the community Communication training (e.g. addressing EOL issues) Particularities in different cultures (e.g. cultural taboos concerning EOL discussions) Spiritual needs of patient/families Palliative care basics, especially for non-pediatricians, nurses and psychosocial professionals

pACP: pediatric advance care planning; EOL: end of life; AD: advance directive.

Our results indicate several perceived benefits of pACP: It reassures HCPs and families, helps to avoid unnecessary suffering, and ensures that the child's care conforms to the parents' and the child's treatment preferences. However, HCP's discomfort with EOL decisions for children represents a considerable challenge to pACP.

According to the interviewees, future pACP should include the following elements: (1) timely and repeated discussions about future treatment preferences, adjusted to the family; (2) coordination by one person/service; (3) shared decision-making in line with the principles of informed consent; (4) valid documentation of the decisions; (5)

transfer of ADs to all relevant providers; (6) regular review of decisions; (7) involvement and education of all relevant HCPs in the community (including psychosocial professionals); and (8) inclusion of daily life issues.

The following barriers to advance care discussions for clinicians have been reported in a recent study:²⁸ unrealistic clinical expectations by parents, differences between physicians' and patients'/parents' understanding of prognosis, parents' unreadiness to have pACP discussions, physicians' concern about taking away hope, as well as their uncertainty about prognosis and about how to address the issue of pACP. Our study provides further information

on important barriers to pACP because we consulted various professional stakeholders (physicians, nurses, social professionals) from different care settings.

The identified requirements for pACP are in line with the core elements of *Respecting Choices*[®] (RC[®]), the so far best evaluated ACP program for adults.²⁹ In a sample of adolescent HIV/cancer patients and their surrogates, these principles have promoted positive emotions, certainty in decision-making, and communication quality.^{30,31} Our results show the need for highly flexible pACP concepts, open to individual adjustments regarding the beginning, evolution, and topics of discussions. This may be particularly important in pediatrics because of the high impact on the family and the many uncertainties among HCPs regarding EOL decisions in children. Our interviewees particularly emphasized the need for one continuous person as pACP facilitator and coordinator. Specialized home pediatric palliative care (SHPPC) teams, which have been implemented in Germany since 2009,³² were suggested for this task. However, systematic implementation of SHPPC-based pACP is unrealistic at present because even in Germany so far only a portion of the country is covered by SHPPC teams. Worldwide, only few countries have already implemented nationwide pediatric palliative care structures.^{33,34} Furthermore, pACP should incorporate timely discussions about treatment and goals of care and should thus be initiated before palliative care is delivered.

With regard to pACP documents, specific requirements are reported in the literature: age-appropriate wording and explanation of key concepts (e.g. life support), extra sections on personal comfort issues, bequeathing (e.g. how one would like to be remembered, bequeathing belongings), spiritual wishes, and organ donation as well as an open page to write letters to loved ones.^{10,19,35} Based on these findings, age-appropriate ACP documents have been developed for children and adolescents in the United Kingdom and the United States.^{5,10,11,36-41} The available tools vary widely in form, length, and content. Some are designed as simple fill-in sheets, while others are personal booklets addressing multiple issues around EOL. The latter are often accompanied by practical step-by-step guides for HCPs to lead them through the pACP process.^{5,41} Our study provides special information on the concerns and needs of HCPs regarding pACP documents for minors and their acceptance. For HCPs, a written care plan would be helpful in reducing their own uncertainty by assuring well-informed choices and providing practical guidance in emergencies. According to our participants, pACP documents therefore need to include brief, clear, and unambiguous instructions; inform about the decision-making process; and be signed by a physician. We argue that it could be helpful to distinguish two types of pACP documents: (1) a medical emergency care plan and (2) an AD booklet that is completed by patients and families and allows for more individualized contents. A recent study

suggests that clinicians use do-not-resuscitate (DNR) orders as tools for broader treatment decisions, and that documents addressing overall treatment goals may be helpful.⁴² Some pediatric hospitals in the United Kingdom already use different documents for different situations and aims.³⁷ Following recommendations in the United Kingdom^{40,43} and in correspondence to the physician orders of life-sustaining treatment (POLST)⁴⁴ and DNR orders in adult care, a British working group has presented a personal resuscitation plan (PRP) for children with life-limiting conditions.⁴⁵ The PRP is completed on a template with the child and the family in repeated discussions. In adult care, it is common practice to document treatment choices for emergency situations in a separate POLST document. POLSTs are completed in addition to ADs because they are required to fulfil specific criteria: brief, clear, and unambiguous instructions documented on standardized form sheets and signed by a physician. Studies show that POLSTs are usually respected and perceived as helpful by physicians and emergency assistants.^{46,47} However, emergency orders for minors are associated with uncertainty about their legal bindingness. Education about legal issues and communication of emergency orders to all relevant care providers may thus be key conditions for ensuring their acceptance.

Legislations in most countries reserve the right to complete legally binding ADs to adults. Nevertheless, an AD/POLST completed by a minor has notable weight in decision-making because it gives strong indications on the patient's presumed will. However, many children with severe illnesses have lost or never attained decision-making capacity. In these cases, their parents have to make surrogate decisions in the child's best interest and complete the pACP document for the child.

POLSTs completed by parents have particular relevance in outpatient care because they provide clear instructions for emergencies when the parents are not available.⁴⁸ Precautionary agreements and their documentation enable parents to make informed treatment choices without time pressure and facilitate communication with the multiple care providers (e.g. emergency service, schools).

A potential limitation to our study is the selection of a convenience sample through personal relations that may have biased our results. However, the interviewer herself had not been known to any of the participants beforehand. All participants came from Munich and surroundings, a leading area in Germany regarding the implementation of pediatric palliative care. Since many interviewees viewed pediatric palliative care providers as important facilitators of pACP, our results may draw an overoptimistic picture of the current pACP practice and HCPs' attitudes toward pACP. However, the experience with pediatric palliative care may also have enhanced the participants' expertise regarding EOL and pACP issues.

Conclusion

The results of our qualitative study allow identifying important information on the attitude of HCPs toward pACP, its perceived benefits, as well as significant barriers and the requirements for its successful implementation. These data now need to be verified in a larger multinational cohort of HCPs. The qualitative findings may inform the development of practice initiatives for pACP that account for the needs of HCPs. Future research should focus on developing and testing strategies for overcoming the barriers identified. These are particularly relevant on the physicians' side because of their key role in medical decision-making and in implementing decisions. Evidence from adult ACP programs may assist in the development of future pACP, but needs to be adapted to the specific requirements of pediatric palliative care.

Acknowledgements

We thank our clinical and research team for their support, the research group of the Institute of Ethics, the Munich network for palliative care research, and the working group in qualitative research methods for their advice and assistance.

Declaration of conflicting interests

None declared.

Funding

This work was supported by the "Stifterverband für die Deutsche Wissenschaft" (grant number: 401.20112934).

References

- Hammes BJ, Rooney BL and Gundrum JD. A comparative, retrospective, observational study of the prevalence, availability, and specificity of advance care plans in a county that implemented an advance care planning microsystem. *J Am Geriatr Soc* 2010; 58: 1249–1255.
- Detering KM, Hancock AD, Reade MC, et al. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *BMJ* 2010; 340: c1345.
- Lotz JD, Jox RJ, Borasio GD, et al. Pediatric advance care planning: a systematic review. *Pediatrics* 2013; 131: e873–e880.
- Together for Short Lives. A Core Care Pathway for Children with Life-limiting and Life-threatening Conditions. In: Widdas D, McNamara K, Edwards F (eds). Bristol: Together for Short Lives, 2013.
- Department of Health (DH). National Framework for Children and Young People's Continuing Care. London, 2010.
- Lyon ME, Garvie PA, Briggs L, et al. Development, feasibility, and acceptability of the Family/Adolescent-Centered (FACE) Advance Care Planning intervention for adolescents with HIV. *J Palliat Med* 2009; 12: 363–372.
- Lyon ME, Jacobs S, Briggs L, et al. Family-centered advance care planning for teens with cancer. *JAMA Pediatr* 2013; 167: 460–467.
- Toce S and Collins MA. The FOOTPRINTS model of pediatric palliative care. *J Palliat Med* 2003; 6: 989–1000.
- Hammes BJ, Klevan J, Kempf M, et al. Pediatric advance care planning. *J Palliat Med* 2005; 8: 766–773.
- Wiener L, Zadeh S, Battles H, et al. Allowing adolescents and young adults to plan their end-of-life care. *Pediatrics* 2012; 130: 897–905.
- Noyes J, Hastings RP, Lewis M, et al. Planning ahead with children with life-limiting conditions and their families: development, implementation and evaluation of 'My Choices'. *BMC Palliat Care* 2013; 12: 5.
- American Academy of Pediatrics. Committee on Bioethics and Committee on Hospital Care. Palliative care for children. *Pediatrics* 2000; 106: 351–357.
- Institute of Medicine. *When children die: improving palliative and end-of-life care for children and their families*. Washington, DC: The National Academies Press, 2002.
- Meyer EC, Ritholz MD, Burns JP, et al. Improving the quality of end-of-life care in the pediatric intensive care unit: parents' priorities and recommendations. *Pediatrics* 2006; 117: 649–657.
- Meert KL, Thurston CS and Sarnaik AP. End-of-life decision-making and satisfaction with care: parental perspectives. *Pediatr Crit Care Med* 2000; 1: 179–185.
- Meert KL, Eggly S, Pollack M, et al. Parents' perspectives on physician-parent communication near the time of a child's death in the pediatric intensive care unit. *Pediatr Crit Care Med* 2008; 9: 2–7.
- Lyon ME, McCabe MA, Patel KM, et al. What do adolescents want? An exploratory study regarding end-of-life decision-making. *J Adolesc Health* 2004; 35: 529.e1–6.
- Erby LH, Rushton C and Geller G. "My son is still walking": stages of receptivity to discussions of advance care planning among parents of sons with Duchenne muscular dystrophy. *Semin Pediatr Neurol* 2006; 13: 132–140.
- Wiener L, Ballard E, Brennan T, et al. How I wish to be remembered: the use of an advance care planning document in adolescent and young adult populations. *J Palliat Med* 2008; 11: 1309–1313.
- Bundesgerichtshof (BGH). Judgment of 11 November 1957; 525–557.
- Jox RJ, Führer M and Borasio GD. Patientenverfügung und Elternverfügung—"Advance Care Planning" in der Pädiatrie. *Monatsschr Kinderheilkd* 2009; 157: 26–32.
- Tong A, Sainsbury P and Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007; 19: 349–357.
- Gläser J and Laudel G. *Experteninterviews und qualitative Inhaltsanalyse* [Expert interviews and qualitative content analysis]. Wiesbaden: VS Verlag für Sozialwissenschaften, 2010.
- Morse JM. Designing funded qualitative research. In: Denzin NK and Lincoln YS (eds) *Handbook of qualitative research*. Thousand Oaks, CA; London; New Delhi, India: SAGE, 1994, pp. 220–235.

25. Helfferich C. *Die Qualität qualitativer Daten: Manual für die Durchführung qualitativer Interviews* (3. edition). Wiesbaden: VS Verlag für Sozialwissenschaften, 2005.
26. Mayring P. Qualitative content analysis. *Forum Qual Soc Res* 2000; 1: 105–114.
27. Meuser M and Nagel U. ExpertInneninterviews—vielfach erprobt, wenig bedacht. In: Bogner A, Littig B and Menz W (eds) *Das Experteninterviews: Theorie, Methode, Anwendung*. Wiesbaden: VS Verlag für Sozialwissenschaften, 2002, pp. 71–93.
28. Durall A, Zurakowski D and Wolfe J. Barriers to conducting advance care discussions for children with life-threatening conditions. *Pediatrics* 2012; 129: e975–e982.
29. Hammes BJ and Briggs L. *Respecting choices advance care planning facilitator manual—revised*. La Crosse, WI: Gunderson Lutheran Medical Foundation, 2007.
30. Lyon ME, Garvie PA, McCarter R, et al. Who will speak for me? Improving end-of-life decision-making for adolescents with HIV and their families. *Pediatrics* 2009; 123: e199–e206.
31. Lyon ME, Garvie PA, Briggs L, et al. Is it safe? Talking to teens with HIV/AIDS about death and dying: a 3-month evaluation of Family Centered Advance Care (FACE) planning—anxiety, depression, quality of life. *HIV AIDS* 2010; 2: 27–37.
32. Groh G, Borasio GD, Nickolay C, et al. Specialized pediatric palliative home care: a prospective evaluation. *J Palliat Med* 2013; 16: 1588–1594.
33. Centeno C, Lynch T, Donea O, et al. *EAPC Atlas of palliative care in Europe 2013* (Full edition). Milan: EAPC Press, 2013.
34. Knapp C, Woodworth L, Wright M, et al. Pediatric palliative care provision around the world: a systematic review. *Pediatr Blood Cancer* 2011; 57: 361–368.
35. Williams AM, Noyes J, Chandler-Oatts J, et al. Children's Health Information Matters: Researching the practice of and requirements for age appropriate health information for children and young people, 2011.
36. Series Editor. My wishes. <http://www.agingwithdignity.org/catalog/nonprintpdf/completedmw.pdf> (accessed September 2013).
37. Mitchell S, Plunkett A and Dale J. Use of formal advance care planning documents: a national survey of UK Paediatric Intensive Care Units. *Arch Dis Child* 2014; 99: 327–330.
38. Fraser J, Harris N, Berringer AJ, et al. Advanced care planning in children with life-limiting conditions – the Wishes Document. *Arch Dis Child* 2010; 95: 79–82.
39. West Midlands Paediatric Palliative Care Network. Advance care plan for a child or young person. West Midlands Paediatric Palliative Care Network Toolkit, 2011.
40. Together for Short Lives. Integrated multiagency care pathways for children with life-threatening and life-limiting illness. Bristol: Together for Short Lives, 2004.
41. National Health Service (NHS) South Central. Guide to using the Child and Young Person's Advance Care Plan, 2010.
42. Sanderson A, Zurakowski D and Wolfe J. Clinician perspectives regarding the do-not-resuscitate order. *JAMA Pediatr* 2013; 167: 954–958.
43. Department of Health (DH). *Commissioning children and young people's palliative care services: a practical guide for NHS commissioners*. London: Department of Health, 2005.
44. Hickman SE, Tolle SW, Brummel-Smith K, et al. Use of the Physician Orders for Life-Sustaining Treatment program in Oregon nursing facilities: beyond resuscitation status. *J Am Geriatr Soc* 2004; 52: 1424–1429.
45. Wolff A, Browne J and Whitehouse WP. Personal resuscitation plans and end of life planning for children with disability and life-limiting/life-threatening conditions. *Arch Dis Child Educ Pract Ed* 2011; 96: 42–48.
46. In der Schmitten J, Rotharmel S, Rixen S, et al. Patientenverfügungen im Rettungsdienst (Teil 2). Neue Perspektiven durch Advance Care Planning und die "Hausärztliche Anordnung für den Notfall." *Notfall Rettungsmed* 2011, http://webcache.googleusercontent.com/search?q=cache:tTOkRhB11WgJ:www.researchgate.net/profile/Georg_Marckmann/publication/227250798_Patientenverfugungen_im_Rettungsdienst_%28Teil_2%29/links/0c96052fe70f48c1cf000000+&cd=1&hl=en&ct=clnk&gl=in&client=firefox-a
47. Schmidt TA, Hickman SE, Tolle SW, et al. The Physician Orders for Life-Sustaining Treatment program: Oregon emergency medical technicians' practical experiences and attitudes. *J Am Geriatr Soc* 2004; 52: 1430–1434.
48. Walsh-Kelly CM, Lang KR, Chevako J, et al. Advance directives in a pediatric emergency department. *Pediatrics* 1999; 103: 826–830.

Appendix 1. Discussion guide.

Key questions	Item checklist	Further questions
1. What is your experience with any forms of advance care planning for severely ill children and adolescents?	Starting point for discussions? Thematic issues, relevant situations? Participants? Roles Initiator of discussions Involvement of minor patients Interprofessional communication? Current forms of pACP? Standards Written advance directives, standard forms Difficulties and barriers?	Can you specify? Can you explain, justify? What else comes in your mind? And then? An example? In what sense? Why?
2. What is your experience with written orders or advance directives in whose completion you have not been involved?	Acceptance? Benefits? Difficulties?	
3. How should advance care planning ideally be conceptualized?	Starting point for discussions? Thematic issues, relevant situations? Participants? Roles Involvement of minor patients Requirements for written documents? Content Form Signatures Need for support? (e.g. trainings, workshops, guidelines)	
Closing questions		
Did we forget anything that you would like to address?		