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"Hope for the best, prepare for the worst": A qualitative interview study on parents' needs and fears in pediatric advance care planning

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Abstract

Background: Pediatric advance care planning is advocated by healthcare providers because it may increase the chance that patient and/or parent wishes are respected and thus improve end-of-life care. However, since end-of-life decisions for children are particularly difficult and charged with emotions, physicians are often afraid of addressing pediatric advance care planning.

Aim: We aimed to investigate parents' views and needs regarding pediatric advance care planning.

Design: We performed a qualitative interview study with parents of children who had died from a severe illness. The interviews were analyzed by descriptive and evaluation coding according to Saldaña.

Setting/Participants: We conducted semi-structured interviews with 11 parents of 9 children. Maximum variation was sought regarding the child's illness, age at death, care setting, and parent gender.

Results: Parents find it difficult to engage in pediatric advance care planning but consider it important. They argue for a sensitive, individualized, and gradual approach. Hope and quality of life issues are primary. Parents have many non-medical concerns that they want to discuss. Written advance directives are considered less important, but medical emergency plans are viewed as necessary in particular cases. Continuity of care and information should be improved through regular pediatric advance care planning meetings with the various care providers. Parents emphasize the importance of a continuous contact person to facilitate pediatric advance care planning.

Conclusion: Despite a need for pediatric advance care planning, it is perceived as challenging. Needs-adjusted content and process and continuity of communication should be a main focus in pediatric advance care planning. Future research should focus on strategies that facilitate parent engagement in pediatric advance care planning to increase the benefit for the families.

Keywords

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

What is already known about the topic?

- Pediatric advance care planning (pACP) is recommended, but most models are based on research in adults.
- Healthcare providers welcome pACP, but find it difficult to implement and are worried about overburdening parents.
- Parents wish for clear information and open communication.

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What this paper adds?

- This study shows that parents have mixed feelings about pACP; they consider it important and helpful but often difficult.
- Advance directives are considered particularly difficult and often unnecessary.
- Important requirements for good pACP include sensitive conversations, a step-by-step process, a family-centered approach, consideration of hope and non-medical concerns, meetings with the relevant care providers and the designation of a main contact person.

Implications for practice, theory, or policy

- The results of this study can inform the development of pACP concepts that are better adjusted to families' needs.
- The identified challenges stress the need for improving communication with families through communication training and for assigning a pACP case manager as continuous contact.

Introduction

Advances in neonatal and pediatric intensive care have led to improved survival, but a rising number of children survive with severe sequelae and life-limiting conditions.[1] In adult medicine, advance care planning (ACP) is increasingly being acknowledged as a way to improve patient-centered care at the end of life.[2–4] ACP is a formalized process of discussing a person's values and preferences for care, aiming to guide future healthcare decisions. Pediatric advance care planning (pACP) is internationally recommended and welcomed by healthcare providers.[5–8] It can increase children's (where applicable) and parents' capacity to anticipate decisions, support family coping, provide peace of mind, increase sense of control, and reduce suffering.[9–11]

Yet, prior studies have shown that professionals experience practical barriers to pACP and that many pACP discussions occur belatedly, in particular, after acute crises.[8,12–14] From the perspective of professionals, major challenges are the uncertainty when and how to raise these sensitive issues, unclear prognoses, unrealistic expectations by parents, concerns of undermining hope, and parents' hesitation to engage in pACP. Moreover, many pediatric patients are too young to express their treatment wishes and surrogate decisions by parents carry a high emotional burden.[15] After having explored these issues in a previous study with healthcare providers,[8] we aimed to investigate parents' experiences and views in order to identify their needs and barriers to pACP.

Methods

This is a qualitative, practice-informing interview study with parents who have already made surrogate decisions for their children in an end-of-life setting. The method and its reporting follow the *Consolidated Criteria for Reporting Qualitative Research (COREQ)*.[16] The raw data are available from the corresponding author.

Sampling

A total of 12 parents of 10 deceased children (two couples) were invited and agreed to participate. Participants were selected by purposeful sampling based on the following inclusion criteria: (1) death of their child due to a life-limiting illness, (2) child died more than 6 months ago, and (3) readiness to talk about the child's care and death. Maximum variation sampling was used in order to collect a variety of perspectives and understand pACP in its complexity. Based on our own experience in the field, we identified the following factors to be varied: child's illness (four groups according to the Association for Children with Life-threatening or Terminal Conditions and their Families (ACT)),[17] child's age, place of death (home, hospital), specialized palliative care involvement, and parent gender. We searched for particularly information-rich and differing cases, identified with the help of the pediatric palliative care team, in order to refine our understanding of pACP needs and challenges.

Recruitment

Eligible parents were identified through gatekeepers from the pediatric palliative care team and the university children's hospital in a metropolitan area of Germany, according to the above-mentioned criteria. None of the participants was acquainted with the interviewer.

Data collection

Parents were contacted by the last author (M.F.) via phone or e-mail. They received an information letter on the background, methods, and data protection measures of the study and gave written consent. Face-to-face interviews were conducted from October 2013 to February 2015 by J.D.L., a psychologist, child psychotherapist in training, and experienced qualitative researcher. The interviews were semi-structured according to Helfferich.[18] The interview guide was reviewed in several research groups with

Table 1. Parent and child characteristics (11 parents of 9 children).

Parent gender	f = 8; m = 3
Parent age (years)	Md = 43; *R* = 36–50
Child gender	f = 5; m = 4
Child age at death (years)	Md = 7.8; *R* = 0.4–23.8
Child illness	Cancer (*n* = 3), spinal muscular atrophy type I (*n* = 1), cystic fibrosis (*n* = 1), leukodystrophy (*n* = 1), hypoplastic left heart syndrome (*n* = 1), complex malformation syndrome (*n* = 1), unknown syndrome (*n* = 1)
Place of death	Home: *n* = 6[a]; hospital: *n* = 3[b]
Time since death (years)	Md = 2.2; *R* = 1.3–3.6
AD	AD: *n* = 2; no AD: *n* = 3; not sure: *n* = 4

f: female; m: male; Md: median; *R*: range; AD: advance directive.
[a]Specialized pediatric palliative home care provided.
[b]Only clinical consultations by the specialized pediatric palliative home care team.

methodological and clinical expertise. All interviews were audiotaped and transcribed verbatim. Words or phrases stressed by the interviewees were transcribed in capital letters. All personal information (personal names, places, and institutions) was irretrievably anonymized, and the audio recordings were deleted. The study protocol and materials were reviewed and approved by the institutional review board of the local University Hospital (no. 049-12).

At the beginning of each interview, parents were given a brief explanation of pACP as "discussing and planning ahead for the child's future care, preparing for future situations and documenting preferences for future treatment in an advance directive (AD)." ADs were defined as documents allowing parents and/or children to state their preferences for the child's future care, in order to ensure that these wishes will be known and respected. Although not legally binding, ADs are often completed in pediatric palliative care settings with parents ("parent AD") and children (if possible) to identify and communicate care preferences and to guide care providers in their decisions. Parents were invited to tell their experiences with their child's care. In particular, two key questions were asked: (1) whether and how professionals had discussed with the parents possible future challenges and decisions in advance and (2) whether and where parents see possibilities to improve pACP. Optional supplementary questions helped to obtain more details about the planning process and parents' experiences, for example, questions on the timing and content of discussions, the participants, written documentation, and on what parents found helpful/difficult. At the end of the interview, participants could add anything else they found important. The following sociodemographic information was collected: parents' age, gender, and profession; child's gender, illness, date and place of death, age at death, and number of siblings; and completion of an AD. The interviews took between 60 and 135 min.

Data analysis

The interview transcripts were analyzed by J.D.L. and M.D. using descriptive and evaluation coding according to Saldaña[19] and the software MAXQDA-10. We coded all data referring to parents' experiences/views on pACP and related topics. Codes were developed inductively from the data. To gain new insights from each case, we successively analyzed each interview in detail, creating new codes and revising existing codes where necessary. To structure the data, each passage was assigned a descriptive code (label) to note the basic topic. Evaluative codes were used to note participants' qualitative comments (positive, negative, and recommendations) about a topic (e.g. pACP conversations). Each created code was described in detail in a memo. Four iterative steps of analysis were performed: (1) independent first-cycle coding of each transcript by the two coders: evaluation coding of participants' qualitative comments, (2) recoding of each transcript and integration into a common coding scheme in joint data sessions, (3) review and revision of the coding scheme, and (4) second-cycle coding: reorganization of the evaluative codes into needs, barriers, and recommendations for practice.[19] A detailed protocol of the coding process is available from the authors.

Results

All 12 parents contacted gave their informed consent and were interviewed. One interview was excluded from the analysis because the interviewee could not remember sufficient details around her child's death. Table 1 lists the demographic characteristics of the remaining 11 parents and their 9 deceased children. We included eight mothers and three fathers; for two children, we interviewed mother and father together. The children's diseases represent all four ACT groups. The child's age at death varied widely (0.4–23.8 years). Six children had died at home.

Participants' statements were categorized into three major topics: (1) pACP conversations, (2) statement of preferences, and (3) infrastructure. Parents' views on each topic will be described in the following sections.

pACP conversations

Most parents were ambivalent about pACP conversations. On the one hand, they indicated that early conversations and planning ahead were helpful through (1) empowering them to make good decisions for their child and be a good parent, (2) facilitating coping, and (3) giving a sense of control and security by preparing for what may come.

On the other hand, parents identified barriers: feeling not ready, wanting to focus on the present, and suppress burdensome thoughts:

> That was actually too quick for me. I knew he would die soon. But I was hoping somehow that we still have him longer than everyone thinks. […]And I then thought to myself: ‚Wait, slow down!' But at the same time, it was also important. We always knew ourselves secured by the team, the drugs and the local doctor who is always available […]. And we knew everything had been arranged. And even if it gets bad one day, one knows what to do. We were not afraid there at all […]. And I think it is also necessary to do this at an early stage. (Mother of a 5-month-old boy with spinal muscular atrophy type I)

Other barriers reported included the physicians' reluctance to engage in pACP conversations because of prognostic uncertainty or because they do not face up to the facts. Moreover, parents considered that their highly individual concerns, needs, and ways of coping might be a challenge for physicians.

Parents expressed the following needs regarding pACP conversations:

1. *Shared decision-making.* All parents wanted to be included in decision-making as partners, to be listened to, and taken seriously. They valued open and honest information, no matter how uncertain or potentially upsetting:

> The reality CANNOT be as bad as the imagination. Waiting and not knowing is MUCH worse than the facts. […] The waiting time is always more difficult than saying: It could be this, it could be that, we do not know, but right now, it looks like this. (Mother of a 5-year-old boy with a malignant tumor)

2. *Gradual and sensitive approach.* Parents unanimously wished for a step-by-step process with repeated discussions and sensitive communication respecting their needs and reservations. Healthcare providers should gently introduce and repeatedly offer pACP conversations but should not put pressure on parents:

> When someone does not want to engage in this, you cannot force him to. But you have to find a careful way […] and to continue working somewhat in this direction. (Mother of a 14-year-old girl with a brain tumor)

   Parents advocated for an individually adapted approach that takes into account the respective situation, needs, and concerns of the whole family. To facilitate pACP conversations, they suggested the following: (1) bringing in an additional, uninvolved "listener" (e.g. a friend), (2) involving nurses to support parents, (3) communication trainings for physicians to improve their communication skills, (4) written material to introduce and inform about pACP because it is seen as less demanding than personal conversations and as allowing parents to determine what they are ready to address, and (5) exchange with other parents in similar situations.
3. *Conversations about hope and non-medical issues.* Psychosocial and daily life issues were particularly important for all parents (see Table 2). Yet, the themes that parents wanted to be addressed in pACP varied considerably. Several parents highlighted the importance of strengthening parents by maintaining hope, for example, that the child lives "longer than expected," that "the days together are good," and that they "can still do a lot for their children" and be good parents.
4. *Involvement of the child.* All parents wanted their child to be involved in pACP (except for infants) relative to its developmental maturity. They felt that their child should be heard and taken seriously even if unable to make treatment decisions.

Statement of preferences

Many parents were reluctant to make decisions in advance but wanted to decide in due course. They found it hard and burdensome to imagine future scenarios and were afraid to bind themselves:

> So, it was ok to DISCUSS this for the day when it would be necessary. But I did not want to commit myself. And I always said: We will see when it comes. (Mother of a 5-month-old boy with spinal muscular atrophy type I)

The possibility to revoke advance decisions was very important for parents. They wished to be encouraged to rethink their decisions. Generally, they ascribed little importance to documenting decisions in a written plan and preferred oral agreements with the care providers. Four parents did not even remember whether they had completed an AD for their child. According to parents, written care plans were mostly needed by healthcare providers to feel safe. Medical care plans for emergency situations were considered more important, especially in settings with frequently changing staff and parents not always present (e.g. in hospital ward):

> But in the hospital it looks like this: When there is nobody there at night and there is an emergency, you have a different

Table 2. Issues relevant for parents in pACP.

Relevant issues[a]	
Medical issues	Parents'/child's treatment goals Anticipated disease course, possible situations, and interventions Treatment limitations: reasons, medical indication Emergency planning: proceeding when parents absent, hospital admission yes/no, other places to go, on-site support for parents Information about dying: process of dying, symptoms, and pain Pain treatment/sedation, rationale, and consequences Genetic screening for future pregnancies
Non-medical issues	Being good parents: caring for the child, satisfying its needs (e.g. breastfeeding), comforting the child Promoting quality of life, having a good time together Possibilities for a break, for example, children hospices Dealing with siblings: paying attention to them, understanding their experiences, talking about dying with siblings Social network, personal support in daily life and crisis situations Offers for psychosocial support, for example, a chaplain Spiritual issues, for example, ideas about life, death, afterlife Planning of the living: school attendance, capacity to work, financial aids, important activities (e.g. school enrollment, driving license) Farewell planning: saying goodbye, leaving messages, creating memories, and bequeathing belongings Planning of the dying: preferred place of death, presence of the family, privacy, proceeding after dying Funeral planning: options, preferences, addresses, and repatriation of the corpse Bereavement care: service offers, being happy again

pACP: pediatric advance care planning.
[a]Listed order does not reflect priority.

> doctor on duty every day, […] this means, you have no choice, but to document somewhere: what should be done and, in such a case, call THIS person. (Mother of a 5-year-old boy with a malignant tumor)

The following requirements were identified by parents for emergency plans: official form with the doctor's personal signature, brief and precise information, and information about diagnosis and treatment preferences. However, some parents reported that such documents were nonetheless disregarded by emergency services and intensive care units or hindered the access to those services.

Infrastructure

Parents identified major infrastructural barriers to pACP: lack of time in routine care, especially in hospitals, and insufficient information transfer and cooperation between and within services (e.g. in emergency departments):

> The worst [are] the explanations again and again what exactly is the matter. That was in fact, I have to say, a disaster. […] There were always different doctors and you always tell them the same things. (Father of a 6-year-old boy with an unknown syndrome)

Parents suggested several structural interventions to improve the coordination between different disciplines and service providers and to foster good communication:

1. Regular pACP meetings with the relevant care providers to reach a common understanding of the goals of care.
2. A continuous contact person in pACP, which was requested by all parents: a physician they trust, who knows the child, the family, and their preferences, is available 24 h/day, leads pACP conversations, coordinates care, and supports families and professionals in critical situations with their decisions.
3. Close involvement of the family physician for on-site support.

Table 3 provides a list of recommendations for pACP developed on the basis of the participants' commentaries.

Discussion

This study provides information about bereaved parents' perspectives on pACP. Prior work shows that pACP benefits families and does not cause significant distress.[9,11] However, healthcare professionals face major barriers and uncertainties in practice, notably parents' uneasiness to engage in pACP.[8,13] Our study indicates that parents find pACP important even though distressing. Previous research on pACP might have underestimated parents' difficulties to engage in pACP. Due to the open, exploratory design and the heterogeneous sample of bereaved parents,

Table 3. Recommendations for pACP.

Recommendations[a]	
pACP conversations	Open and honest communication, transparency, and shared decision-making
	Repeated offers for pACP conversations by healthcare providers
	Sensitive and stepwise process, adapted to individual situation, concerns, and needs
	Ongoing process, scheduled follow-up discussions
	Booklets and written information for self-determination
	Resource-oriented conversations: consider family hopes and strengths
	Planning for psychosocial needs and the living
	Focus on empowerment, coping, and psychological preparation
	Support by nurses and a third person (e.g. a friend)
	Facilitating exchange with other parents
	Involving the child in an appropriate way, talking with the child
Statement of preferences	Differentiation between emergency plan and end-of-life plan
	Emergency plan with specific requirements: standard form, brief, validated by physician, distributed to family and local services
	Revocability of decisions, information for parents
Infrastructures	Round tables with service providers for communication and coordination
	One continuous person as facilitator and main contact
	Cooperation with family physician
	Timely planning of future care services and transitions
	Systematic incorporation of pACP in the healthcare system: working structures, time, responsibilities
	Professional education, pACP conversation trainings, and guidelines

pACP: pediatric advance care planning.
[a]Listed order does not reflect priority.

this study gives a more differentiated picture of the parent perspective. It indicates (1) in which ways pACP can be helpful, (2) what parents' priorities and special needs are, (3) why parents find pACP difficult, and (4) how identified barriers can be met in practice.

The results indicate that parents prioritize regular and sensitive conversations over written ADs, emphasizing their positive *psychological* effects, particularly empowerment, facilitation of coping, and peace of mind. This is in line with previous work showing the importance of honest and sensitive communication, empowered decision-making, and preparation for parents.[10,20,21] Our results thus suggest that in pACP, more weight should be put on the communication process rather than on written pACP documents. However, the parents in our study found it difficult to actually engage in pACP, even though they considered it important. They often felt not ready to think ahead and preferred living in the here and now. In the following, the suggestions made by parents on how to facilitate the process will be discussed.

pACP is often misconceived as giving up hope, and pediatricians are worried about taking away hope through pACP.[13] Our results highlight that holding on to hope is important and might facilitate parental engagement in pACP. Parents can remain hopeful and still understand their child's serious condition.[22] Honest conversations can even support hope,[23] allowing to define alternative aims and hopes, for example, hope for quality time together, quality of life, spiritual well-being, normality, a good day, or no suffering.[22,24] Our results suggest that this approach needs to be applied to pACP. Hope should be directly addressed in pACP conversations in order to elicit realistic hopes and make meaningful plans, following the principle "hope for the best, prepare for the worst."[22,25]

Our data underline that pACP should encompass different elements: (1) crisis and end-of-life planning, (2) planning for the living, that is, addressing wishes and needs during life, and (3) planning of farewell and funeral. Since previous work suggests that physicians tend to mainly focus on medical information,[26] they should be encouraged and trained to address non-medical aspects of a child's life with a severe illness. Written material and the involvement of non-medical professionals (e.g. social worker, chaplain) may be conducive to this aim. Some pACP tools for families and professionals already meet these requirements.[27–29]

The parents in our study emphasized the importance of a continuous main contact person in the care of their child. This need has already been addressed in previous work and been stressed by healthcare professionals.[6,8] Our results underline that pACP requires a "case manager" who can build a trusting relationship with the child and the family, lead the conversations, coordinate care, communicate care plans, and can be called in critical situations to support parents and professionals. However, as a 24/7 availability of one person is unrealistic in practice, this function might, for example, be assigned to specialized pediatric palliative home care (SPPHC) teams where available.[30]

An important finding was that parents had little interest in creating an AD. This contrasts with prior studies concentrating on the benefits of and requirements for written ADs.[10,31] Healthcare providers attach much importance to consensual pACP documents, in order to feel more secure in critical situations.[8] Interventions aimed at improving pediatricians' communication skills as well as professionals' and parents' understandings of pACP might help to reduce parental distress and avoid conflicts related to ADs.[32] Additionally, age-appropriate tools may be useful in order to include the children in the process.[29,31,33]

Emergency plans were considered necessary for specific settings such as emergency departments and hospital wards with changing staff. Previous work also shows that frequent emergency department visits increase parents' interest in creating a written care plan.[32] Parents and professionals agree that specific medical emergency plans might be useful, similar to the Physician Orders for Life-Sustaining Treatment (POLST) that have become common in adult care.[8,34] However, this study and others show that intensive care and emergency physicians do not always accept such documents.[8,10] Professional education on pACP and a "case manager" as main contact might help reducing uncertainty and increasing acceptance of such documents.

In summary, based on our results and the literature, we suggest the following interventions and principles to facilitate a sensitive pACP approach: (1) communication training and guides on pACP to improve pediatricians' communication skills and reduce uncertainty;[35] (2) individually adjusted step-by-step conversations, supported by written material;[36] (3) a family-centered approach;[37,38] (4) consideration of hope, non-medical needs, and relationships in pACP; and (5) a central contact in pACP that guarantees continuity.[6,8]

A limitation of our study is that our interviewees were recruited by the help of personal contacts of M.F., which may have biased the results. However, none of the parents had known the interviewer beforehand. Most families had been supported by a SPPHC team; therefore, our study may not match the needs and barriers relating to pACP in other care settings when families receive less support. On the other hand, the experience with pediatric palliative care may also have enhanced the parents' knowledge about pACP. Additionally, the retrospective design may still underestimate barriers to pACP because in retrospect parents may be more aware of the benefits.

Conclusion

Our study identified important information on the experiences and views of parents relating to pACP and allows the formulation of concrete practice recommendations. These findings, together with those obtained in studies with healthcare professionals, may inform the development of pACP models that can be piloted and evaluated in practice. Future research should also focus on the identified communication barriers in order to improve the quality of pACP conversations.

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