Pediatric Advance Care Planning: A Systematic Review

BACKGROUND AND OBJECTIVES: Advance care planning (ACP) is increasingly regarded as the gold standard in the care of patients with life-limiting illnesses. Research has focused on adults, but ACP is also being practiced in pediatrics. We conducted a systematic review on empirical literature on pediatric ACP (pACP) to assess current practices, effects, and perspectives of pACP.

METHODS: We searched PubMed, BELIT, and PSYCinfo for empirical literature on pACP, published January 1991 through January 2012. Titles, abstracts, and full texts were screened by 3 independent reviewers for studies that met the predefined criteria. The evidence level of the studies was assessed. Relevant study outcomes were retrieved according to predefined questions.

RESULTS: We included 5 qualitative and 8 quantitative studies. Only 3 pACP programs were identified, all from the United States. Two of them were informed by adult programs. Major pACP features are discussions between families and care providers, as well as advance directives. A chaplain and other providers may be involved if required. Programs vary in how well they are evaluated; only 1 was studied by using a randomized controlled trial. Preliminary data suggest that pACP can successfully be implemented and is perceived as helpful. It may be emotionally relieving and facilitate communication and decision-making. Major challenges are negative reactions from emergency services, schools, and the community.

CONCLUSIONS: There are few systematic pACP programs worldwide and none in Europe. Future research should investigate the needs of all stakeholders. In particular, the perspective of professionals has so far been neglected. Pediatrics 2013;131:e873–e880
End-of-life (EOL) decisions in children with life-threatening or life-limiting conditions are a major challenge in pediatrics. Timely discussions with parents and the child (if possible) about treatment options and decisions they will face over time may be helpful to improve understanding of the child’s prognosis and preparing for future situations. The concept of advance care planning (ACP) aims at respecting the patients’ autonomy and at improving their EOL care. So far, ACP programs and research have been almost exclusively focused on adult patients, particularly in the geriatric setting. The pediatric setting is characterized by complicating factors such as a high prognostic uncertainty, lack of decision-making capacity in most patients, and the complexity of the social environment involved. Although there is growing research interest in pediatric ACP (pACP), to our knowledge, no systematic review on the issue has been performed. Our goal was, therefore, to fill this gap and to systematically review the empirical literature on pACP for severely ill children and adolescents to outline the current practice and effects of, as well as perspectives on, pACP.

METHODS
We conducted a systematic review of empirical research on pACP for severely ill children and adolescents. Details on the process are given in a separate review protocol (available from the authors). The protocol is based on the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) statement checklist for the reporting of systematic reviews. This 27-item checklist helped us in defining a priori our research question, eligibility criteria, and methods for the review.

Eligibility Criteria and Search Strategy
Final criteria for eligible publications were as follows: (1) Studies with an explicit focus on pACP, defined as thinking ahead to treatment choices and goals of care in consultation with health care providers, family members, and important others; (2) studies revealing either forms and elements of pACP, participants in pACP, and effects or perspectives of pACP; (3) studies addressing pediatric patients with life-limiting conditions, their surrogates or health care providers; (4) reports of empirical data (qualitative and quantitative) or systematic reviews/meta-analysis of empirical studies; (5) articles in English, German, or French, published January 1, 1991 through January 20, 2012. We excluded studies on perinatal issues and patients with a primary psychiatric diagnosis, and studies that merely revealed the prevalence and predictors of do-not-resuscitate (DNR) orders.

We performed searches in PubMed, BELIT, and PSYCinfo. Relevant descriptors and key words were identified by searching the databases’ thesauri and by preliminary searches with at least 1 pACP-related descriptor. For PubMed, this yielded the following MeSH-terms: “advance care planning,” “advance directive,” and “resuscitation order.” These terms were also searched in all fields, with synonyms and truncations added. All terms were combined in 1 search strategy by the Boolean operator “OR.”

We conducted supplemental searches in BELIT and PSYCinfo to account particularly for bioethical and psychological publications. Finally, the reference lists of included articles were hand-searched, applying the same eligibility criteria.

Study Screening
Selection of relevant articles followed a screening process in 3 stages. Figure 1 illustrates this process.

Phase 1
Retrieved references were imported by using EndNote, and titles were screened on the basis of the prespecified selection criteria. Articles of doubtful eligibility were retained in phase 1.

Phase 2
Abstracts of retained articles were scrutinized by 1 of the authors (Ms Lotz). If any of the exclusion criteria were met, the article was rejected. Articles of doubtful eligibility were retained. Abstracts were cross-checked by 1 of 2 independent reviewers (one-half by Dr Führer, the other by Dr Jox) and disagreements discussed.

Phase 3
For the remaining articles, full articles were reviewed in-depth twice by the first reviewer to make final decisions about inclusion. All articles excluded in this phase were further re-examined by 1 of the second reviewers to prevent overexclusion.

Data Synthesis and Study Quality Assessment
Full articles were reviewed for systematic coding of the following characteristics of the reported studies: country of origin, study design, setting, sample, and evidence level. The following questions for extracting relevant data were theoretically defined according to our research aim:

1. How frequently are pACP features applied in pediatric care?
2. What are the main elements of pACP programs?
3. Who participates in pACP?
4. What are the effects of pACP?
5. How is pACP perceived by the relevant stakeholders (patients, surrogates/families, and health care providers)?
We extracted all findings that referred to our formulated questions and summarized them across articles into broader themes, checking back with the original data. These themes were then used to answer the research questions.

RESULTS

Thirteen articles met the inclusion criteria, of which 5 present qualitative and 8 quantitative data. Three articles reveal data on the same randomized controlled trial (RCT). Twelve publications are from the United States and 1 from South Australia. No European publications were identified. Table 1 provides a summary of design and quality of the reported studies. Overall, patients’ ages ranged from ≤6 months to 37 years. The studies were on patients with HIV infection, cancer, muscular dystrophy, other severe illnesses, and healthy adolescents. Four studies interviewed adolescents and young adults (13–28 years). 5 studies interviewed family members of pediatric patients (2 months to 37 years), and 3 studies analyzed documented records of pediatric patients (≤6 months to 15 years). One study was on 214 school nurses. Quantitative studies each included at least 50 participants. Only 1 RCT was identified but without blinding, and on a small and selective sample (38 HIV-infected adolescents, 14–21 years, with an available surrogate, 92% African Americans, no severely depressed patients). No means, SDs, confidence intervals, and effect sizes are reported. All other studies used qualitative or descriptive methods of analysis.

We identified 3 pACP programs. They resemble each other in their overall design but differ in terms of care setting, target population, participants, and the form of advance directive (AD). Table 2 compares the core elements of the programs.

Frequency of pACP

Three studies suggest that qualified pACP promotes the completion of ADs and can be successfully implemented in the community. In a qualitative study on patients with muscular dystrophy in regular care (8–21 years), only 1 patient had an AD, whereas all patients participating in a pACP program had an AD. In an RCT, adolescents enrolled in pACP had more frequently an AD than controls at 3 months postintervention (95% vs 11%). Patients and physicians make increasingly use of pACP. This is shown by physicians referring more and more children to pACP, and increasingly more children adhering to and spending longer times in the program.

Three studies reveal that patients and parents have discussions about the future even without the help of a facilitator. In a quantitative study, 44% of 50 adolescent patients with various illnesses (13–21 years) reported that they had discussed EOL issues with someone. In a qualitative study, families of patients with muscular dystrophy (2–37 years) mainly discussed nonmedical issues such as the child’s educational and financial future and how to deal with growing independence needs.

Participants in pACP

Two retrospective qualitative studies investigated who initiates and participates in pACP. Findings suggest that pACP encourages parents to initiate discussions about treatment preferences for future situations. This is shown by parents in a pACP program initiating more often such discussions than parents in a regular ICU.

Persons who are either actively involved in or witnessing pACP include the following: family members, other patients’ surrogates, ethicists, a trained...
TABLE 1 Study Characteristics and Quality, in Chronological Order (n = 13)

<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Setting</th>
<th>Sample</th>
<th>LoE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jefferson et al 1991</td>
<td>Qualitative, retrospective</td>
<td>ICU</td>
<td>17 patients with various illnesses (2 mo–15 y)</td>
<td>IV</td>
</tr>
<tr>
<td>Wharton et al 1996</td>
<td>Qualitative, descriptive</td>
<td>NS</td>
<td>Convenience sample of 76 parents of patients with physical/cognitive disabilities and/or chronic illnesses (mean = 8.4 y)</td>
<td>IV</td>
</tr>
<tr>
<td>Schultz-Grant et al 1998</td>
<td>Quantitative, descriptive</td>
<td>School</td>
<td>Convenience sample of 214 school nurses</td>
<td>IV</td>
</tr>
<tr>
<td>Parker et al 1999</td>
<td>Qualitative</td>
<td>Inpatient, outpatient</td>
<td>Convenience sample of 13 family members of patients with DMD, BMD, or SMA (mean = 16.4 y; range: 8–21 y)</td>
<td>IV</td>
</tr>
<tr>
<td>McAliley et al 2000</td>
<td>Quantitative, descriptive</td>
<td>Different schools, hospital</td>
<td>107 adolescents, healthy or with various illnesses (15–18 y)</td>
<td>III</td>
</tr>
<tr>
<td>Toce and Collins 2003</td>
<td>Quantitative, descriptive</td>
<td>NS</td>
<td>Carers of 83 pediatric patients with various life-limiting illnesses, 40% imminently dying (30% ≥ 6 mo at enrollment in program)</td>
<td>IV</td>
</tr>
<tr>
<td>Lyon et al 2004</td>
<td>Quantitative, descriptive</td>
<td>Inpatient, outpatient</td>
<td>Convenience sample of 50 patients, 50% with chronic illnesses (13–21 y)</td>
<td>IV</td>
</tr>
<tr>
<td>Erby et al 2006</td>
<td>Qualitative mainly NS</td>
<td>24 and 17 parents of patients with DMD (2–37 y)</td>
<td>IV</td>
<td></td>
</tr>
<tr>
<td>Hammes et al 2005</td>
<td>Quantitative, retrospective NS</td>
<td>17 patients with AD and various illnesses (2 mo–12 y)</td>
<td>IV</td>
<td></td>
</tr>
<tr>
<td>Wiener et al 2008</td>
<td>Qualitative</td>
<td>Outpatient</td>
<td>20 patients with HIV-1 or cancer (16–28 y)</td>
<td>IV</td>
</tr>
<tr>
<td>Lyon et al 2009a,11 2009b,12</td>
<td>Quantitative, RCT</td>
<td>Outpatient HIV-adolescent clinics</td>
<td>38 dyads of HIV-infected patients (14–21 y) and surrogates</td>
<td>I</td>
</tr>
</tbody>
</table>

BMD, Becker muscular dystrophy; DMD, Duchenne muscular dystrophy; LoE, level of evidence: I. RCT, II. non-RCTs, III. Observational studies with controls, IV. Observational studies without controls and qualitative studies. NS, not stated; SMA, spinal muscular atrophy.

TABLE 2 Pediatric ACP Programs (n = 3)

<table>
<thead>
<tr>
<th>Program Characteristics</th>
<th>Full name</th>
<th>FACE Intervention 10–12</th>
<th>Footprints Model 21</th>
<th>Hammes et al 2005 17</th>
</tr>
</thead>
<tbody>
<tr>
<td>Basis</td>
<td>Empirical, RC program, 29 Five Wishes 28</td>
<td>Empirical, ethics committee discussions</td>
<td>Designed by RC team</td>
<td></td>
</tr>
<tr>
<td>Care setting</td>
<td>Outpatient</td>
<td>Mainly outpatient</td>
<td>In- and outpatient</td>
<td></td>
</tr>
<tr>
<td>Target population</td>
<td>HIV-infected adolescents</td>
<td>Patients with various life-limiting illnesses</td>
<td>Patients with various life-limiting illnesses</td>
<td></td>
</tr>
<tr>
<td>Interventions</td>
<td>3 weekly standardized sessions</td>
<td>Interdisciplinary care conference (90 min) and scheduled follow-up meetings</td>
<td>2–3 sessions (30–40 min)</td>
<td></td>
</tr>
<tr>
<td>Standard participants in pACP</td>
<td>Patients, parents, trained interviewer</td>
<td>Family, patients (developmentally adapted), continuity physician, nurse, social worker, chaplain, community physician, other providers</td>
<td>Surrogates, competent patients, hospital ethicist, chair of the Ethics Committee, physician</td>
<td></td>
</tr>
<tr>
<td>Optional participants</td>
<td>Chaplain, psychotherapist, hospital ethicist</td>
<td>Ethics committee</td>
<td>Chaplain</td>
<td></td>
</tr>
<tr>
<td>AD form</td>
<td>Standard form with open section, copy to family and physician</td>
<td>Standard form, copy to relevant providers (eg, EMS personnel, equipment providers, police, funeral director, coroner)</td>
<td>Letter format</td>
<td></td>
</tr>
<tr>
<td>Review of the care plan</td>
<td>NS</td>
<td>Individually scheduled</td>
<td>Annually</td>
<td></td>
</tr>
<tr>
<td>Issues addressed</td>
<td>Medical, psychosocial, and spiritual</td>
<td>Medical, psychosocial, and spiritual</td>
<td>Medical</td>
<td></td>
</tr>
</tbody>
</table>

EMS, emergency medical services; FACE, family/adolescent centered; NS, not stated; RC, Respecting Choices.

Effects of pACP

One qualitative review of ICU chart records reveals that medical treatment is modified after the implementation of an AD.20 For most patients, ventilator support and catecholamines were withdrawn and narcotics added. However, in an RCT in adolescents with HIV, pACP had no influence on decisions to discontinue treatment.12 Two studies suggest that pACP promotes home deaths for children.17,20 Only 1 of 13 ICU patients without pACP died at home,20 compared with 7 of 9 patients who were enrolled in a pACP program.17

The only RCT identified indicates that pACP triggers positive emotional experiences in HIV-infected adolescent patients and their surrogates.10,11 All participants showed significantly more positive emotions immediately after pACP discussions, and patients also showed less negative emotions.10 In addition, pACP reduced the patients’ difficulties in making treatment decisions. They felt significantly better informed and marginally more certain about their decisions.11 The discussions also improved the surrogates’ understanding of the patient’s
treatment preferences. Participants in the intervention rated the quality of the communication with the interviewer significantly higher than the control group. At 3 months postintervention, adolescents in the intervention group still reported no clinically significant levels of depression and anxiety, and a maintained quality of life. There were no significant differences to controls.12

Perspectives on pACP

Most articles provide some data on the perspectives of different stakeholders on pACP. We identified positive perspectives on pACP, perceived problems with pACP, and needs relating to pACP.

Positive Perspectives on pACP

Three quantitative studies reveal that ADs for children and adolescents find support among patients, surrogates, and school nurses.16,18,22 In a study on parents of children with special health care needs (mean = 8.4 years), 57% of 76 parents were favorable toward completing an AD for their child.16 In a study on 107 healthy and ill adolescents (15–18 years), 87% of them found that having an AD was at least somewhat important for people of their own age or health state, and 90% to 93% found it very important for people with a chronic or life-threatening illness or before a major surgery.18 In another study, school nurses reported that families occasionally ask for ADs in the school setting.22 In a quantitative evaluation of a pACP program for HIV-infected adolescents (14–21 years), 92% of 76 families were overall satisfied with the intervention, and 93% attended all sessions.10 A quantitative and a qualitative study suggest that physicians and health institutions are supportive of pACP and that emergency services are willing to accept ADs for children.17,21

Two qualitative studies reveal benefits of pACP experienced by parents and adolescents.14,17 Parents of severely ill children (2 months to 12 years) who were interviewed on their experiences with a pACP intervention found it helpful in ensuring the best care, providing time for discussions and decision-making, facilitating the communication of their wishes to different caregivers, and in providing peace of mind.17 A qualitative study on young patients with HIV-1 or cancer (16–28 years) reveals that the majority found it helpful to discuss and document their EOL wishes and that this made them feel more cared for as a person.14 They especially appreciated being able to make final arrangements for their death and to leave a message to their loved ones. The findings of 2 studies reveal that most children’s treatment plans met the wishes of the parents.16,17

Three studies suggest that common fears about increasing distress in patients through pACP may be unjustified.12,14,18 Young patients with HIV-1 or cancer (16–28 years) did not feel really distressed by AD discussions,14 and 79% of 107 healthy or ill adolescents (15–18 years) felt comfortable with discussing ADs.18 Adherence to pACP did not have any negative long-term effects on the self-rated psychological well-being of HIV-infected adolescents (14–21 years).12

Only 1 quantitative study investigated physicians’ perspectives on pACP.21 Forty percent of 55 physicians felt better educated in palliative care after the implementation of a pACP program.

Needs of Patients and Caregivers

A consistent finding across different studies is that up to 100% of patients and surrogates wished to get more and appropriate information and to participate in decision-making.13,15,16,19 Eighty-two percent of 76 parents of children with special health care needs (mean = 8.4 years) wanted their child to participate in decision-making.16 Eighty percent advocated written guidelines for critical life situations in their children.16

Two studies investigated the wishes of adolescents.14,18 In a quantitative study, 72% of 50 adolescent patients with various illnesses (13–21 years) preferred to have earlier discussions about EOL care in the course of their illness.19 In a qualitative study, HIV-1 and patients with cancer (16–28 years) made several suggestions regarding an appropriate AD form, including an open-ended format, issues on personal comfort at the EOL, an optional section on spiritual issues, and the possibility to designate several surrogate decision-makers.14

In 2 qualitative studies on patients with muscular dystrophy (2–37 years), the families expressed the wish for a better and more continuous support by health care professionals and school staff and for more help in communicating with the child.13,15 They felt that establishing a trusting and ongoing relationship with physicians would help in addressing difficult questions.15 They also wished to establish a good rapport with the bereavement worker before bereavement.13

Four studies reveal that there is a need to provide more information about pACP.15,16,19,22 In a sample of 76 parents of children with special health care needs (mean = 8.4 years), 79% had no understanding of ADs and 88% asked for more information on this topic.16 In another quantitative study, 44% of 50 adolescent patients (13–21 years) were uncertain if their decisions were revocable, and 26% were uncertain if their AD would be honored.19 School nurses only showed moderate knowledge about ADs.22

Perceived Problems With pACP

A major problem experienced by parents is the discomfort of emergency personnel with ADs for children, as
revealed by 2 qualitative studies. Parents also struggle with disregard from the community; they may have to face refusals by schools to accept their child's AD, as well as negative reactions from other people, and they even may have to defend their child's AD in court.

Two qualitative studies on parents of patients with muscular dystrophy (2–37 years) reveal that some families have difficulties thinking about a dismal future. Parents reported to cope with their situation by denying reality and avoiding thinking of the future and by living in the moment. Discussing medical treatment and shortened lifespan may be particularly distressing for some parents and adolescent patients. In a follow-up of an RCT, surrogates rated adolescents' emotional and school-related quality of life lower in the intervention than in the control group. In addition, levels of HIV-specific symptoms were overall low but tended to be slightly higher for intervention adolescents regarding rash and itching, fatigue, and trouble sleeping.

Only 1 quantitative study reveals problems from the perspective of professionals: just 3 of 214 school nurses expressed their opposition to ADs in schools in a free comments section; reasons for their opposition were not reported.

**DISCUSSION**

Overall, the evidence is insufficient to make definite conclusions about pACP. The data suggest that pACP can be implemented successfully. It may enhance positive emotions and facilitate communication with the patient and decision-making. Interventions are perceived as helpful by families and patients. However, patients and surrogates seem to have little understanding of pACP. Problems that persisted within pACP were the discomfort of professionals with ADs and families' reluctance to anticipate a dismal future. There are few systematic pACP programs worldwide and none in Europe. One program stems from the Respecting Choices (RC) research team in La Crosse, Wisconsin, and is rendered by the same health care service provider, whereas another has been informed by RC. The RC approach includes the following elements: (1) timely discussions about future treatment preferences, facilitated by a trained interviewer; (2) shared decision-making in line with the principles of informed consent; (3) documentation of the decisions in a significant and valid AD; (4) distribution of the AD to all relevant providers; (5) regular review of the AD; (6) formal regulations on how to complete and deal with ADs; (7) information of all care providers; and (8) training of certified facilitators and education of the medical personnel.

The pACP programs that we identified incorporate each some of those aspects. Shared elements are as follows: repeated discussions with the parents, shared decision-making, and the completion of an AD. Only 1 program comprises a curriculum for education of hospital and community providers and distributes a child's AD to all relevant community care providers. Another program is the only 1 to include certified facilitators that are trained according to the RC competency criteria. This program further uses an adaption of the RC interview for the discussions.

RC has been successfully implemented in adult patient populations in the United States and Australia, and repeatedly evaluated. Positive outcomes include a higher frequency and availability of ADs, better quality and acceptance of ADs, more respect for patient preferences at the EOL, greater satisfaction by patients and relatives, as well as reduced stress, anxiety, and depression in the bereaved. Currently, a German adaptation is being piloted in geriatric nursing homes. These experiences may inform the development of pACP. However, findings on adult ACP may not always be transferable to pediatrics, and research on pACP should focus more on the particularities of the pediatric setting. Pediatric programs need to address the young patients, the parents, and other family members, to include specific EOL issues that are important to them, to find regulations on when and how to involve the child in the discussions, to promote acceptance of ADs for children by providing special support for the care providers, and to focus particularly on psychosocial issues of EOL-planning. One study included in our review and a recently published follow-up reveal that an ACP document for adolescents with a life-threatening illness should provide some particular characteristics: developmentally appropriate wording and explanation of key concepts (eg, life support), specific questions on how one would like to be remembered by family and friends, on bequeathing belongings and donating one's body, as well as a separate page for spiritual wishes and an open page to write letters. Incorporating those findings, the performing research team has developed an adaption of the Five Wishes document, titled Voicing My Choices.
pACP, such as the reduction in adolescents’ emotional and school-related quality of life as reported by their parents, should be further investigated. However, those effects may be due to parents’ improved awareness of the adolescents’ wishes and fears. Evidence suggests that parents capture adolescents’ treatment preferences more accurately after pACP and that the intrafamily communication improves.

There are no comparative studies on the frequency of home deaths in children with and without pACP. However, the findings from 2 studies suggest that pACP may lead to a higher frequency of children dying at home. Future studies should investigate whether pACP includes discussions about the preferred place of death and whether it facilitates the care of the child at home.

A main limitation of this review is that the included studies address different patient populations, care settings, and outcomes. Also, the studies present major methodological shortcomings in their design and reporting. Only 1 RCT has been conducted but with methodological limitations. Lacking effects may be due to the small and selective sample. Most of the other studies involve convenience samples and use non-validated instruments. In qualitative studies, methods of analysis are insufficiently documented.

A core challenge to our systematic approach was that there is no concordant notion of pACP in the literature. This made it difficult to search for studies and distinguish pACP from other related or subsidiary practices such as DNR orders and shared decision-making. We may have missed articles on pACP that use notions that we did not include in our search. Also, the limitation to English, German, and French articles may have led to the missing of some European studies and thus bias our results.

Our review results are not necessarily applicable to other populations and care settings than those addressed by the included studies. Several studies focus on specific patient populations. Also, the perspective of professionals has been widely neglected. However, this may be essential for a successful implementation of pACP. Only 1 study with school nurses has been performed and reveals that there is hardly any opposition toward ADs for children. This finding seems to contradict the reports by parents that their child’s AD was not accepted by the school. However, this highlights the need for the development of school policies regarding ADs to facilitate their application.

One very new study that has been published after our search deadline addresses barriers to pACP from the perspective of physicians and nurses. The main barriers reported are unrealistic clinical expectations by parents, differences between physicians’ and patients’ or parents’ understanding of prognosis, reluctance of parents to have pACP discussions, physicians’ concerns about taking away hope, as well as their uncertainty about prognosis and about how to address the issue. In addition, 71% of physicians felt that pACP happened too late. Future research should tie in with those findings by investigating the needs of all stakeholders: patients, families, facilitators of pACP, and recipients of ADs. Finally, we do not know if the 3 American pACP approaches that we identified in our review are applicable to other cultural and social contexts. Studies on pACP in other countries are needed.

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REFERENCES


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