

3.1 ACP in Specific Populations

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Advance care planning and palliative care for homeless people in medical respite shelters: a retrospective record review

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Background: To improve advance care planning and palliative care for severely ill homeless people, insight into current practice is required. Therefore, the present study aims to describe the characteristics of people who deceased after having been homeless, the care preferred and received at the end of life, and difficulties in medical decision-making at medical respite shelters.

Methods: We conducted a quantitative and qualitative retrospective record review at two Dutch medical respite shelters. Included were the medical and nursing records of 61 homeless clients who were known to be deceased between 2009 and 2016 and had resided in one of both shelters for at least one night in the three months before death.

Results: The large majority of patients had a combination of somatic (98%), psychiatric (85%) and substance use problems (93%). Discussions about imminent death were reported for 75% of the patients for whom it was recognized. Twenty-six percent of records provided information about patients' preferred place of death, which mostly was the shelter. For 36% of patients, hospital admissions had been considered undesirable by their clinician(s). In the three months before death, 75% of patients had at least one such admission. Documented difficulties in medical decision-making mainly concerned impaired decisional capacity of patients, language barriers, and fragmentation and discontinuity of care.

Conclusion: At the end of life, homeless people suffer from multiple health-related problems that require specific expertise. They experience multiple, often undesired hospital admissions. This could be avoided by more comprehensive collaboration between psychosocial, medical, and palliative care.

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Confronting versus Comfortable: two approaches to the recruitment of people with learning disability in an Advance Care Planning study

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Background: Supporting people with learning disability to complete Advance Care Plans is relatively new and there is a lot to learn. This presentation discusses the recruitment processes and outcomes of two New Zealand based studies on this topic. The learnings from this may help us to increase the uptake of Advance Care Planning with people who have learning disabilities.

Methods: Both studies are qualitative action research projects, both attempted to recruit 10 people with learning disability. A key difference is that the initial study recruited participants who were dying (and aware of that), while the current study recruited participants who were well. Recruitment data from both projects was analysed thematically to identify commonalities and differences in processes and outcomes.

Results: Recruitment for the initial study was difficult, resulting in four participants. In contrast, recruitment for the current study was over-subscribed. Removing the need for participants to have a life-limiting condition contributed to this. In part this was because disability service staff, who sought expressions of interest for the study, were more comfortable talking about Advance Care Planning within a pro-active context.

Conclusion: Pro-active approaches to Advance Care Planning appear to be less confronting and more comfortable for disability staff. Taking a pro-active approach could increase uptake of Advance Care Planning for people with learning disability, who are clear that it is their right to plan for the end of their lives.

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The Application of SDM Regarding People with Intellectual Disabilities as part of the ACP process: a Scoping Review.

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Background: Shared decision making (SDM) is the process in which the professional caregiver and patient (or the representative) both provide input and jointly discuss and decide which treatment policy will be followed. SDM is seen as an important component of the ACP process. Little is known about SDM in people with intellectual disabilities (ID).

Aims: To provide an overview of the application of SDM in people with ID in the palliative care phase.

Methods: In this scoping review, we systematically searched in the Embase, Medline and PsychINFO databases for studies that evaluated the SDM process in people with ID in the palliative phase.

Results: Of 402 titles and abstracts, 14 full studies were included. 10 were empirical studies, 3 were opinion papers and 1 was a legal report. Papers show an increasing focus on the importance of involvement of people with ID themselves, or - if applicable - their loved ones, in making medical decisions around the end of their lives. None of the papers described SDM in the palliative care phase, and no best practices, guidelines or definitions were shown for SDM in the palliative care phase.

Conclusion: This study shows that there is no consensus-based model about what SDM regarding people with an ID should look like. General recommendations indicate that we should involve people with an ID more in the

decision-making process by providing them an appropriate environment full of support.

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'Like pearls on a string': Developing a pediatric advance care planning intervention with a step-by-step modular design

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Background: Advance care planning concepts for adults are not directly applicable to the pediatric setting. Aim of the study was to develop a specific pediatric advance care planning (pACP) intervention using a participatory approach.

Methods: Bereaved parents and healthcare professionals selected by purposeful sampling participated in two transdisciplinary workshops. In the first workshop, discussion groups identified key elements of pACP. In the second, participants organized the key elements and visualized the pACP process on a timeline. Results were systematized, translated into a modular program, and sent back to participants for validation.

Results: The structured intervention organizes pACP elements in a modular design. First steps include 1) *Preparation*: building up trustful relationships; 2) *Opening discussions*: framing the process, making participants' expectations and aims explicit.

The next modules can be arranged in accordance with participants' priorities: 3) *Focusing on the child*: quality of life, wishes and hopes; 4) *Medical topics*: emergency situations and disease-specific crises discussed in hypothetical scenarios; 5) *End of life issues*: optional.

Final steps: 6) *Concluding discussions*: validation of written documents (e.g. parental advance directives), discussion on their implementation; 7) *Implementation*: informing all relevant stakeholders.

Timing (initiation, appropriate intervals, actualization), *communication*, *documentation* (emergency and care plans, advance directives, discussion protocols), and *age-appropriate participation of children and adolescents* are transversal aspects pertaining to the whole process.

Conclusion: The developed pACP program exhibits a modular design ensuring a structured step-by-step approach as well as a personalized process aimed at meeting the highly individual needs of the child and the family.

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Pediatricians' experiences and attitudes regarding Advance Care Planning

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Background: Advance Care Planning (ACP) enables individuals together with their relatives and health care professionals to discover, discuss and document their values, preferences and goals for care.

Objective: To evaluate the involvement of pediatricians taking care of children with life-limiting conditions in ACP.

Methods: All pediatricians from six Dutch pediatric hospitals completed a survey about experiences with ACP in their most recent case of a deceased child.

Results: Of the 207 participating pediatricians (response 36%), 168 completed the questionnaire (81%), of which 86% described a case. Of these children, 53% died before the age of 5 years. ACP conversations always took place with parents, mostly about diagnosis, life expectancy, goals of care, fears and worries and code status. In 23%, ACP conversations occurred with children (age: range 2.2-17.3 years, median 11.5 years), discussing mostly joy of life, hope, diagnosis and fears and worries. 94% of pediatricians were satisfied with their conversations skills. The occurrence rate of ACP conversations was indicated as insufficient by 49%. Pediatricians stated in 60% that ACP conversations have to result in a documented code status. 37% said ACP conversations intend mainly to provide information to families. Reported barriers to ACP conversations were mostly parent-related, while facilitators concerned continuity of care and a multidisciplinary approach.

Conclusion: Pediatricians reported to have ACP conversations mainly with parents with a focus on medical issues. Insight in the perspective of the child is limited. Education on the holistic approach of ACP and on involvement of children in ACP is needed.

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Talking about life and death - using films in intercultural palliative care

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Background: The number of first generation migrants needing care in the final phase of life is growing. However, they make little use of care facilities and support, while they do need it. Care providers feel insufficiently capable to provide good care to this group.

Method: Based on research by Roukayya Oueslati (LUMC, publication pending) the Pharos short films 'Conversations about life and death' show situations from the last phase of life of a patient with a migration background and their immediate family members. The films are available in four languages at <https://www.eventure-online.com/eventure/www.pharos.nl/ingesprek>

The films show multiple perspectives and therefore every family member, including the patient can identify. Watching the films in a migrant gathering or information meeting, in a family setting, or possibly together with a care provider, provides a good opening for a conversation about the needs, fears, and wishes of a patient. The films can be viewed as a whole, or in fragments (of just a few minutes), e.g. the fragment about disclosure or about pain relief.

Results: We see that the films are conversation starters for both migrants and care providers. People are informed about supportive care and realize they can make choices.

Conclusions: Pharos wants these films to be seen by many more people and 'spreads the word'. We would love to

show the films at the congress, provide translation in English on the spot, and discuss their usefulness with the public.