

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.

OP44 '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.

OP45 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.

OP46 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