

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.

OP47

EXPERIENCES, KNOWLEDGE AND ATTITUDES OF INFORMAL CAREGIVERS REGARDING ADVANCE CARE PLANNING. A SYSTEMATIC REVIEW AND META SYNTHESIS OF QUALITATIVE STUDIES

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Background Advance Care Planning (ACP) is a communication process about a person’s preferences for treatment and care in case of physical or mental deterioration, when the person is unable to express these wishes. Trained health professionals act as facilitators and relatives may be involved. The aim of our review is to explore the experiences and attitudes of informal caregivers, and their knowledge regarding ACP.

Methods A systematic literature search was conducted (participants: informal caregivers, intervention: advance care planning; databases: MEDLINE, PsycINFO, CINAHL, Cochrane Library). Eligible studies were assessed by two independent reviewers. Quality appraisal was conducted using the Critical Appraisal Skills Programme (CASP) checklists. Thematic synthesis was applied for qualitative studies. Results from quantitative studies were associated to the meta categories of the thematic synthesis.

Results 41 studies met the inclusion criteria, of which 37 qualitative studies were included in the thematic synthesis. Major themes found were: “ACP-structures”, “Roles and Relationships”, “Perceptions of ACP”, “Caregivers’ Knowledge”, “Attitudes”. Barriers to and facilitators for ACP from the viewpoint of caregivers were described following the structure of the major themes. The importance of caregivers’ role perceptions and the mutual influence of ACP and family relationships were highlighted.

Conclusion It is widely accepted, that ACP interventions have to take caregivers’ points of view into account. Our review provides a rich description of caregivers’ experiences, knowledge, attitudes, and needs regarding ACP. The results will support the development of patient- and family-centred ACP interventions and of instruments that measure effects of these interventions in caregivers.

OP48

PLANNING AHEAD WITH HEALTHCARE: PROXIES’ NEEDS AND EXPERTS’ RECOMMENDATIONS TO SUPPORT ADVANCE CARE PLANNING IN SWITZERLAND

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Background When there is no advance care planning (ACP), relatives feel uncomfortable and ambivalent when deciding on behalf of someone who has lost decision-making capacity. The aim of this study was to understand proxies’ needs and gather experts’ views on how to improve ACP in Switzerland.

Methods We conducted 20 interviews with proxies and four with experts in the three linguistic regions of Switzerland.

Results Half of the proxies were not familiar with ACP and spoke about living wills, testaments, and financial and organizational challenges of daily care. Only four people had the opportunity to advance decisions about healthcare with their kin when s/he was diagnosed with a neurocognitive disease. Most interviewees became proxies by the circumstances and did not discuss their role further with the patient or other relatives. For most people, ACP was made difficult by caregivers not being explicit about disease progression and potential complications and proxies’ role in future decision-making. When patients were very sick but still competent, professionals tended to exclude proxies albeit decisions had huge impact not only on the patient but also on their families. Communication and coordination with professionals and money are major concerns for most interviewees, in particular parents of disabled children. Experts’ views are consistent with interviewees’ experiences.

Conclusions Recommendations to improve ACP in Switzerland include increasing awareness in both professionals and the public, improving communication and coordination between professionals, patients and their proxies, better supporting relatives in their most urgent needs, and broaching ACP when discussing ongoing care plans.

OP49

WELLBEING OF FAMILY CARERS OF PEOPLE WHO DIED OF CANCER: PRELIMINARY RESULTS OF THE ACTION ADVANCED CARE PLANNING (ACP) TRIAL

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Background Previous studies showed that family carers (FCs) who engaged in formal ACP had fewer adverse outcomes in wellbeing compared with FCs who did not. The ACTION trial is the first multicentre randomized controlled trial of ACP in six European countries. This study will report on the effect of ACP on the wellbeing of bereaved FCs.

Methods 451 questionnaires were sent to bereaved FCs 3 months after the patient participating in the trial had died; 163 were returned (response rate: 36.1%; N control= 93, N