

SESSION 7180 (SYMPOSIUM)

PALLIATIVE CARE WITH DEMENTIA AND FAMILY CAREGIVER INVOLVEMENT (A COLLABORATIVE SYMPOSIUM BETWEEN THE HOSPICE, PALLIATIVE, AND END-OF-LIFE CARE AND NURSING CARE OF OLDER ADULTS INTEREST GROUPS)

Chair: Jenny van der Steen

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This collaborative symposium offered by the Hospice, Palliative, and End-of-Life Care and Nursing Care of Older Adults Interest Groups addresses palliative care including advance care planning considerations for family caregivers and persons with dementia. Family caregivers may need information about palliative and end-of-life care that is specific to the person, the situation or the stage of dementia. This symposium shows information needs also differ by country and setting. Conversations about symptoms, and about current and end-of-life treatment preferences need support from healthcare professionals. The symposium shows results of a study on video recordings with end-of-life preferences and how, as a stand-alone, they may not inform palliative care practice, and integration of information sources for advance care planning is needed. We will also show that a question prompt list with examples of questions to encourage family caregivers to ask healthcare professionals can and should have different contents for different countries as the content reflects socio-cultural differences. In more studies, participants clearly need information on the disease trajectory and available services. Such needs go beyond need for information on pain and other symptoms, as family caregivers often appreciate opportunities for social activities for persons with dementia. A decision aid study shows that persons with dementia and family caregivers can participate in advance care planning conversations when supported by the right tools. We argue that local client participation is important when developing tools. Overall, the symposium highlights the need for tailored tools to support face-to-face conversations with all stakeholders to encourage person-centred caregiving.

DEVELOPING COUNTRY-SPECIFIC QUESTION PROMPT LISTS ABOUT DEMENTIA PALLIATIVE CARE FOR FAMILY CAREGIVERS

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We aimed to develop question prompt lists for family caregivers of nursing home residents with advanced dementia to augment advance care planning conversations. In the context of a joint European-Canadian study, we used standardized nominal group methods to create country-specific lists of questions. (Bereaved) family caregivers of persons with dementia read an information booklet about end-of-life care for people with dementia, and generated

questions to ask healthcare professionals. They also marked the most important questions from pre-selected questions from other lists. In the Netherlands, 20 participants contributed to a question prompt list of 24 questions that gravitated towards questions about terminating life and the responsibilities of physicians and family involved in decision making. In Canada, 4 participants came up with a question prompt list of 15 questions, related mostly to staff-family communication, with some the same as selected in the Netherlands. Data from the other countries will be presented too.

ME & MY WISHES VIDEOS: CONGRUENCE OF END-OF-LIFE PREFERENCES BETWEEN RESIDENTS WITH DEMENTIA, FAMILY, AND STAFF

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Me & My Wishes are person-centered videos of long term care residents (ages 65-95) living with dementia discussing their preferences for care including end-of-life (EOL) medical intervention. We evaluated the congruence of six EOL treatment preferences between the residents' personal videos, medical records (e.g. advance directive), and surveys of family (n= 49) and staff (n=37; 118 responses) knowledge of their preferences. Results were highly discordant. Treatments with the most discordance when comparing videos to comparison groups were IV fluids (medical record, 57.1%) and life support (family, 69.4%; staff, 82.2%). Residents reported EOL treatments were considered acceptable if they were temporary, would relieve suffering, or enabled a return to baseline health. These caveats may lead to discordance if they are not conveyed to family or staff. Our findings highlight the need for conversations among residents living with dementia and their caregivers to improve understanding, congruence and adherence of resident EOL preferences.

IMPACT OF PAIN AND DISCOMFORT ON THE LIVES OF COGNITIVELY IMPAIRED OLDER ADULTS AND THEIR INFORMAL CAREGIVERS

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This qualitative study explored the impact of pain and discomfort on the lives of cognitively impaired older adults and their caregivers from the caregiver perspective. Forty-three individuals of age 19+, who identified themselves as primary caregiver to a chronically or seriously ill older adult (age 50+) with cognitive impairment, such as Alzheimer's Disease and Related Dementia, were recruited at various community settings. Individual, face-to-face interviews were conducted to ask participants how they thought their care-recipient's pain and discomfort affected the care-recipient's and the caregiver's life respectively. Inductive, thematic analysis of interview transcripts revealed several key themes: compromised mobility, limited social interaction or activities, and depressive symptoms in both care-recipients and caregivers; aggravated cognitive decline in care-recipients; and poorer physical health in caregivers. Participants wanted more information on the disease trajectory and available services, particularly home-based therapies and social activities for care-recipients, which provides future program/practice implications.