AN EXPLORATORY STUDY ON THE VIEWS OF CANCER PATIENTS’ INFORMAL CAREGIVERS ABOUT ADVANCE CARE PLANNING

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Background In oncology, informal caregivers often partake in patient-medical consultations and treatment decision making, yet little is known about their views on advance care planning (ACP). Understanding what caregivers want to communicate with cancer patients and health workers, regarding advance care wishes and goals, may complement and potentially further advance the development of an appropriate ACP framework in an integrative cancer centre.

Aim To understand caregivers’ perspectives about ACP in relation to potential limitations, barriers, and facilitators of communication that may exist between patients and themselves.

Methods Constructivist approach with grounded theory design. Participants participated in either focus groups (13) or semi-structured interviews (5), assisted by the vignette technique. Qualitative inter-rater reliability was integrated.

Results Eighteen caregivers (13 female; mean 49.1 years) of 17 patients from lung (5) and gastrointestinal (12) tumour streams participated. 24 declined participation. Caregivers’ difficulties in approaching ACP can relate to information access, mismatched desires with patients for conversations, competing care roles, and its confrontational nature. Caregivers may also have a role in supporting patients through careful initiation of discussions and/or their own ‘provisional ACPs’. Many participants requested caregiver specific ACP information and recommended support to help them assist patients with ACP or their caring when patients decline ACP.

Discussion Caregivers can be conduits through which hospitals can assist oncology patients to approach ACP.

Conclusion This study supports development of an ACP framework which recognises opportunities for caregiver involvement through providing information and support which helps them to sensitively initiate ACP discussions with patients.