THE DEVELOPMENT AND VALIDATION OF A QUESTIONNAIRE TO AUDIT ADVANCE CARE PLANNING (ACP)

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ACP is an established standard of care in many settings. However, no validated tool exists to evaluate patients’ and their families’ perspectives on ACP. The purpose of this study was to develop and validate a novel questionnaire to evaluate the quantity and quality of ACP from the perspective of a patient and their family member. To develop the questionnaire, items were generated from focus groups with health care professionals and face to face interviews with hospitalised patients. This questionnaire was then piloted and evaluated by a sample of hospitalised patients who had advanced illnesses and their family members. The questionnaire was divided into 2 parts, the first part covering ACP activities before hospital admission (6 questions) and the second part relating to ‘goals of care’ discussions that occurred during hospitalisation (8 questions). 27 patients and 24 family members participated in the pilot. All respondents rated the language, clarity, fit, acceptability, and relevance as ‘fair’ to ‘excellent.’ On a 10 point scale where 1=“Not a burden at all” and 10= “Extremely burdensome,” the average (SD) burden score of patients was 2.2 (1.7) and for family members was 1.6 (0.9). Revisions to the questionnaire were made based on the feedback from respondents. We conclude that our questionnaire to evaluate key ACP practices has face and content validity. Our pilot study demonstrates the feasibility and acceptability of this evaluative approach. By auditing ACP practices, from the patient/family perspective,
practitioners may gain key insights into how to improve ACP processes in their settings.