

MEASURING PERSONAL PRESERVATION IN HEMODIALYSIS PATIENTS

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Purpose: Formulation of directions for end-of-life care is an important aspect of planning care for individuals with end-stage renal disease (ESRD). The purpose of this study is to present the results of the first two steps of the development of a tool to assess readiness of patients to participate in discussions and formulations of plans concerning end-of-life care.

Method: The first step of the development of the tool generated an item pool representative of the theory of personal preservation (Calvin, 2004). Direct quotations from patients provided guidance for the generation of 48 items representing the theory of preservation. The second step was to assess the content validity of the items using both a professional panel of four experts in end-of-life care and a patient panel of 10 persons currently being treated with hemodialysis. Both panels were asked to rate each item on two factors, relevancy and clarity, using a scale of 1-4 (one being lowest and four being highest). The professional panel was contacted by e-mail with an attached form to complete the ratings and add any comments they deemed helpful. The patient panel form was the same as that presented to the professional panel but was used by the investigator face to face during hemodialysis treatment. Discussion with the patients regarding the relevance and clarity of the items was recorded and used to further enhance understanding of issues regarding the items.

Findings: The four members of the professional panel had good agreement on the assessment of the relevance and clarity of the majority of the 48 items. Items that scored less than three were reviewed and some were reworded to address issues raised. Some of the items were not reworded, waiting for the responses of the patient panel.

Discussion: The patient panel will be completed this summer. Once the patient panel ratings are completed they will be compared with the expert panel ratings. The investigators will then review all of the items that score less than a three by either the professionals or the patients in either relevance or clarity for rewording or deletion. Since the purpose is to represent patient views, their views will take precedence over the views of the professionals.

Calvin, A. O. (2004). Haemodialysis patients and end-of-life decisions: A theory of personal preservation. *Journal of Advanced Nursing*, 46(5), 558-566.