

Using the Think Aloud Method to Evaluate Instrument Design for a New Survey of Patient Engagement with Advance Care Planning (ACP): Behaviours in Advance Care Planning and ACTIONS Survey (BACPACS)



Aliya Kassam, PhD, Assistant Professor, Department of Community Health Sciences, Cumming School of Medicine, University of Calgary

Shannon Cunningham*, PhD, Technology Evaluation in the Elderly Network Fellow, Department of Medicine

Maureen L. Douglas*, BA LLB, Senior Project Coordinator, Advance Care Planning CRIO Program

Konrad Fassbender*, PhD, Scientific Director, Covenant Health Palliative Institute & Assistant Professor, Palliative Care Medicine

Jessica Simon, MD, FRCPC, Palliative Consult Team, Alberta Health Services, Calgary

Sara Davison*, Professor of Medicine, Division of Nephrology & Immunology

*University of Alberta

Aliya Kassam

kassama@ucalgary.ca

ACP: Advance Care Planning
GCD: Goals of Care Designation

ABSTRACT

Background: Various survey design problems may introduce error and hinder the measurement of patient engagement with Advance Care Planning (ACP). The think aloud method allows for clarification of instructions, constructs, items, survey logic and flow.

Aim: To apply the use of “think aloud methods” to detect design issues in a new survey developed to measure patient engagement with ACP.

Methods: Patients with chronic diseases related to renal function (n=4), cardiac function (n=3), and cancer (n=7), as well as healthier patients at family practice clinics (n=7) were recruited to “think out loud” when completing a new survey evaluating patient engagement with ACP. Survey modes included hardcopy or electronic using an iPad. Think aloud interviews were audio-recorded and analyzed using the constant comparison method. Three reviewers independently listened to the interviews, summarized findings and discussed discrepancies until consensus was achieved.

Results: Two rounds of interviews were needed until saturation for patient clarity was achieved. We found issues related to constructs, response options, instructions and language pertaining to patient engagement in ACP. Most patients were aware of ACP in the legal domain as opposed to the healthcare domain. Those with chronic diseases were likely to have an ACP agent.

Discussion: The think aloud method was useful in refining the new survey instrument entitled Behaviours in Advance Care Planning and ACTIONS Survey (BACPACS). It also revealed patient confusion about the documents used in Alberta to record ACP decisions while raising patient awareness. The findings will help establish the validity of the new survey.

Conclusion: This method was useful for instrument design while also providing information about how patients engage with ACP.

OBJECTIVES

The objectives of the study were as followed:

1. To explain our decision to refine an existing tool
2. To describe the process of establishing a validity argument
3. To outline what we have done so far to establish validity
4. To conduct our think aloud study

RATIONALE

An ACP CRIO randomized controlled trial is taking place to examine the effectiveness of Alberta Health Services' ACP and GCD videos. There was a need for a valid, reliable and **feasible** tool. The primary outcome was participants' ACP level of engagement and GCD preferences. Our original plan was use PREPARE survey (116 items). After participating in a pilot test of the feasibility of the tool with the national iDecide study team however, existing tools did not meet the objectives for the trial and/ or had too many items.

METHOD

- Concurrent think-aloud study without the use of specific probes
- Audio-recorded
- Collect data from chronic disease population and family practice clinic, aged 50+
- Collect data until saturation
- 3 reviewers (in addition to interviewer or including interviewer)
- Listen to interviews and ask whether they understood question and whether they could respond

RESULTS

Two rounds of data collection led to the recruitment of 21 patients. We ensured all possible branching was achieved throughout the BACPACS (i.e. people with and without an agent).

Components of a Validity Argument	Evidence to date for BACPACS
Content Evidence	• Use of existing survey (PREPARE survey), item reduction based on conversation analysis, key content expert review and refinement of items
Response Process Evidence	• Think aloud study
Internal Structure Evidence	• To be determined from randomized controlled trial data
Relations with Other Variables	• To be determined from randomized controlled trial data
Consequences Evidence	• To be determined from randomized controlled trial data

RESULTS

- Issues related to constructs, response options, instructions and language pertaining to patient engagement in ACP were brought out by the think aloud process.
- Most patients were aware of ACP in the legal domain as opposed to the healthcare domain.
- Those with chronic diseases were likely to have an ACP agent.
- The administration of the BACPACS was feasible using an electronic device such as an iPad.

Results of the Think Aloud Study using the BACPACS	Examples
Issues related to constructs	Most patients had heard of legal documents with respect to ACP but not a health care document. The majority of patients also would not have thought about talking to a health care provider. Most patients had never seen GCD form.
Issues related to response options	When patients were asked YES/NO questions that required elaboration, the survey was changed to have them answer YES/NO first and then elaborate on their choice rather than elaborating with their YES/NO answer.
Issues related to instructions	Many patients did not know what resuscitative care meant. In the instructions for the Type of Medical Care section of questions, a detailed definition of resuscitative care was provided.
Issues related to language	The concept of a legal document such as a <i>Personal Directive</i> was separated from the concept of a <i>Goals of Care Designation</i> form. Most patients only thought of ACP with respect to legal documents.

CONCLUSIONS

The think-aloud method was useful in refining the BACPACS. It revealed patient confusion about the documents used in Alberta to record ACP decisions while raising patient awareness. These findings will help establish a preliminary validity argument for the BACPACS. Future research directions include collecting psychometric data to establish validity evidence for the internal structure, relations with other variables and consequences evidence for the BACPACS. The idea that completing the BACPACS itself led participants to think about ACP and GCD also warrants further investigation of it as a tool that may aid in decision making for ACP and GCD.