Using the Think Aloud Method to Evaluate Instrument Design for a New Survey of Patient Engagement with Advance Care Planning (ACP)

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Acronyms

- ACP – Advanced Care Planning
- GCD – Goals of Care Designation

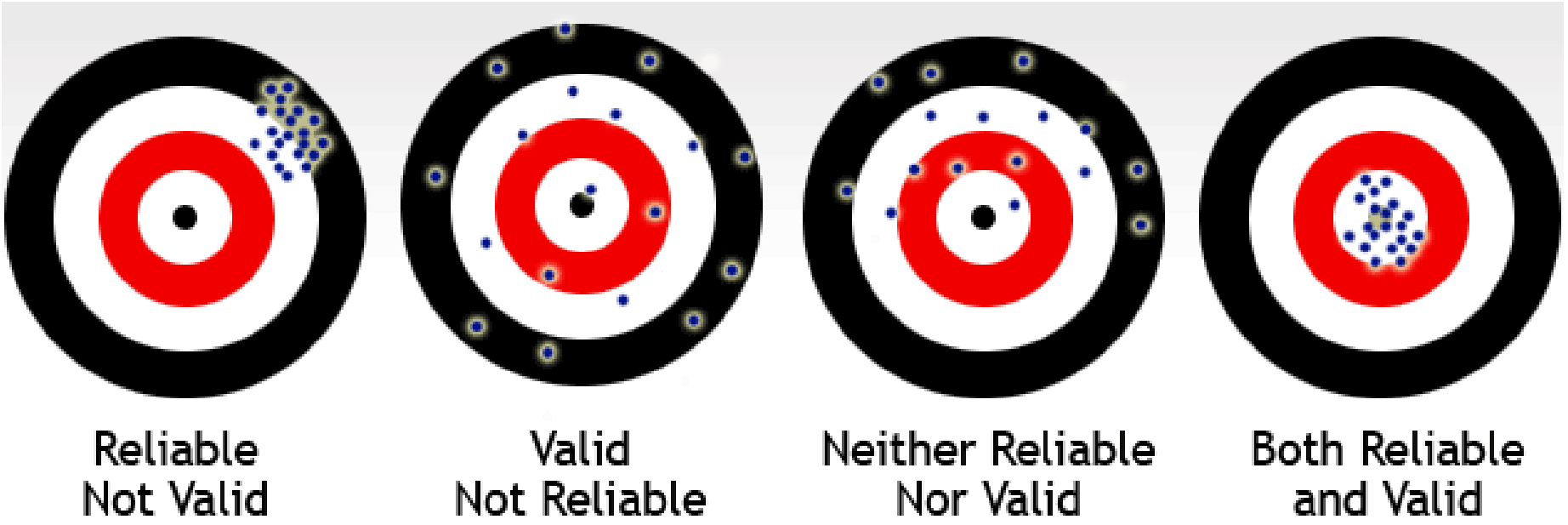
Context

- ACP has been re-conceived to include a range of behaviours beyond completing an advance directive, such as conversations with physicians and family.
- ACP interventions must be tailored to the readiness of the individual.
- ACP should be conceptualized as a health behaviour
- Behaviour change theories provide the framework for analysis and measurement development.

Advanced Care Planning

- An ACP CRIO randomized controlled trial will examine the effectiveness of Alberta Health Services' ACP and GCD videos
- Primary outcome will be participants' ACP level of engagement and GCD preferences
- Original plan was use PREPARE survey (116 items)
- Need for a valid, reliable and **feasible** tool

Reliability vs. Validity



Objectives

- To describe current tools used to measure ACP engagement
- To explain our decision to refine an existing tool
- To describe the process of establishing a validity argument
- To outline what we have done so far to establish validity
- To present the results of our think aloud study

Current tools used to measure ACP engagement

Literature review

- To date, there are four tools that have been developed that measure the broader range of ACP behaviours

Literature review cont.

- Sudore et al., 2013 developed PREPARE tool has been pilot tested (n=50) and evaluated for internal consistency and test-retest reliability.
- Fried et al., 2009, 2012 developed two tools measuring ACP participation:
  - the first measures stages of change;
  - the second measures decisional balance, ACP values/beliefs and processes of change.
  - These two surveys have been validated.
  - The validated versions of the decisional balance, ACP values/belief and processes of change scales contains 12, 7 and 15 items, respectively.
- Foti et al., REAP (Readiness to Engage in Advance Care Planning) was developed and copyrighted by Dr. Mary Ellen Foti of the Massachusetts Medical School.
  - There are no publications describing this tool's development and validation.
  - Asks about the multiple components of ACP (communication with surrogates and physicians, and completion of advance directives) in a single item.

Key authors: Measuring Patient Engagement for ACP

- Dr. Terri Fried
- Dr. Rebecca Sudore

Work based on trans-theoretical model (TTM) or "Stages of Change" model

Trans-theoretical Model

- Fried's survey uses stages of change scale:
  - pre-contemplation (no intention to change in the near future),
  - contemplation (thinking about changing in the near future),
  - preparation (commitment to changing the behaviour soon),
  - action (a recent change in behaviour)
  - maintenance (ongoing behaviour change)

Fried et al. 2009, 2012

- Fried subsequently developed and validated measures of the additional TTM constructs:
  - decisional balance
  - processes of change
- Decisional balance takes into account an individual's weighing of the pros and cons of changing their behaviours. It assesses patient's attitudes about common barriers to and facilitators of behaviour change.
- Process of change, measures overt and covert activities, or strategies, that people use to progress through the stages of change.

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PLOS ONE

Development and Validation of a Questionnaire to Detect Behavior Change in Multiple Advance Care Planning Behaviors

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Abstract

Introduction: Advance directives have traditionally been considered the gold standard for advance care planning. However, recent evidence suggests that advance care planning involves a series of multiple discrete behaviors for which people are in varying stages of behavior change. The goal of our study was to develop and validate a survey to measure the full advance care planning process.

Methods: The Advance Care Planning Engagement Survey assesses "Process Measures" of factors known from Behavior Change Theory to affect behavior (knowledge, contemplation, self-efficacy, and readiness, using 5-point Likert scales) and "Action Measures" (yes/no) of multiple behaviors related to surrogate decision makers, values and quality of life, flexibility for surrogate decision making, and informed decision making. We administered surveys at baseline and 1 week later to 50 diverse, older adults from San Francisco hospitals. Internal consistency reliability of Process Measures was assessed using Cronbach's alpha (only continuous variables) and test-retest reliability of Process and Action Measures was examined using intraclass correlations. For discriminant validity, we compared Process and Action Measure scores between this cohort and 20 healthy college students (mean age 23.2 years, SD 2.7).

Results: Mean age was 69.3 (SD 10.5) and 42% were non-White. The survey took a mean of 21.4 minutes ($\pm$6.2) to administer. The survey had good internal consistency (Process Measures Cronbach's alpha, 0.94) and test-retest reliability (Process Measures intraclass correlation, 0.70; Action Measures, 0.87). Both Process and Action Measure scores were higher in the older than younger group, $p<.001$.

Conclusion: A new Advance Care Planning Engagement Survey that measures behavior change (knowledge, contemplation, self-efficacy, and readiness) and multiple advance care planning actions demonstrates good reliability and validity. Further research is needed to assess whether survey scores improve in response to advance care planning interventions and whether scores are associated with receipt of care consistent with one's wishes.

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Differing views…..

- Prior to the Sudore et al., 2013 publication, Fried observed that Sudore had treated the behaviours as linear – meaning patients move in a predictable sequence from one behaviour to another.
- Fried claimed Sudore had focussed on stages of change measures and had not developed measures for the other TTM constructs of decisional balance, ACP values/beliefs and process of change.
- Sudore clearly includes some processes of change and attitudes (relating to quality of life)
- Sudore's tool measures self-efficacy whereas Fried's does not.

Our decision to refine an existing tool

Our decision to refine an existing tool

- Participating in a pilot test of the feasibility of the tool with the national iDecide study team
- Collecting data from 150 participants in collaboration with Rebecca Sudore
- Rebecca's tool more thorough than Fried's
- But too long!!!!!! (116 items)

The process of establishing a validity argument

The process of establishing a validity argument

- Previous classical framework for determining validity identifies 3 distinct types:
  - content, criterion, and construct validity,
  - reliability is considered a psychometric property of its own.

- Since 1999 a more cohesive and unified framework proposed adopted by the American Educational Research Association (AERA), American Psychological Association (APA), and the National Council on Measurement in Education (NCME) as a field standard

Validity framework

- All forms of validity are considered to be construct validity, and evidence for the presence of construct validity is collected from five different sources

Construct validity re-visited

- The degree to which inferences can be made appropriately from observations or measurements;
- If the question or test measures what it is supposed to as defined by the construct

Validity framework: 5 Sources of evidence

1. Content evidence
2. Response process evidence
3. Internal structure evidence
4. Relations with other variables evidence
5. Consequences evidence

1. *Content evidence*

- A series of measures taken to examine if the assessment content are representative of the intended measurement construct.
- This may consist of: formulation based on prior instruments, seeking expert review, or utilizing an assessment framework.

2. *Response process evidence*

- Evaluation of how well the responses or raters actions relate with the intended measurement construct.

- This includes: assessment security, quality control, and the analysis of the respondents' thoughts and/or actions during assessment completion

3. *Internal structure evidence*

- Evaluation of how well assessment items align with the overall construct.
- This should include a measure of reliability across items or raters, but also may include item analysis or factor analysis

4. *Relations with other variables evidence*

- Statistical associations between the assessment rating and other measures or features that could influence or have a relationship.

- This can include: Correlations, analysis of variances (ANOVA), t-tests to reveal significant differences between variable means

5. *Consequences evidence*

- The result (beneficial or harmful) of the assessment, and the subsequent decisions or actions.
- This includes what distinguishes or influences such outcomes.

What we have done so far to establish validity

What we have done so far to establish validity

- Content evidence – use of existing survey, item reduction based on conversation analysis, key content expert review
- Response process evidence – Think Aloud study

- Other sources of validity evidence to come from RCT data collection

Content Evidence – Part 1

- The question groups in each section of the PREPARE survey (Sudore et al., 2013) are sequentially organized with the assumption that respondents have *not* engaged in any components of ACP
- That is, respondents are asked in all four sections about their (1) *thoughts* about, (2) *confidence* level doing (i.e., self-efficacy), (3) *readiness* to do, and (4) *actions* taken.
- Specifically, if a respondent has not *thought* about an element of the process, (s)he is still asked to answer irrelevant questions about *confidence* level, *readiness* and *actions*.
- Likewise, respondents who have taken action must answer a series of questions regarding their *thoughts*, *confidence* level and *readiness* to take action before they are able to declare their *action*.

Content Evidence – Part 1

- Enquire about the *action* first and then work backwards towards *confidence* level, *readiness* and *thoughts* if the prior element has not been done).
- Respondents who indicate a higher level involvement in a component of ACP are not asked about lower levels of involvement.
- Allows respondents to indicate at which point they are in the process without expecting them to answer redundant questions.
- Structural and sequence organizational modifications reduced the questions asked from 116 (PREPARE survey) to a range of 24-38 questions.
- The revised version of the ACP survey contains branching logic.
- In most cases, answering 'yes' resulted in more follow up questions than answering 'no.'

Content Evidence – Part 2

- Information from pilot for national study (iDecide) and item reduction to inform key content expert review
- Refinement of items in terms of words
- High level

Response process evidence - Think Aloud Study

- Quality assurance
- Tool to support usability testing
- Feasibility with iPads

Types of think-aloud techniques

- Two basic types of think-aloud: the
  - concurrent think-aloud in which participants verbalize their thoughts during task execution
  - retrospective think-aloud in which participants do so after task completion

Relaxed vs. interactive think-aloud

- Relaxed – no probes or intervention
- Interactive – use of probes
  - evaluator probes may be a significant threat to the validity and reliability of the resulting data

Our think-aloud 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 of the think-aloud study

Results of the think-aloud study

- 2 rounds of data collection
  - renal function (n=4)
  - cardiac function (n=3)
  - cancer (n=7)
  - family practice clinics (n=7)
- Ensured branching was achieved (people without an agent)

Results cont.

- 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.

Results – issues with construct

- ACP vs. legal documents
- Talking to a health care provider
- Most had never seen GCD form

Results – issues with instructions

- ***WHAT TYPE OF MEDICAL TREATMENT YOU WANT***

Some people know that if they are very sick, seriously injured, or near the end of their life, they would or would not want specific medical treatments. For example, some people know they would WANT resuscitative care.

"Resuscitative care" means intensive or aggressive treatments to keep a person alive as long as possible. This could include being treated in the intensive care unit and having machines to aid their breathing, having doctors push on their chest or administer shocks to restart their heart, and all life-sustaining machines and treatments deemed appropriate by a doctor.

Results - issues with response options

Have you talked with a healthcare provider about whom you have picked to be your agent?

_____Yes, we had a very detailed talk
_____Yes, but we had just a general talk
_____Yes, but we only talked briefly
_____ No, I think they know my wishes
_____ No, I am not ready to do that yet
_____ No, I am planning on doing that at some point
_____ No, I am definitely going to do that at my next healthcare visit
_____ No, I am not going to do that

Results – issues with response options

Have you talked with a healthcare provider about whom you have picked to be your agent?

Yes ___ No ___

- Please elaborate on your 'Yes' answer:
  - _____Yes, we had a very detailed talk
  - _____Yes, but we had just a general talk that lacked detail
  - _____ No, I think the healthcare provider knows my wishes

- Please elaborate on your 'No' answer:
  - _____ No, I have never thought about that
  - _____ No, I think the healthcare provider knows my wishes
  - _____ No, I am not ready to do that yet
  - _____ No, I am planning on doing that at some point
  - _____ No, I am definitely going to do that at my next healthcare visit
  - _____ No, I am not going to do that

Results - language pertaining to patient engagement in ACP

- "There are documents that you may ask your lawyer to prepare either to deal with your property and finances (for example, your Will or an Enduring Power of Attorney) or your health care preferences (called a Personal Directive). This is an example of a Personal Directive. A Personal Directive may also be downloaded by you from the Government of Alberta website.

- There is also a document that you may discuss with your health care provider that deals with the general aims of your healthcare, the kind of treatments that might be used and the preferred location of that care. This is called a "Goals of Care Designation form". This is the Goals of Care Designation form. It is a medical order signed by a doctor or nurse practitioner after talking with you."

- Separated these concepts above

Discussion

- Think-aloud method is useful in refining the survey instrument.
- Revealed patient confusion about the documents used in Alberta to record ACP decisions while raising patient awareness.
- These findings will help establish the validity of the new survey.

Conclusions

- This method was useful for instrument design while also providing information about how patients engage with ACP.
- Going through the survey may get people engaged in thinking about ACP.

Thank you!

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