

Every time that month comes, I remember.

Using cognitive interviews to adapt grief measures for use with bereaved adolescents in South Africa

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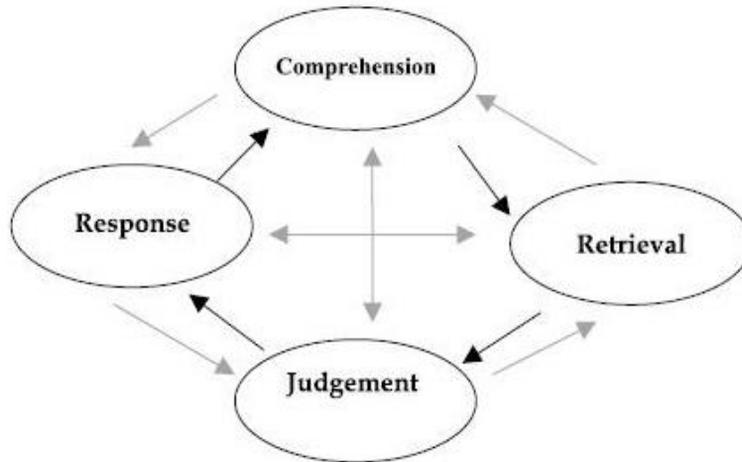


Background

- Social psychology in survey design
- What is cognitive interviewing?
- Orphanhood in South Africa
- Measuring grief related to a loss



How do survey questions work?



Source: Collins, D. (2003). Pretesting survey instruments: an overview of cognitive methods. *Quality of life research*, 12(3), 229-238.

Cognitive interviewing

- ❑ Cognitive interviewing is a qualitative research method derived from social psychology
- ❑ Used as part of survey pre-testing, it is a cost-effective way to identify issues compromising question validity, reliability and acceptability
- ❑ Participants discuss how they think and feel about candidate survey questions, either via “thinking aloud” or in response to focused probes

Sample verbal probes

- **Comprehension:** “What does the phrase ‘to pine for’ mean to you?”
- **Paraphrasing:** “Can you repeat the question for me in your own words?”
- **Confidence judgement:** “How sure are you that 2009 is the year your father passed away?”
- **Recall:** “Can you tell me how you remember that you thought about your mother five times in the past four weeks?”

Orphanhood in South Africa

- Around 3.7 million children in South Africa are orphans; half have lost a parent to AIDS
- From 2002 to 2006 the number of double orphans grew from 360,000 to 660,000
- Orphans are at increased risk for psychological problems that may include problematic grief, depression, anxiety, and post-traumatic stress disorder
- Psychological support for orphans and vulnerable children is a PEPFAR priority; a number of programs are already developing or providing these services

Measuring grief

- ❑ Self-reported measures of grief have been in use by psychologists and researchers for decades
- ❑ No current consensus on best scale or set of measures, or on what constitutes problematic grief
- ❑ Most instruments have been developed and validated in Western contexts, calling their cross-cultural applicability into question

Methods and materials

- The study population
- Instruments tested
- The cognitive interview process



Study population

- We worked with Child Welfare Bloemfontein & Childline Free State to recruit former participants in school-based bereavement support groups
- Twenty-one Sesotho-speaking adolescents ages 14-17 from two urban (Bloemfontein) and two rural (Ficksburg) sites took part in cognitive interviews over a two-week period

Instruments tested

- Participants completed a cognitive interview focused on one of three standard instruments:
 - Core Bereavement Items questionnaire (CBI)
 - Grief Cognitions Questionnaire for Children (GCQ-C)
 - Intrusive Grief Thoughts Scale (IGTS)
- Instruments were translated into Sesotho by two different translators, then back-translated by a third to verify accuracy

The interview process

- Interviews were conducted individually in classroom and office spaces with visual and auditory privacy
- Each interview lasted approximately 30 minutes and was digitally audio-recorded with the participant's consent
- The interviewer was a multilingual, native Sesotho speaker with training and experience in education, psychology and qualitative research methods

Study results

- Reactions to the cognitive interview process
- Lexical issues
- Manifestations of grief



Participant reactions

- Many Sesotho-speaking adolescents had trouble completing an interview exclusively in Sesotho
- Participants required frequent prompting to elaborate on their thought processes
- Long and/or multi-part questions were especially challenging for interviewees to discuss
- Sensitive subject matter and in-depth questioning posed a high emotional burden for some

Lexical issues

- Meaning distinctions were sometimes lost. *Distressed* was understood to mean *depressed*; respondents could not distinguish *remembering* from *missing*
- Interviewees had trouble using non-specific response categories like *a lot of the time* and *hardly ever*
- Clear preferences existed for particular language around loss (e.g. “passed away” instead of “died”)

Manifestations of grief

- Respondents identified “the loss that affected [them] the most” as the one with the greatest influence on their basic survival, not emotional health
- Some questions that reflected a sense of guilt or responsibility about the loss seemed irrelevant to participants’ experience
- Adolescents expressed that thinking often about a deceased loved one is an important sign of respect, highlighting the potential for social desirability bias

Lessons learned

- Cross-cultural cognitive interviewing
- The polyglot research environment
- Implications for evaluation
- Implications for programs



Cross-cultural cognitive interviewing

- Cognitive interviewees in cross-cultural settings may require more extensive orientation and practice to increase their fluency and comfort level
- Future research could also help identify the kinds of interview protocols and probes that work best with adolescent populations in African contexts

The polyglot research environment

- Environments where multilingualism is entrenched pose additional implementation challenges
- Instrument translation into several languages, and allowing respondents to use their language(s) of choice in cognitive interviews, may be advisable
- Findings can be used by researchers to make decisions about language use in the eventual survey

Implications for evaluation

- Standard grief measures should be understood to reflect concerns about basic survival among orphaned and vulnerable children
- Questions should be shortened and simplified for use with this population; response options should be specific
- Grief cognitions may be overreported due to social desirability, potentially requiring adjustment to thresholds for this scale

Implications for programs

- Improving tools to measure grief and other psychological consequences of loss can help programs target services to those most in need
- Findings from cognitive interviews can also promote preferred language for program materials, offer new insights about working with adolescents, etc.

“Future interventions might focus on provision for mental health support for children around grief and loss and providing systematic tools and measurement to improve the evidence base.”

Sherr & Mueller. (2008). *Where is the evidence base? Mental health issues surrounding bereavement and HIV in children.*

OUR THANKS TO:

- Anita Sampson and Naletsana Masango of USAID Southern Africa
- Emma Francis, Busisiwe Madikizela and William Gombe at Child Welfare Bloemfontein & Childline Free State
- Hannietjie and Marcus Sapire at the Bangula Lingo Centre
- The guardians who allowed us to learn from the adolescents in their care
- The participants who generously shared their insights with us

Support for this project is provided by USAID Southern Africa under the President's Emergency Plan for AIDS Relief (PEPFAR) through a Cooperative Agreement [AID-674-A-12-00002] awarded to Tulane University. The views expressed in this document do not necessarily reflect those of USAID or the United States government.

