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Agenda

1. Introduction to the measurement of burden
2. Origins and definition of burden: The Zarit Burden Interview (ZBI)
3. Burden and the stress process
4. Uses of the ZBI
5. Issues in the measurement of burden
6. Discussion and conclusions
Key Discussion Points

1. Caregivers’ subjective feelings of burden are critical for understanding their circumstances and decisions.

2. Burden has been defined in many different ways. Using models of stress can clarify the meaning of burden measures and lead to better choices of measures.

3. The Zarit Burden Interview (ZBI) has been widely used internationally for a variety of research purposes.

4. The psychometric properties of the ZBI are sound but like any measure it is important to understand the ZBI’s limitations.

5. The ZBI represents a good choice for measurement of subjective burden.
Introduction to the measurement of burden

- The critical role of the caregiver in health care and long-term care
- The Zarit Burden Interview (ZBI) of caregivers’ subjective burden
  - Widely used – over 350 pub med articles
  - Used internationally: Over 100 translations
  - Good acceptability and psychometrics
Introduction to the measurement of burden

- Uses of the ZBI
  - Screening
  - Comparison of populations
    - International comparisons
  - Treatment planning
  - Predicting care outcomes
  - Treatment outcomes
  - Use with multiple caregiver populations
  - 22 Item ZBI and 12 Item ZBI
Origins and definition of burden

- Burden as the *subjective* experience of the demands placed on the caregiver and the *subjective* response to how those demands affect different areas of the caregiver’s life (family, leisure & social activities)
- The caregiver’s subjective experience is critical to the course of care
- Early work:
  - Grad & Sainsbury, 1963; 1968
  - Lowenthal & Berkman, 1968
  - Pasamanick & colleagues, 1967
Origins and definition of burden

- Development of the ZBI
- Burden as the *subjective* experience of the *demands* placed on the caregiver
- and the *subjective* response to how those demands affect different areas of the caregiver’s life (family, leisure & social activities)
  - Making life difficult or unbearable in some way
- Differences between a subjective and objective measure
Other definitions of burden

- Multiple definitions and measures of burden
- Clarifying the meaning of burden using models of the stress process (Pearlin et al., 1990; Aneshensel et al., 1995)
- Choosing the right measure for your research purposes
Objective and Subjective Stressors

Objective Stressors → Subjective Stressors
Objective and Subjective Stressors

- Objective (illness) vs. subjective burden
  - Illness severity and symptoms
  - Why symptoms are important?
  - Why symptoms do not replace subjective burden
    - Variable responses to symptoms
    - Symptoms are not always the most important stressor
Subjective Stressors: Appraisals and Impact on One’s Life

- Stressor Appraisals
  - Primary Subjective Stressors
  - Secondary Subjective Stressors

- Objective Stressors
Subjective Stressors: Appraisals and Impact on One’s Life

- Primary appraisals (Lazarus & Folkman, 1984)
  - Examples: Behavior problems
- Uses: Which problems are experienced as most stressful
- Limitations: Behavior problems as only part of the impact on the caregiver’s life
Subjective Burden from a Stress Perspective

Objective Stressors -> Stressor Appraisals

- Burden Subjective Exp. Of Demands
- Burden Subjective Exp. On One’s Life

ZBI
Relation of Burden to Emotional Distress

Stressor Appraisals

Objective Stressors

Burden Subjective Exp. Of Demands

Burden Subjective Exp. On One’s Life

Distress and health
Understanding Limitations of the ZBI

- Cut-off scores
  - Different populations
  - What criteria for cut-off? (Arai, 2014; in progress; Rankin et al., 1994)
Reliability and Factor Structure

- High internal reliability has been reported consistently
- Factor structure has varied across populations (Knight at al., 2000; Longmire & Knight, 2011)
  - International and within country differences
  - Differences in caregiver samples
ZBI as a Treatment Outcome Measure

- Caregiving samples vary in initial levels of burden
- Burden can be lowered only if it is high in the first place
  - Select people with high burden
  - (initial burden x treatment interaction)
- Initial burden as a moderator of treatment effects (Mausbach et al., 2011)
How to Access the ZBI

- Centralization of information and translations
- Licensing process
- Distribution
- Coordination of new translations

handled by Mapi Research Trust on behalf of Dr Zarit
ZBI: Conditions of Use

- Conditions of use available and detailed on PROQOLID via our ePROVIDE platform (https://eprovide.mapi-trust.org)

- Process:
  - Signature of a User Agreement for each study
  - Free access for Non-Funded Academic Users:
    - Easy and quick access to the ZBI for Non-Funded Academic Users via Online Distribution process on PROQOLID
  - Payment of access fees if the ZBI is used in:
    - Funded academic research
    - Commercial studies
  - When the process is completed, Mapi Research Trust delivers:
    - Needed language versions (if available)
    - Scoring instructions
ZBI: Available Language Versions

- Original language of development:
  - English (USA)

- More than 100 translations available, following a specific linguistic validation methodology
## ZBI-22: Available Language Versions

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* translation produced by Mapi
## ZBI-12: Available Language Versions

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Translations: Linguistic Validation Methodology

- **Objective:** Obtain translations that are:
  - Faithful to the concepts in the original measure
  - Suitable to the linguistic and cultural context of the target country
  - Easy to understand for respondents
  - Suitable for use in the context of international studies with pooling and/or comparison of data

- **Methodology:**
  - Conceptual definition
  - Forward translation step (2 forward translations, reconciliation)
  - Backward translation step including review of documentation by Pr. Zarit
  - Review by in-country clinician
  - Cognitive interviews with caregivers of patients
  - Proofreading & finalisation
  
  Conducted in close collaboration with Pr. Zarit.
Challenges in Translating the ZBI-22

- Description of caregiver’s **feelings & emotions**
  - One of the greatest challenges in translating questionnaires, much more difficult than e.g. daily functioning

- Example:
  - ‘Do you feel **stressed**’ (item 3)
  - ‘Do you feel **embarrassed**’ (item 4)
  - ‘Do you feel **angry**’ (item 5)
  - ‘Do you feel **strained**’ (item 9)
  - ‘Do you feel **uncomfortable**’ (item 13)

  Same semantic field for all 5 adjectives
  But have to be differentiated: each carries a specific dimension not present in the others.
  Difficulty in finding the exact equivalent of each adjective in some languages

- ‘Are you **afraid** of what the future holds for your relative?’ (Item 7)
  - ‘Afraid’ translated as ‘concerned’ or ‘worried’ in many languages vs. a direct translation of ‘afraid’
Challenges in Translating the ZBI-22

- Translation issues encountered were mostly **semantic**
  - ‘Are you afraid of **what the future holds** for your relative?’ (Item 7)
    - ‘Of what the future holds’ wouldn’t have worked well if directly translated and was therefore simplified to ‘about your relative’s future’ in some languages
  - ‘Do you feel uncomfortable about **having friends over**, because of your relative?’ (Item 13)
    - For ‘having friends over’, translations used ‘receiving friends’, ‘receiving visits from friends’, ‘inviting friends’, ‘inviting friends’, ‘asking friends to come’ etc.
  - ‘Do you feel you have **lost control of your life** since your relative’s illness?’ (Item 17)
    - For ‘Lost control of your life’ a direct translation was possible in many languages, but in some variations had to be used like ‘you do not have your life under control’, ‘you do not have control over your life’, ‘you can no longer control your life as well’,
Translating the ZBI-22: Conclusions

- No cultural issues were identified during linguistic validation

- Pr. Zarit’s input in providing conceptual definitions & clarifications has been essential in ensuring appropriate decisions were made for translations.

- Cognitive interviews with caregivers in the countries have been crucial in the development of translations:
  - To ensure items were understood as intended
  - And to help solving some of the translation issues.
Conclusion
Key Takeaways

- Burden is best viewed as the subjective experience of caregivers.
- Burden has implications for the caregiver’s health and well-being and ability to continue providing care.
- The ZBI represents a useful tool for measures subjective burden.
- The ZBI is available in 71 validated translations.
- The dimensions of the ZBI can be understood from the perspective of stress theory.
Thank You!

Additional Questions? Ask our Webinar Host(s) directly!

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Grad, J., & Sainsbury, P. (1968). The effects that patients have on their families in a community care and a control psychiatric service: A two year follow-up. *British Journal of Psychiatry, 114*, 265-278.


Selected References


Selected References


