Measures on Dementia Caregiving

Much literature has been written on the positive and negative aspects of being a family caregiver. The negative aspects of caregiving have been likened to the consequences of being exposed to long-term and chronic stressors, which compromise caregivers' physical, psychological and emotional health and well-being, family relationships, work and financial status.[1-3] At the same time, some caregivers have also reported positive outcomes, such as enhanced self-confidence, personal growth, improved relationships with care recipients and families, and increased meaning and purpose in life.[4,5]

Approximately a hundred tools have been developed to measure various negative and positive aspects of caregiving (such as caregiving burden and strains, their physical health, emotional health, life satisfaction/quality of life, social isolation, willingness to assume care, etc.), and have been used on various populations and settings. While most of these instruments measure caregiving in general, a number of disease-specific instruments have been tested on caregivers of persons with Alzheimer's disease or dementia. The majority of the caregiving instruments focus on either the negative aspects, or both the positive and negative aspects; some examples include the widely-used Zarit Burden Interview[6] and Caregiver Burden Inventory[7] which both measure caregivers' levels of perceived stress and screen for burden and strain. Some tools measure only the benefits of caregiving, such as satisfaction from assisting care recipients and developing new skills/competencies. Two examples of these tools are the Positive Aspects of Caregiving Instrument[8] and the Picot Caregiver Rewards Scale[9].

List of Systematic Reviews on Existing Caregiving Tools

Organisations and researchers have created summaries of existing caregiving tools and conducted systematic reviews which compare their psychometric properties and feasibility respectively. These instruments have been administered on various populations (caregivers of care recipients with different medical conditions) and settings. Please refer to the following articles to read the summaries and systematic reviews of the caregiving tools in detail:

1. Center for Gerontology and Health Care Research, Brown Medical School. (2004). *TIME: Toolkit of instruments to measure end-of-life care.* http://www.chcr.brown.edu/PCOC/familyburden.htm#Disease-specific%20instruments
2. Deeken, J. F., Taylor, K. L., Mangan, P., Yabroff, K. R., & Ingham, J. M. (2003). Care for the caregivers: A review of self-report instruments developed to measure the burden, needs, and quality of life of informal caregivers. *Journal of Pain and Symptom Management, 26*(4), 922-953. https://doi.org/10.1016/S0885-3924(03)00327-0
3. Dow, J., Robinson, J., Robalino, S., Finch, T., McColl, E., & Robinson, L. (2018). How best to assess quality of life in informal carers of people with dementia; A systematic review of existing outcome measures. *PLoSONE 13*(3), 1-18. https://doi.org/10.1371/journal.pone.0193398
4. Family Caregiver Alliance. (2012, December 10). *Selected caregiver assessment measures: A resource inventory for practitioners (2012).* https://www.caregiver.org/sites/caregiver.org/files/pdfs/SelCGAssmtMeas_ResInv_FINAL_12.10.12.pdf
5. Michigan Dementia Coalition. (2009). *Introduction to Caregiver Assessment Tool Grid.* http://www.rosalynncarter.org/wp-content/uploads/2019/05/Michigan-Assessment-Grid.pdf
6. Van Durme, T., Macq, J., Jeanmart, C., & Gobert, M. (2012). Tools for measuring the impact of informal caregiving of the elderly: A literature review. *International Journal of Nursing Studies, 49*(4), 490-504. doi:10.1016/j.ijnurstu.2011.10.011

Drawing from the information gathered in the abovementioned resources, the following list of dementia-specific caregiving tools (or instruments that have been initially tested with caregivers of persons living with Alzheimer's disease and dementia) that have been mentioned in these articles:

1. Caregiver Burden Inventory[7]
2. Caregiving Stress Inventory[10]
3. Caregiver Activity Survey[11]
4. Care-giving Burden Scale[12]
5. Caregiving Hassles Scale[13]
6. Caregiving Hassles and Uplifts Scale[14]
7. Caregiver Self-Care Self-Efficacy and Caregiver Problem-Solving Self-Efficacy[15]
8. Finding Meaning Through Caregiving[16]
9. Frustration Scale[17]
10. Neuropsychiatric Inventory Caregiver Distress Scale, NPI-D[18]
11. Relatives Stress Scale[19]
12. Screen for Caregiver Burden[20]
13. Sense of Competence Questionnaire[21]
14. Subjective Burden Scale[22]

Tools Used in the Singapore Context

In Dementia Singapore, two tools are often used to assess the well-being of caregivers who utilise our programmes and services. The first is the Gain in Alzheimer care Instrument[23] (GAIN), which focuses on the positive gains in being a caregiver of a person living with dementia, and has been developed in the Singapore context. The second instrument that Dementia Singapore often uses is the widely-used Zarit Burden Interview[6], which measures the negative aspects of caregiving. By using these two tools at the same time, we can have a better understanding of whether the positive aspects of caregiving outweigh the negative ones. The table below summarises the domains measured, strengths and limitations, and psychometric properties of the caregiving instruments that Dementia Singapore uses:

Tool & Developer(s)	Items	Domains Measured	Strengths & Limitations	Psychometric Properties	Permission to Use
Gain in Alzheimer care INstrument[23] (GAIN) Click here to access the journal article. *Note: The tool's items and scale options are included in the journal article.*	10	• Personal gains • Gains in relationship • Higher level gains	**Strengths:** • Specific to dementia caregiving • Tool developed in the Singapore context • Quick to complete **Limitations:**	**Reliability:** • Good internal consistency, Cronbach's α =.89 • Acceptable test-retest reliability (2 weeks), Intraclass Correlation Coefficient = .70 **Validity:**	Credit and cite the developers to use the tool. No other permissions are required.

			● Limited studies to establish its psychometric properties and utility on other settings	● Evidence of construct validity – GAIN significantly correlated: ○ Strongly with Positive Aspects of Caregiving, *r* = .68 ○ Moderately with Dementia Management Strategies Scale (DMSS, encouragement), *r* = .35 ○ Moderately with DMSS (active management), *r* = .42 ○ Modestly with DMSS (criticism), *r* = -.14 ○ Modestly Zarit Burden Interview, *r* = -.15 ● Evidence of factor validity – Principal component analysis revealed a single component with an Eigen value >1 at 5.28, accounting for 52.8% of the variance.	

Tool & Developer(s)	Items	Domains Measured	Strengths & Limitations	Psychometric Properties	Permission to Use
Short Form Zarit Burden Interview[24] (ZBI-12) Click here to access the ZBI-12 form and here for the journal article.	12	Perceived impact of providing care on caregiver's: ● Health ● Personal and social life ● Financial situation ● Emotional wellbeing ● Interpersonal relationships	**Strengths** ● Shorter and faster to administer ● Widely used around the world ● Translated into different languages (Spanish, Japanese, Chinese) ● Sensitive to detect changes **Weakness** ● Though it is a generic caregiving instrument, its psychometric properties are not well-established in other populations besides older adults.	**Reliability** Multiple studies have reported good to excellent internal consistency, with: ● Overall Cronbach's α at baseline ranging from .83 to .91 ● Cronbach's α for sub-scale *Personal Strain Factor* ranged from .80 to .89 ● Cronbach's α for sub-scale *Role Strain Factor* ranged from .77 to .81 **Validity:** Evidence of convergent validity: Correlations between the ZBI-12 and the full version (ZBI-22) ranged from 0.92 to 0.97	Credit and cite the developers to use the tool. No other permissions are required.

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3. Shaji, K. S., Smitha, K., Lal, K. P., & Prince, M. J. (2003). Caregivers of people with Alzheimer's disease: A qualitative study from the Indian 10/66 Dementia Research Network. *International Journal of Geriatric Psychiatry*, *18*(1), 1-6. https://doi.org/10.1002/gps.649

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