



MEASURES ON DEMENTIA CAREGIVING

TOOLS FOR **DEMENTIA** PRACTICE & RESEARCH

TOOLS FOR **DEMENTIA** PRACTICE & RESEARCH

MEASURES ON DEMENTIA CAREGIVING

Measures on Dementia Caregiving

Much literature has been written about the positive and negative aspects of being a caregiver of a family member. 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, caregivers have also reported positive outcomes such as enhanced self-confidence, personal growth, improved relationships with care recipients and families, and enhanced meaning and purpose in life.^{4,5}

Approximately a hundred tools have been developed to measure negative and positive aspects of caregiving (such as caregiving burden and strains, caregiver physical health, emotional health, life satisfaction and 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 (as opposed to caregiving for persons who have specific conditions), disease-specific instruments have been tested on caregivers of persons living with Alzheimer's disease or dementia.

Most of the caregiving instruments focus on either the negative aspect of caregiving, or both the positive and negative aspects. Some examples include the widely used Zarit Burden Interview⁶ and Caregiver Burden Inventory⁷ which measures caregivers' levels of perceived stress and screens for burden and strain. Some tools measure only the benefits of caregiving, such as satisfaction experienced from assisting care recipients and developing new skills or competencies. Two examples of these tools are the Positive Aspects of Caregiving Instrument⁸ and the Picot Caregiver Rewards Scale⁹.

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 with various populations (caregivers of care recipients with different medical conditions) and settings. Please refer to the following articles for summaries and systematic reviews of these 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](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. *PLoS ONE* 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/resource/selected-caregiver-assessment-measures-a-resource-inventory-for-practitioners-2012/>
5. Michigan Dementia Coalition. (2009). *Introduction to Caregiver Assessment Tool Grid*. <https://rosalyncarcarter.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. <https://doi.org/10.1016/j.ijnurstu.2011.10.011>

Drawing from the abovementioned resources, the following is a list of dementia-specific caregiving tools or instruments that have been initially tested on caregivers of persons living with Alzheimer’s disease and dementia:

1. Caregiver Burden Inventory⁷
2. Caregiving Stress Inventory¹⁰
3. Caregiver Activity Survey¹¹
4. Caregiving Burden Scale¹²
5. Caregiving Hassles Scale¹³
6. Caregiving Hassles and Uplifts Scale¹⁴
7. Caregiver Self-Care Self-Efficacy and Caregiver Problem-Solving Self-Efficacy¹⁵
8. Finding Meaning Through Caregiving Scale¹⁶
9. Frustration Scale¹⁷
10. Neuropsychiatric Inventory Caregiver Distress Scale, NPI-D¹⁸
11. Relatives Stress Scale¹⁹
12. Screen for Caregiver Burden²⁰
13. Sense of Competence Questionnaire²¹
14. Subjective Burden Scale²²

Tools Used in the Singapore Context

Two tools are often used in Dementia Singapore to assess the well-being of caregivers who utilise our programmes and services. The first is the Gain in Alzheimer care Instrument²³ (GAIN) which focuses on positive gains as 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 Interview⁶ which measures negative aspects of caregiving. Using these two tools together allows us to have a better understanding of whether the positive aspects of caregiving outweigh the negative ones. The table below summarises the domains measured, the instruments’ strengths and limitations, and the 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.	10	<ul style="list-style-type: none"> ● Personal gains ● Relationship gains ● Higher level gains 	<p>Strengths:</p> <ul style="list-style-type: none"> ● Specific to dementia caregiving; ● Tool is developed in the Singapore context; and ● Quick to complete. <p>Limitations:</p>	<p>Reliability:</p> <ul style="list-style-type: none"> ● Good internal consistency, Cronbach's $\alpha = .89$ ● Acceptable test-retest reliability (2 weeks) Intraclass Correlation Coefficient = .70 	Credit and cite the developers to use the tool. No other permissions are required.

<p><i>Note: The tool's items and scale options are included in the journal article.</i></p>			<ul style="list-style-type: none"> Limited studies to establish the tool's psychometric properties and utility on other settings. 	<p>Validity:</p> <ul style="list-style-type: none"> Evidence of construct validity - GAIN significantly correlated: <ul style="list-style-type: none"> 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 for the journal article.	12	Perceived impact of providing care on caregiver's: <ul style="list-style-type: none"> ● Health; ● Personal and social life; ● Financial situation; ● Emotional well-being; and ● Interpersonal relationships. 	Strengths <ul style="list-style-type: none"> ● Shorter and faster to administer; ● Widely used around the world; ● Translated into different languages (Spanish, Japanese, Chinese); and ● Sensitive to detect changes. Weakness <ul style="list-style-type: none"> ● Though ZB-12 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: <ul style="list-style-type: none"> ● Overall Cronbach's α at baseline ranging from .83 to .91 ● Cronbach's α for sub-scale <i>Personal Strain Factor</i> ranged from .80 to .89 ● Cronbach's α for sub-scale <i>Role Strain Factor</i> 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.

References

1. Anehensel, C., Pearlin, L., Mullan, J., Zarit, S., & Whitlatch, C. (1995). *Profiles in caregiving: The unexpected carer*. Academic Press.
2. George, L. K., & Gwyther, L. P. (1986). Caregiver well-being: A multidimensional examination of family caregivers of demented adults. *The Gerontologist*, 26(3), 253-259. <https://doi.org/10.1093/geront/26.3.253>
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>
4. Nolan, M., Grant, G., & Keady, J. (1996). *Understanding family care: A multi-dimensional model of caring and coping*. Open University Press.
5. Sanders S. (2005). Is the glass half empty or full? Reflections on strain and gain in caregivers of individuals with Alzheimer's disease. *Social work in health care*, 40(3), 57–73. https://doi.org/10.1300/J010v40n03_04
6. Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: correlates of feelings of burden. *The Gerontologist*, 20(6), 649-655. <https://doi.org/10.1093/geront/20.6.649>
7. Novak, M., & Guest, C. (1989). Application of a multidimensional caregiver burden inventory. *The Gerontologist*, 29(6), 798-803. <https://doi.org/10.1093/geront/29.6.798>
8. Tarlow, B. J., Wisniewski, S. R., Belle, S. H., Rubert, M., Ory, M. G., & Gallagher-Thompson, D. (2004). Positive aspects of caregiving: Contributions of the REACH project to the development of new measures for Alzheimer's caregiving. *Research on Aging*, 26(4), 429-453. <https://doi.org/10.1177/01640275042644>
9. Picot, S. J. F., Youngblut, J., & Zeller, R. (1997). Development and testing of a measure of perceived caregiver rewards in adults. *Journal of Nursing Measurement*, 5(1), 33-52. <https://doi.org/10.1891/1061-3749.5.1.33>
10. Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist*, 30(5), 583–594. <https://doi.org/10.1093/geront/30.5.583>

11. Davis, K. L., Marin, D. B., Kane, R., Patrick, D., Peskind, E. R., Raskind, M. A., & Puder, K. L. (1997). The Caregiver Activity Survey (CAS): Development and validation of a new measure for caregivers of persons with Alzheimer's disease. *International Journal of Geriatric Psychiatry*, 12(10), 978-988. [https://doi.org/10.1002/\(SICI\)1099-1166\(199710\)12:10<978::AID-GPS659>3.0.CO;2-1](https://doi.org/10.1002/(SICI)1099-1166(199710)12:10<978::AID-GPS659>3.0.CO;2-1)
12. Gerritsen, J. C., & van der Ende, P. C. (1994). The development of a care-giving burden scale. *Age and Ageing*, 23(6), 483-491. <https://doi.org/10.1093/ageing/23.6.483>
13. Kinney, J. M., & Stephens, M. P. (1989). Caregiving Hassles Scale: Assessing the daily hassles of caring for a family member with dementia. *The Gerontologist*, 29(3), 328-332. <https://doi.org/10.1093/geront/29.3.328>
14. Kinney, J. M., & Stephens, M. A. P. (1989). Hassles and uplifts of giving care to a family member with dementia. *Psychology and Aging*, 4(4), 402-408. <https://doi.org/10.1037/0882-7974.4.4.402>
15. Zeiss, A. M., Gallagher-Thompson, D., Lovett, S., Rose, Jonathan, & McKibbin, C. (1999). Self-efficacy as a mediator of caregiver coping: Development and testing of an assessment model. *Journal of Clinical Geropsychology*, 5, 221-230. <https://doi.org/10.1023/A:1022955817074>
16. Farran, C. J., Miller, B. H., Kaufman, J. E., Donner, E., & Fogg, L. (1999). Finding meaning through caregiving: Development of an instrument for family caregivers of persons with Alzheimer's disease. *Journal of Clinical Psychology*, 55(9), 1107-1125. [https://doi.org/10.1002/\(SICI\)1097-4679\(199909\)55:9<1107::AID-JCLP8>3.0.CO;2-V](https://doi.org/10.1002/(SICI)1097-4679(199909)55:9<1107::AID-JCLP8>3.0.CO;2-V)
17. Motenko, A. K. (1989). The frustrations, gratifications, and well-being of dementia caregivers. *The Gerontologist*, 29(2), 166-172. <https://doi.org/10.1093/geront/29.2.166>
18. Kaufer, D. I., Cummings, J. L., Christine, D., Bray, T., Castellon, S., Masterman, D., MacMillan, A., Ketchel, P., & DeKosky, S. T. (1998). Assessing the impact of neuropsychiatric symptoms in Alzheimer's disease: The neuropsychiatric inventory caregiver distress scale. *Journal of the American Geriatrics Society*, 46(2), 210-215. <https://doi.org/10.1111/j.1532-5415.1998.tb02542.x>
19. Greene, J. G., Smith, R., Gardiner, M., & Timbury, G. C. (1982). Measuring behavioural disturbance of elderly demented patients in the community and its effects on relative: A factor analytic study. *Age and Ageing*, 11(2), 121-126. <https://doi.org/10.1093/ageing/11.2.121>
20. Vitaliano, P. P., Russo, J., Young, H. M., Becker, J., & Maiuro, R. D. (1991). The screen for caregiver burden. *The Gerontologist*, 31(1), 76-83. <https://doi.org/10.1093/geront/31.1.76>

21. Vernooij-Dassen, M. J. F. J., Persoon, J. M. G., & Felling, A. J. A. (1996). Predictors of sense of competence in caregivers of demented persons. *Social Science & Medicine*, 43, 41-49. [https://doi.org/10.1016/0277-9536\(95\)00332-0](https://doi.org/10.1016/0277-9536(95)00332-0)
22. Matsuda, O. (1999). Reliability and validity of the subjective burden scale in family caregivers of elderly relatives with dementia. *International Psychogeriatrics*, 11(2), 159-170. <https://doi.org/10.1017/S1041610299005712>
23. Yap, P., Luo, N., Ng, W. Y., Chionh, H. L., Lim, J., & Goh, J. (2010). Gain in Alzheimer care INstrument: A new scale to measure caregiving gains in dementia. *American Journal of Geriatric Psychiatry*, 18(1), 68-76. <https://doi.org/10.1097/JGP.0b013e3181bd1dcd>
24. Bédard, M., Molloy, D. W., Squire, L., Dubois, S., Lever, J. A., & O'Donnell, M. (2001). The Zarit Burden Interview: A new short version and screening version. *The Gerontologist*, 41(5), 652-657. <https://doi.org/10.1093/geront/41.5.652>