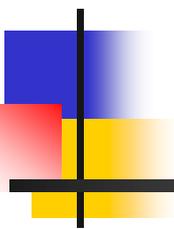


Eighth Family Research Network (FRN) Forum

***“Caregiving in Singapore: Insights,
Highlights and Experiences”***

**Tuesday, 7 August 2012
Auditorium, Level 1, Civil Service College**

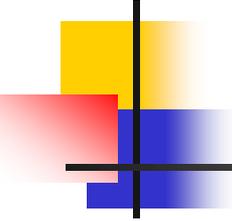
Measuring family member's caregiving burden using the Zarit Burden Interview



Luo Nan, PhD

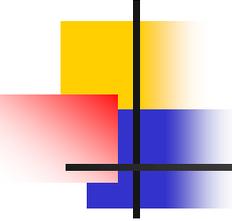
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Zarit Burden Interview (ZBI)

- **Developed by:** Steven H. Zarit (USA) in 1980
- **Objective:** To assess the level of burden experienced by the principal caregivers of older persons with senile dementia and disabled persons
- **User agreement:** required
- **Access fees:** free of charge for not-funded academic research
- **New translations:** coordinated by MAPI Institute
- **Contact information:** PROinformation@mapi-trust.org



Data collection form

- Questionnaire for self/interviewer-administration
- 22 negatively phrased questions/statements each with a 5-point Likert response scale
 - Never=0
 - Rarely=1
 - Sometimes=2
 - Quite frequently=3
 - Nearly always=4

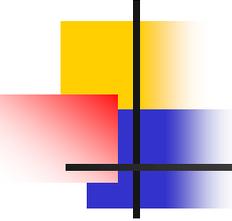
Burden Interview

The questions below reflect how you sometimes feel when you are taking care of your relative. After each statement, circle the number that best describes how often you feel that way. There is no right or wrong answer.

(Circle only one number for each item)

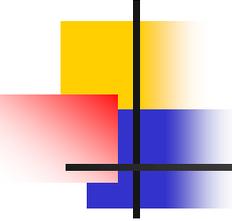
CIRCLE THE RESPONSE THAT BEST DESCRIBE HOW YOU FEEL	Never	Rarely	Some times	Quite frequently	Nearly always
1. Do you feel that your relative asks for more help than he/she needs?	0	1	2	3	4
2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0	1	2	3	4
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4
4. Do you feel embarrassed over your relative's behavior?	0	1	2	3	4
5. Do you feel angry when you are around your relative?	0	1	2	3	4
6. Do you feel your relative currently affects your relationships with other family members or friends in a negative way?	0	1	2	3	4
7. Are you afraid what the future holds for your relative?	0	1	2	3	4
8. Do you feel your relative is dependent on you?	0	1	2	3	4
9. Do you feel strained when you are around your relative?	0	1	2	3	4
10. Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4
11. Do you feel that you don't have as much privacy as you would like because of your relative?	0	1	2	3	4

12. Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4
13. Do you feel uncomfortable about having friends over because of your relative?	0	1	2	3	4
14. Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?	0	1	2	3	4
15. Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?	0	1	2	3	4
16. Do you feel that you will be unable to take care of your relative much longer?	0	1	2	3	4
17. Do you feel you have lost control of your life since your relative's illness?	0	1	2	3	4
18. Do you wish you could leave the care of your relative to someone else?	0	1	2	3	4
19. Do you feel uncertain about what to do about your relative?	0	1	2	3	4
20. Do you feel you should be doing more for your relative?	0	1	2	3	4
21. Do you feel you could do a better job in caring for your relative?	0	1	2	3	4
22. Overall, how burdened do you feel in caring for your relative?	0	1	2	3	4



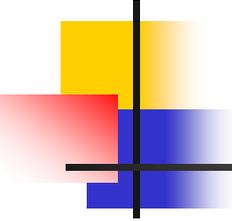
Scoring and interpreting ZBI

- ZBI total score: a summation score of all 22 item scores (range: 0 to 4)
- Score range: 0 to 88
 - 0–20: no to mild burden
 - 21–40 mild to moderate burden
 - >40 high burden
- A cut-off score ranging from 24-26 has significant predictive validity for identifying caregivers at risk for depression (Schreiner et al., 2006)



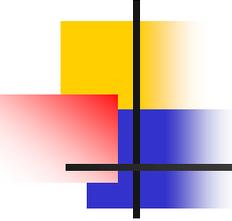
Is ZBI a reliable measure?

- Internal consistency reliability
 - *Cronbach's alpha*: 0.82 (Turkey) to 0.93 (Singapore)
- Test-retest reliability
 - *Intra-class correlation coefficient (ICC)*: 0.88 (2-week, Japan) to 0.89 (2-week, Singapore)



Is ZBI a valid measure?

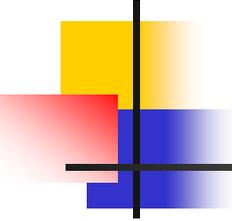
- ***Construct validity:*** association with 1) other caregiving burden scales, 2) caregivers' quality of life, 3) caregivers' socio-economic status, and 4) health and functional status of care recipients.



Validity of the Zarit Burden Interview in assessing caregiving burden in Singapore

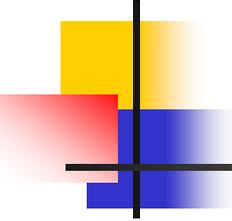
Study sample

- A consecutive sample of study subjects were recruited from two sources from June 2008 to Feb 2009:
 - Alexandra Hospital
 - Alzheimer's Disease Association of Singapore
- Inclusion criteria:
 - 1) Family member aged ≥ 18 years providing care or assistance to a relative with dementia
 - 2) Literacy in English and able to complete a survey questionnaire



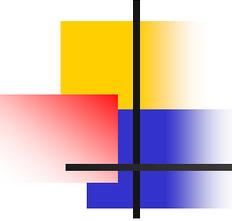
Procedures

- Subjects asked to self-administer:
 - Zarit Burden Interview (ZBI)
 - Burden Assessment Scale (BAS)
 - General Health Questionnaire (GHQ-28)
 - Dementia Management Strategies Scale (DMSS)
 - Revised Memory and Behavior Problems Checklist (RMBPC)
- Subjects completing the questionnaires on-site or off-site
- A subgroup of subjects completing the ZBI a second time 2 weeks after the first survey



Hypotheses for testing construct validity (excerpt)

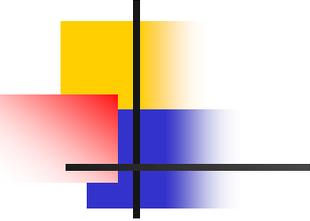
- ZBI would be strongly or moderately correlated with the BAS, GHQ-28, RMBPC and the DMSS criticism subscale.
- Caregivers who played a major role in caregiving would have higher ZBI scores compared to those who played a minor role in caregiving.
- Caregivers who reported greater financial problems or were taking care of more dependent patients would have higher ZBI scores than those with fewer financial problems or who were dealing with less dependent patients.



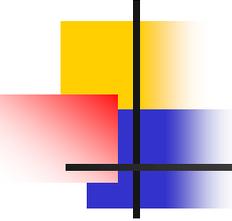
Correlation results

- ZBI was highly correlated with BAS (0.73, $p < 0.0001$) and the GHQ-28 (0.62, $p < 0.0001$).
- ZBI score was strongly correlated with patients' dementia symptoms measured by RMBPC (0.53, $p < 0.0001$).
- The correlation between ZBI and DMSS criticism subscale was 0.53 ($p < 0.0001$), indicating that caregivers who tended to criticize their patients reported higher level of burden than those who utilised less criticism in their management strategy.

ZBI scores for subgroups of caregivers



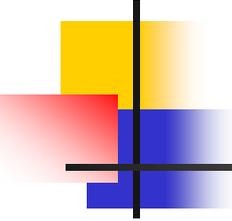
	N	Mean (SD)	P-value
Main Caregiver			
Yes	184	37.3 (15.5)	0.0004
No	54	29.0 (13.6)	
Duration			
<1 year	30	26.0 (14.8)	0.0003
>=1 year	207	36.9 (15.1)	
Time contributed			
< 20%	64	31.5 (15.4)	0.0552
21% to 60%	84	37.4 (14.3)	
> 60%	90	36.5 (16.4)	
Financial Problems			
Not at all/a little	120	33.0 (14.0)	<0.0001
Some	33	44.5 (13.3)	
A lot	16	47.1 (20.8)	
Patient Stage			
Independent	58	33.7 (18.0)	0.3642
Need assistance	113	35.0 (13.8)	
Need round clock	66	37.6 (16.0)	



Is ZBI responsive to change in burden levels?

Findings from randomized controlled trials:

- Counseling and support lowered the ZBI score in caregivers of people with Alzheimer's disease during the transition to institutionalization; nursing home admission lowered the ZBI score (Gaugler et al., 2008).
- A nurse-led comprehensive geriatric evaluation and management programme for caregivers of community-dwelling frail older people **did not** lower the ZBI score (Melis et al., 2009).
- A new palliative care service lowered the ZBI score in caregivers of patients with multiple sclerosis (Edmonds et al., 2010)
- A caregiver intervention lowered the ZBI score of caregivers of people with dementia (Guerra et al., 2010)



Potential issue: what burden does ZBI measure?

Findings from factor analysis:

- 1 factor (inpatients)
- **2 factors: personal strain and role strain (dementia)**
- 3 factors: effect on the social and personal life, psychological burden, and guilt (dementia)
- 5 factors: oversacrifice, patient's dependence, negative emotion, inadequacy, and uncertainty about patient's future (dementia)
- 6 factors: interference in personal life, patient's dependence, irritation or intolerance, and guilt (OCD)

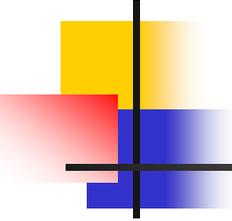
Factor analysis of Zarit Burden Interview

Item	Factor 1	Factor 2	Factor 3
	Personal strain	Role strain	Guilt
1. I feel that the person I care for asks for more help than he/she needs.	X		
4. I feel embarrassed over his/her behaviour.	X		
5. I feel angry when I am around the person I care for.	X		
6. I feel that he/she currently affects my relationship with other family members or friends in a negative way.	X		
9. I feel strained when I am around the person I care for.	X		
13. I feel uncomfortable about having friends over because of him/her.	X		
14. I feel that this person expects me to take care of him/her as if I was the only one he/she could depend on.	X		
16. I feel that I will be unable to take care of him/her much longer.	X		
18. I wish I could leave the care of this person to someone else.	X		
19. I feel uncertain about what to do about the person I care for.	X		
2. Because of the time I spend with him/her, I do not have enough time for myself.		X	
3. I feel stressed between caring for him/her and trying to meet other responsibilities for my family or work.	X	X	
7. I am afraid of what the future holds for the person I care for.		X	
8. I feel he/she is dependent upon me.		X	
10. I feel that my health has suffered because of my involvement with the person I care for.		X	
11. I feel that I do not have as much privacy as I would like because of the person I care for.	X	X	
12. I feel that my social life has suffered because I am caring for this person.		X	
15. I feel that I do not have enough money to support this person in addition to the rest of our expenses.		X	
17. I feel that I have lost control of my own life since this person's illness.		X	
20. I feel I should be doing more for him/her.			X
21. I feel I could do a better job in caring for him/her.			X
22. Overall, how burdened do you feel in caring for this person?	X	X	

Short forms of Zarit Burden Interview

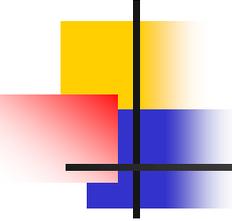
Item	Bedard et al's ZBI-12 (2001)	Arai et al's ZBI-8 (2003)	Gort et al's ZBI-7 (2005)	Higginson et al's ZBI-6 (2010)	Bedard et al's ZBI-4 (2001)	Higginson et al's ZBI-1 (2010)
1. Do you feel that your relative asks for more help than he/she needs?						
2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	X		X	X	X	
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	X		X	X	X	
4. Do you feel embarrassed over your relative's behavior?		X				
5. Do you feel angry when you are around your relative?	X	X				
6. Do you feel your relative currently affects your relationships with other family members or friends in a negative way?	X	X	X	X		
7. Are you afraid what the future holds for your relative?						
8. Do you feel your relative is dependent on you?						
9. Do you feel strained when you are around your relative?	X	X	X	X	X	
10. Do you feel your health has suffered because of your involvement with your relative?	X		X	X		
11. Do you feel that you don't have as much privacy as you would like because of your relative?	X					
12. Do you feel that your social life has suffered because you are caring for your relative?	X	X				
13. Do you feel uncomfortable about having friends over because of your relative?		X				
14. Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?						
15. Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?						
16. Do you feel that you will be unable to take care of your relative much longer?						
17. Do you feel you have lost control of your life since your relative's illness?	X		X	X		
18. Do you wish you could leave the care of your relative to someone else?		X				
19. Do you feel uncertain about what to do about your relative?	X	X			X	
20. Do you feel you should be doing more for your relative?	X					
21. Do you feel you could do a better job in caring for your relative?	X					
22. Overall, how burdened do you feel in caring for your relative?			X			X

Source: Higginson et al., 2010



Further testing of ZBI in Singapore

- Chinese and Malay versions
- Equivalence of local language versions
- Dimensionality of ZBI



Summary

- ZBI is a promising measure for caregiving burden experienced by family members of older patients.
- More work is needed to test and develop ZBI into a useful tool in Singapore.