

Family Caregiver Stress

How to Measure it and Why



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Learning Objectives

1. Review the rationale for screening caregiver quality of life
2. Discuss general properties of effective quality of life measures
3. Shares results of a systematic review of existing caregiver measures
4. Discuss potential screening tools for use in healthcare settings

Project

Background



Project

Rationale

Caregiving by the Numbers

Why it is vital for those giving care to take care of themselves too.

43 million: Nearly 1 in 5 Americans serves as an unpaid caregiver

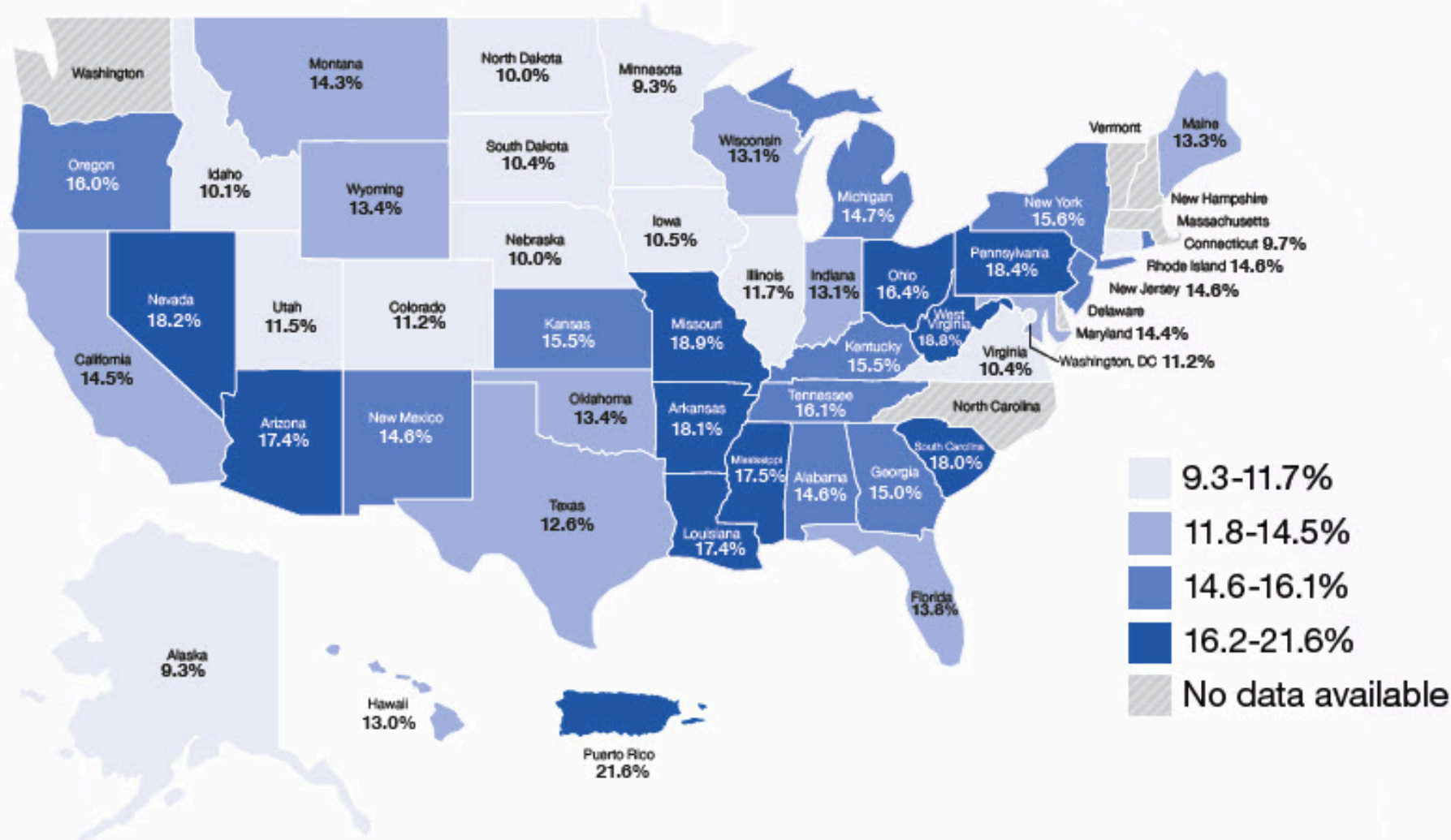
24 hours: Average time caregivers help family members and friends each week

2 in 5: Caregivers consider their roles to be highly stressful

17: Percentage of caregivers who describe their health as fair or poor

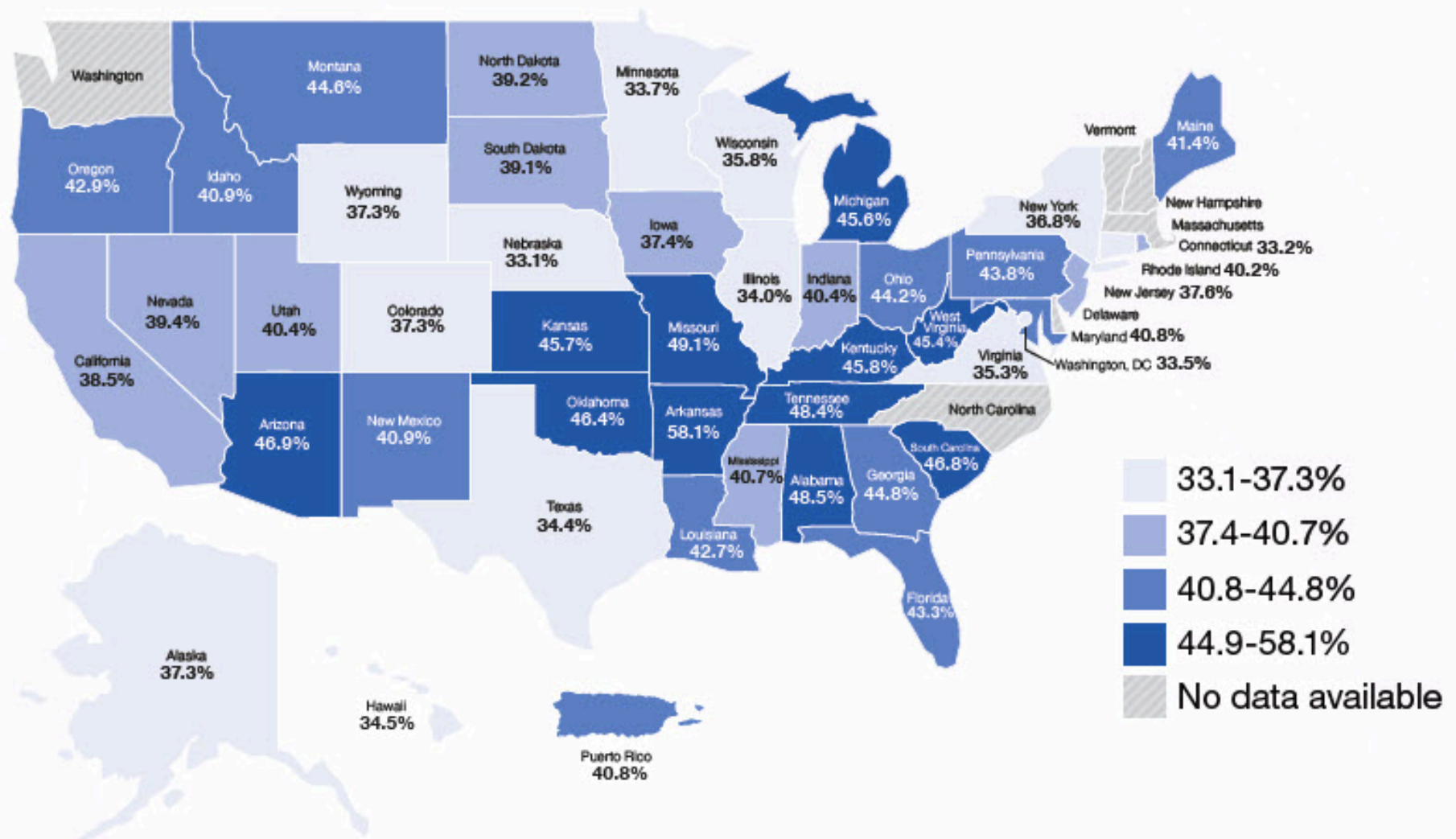
Health Status of Caregivers: Unhealthy Days and Insufficient Sleep

Figure 3: Caregivers aged 45 years or older who reported frequent mental distress



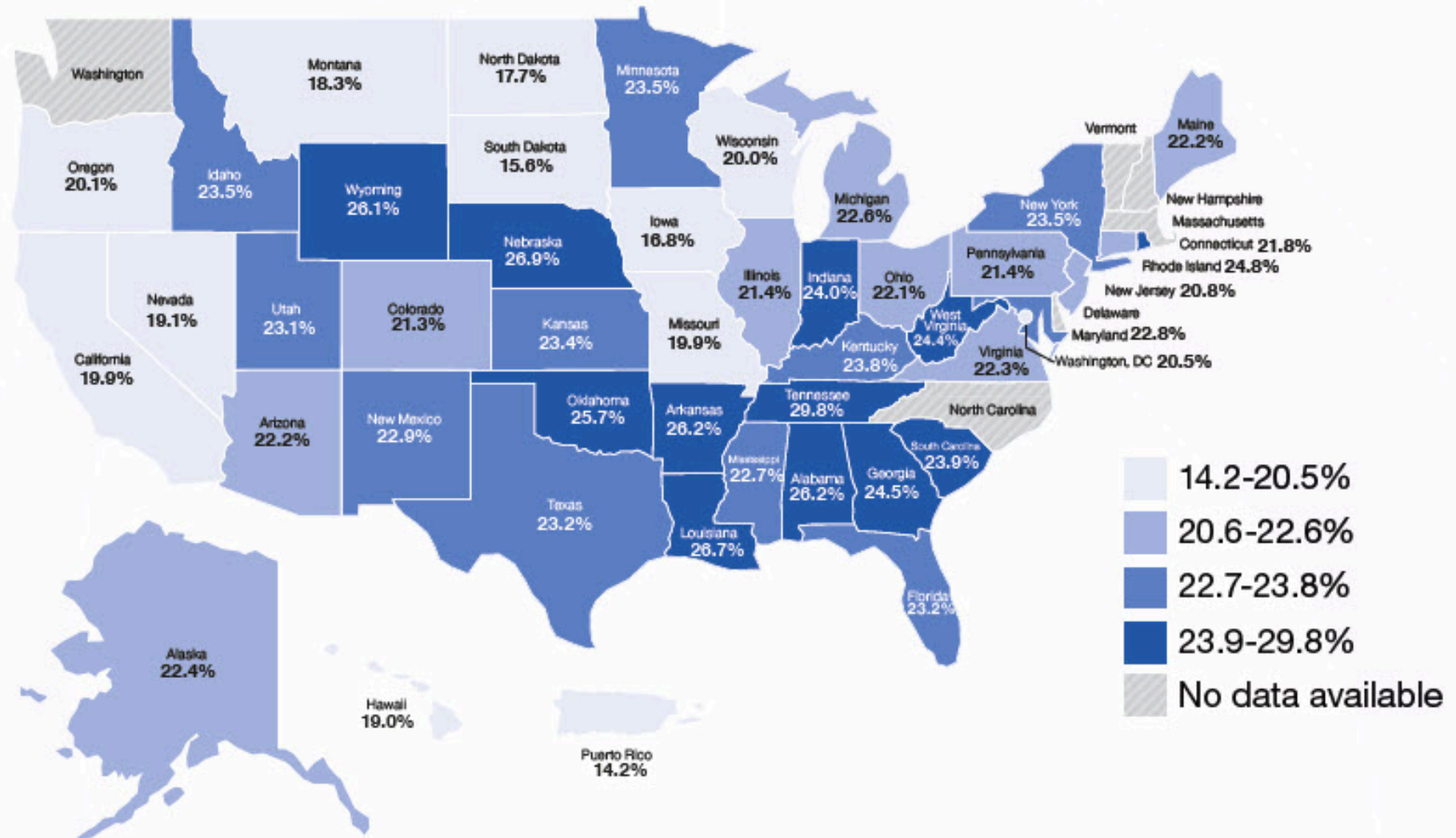
Health Status of Adult Caregivers: Prevalence of Chronic Diseases and Disability Status

Figure 4: Caregivers aged 45 years or older who reported having 2 or more chronic diseases



Characteristics of Caregivers and the Caregiving Situation

Figure 1: Adults aged 45 years or older who reported being a caregiver to a friend or family member



Caregiving is a burden, right?

Clear: informal caregiving is prevalent, demanding, and stressful¹⁻²

Unclear: older research suggests caregiving increases mortality risk, while more recent, population-based research suggests caregiving has protective benefits³⁻⁴

Do we have a balance and updated perception of informal caregiving?

Value of a good caregiver measure

- ***Help the caregiver, help the patient***
- ***Measurement technology***: timely, accurate, and efficient
- ***Single-item measure***: does it exist?

The quality and feasibility of existing caregiver screening tools are unclear

Project Aims

Primary Aim

- Identify effective brief and single-item measures of caregiver quality of life

Secondary aims

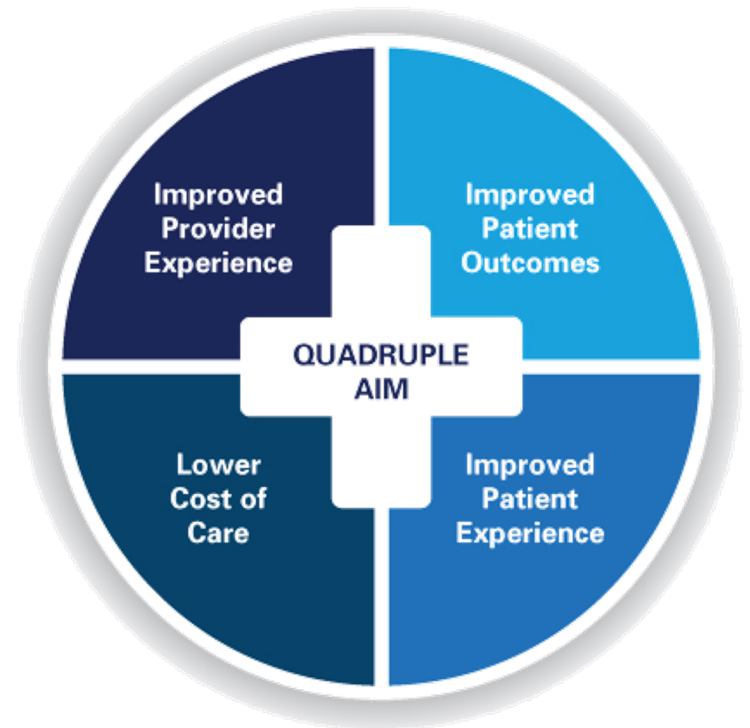
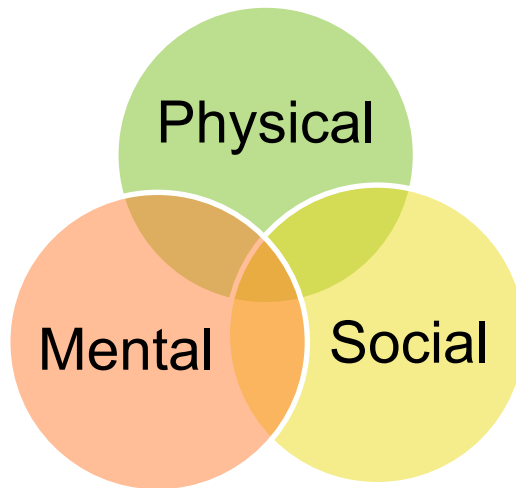
- Determine the range and frequency of caregiver QOL domains
- Identify potential areas of new research

Properties of a **Good Measure**

Measurement in Healthcare

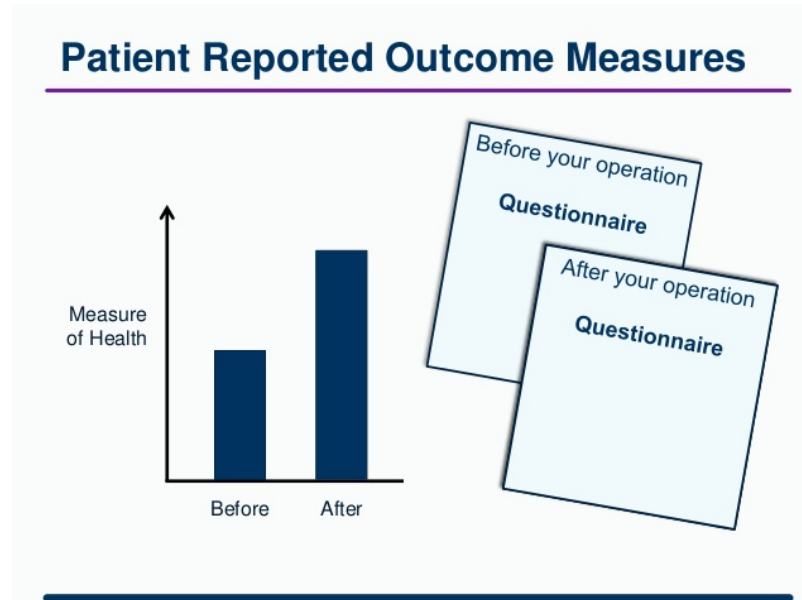
- *What are we measuring?*
- *Why is measurement important in healthcare?*

QoL = Well-being + Functional status



Measurement in Healthcare: PRO/PROMs

- *What are patient reported outcome measures?*



PROs

- ✓ Health-related quality of life (HRQOL)
- ✓ Symptoms
- ✓ Function
- ✓ Satisfaction with care or symptoms
- ✓ Adherence to prescribed medications or other therapy
- ✓ Perceived value of treatment

PRO Characteristics

- ***Variability in formatting*** (tense, recall period, & response options)
- ***Generic vs. disease-specific***
- ***Scoring – index vs. multidimensional***
- ***Scoring – population-based vs. individualized norms***

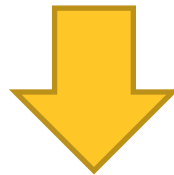
Measurement in Healthcare

- ***Why use patient-reported outcome measures (PRO/PROMs)?***
- Consistent with patient-centered care & value-based payment models
 - Focus on outcomes most important to patients
 - Facilitates patient/provider collaboration
 - Improved patient experience & outcomes
 - Improved coordination of care
 - Increased efficiency of care



PRO Limitations

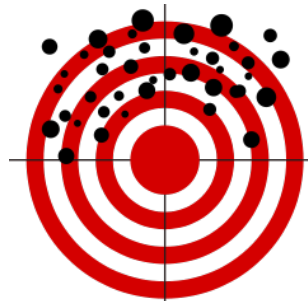
- *Cannot measure experiences directly, only features or attributes*
- *Any PRO measure includes error*
- *May be disparities between experience & clinical effectiveness data*
- *No single approach to measurement of any construct is universally accepted (including caregiver QoL)*



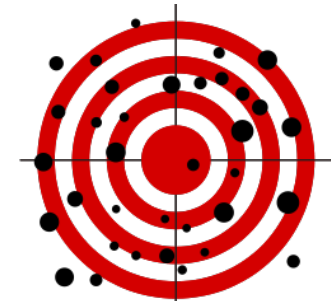
- *Need validated measures*
- *Supplement experience data with outcome data*

Characteristics of Good Measures

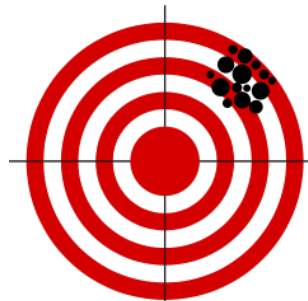
- *Reliability*
- *Validity*
- *Sensitivity to change*
- *Clinically relevant*
- *Actionable*



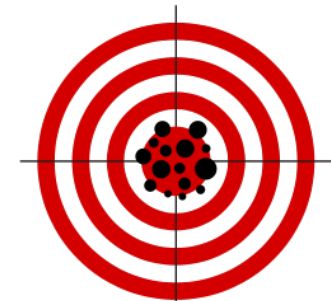
Unreliable & Unvalid



Unreliable, But Valid

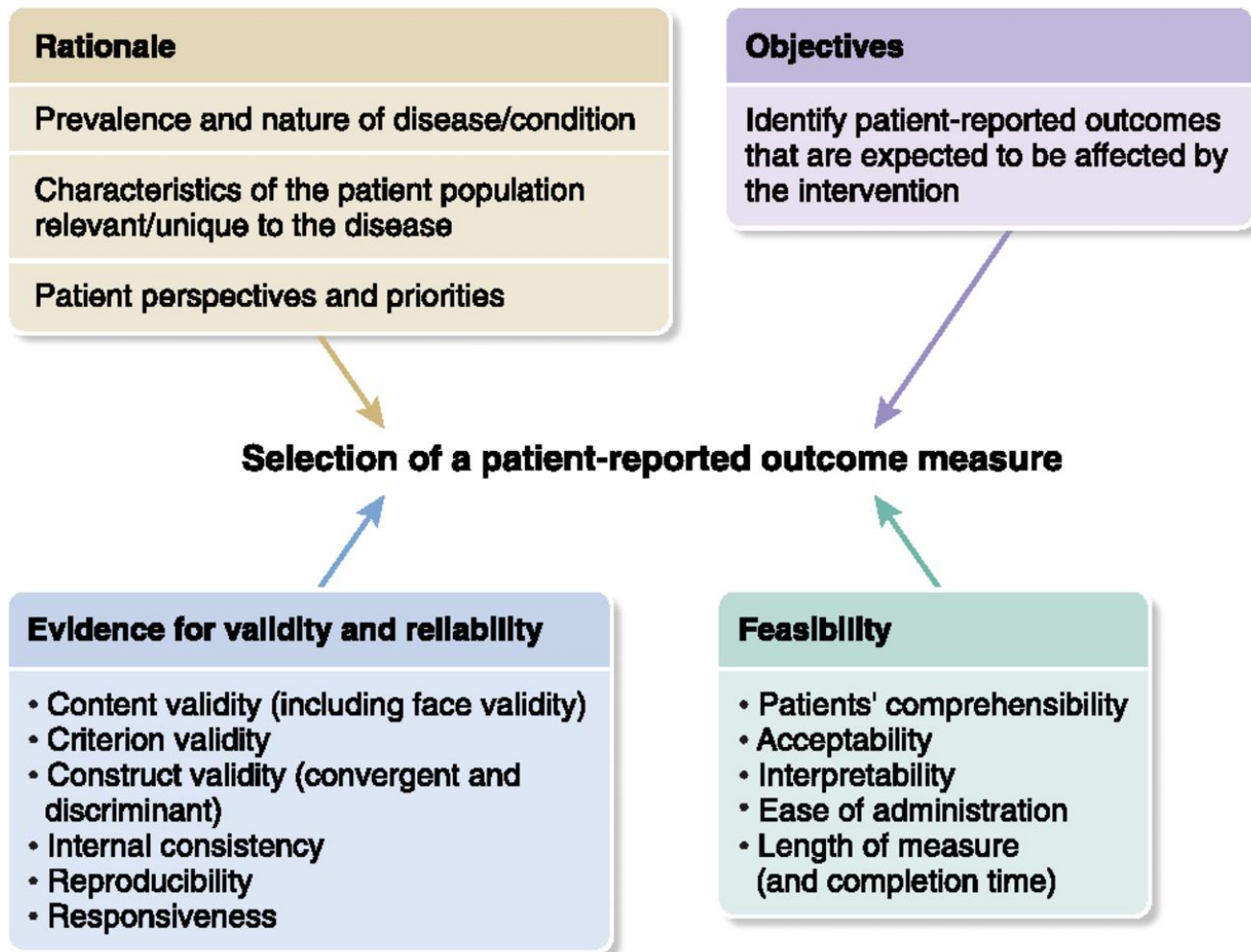


Reliable, Not Valid



Both Reliable & Valid

Characteristics of Good Measures



Project Results

Methods

Search

- CINAHL & PsychINFO
- “Tests and Measures” repository

Criteria

- Caregiver QOL measure
- Psychometric properties & domains

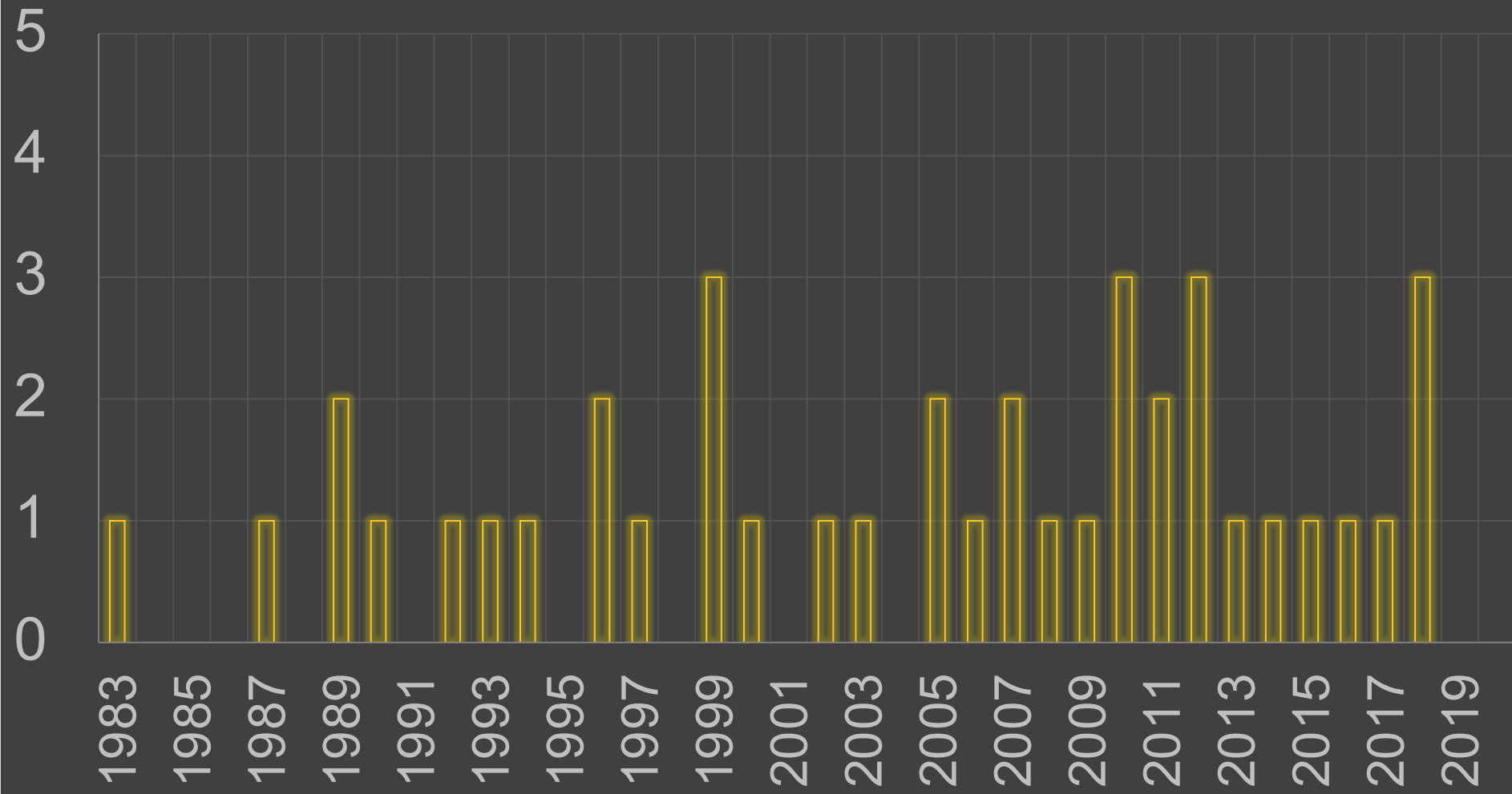
Review

- Screen > Full text > Extraction
- Excel sheet

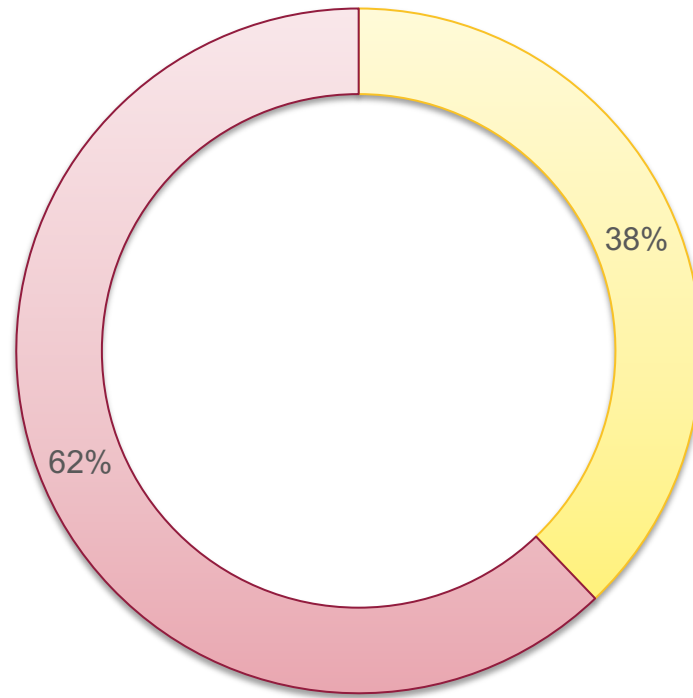
Studies screened: 1524

Total number of measures found: 96

number of published caregiver measures by year (N=96)



Measures with Illness-Specific or Generic Attribution



■ Specific attribution ■ Generic attribution

EXAMPLES

SPECIFIC:

Family Caregiver Delirium Burden (DEL-B-C)
Traumatic Brain Injury Caregiver Quality of Life

GENERIC:

Zarit Burden Interview
Burden Scale for Family Caregivers (BSFC)

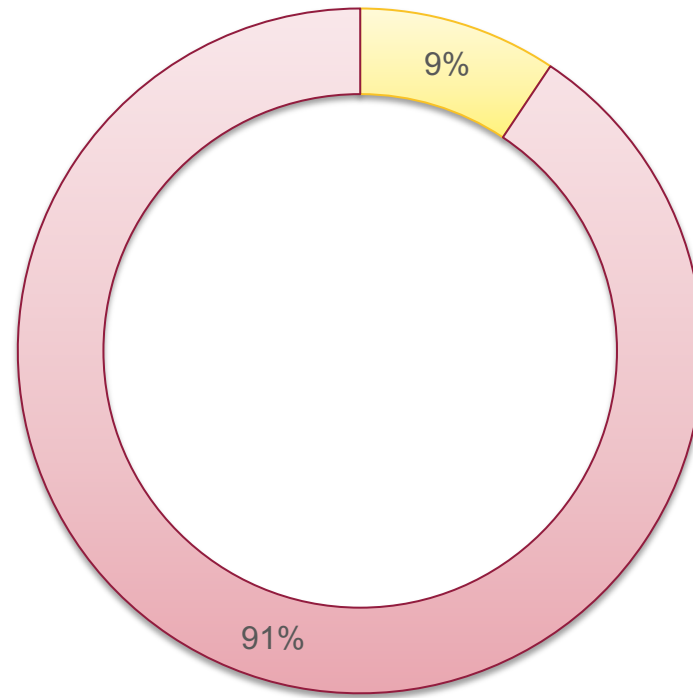
FREQUENT SPECIFIC ATTRIBUTIONS

Dementia, Alzheimer's, Delirium: 11

Mental health, ID, DD: 8

Cancer: 4

Frequency of Positive Appraisal



■ Positive ■ Negative

Adult Carers Quality of Life Questionnaire

Brief Assessment Scale for Caregivers

Caregiver Strain Index Plus Positive (CSI+)

Caregiver Targeted Quality of Life (CGQoL)

Carers of Older People in Europe (COPE) Index

Carers' Assessment of Satisfaction Index (CASI)

Family Appraisal of Caregiving Questionnaire for Palliative Care

Kansas Inventory of Parental Perceptions

Positive Aspects of Caregiving (PAC)

Carers of Older People in Europe (COPE)

- McKee et al., 2003 (15 items)
- Six-point response scale: (5) all the time – (0) at no time
- Domains: negative impact, positive value, quality of support
- Positive value does not correlate as highly as other domains
- Internal consistency: Cronbach's alpha range .64-.83
- Good model fit
- Modest criterion validity correlation sizes

- 1 Do you feel you cope well as a caregiver?
- 2 Do you find caregiving too demanding?^a
- 3 Does caregiving cause difficulties in your relationships with friends?^a
- 4 Does caregiving have a negative effect on your physical health?^a
- 5 Does caregiving cause difficulties in your relationship with your family?^a
- 6 Does caregiving cause you financial difficulties?^a
- 7 Do you feel trapped in your role as a caregiver?^a
- 8 Do you feel well supported by your friends and/or neighbours?
- 9 Do you find caregiving worthwhile?
- 10 Do you feel well supported by your family?
- 11 Do you have a good relationship with the person you care for?
- 12 Do you feel well supported by health and social services?
- 13 Do you feel that anyone appreciates you as a caregiver?
- 14 Does caregiving have a negative effect on your emotional wellbeing?^a
- 15 Overall, do you feel well supported in your role of caregiver?

Caregiver Strain Index Plus Positive (CSI+)

- Al-Janabi et al., 2010 (18 items)
- Yes or no response scale
- Five positive items added to original CSI
- Domains: Financial, Physical, Psychological, Social, and Personal plus 5 positive items
- Feasibility good
- Convergent validity improved
- Factor analysis suggests positive aspects of care could be grouped into coping and attitudinal factors

	Yes	No
1. Sleep is disturbed (e.g. because _____ is in and out of bed or wanders around at night)	_____	_____
2. It is inconvenient (e.g. because helping takes so much time or it's a long drive over to help)	_____	_____
3. The _____ appreciates everything I do for him/her	_____	_____
4. It is a physical strain (e.g. because of lifting in and out of a chair; effort or concentration is required)	_____	_____
5. It is confining (e.g. because helping restricts free time or cannot go visiting)	_____	_____
6. Besides the care I provide to _____ I have enough time for myself	_____	_____
7. There have been family adjustments (e.g. because helping has disrupted routine; there has been no privacy)	_____	_____
8. There have been changes in personal plans (e.g. because had to turn down a job; could not go on vacation)	_____	_____
9. There have been other demands on my time (e.g. from other family members)	_____	_____
10. There have been emotional adjustments (e.g. because of severe arguments)	_____	_____
11. I can handle the care for _____ fine	_____	_____
12. Some behaviour is upsetting (e.g. because of incontinence; _____ has trouble remembering things; concerns about how you will manage)	_____	_____
13. It is upsetting to find that _____ has changed so much from his/her former self (e.g. because he/she is a different person than he/she used to be)	_____	_____
14. I am happy to care for _____	_____	_____
15. There have been work adjustments (e.g. because of having to take time off)	_____	_____
16. Feeling completely overwhelmed (e.g. because of worry about _____; concerns about how you will manage)	_____	_____
17. It is a financial strain	_____	_____
18. Taking care for _____ is important to me	_____	_____

Zarit Burden Interview screening (ZBI-1)

- Higginson, 2010
- Do you feel ... (0 = never, 1 = rarely, 2 = sometimes, 3 = quite frequently, 4 = nearly always)
- All short forms displayed good correlations with ZBI-22
- **Cronbach's alphas** suggested high internal consistency
- **Discriminative ability** was good for all short forms
- ZBI-12 is best short-form version (ZBI-7 and 6 show almost equal properties)
- ZBI-4 and ZBI-1 are suitable for screening

ZBI-1

Overall, how burdened do you feel in caring for your relative?

(ZBI-4) Do you feel ...

1. that because of the time you spend with your relative that you don't have enough time for yourself?
2. stressed between caring for your relative and trying to meet other responsibilities (work/family)?
3. strained when you are around your relative?
4. uncertain about what to do about your relative?

Psychometric Properties



Summary & Implications

Summary

- Extensive literature
- Multitude of caregiver measures
 - Most have generic attribution
 - Most do not measure positive appraisal
 - Most have promising psychometric properties

Implications

- Clinical

- Use screener (e.g., ZBI-1)
- If positive screen, use full screen (ZBI-7 or CSI+)

- Research

- Effectiveness and feasibility of screener and measure with positive appraisal

Implications

- Breadth vs. depth

- Ethical considerations

Pragmatic considerations for measure selection:

- What is our intended purpose? (e.g. identify current needs vs. measure change over time)
- Is this measure validated for our population?
- How will scores guide clinical decision making?
- Do we have adequate resources for follow-up/support?

References

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3. Schulz R, Beach SR. Caregiving as a Risk Factor for Mortality: The Caregiver Health Effects Study. JAMA. 1999;282(23):2215–2219. doi:10.1001/jama.282.23.2215
4. David L. Roth, PhD, Lisa Fredman, PhD, William E. Haley, PhD, Informal Caregiving and Its Impact on Health: A Reappraisal From Population-Based Studies, The Gerontologist, Volume 55, Issue 2, April 2015, Pages 309–319, <https://doi.org/10.1093/geront/gnu177>