



INTRODUCTION

- Caregiver burden (CB) is a critical aspect of informal caregiving that is typically self-assessed by caregivers.
- However, an emerging concept is the assessment of CB by the recipients of care, i.e., the patients.
- Two perspectives can potentially be obtained to inform decision making: care recipient self-perceived burden to caregiver, or as a proxy intended to substitute for caregiver self-assessment.



OBJECTIVES

Our specific objectives were:

- to assess the level of agreement between care recipients' and caregivers' view on CB, across financial, physical, emotional, and social domains;
- explore two care recipient perspectives: their self-perceived burden (CR-SPB), and their interpretation of the caregiver's view (Proxy-CB).



METHODS

Population

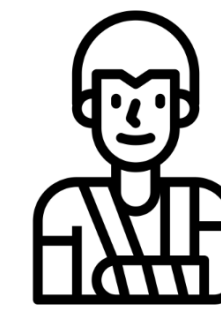
Caregivers



N=504
49 (SD 15) years
Female 58%

Spouse (35%)
Child (30%)
Friend/family friend (12%)
Grandchild (8%)

Care recipients



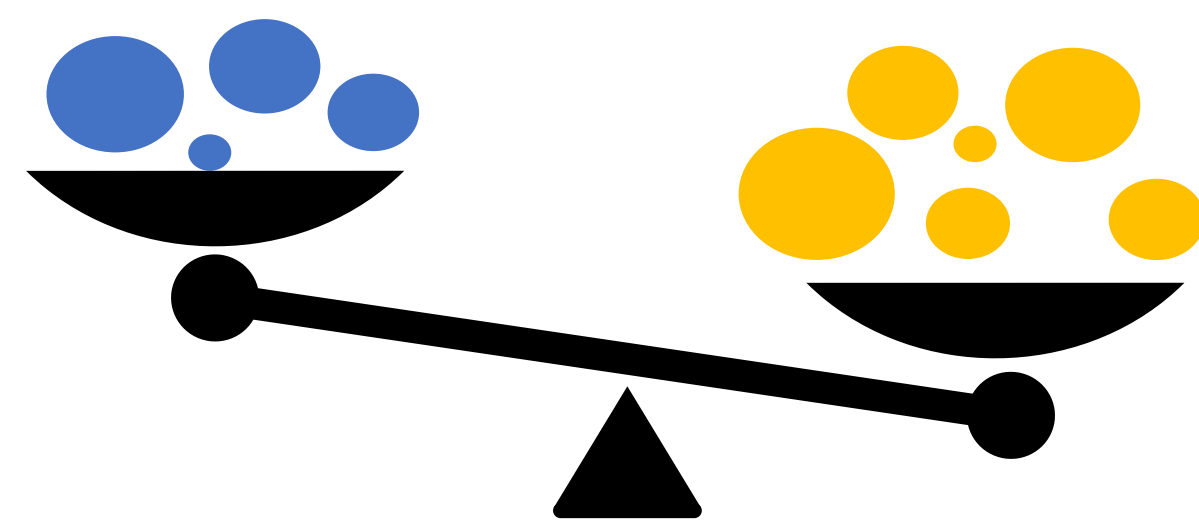
N=504
63 (SD 19) years
Female 52%

- Caregiver-care recipient dyads were recruited using an online Qualtrics panel in the U.S.

Level of agreement



Caregiver perspective



Proxy-CB perspective

Care recipient self-perceived burden perspective



- Items:** weighted kappa (κ) coefficients
- Index/summary scores:** Intraclass correlation coefficients (ICC)
- Magnitude of difference between perspectives:** Cohen's effect size (ES)



METHODS

Burden Assessment

"I am (...) burdened by caring for my care recipient due to their health situation"

Caregiver perspective

My opinion

- ☐ Not at all
- ☐ Slightly
- ☐ Moderately
- ☐ A lot
- ☐ Extremely



- ✓ **Physical**
- ✓ **Emotional**
- ✓ **Financial**
- ✓ **Social**

"I am a (...) burden to my caregiver due to my health situation"

Proxy-CB perspective: proxy for caregiver burden

How I think my caregiver would answer about me

- ☐ Not at all
- ☐ Slightly
- ☐ Moderately
- ☐ A lot
- ☐ Extremely

Care recipient perspective: self-perceived burden

My opinion

- ☐ Not at all
- ☐ Slightly
- ☐ Moderately
- ☐ A lot
- ☐ Extremely



RESULTS

Inter-rater gap – difference between caregiver's assessment and care recipient's proxy assessment of caregiver burden

Intra-proxy gap – difference between care recipient's proxy assessments of caregiver burden and their own self-perceived burden to caregiver

Caregiver vs Proxy-CB
ES = 0.22

Caregiver vs
Care recipient self-perceived
burden
ES = 0.23

Proxy-CB vs
Care recipient self-perceived burden
ES = 0.43

Caregiver perspective

Proxy-Caregiver Burden perspective

Care recipient perspective: care recipient self-perceived burden to caregivers

ICC = 0.76
Physical κ = 0.58
Emotional κ = 0.48
Financial κ = 0.66
Social κ = 0.48

ICC = 0.60
Physical κ = 0.42
Emotional κ = 0.34
Financial κ = 0.52
Social κ = 0.36



CONCLUSION

Results demonstrate there is a difference between perspectives. Strong agreement suggests that care recipients can potentially substitute for caregivers depending on the dimension. Patient/care recipient self-perceived burden agrees less with caregivers and may provide complementary information.

