

Impact of Serious Illness on Caregivers

Findings from the COMPASS study

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The Experiences of Informal Caregivers



- Caregiving burden over time 
- Dyadic distress over time 
- Caregiver distress pre- and post-patient death 
- Risk and protective factors 

Study Participants

Caregivers

One of the main persons:

- Providing care to the patient
- Ensuring provision of care to the patient
- Involved in treatment decisions on the behalf of the patient

≥21 years, not FDW

Patients

- Diagnosis of stage IV solid cancer
- ECOG ≤ 2
- Those above 60years, passed AMT
- ≥21 years, SC/ SPR

Caregiver Characteristics (N=346)

Age, M (SD)	49.7 (14.2)
≥65 years	55 (16%)
Gender	
Male	118 (34%)
Female	228 (66%)
Ethnic group	
Chinese	261 (75%)
Malay	56 (16%)
Indian/others	29 (8%)
Education	
No formal education/primary	56 (16%)
Secondary	95 (28%)
Vocational/ JC/ Polytechnic/ Diploma	91 (26%)
University and above	102 (30%)
Working	
Full-time/ part time	208 (60%)

Relationship to patient	
Spouse	164 (47%)
Child/child-in-law	143 (41%)
Others	39 (12%)
Additional help received	
Yes	241 (70%)
No	105 (30%)
Patient ECOG 0 at baseline	325 (94%)

Emotional closeness to patient	
Perceived financial adequacy	
Adequate/ More than adequate	226 (66%)
Occasionally adequate	69 (20%)
Usually inadequate	45 (13%)

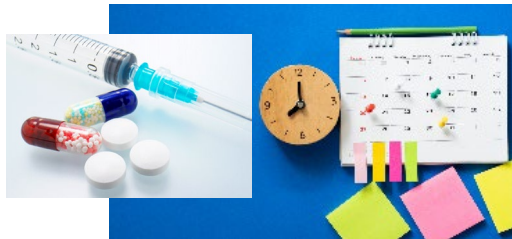
Caregiver Burden

“The strain or load borne by a person who cares for a chronically ill, disabled, or elderly family member”

Stucki & Mulvey, 2000

“Self-perceived, multi-faceted strain over time”

Liu et al, 2020



Caregiving Esteem



“Sense of value and worth as a caregiver”

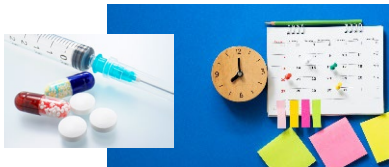
Kim et al. 2006

Associated with lower caregiving stress and depression

Teo et al. 2020, Loh et al. 2022, Yang et al. 2022

Study Aim

To identify joint trajectories of caregiver burden and esteem over 24 months (9 time points) among family caregivers of advanced cancer patients



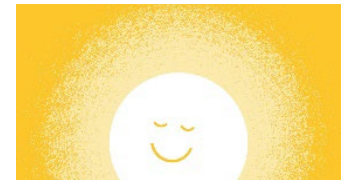
Impact on
Schedule & Health



Impact on
Finances



Lack of
Family Support



Caregiving esteem

Caregiver trajectories (n = 346)

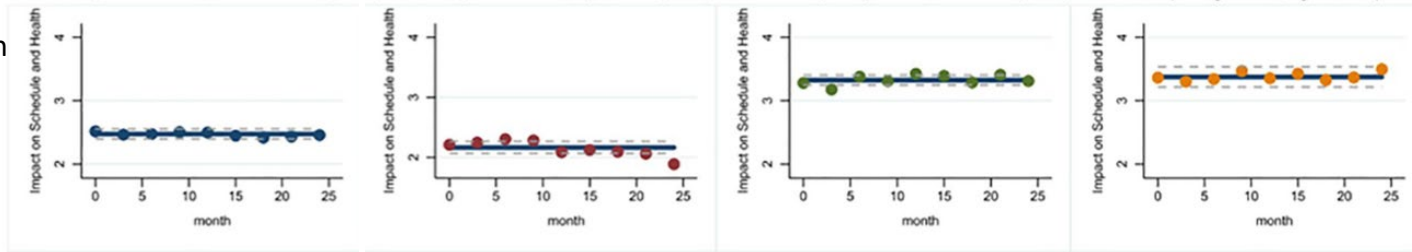
**Group 1
(38%)**

**Group 2
(20%)**

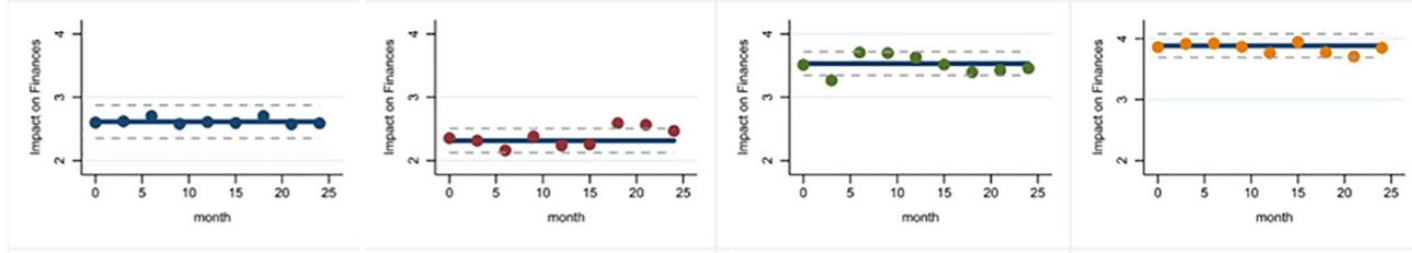
**Group 3
(16%)**

**Group 4
(25%)**

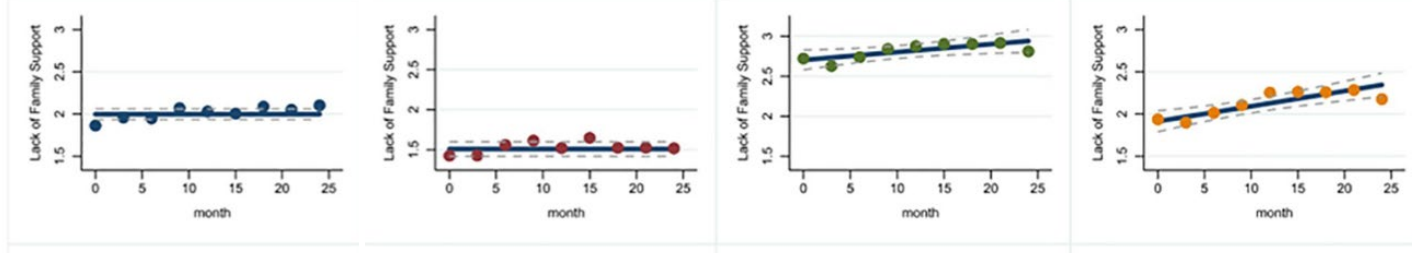
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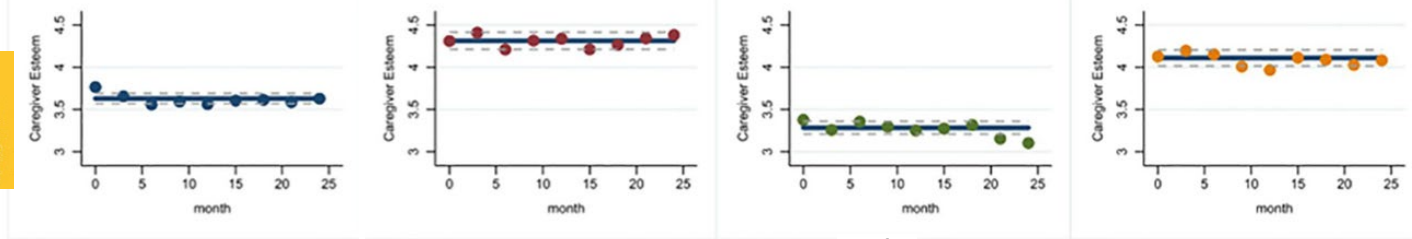
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Lack of
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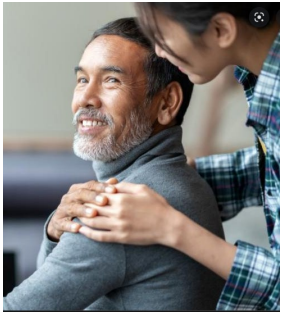
Esteem



See FJW, Teo I, Malhotra C. 2022. *Psycho-Oncology*

 **Financial inadequacy**

Caregiver-Patient Dyad Distress



Expected prevalence among advanced cancer patients to be approx. 30%

Hotopf et al. 2002, Krebber et al. 2013, Riedl et al. 2021

Expected prevalence among caregivers to be approx. 50%

Merckaert et al., 2012, Geng et al. 2018

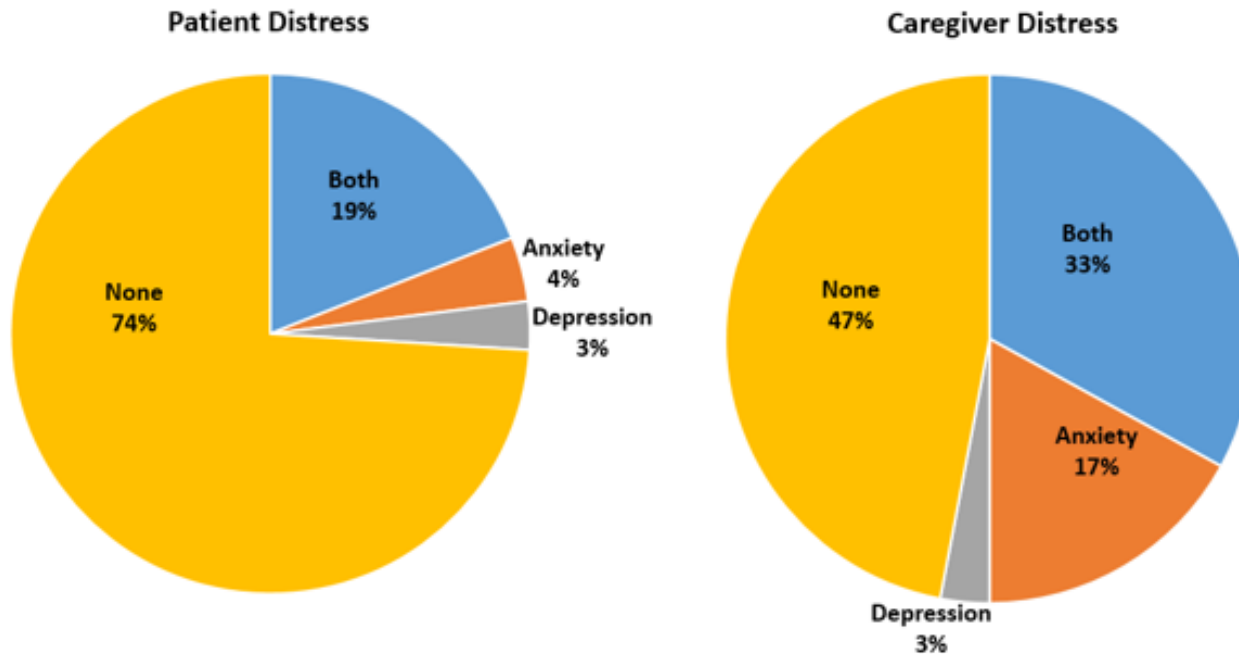
Prior studies suggest there are interdependencies, though most studies are cross-sectional.

Streck et al. 2021

Study Aim

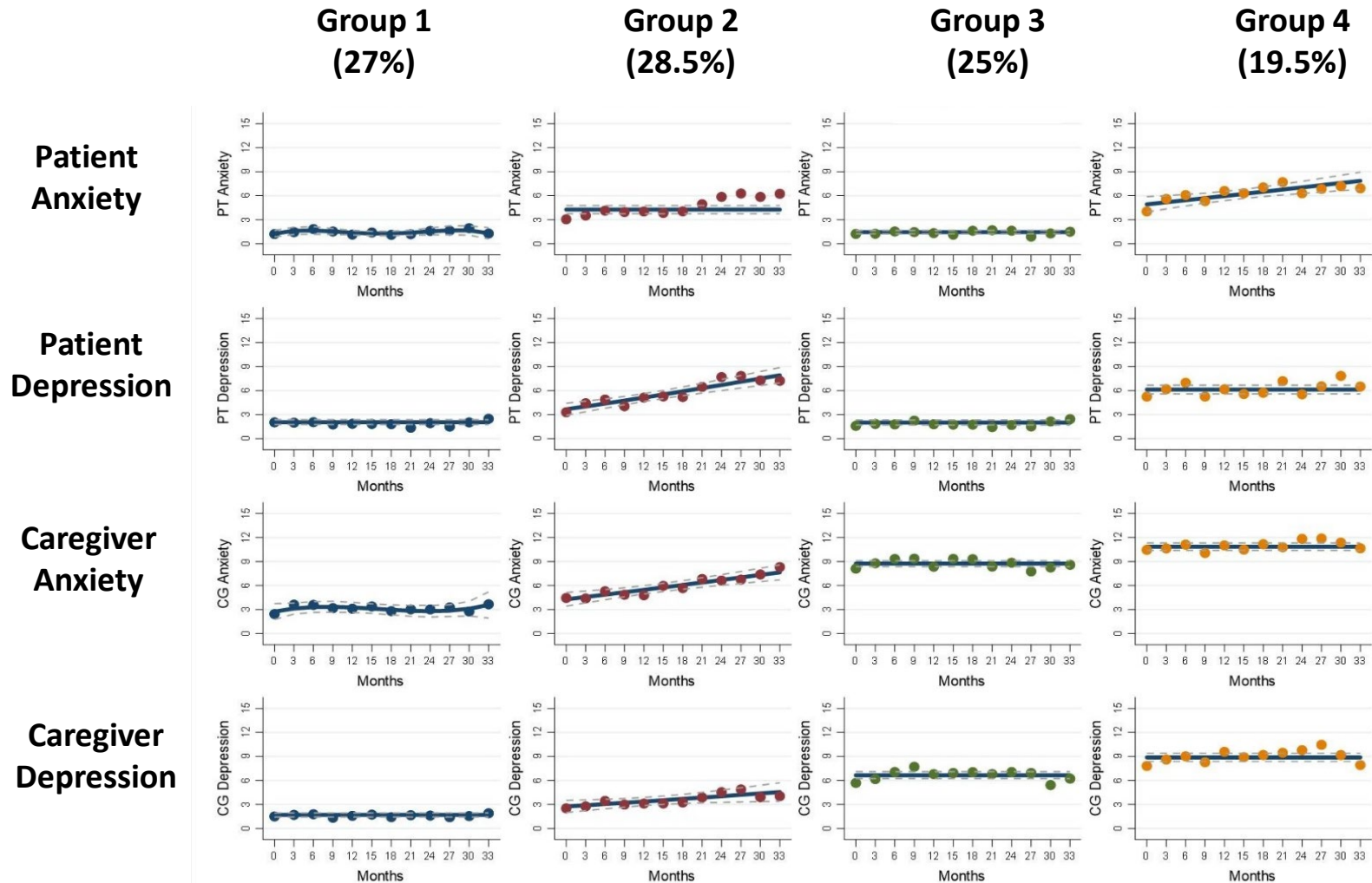
To describe the joint trajectories of psychological distress among patient - caregiver dyads over 33 months (12 time points).

Patient & Caregiver Distress (n=299)



Assessed using the Hospital Anxiety Depression Scale (HADS) (score of ≥ 8 respectively)

Patient & Caregiver Trajectories (n=299)



⚠️ CG working

⚠️ Patient <50yo

Caregiver distress & bereavement adjustment

Currently there are few cohort studies that assess psychological well-being of caregivers of cancer patients from pre- to post-death.

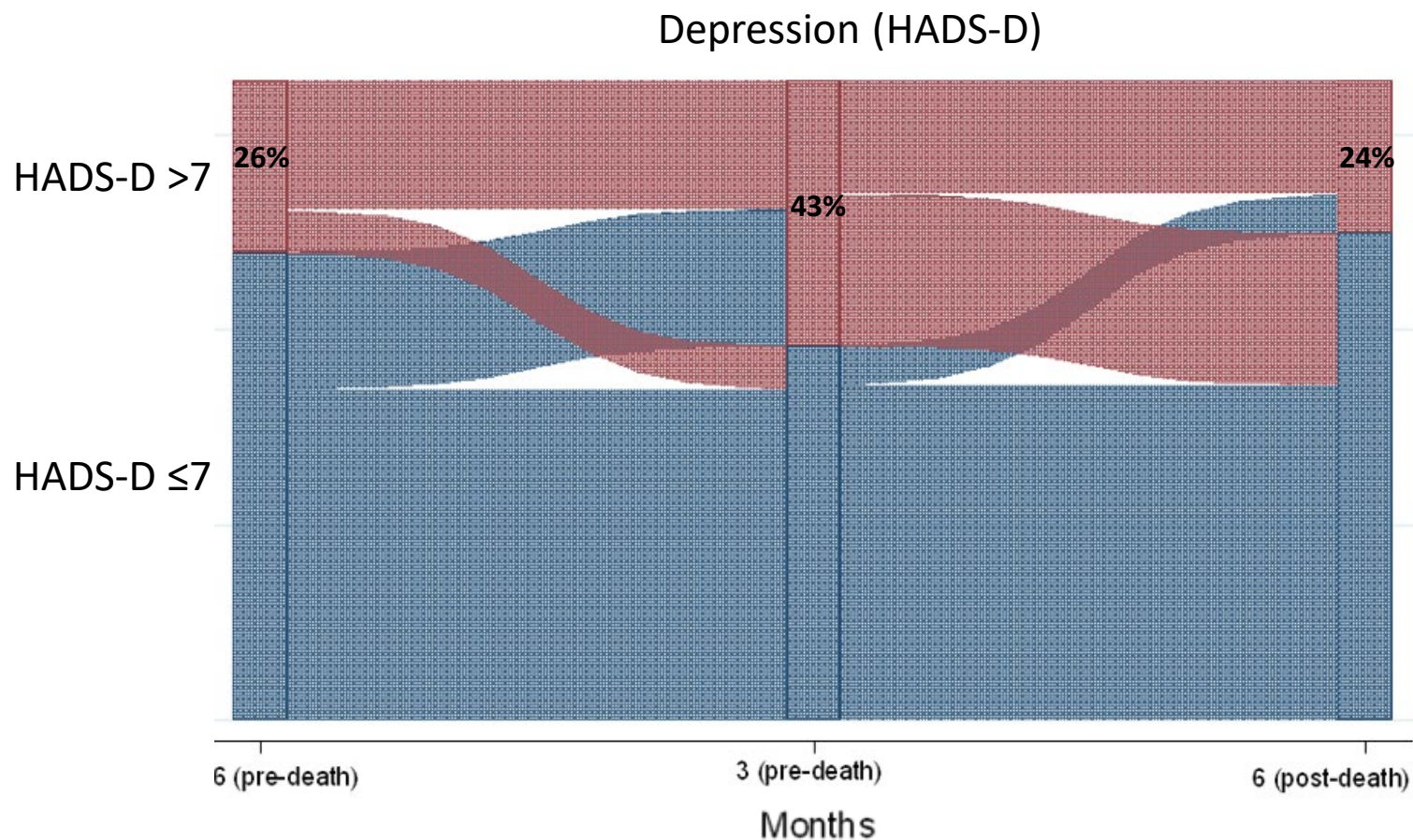
Complicated grief is an intense, persistent grief causing functional impairment more than 6 months into bereavement. It is associated with concurrent depression, suicidality, and adverse health outcomes.

Shear et al. 2012

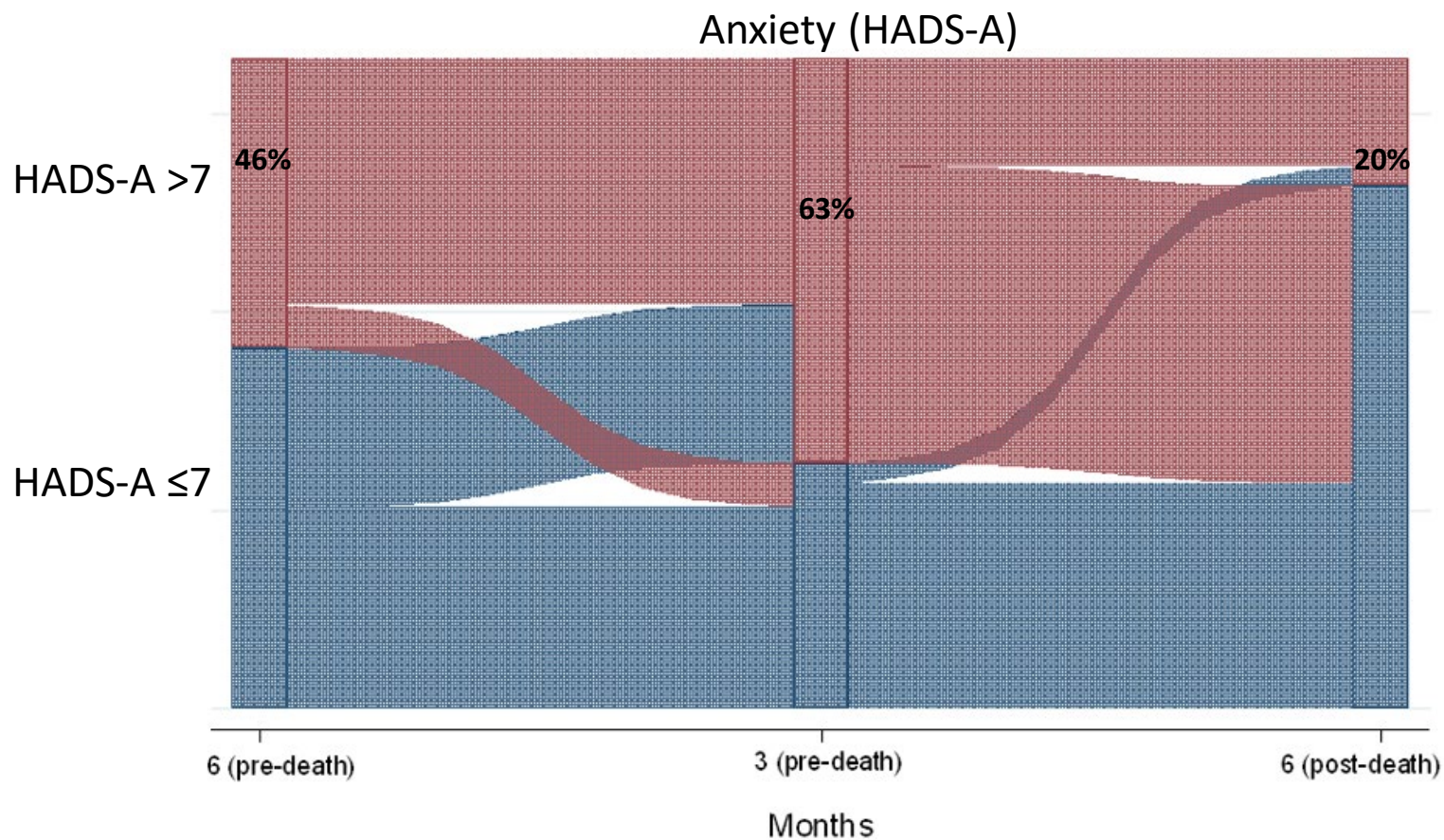
Study Aims

1. To examine caregiver distress pre- to post- patient death across 3 time points
2. To examine prevalence of caregiver bereavement adjustment difficulties at 6m's post-patient death
3. To examine predictors of bereavement adjustment difficulties

Caregiver Distress Pre- and Post-Patient Death (N=189)

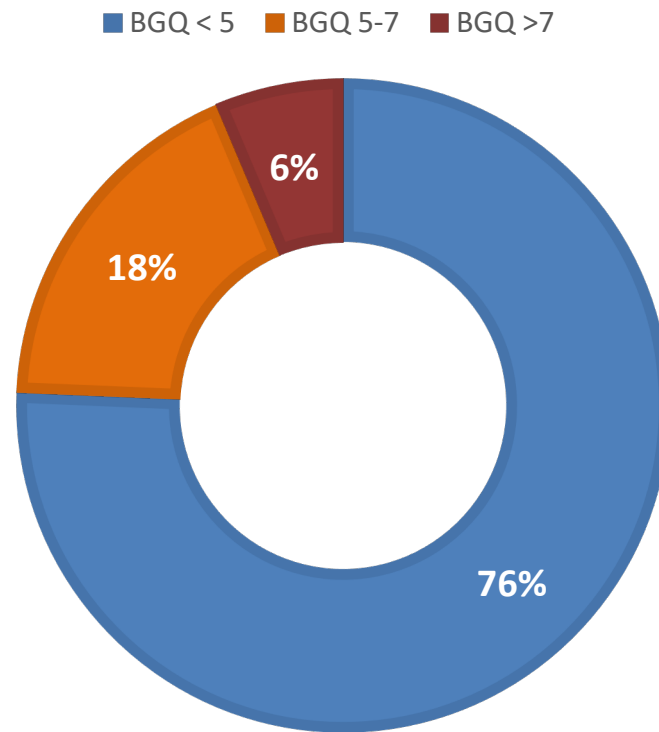


Caregiver Distress Pre- and Post-Patient Death (N=189)



Bereavement Adjustment Difficulties (N=189)

SCREENED USING THE BRIEF GRIEF QUESTIONNAIRE (BGQ)



Depression, $r = 0.33$



Anxiety, $r = 0.39$

Physical symptoms, $r = 0.38$

Peace, $r = -0.16$

Predictors of Bereavement difficulties & Distress




Pre-death factors

	BGQ		HADS Depression		HADS Anxiety	
	Coef. (SE)	[95% CI]	Coef. (SE)	[95% CI]	Coef. (SE)	[95% CI]
 Quality of relationship	0.27 (0.06)	[0.15, 0.4]	0.25 (0.1)	[0.05, 0.45]	0.08 (0.1)	[-0.11, 0.27]
Prior anxiety	-0.04 (0.05)	[-0.15, 0.06]	0.11 (0.08)	[-0.05, 0.28]	0.11 (0.08)	[-0.05, 0.28]
Prior depression	0.1 (0.05)	[-0.01, 0.2]	0.24 (0.08)	[0.09, 0.39]	0.12 (0.08)	[-0.04, 0.28]
 Sense of Peace	-0.09 (0.03)	[-0.15, -0.03]	-0.18 (0.04)	[-0.27, -0.09]	-0.11 (0.04)	[-0.2, -0.02]
Physical wellbeing	-0.03 (0.09)	[-0.2, 0.15]	-0.01 (0.15)	[-0.29, 0.28]	0.09 (0.14)	[-0.19, 0.36]

Note. Controlling for age, gender, relationship

Predictors of Bereavement difficulties & Distress

Post-death factors

	BGQ		HADS Depression		HADS Anxiety	
	Coef. (SE)	[95% CI]	Coef. (SE)	[95% CI]	Coef. (SE)	[95% CI]
 Perceived patient suffering	0.44 (0.16)	[0.12, 0.76]	0.63 (0.3)	[0.05, 1.22]	0.6 (0.26)	[0.08, 1.12]
 Decision making involvement	-0.38 (0.19)	[-0.75, -0.01]	-0.52 (0.34)	[-1.19, 0.16]	-0.29 (0.3)	[-0.89, 0.31]
 Prepared for patient death	-0.12 (0.06)	[-0.23, 0]	-0.02 (0.1)	[-0.22, 0.18]	-0.15 (0.09)	[-0.33, 0.03]

Note. Controlling for age, gender, relationship

Discussion

- **Caregiver burden**
 - Can co-exist with high caregiving esteem
 - Risk factor: \$\$ inadequacy
- **Dyadic distress**
 - Larger proportion of caregivers report distress
 - Risk factors: younger patients, \$\$ inadequacy, caregivers working
- **Pre-post death adjustment**
 - Distress increase closer to patient death – support then?
 - About 6% screened for complicated bereavement, while 18% were sub-threshold
 - Feeling at peace, being involved in decision making

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