

Mental health and caregiving: Reciprocal influences for familial caregivers and those in their care



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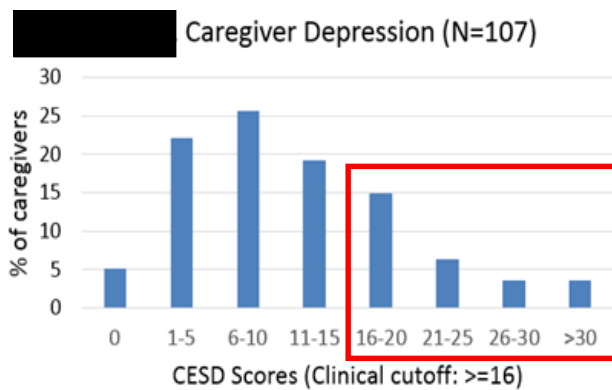
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Individuals with dementia and caregivers: A shared journey

The PWD's journey	The caregiver's journey
<ul style="list-style-type: none">• Changes in cognitive, emotional, and motor functioning• Progressive• No cures	<ul style="list-style-type: none">• Changes in mental health<ul style="list-style-type: none">• 2-4X rates of depression• 3X rates of anxiety• Greater use of psychotropic medications• Changes in physical health<ul style="list-style-type: none">• Declines in physical health• Greater health care utilization• Declines in immune functioning• Preventable?

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But every caregiver's journey is not the same



Three big questions

1. What happens to patients when caregivers get sick?
2. Why do some caregivers get sick while others do not?
3. How can we protect caregivers' health?

Depressive symptoms in 107 familial caregivers assessed at UC, Berkeley

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Question 1: What happens to patients when caregivers get sick?

Participants

- 176 individuals with neurodegenerative diseases and their familial caregivers

Procedure

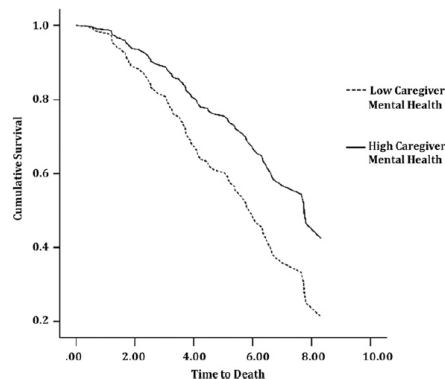
- Tracked patient mortality during an 8.5 year period after they were evaluated at Berkeley

Analysis

- Survival analysis controlling for patient factors (diagnosis, age, sex, dementia severity, mental health) and caregiver physical health

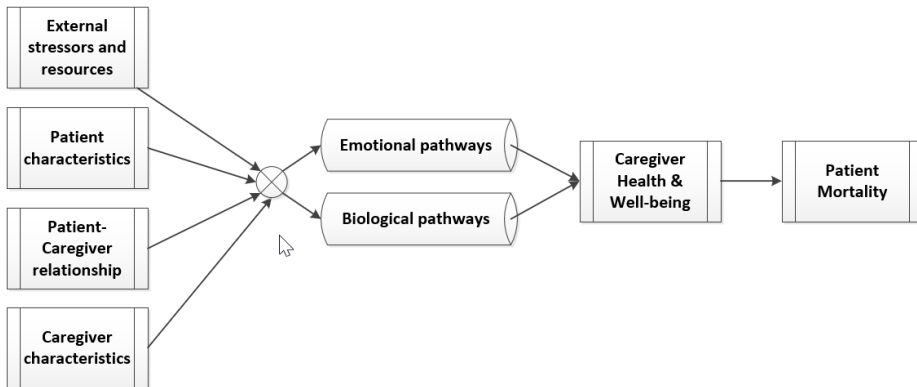
Results

- Patients being cared for by caregivers in poor mental health at start of period were 47% more likely to have died after 8.5 years than caregivers who weren't depressed



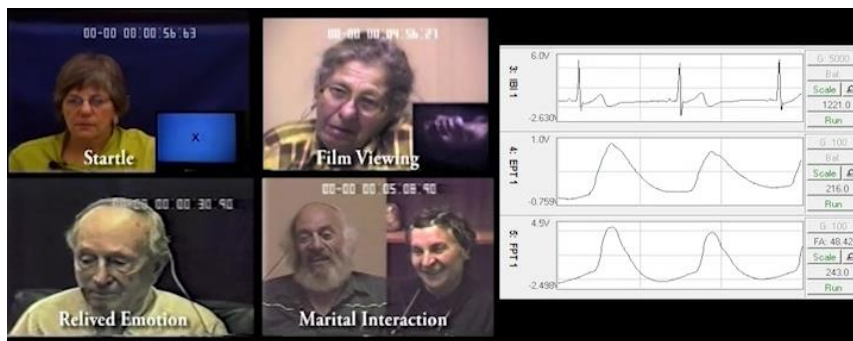
Lwi, S.J., Ford, B.Q., Casey, J.J., Miller, B.L., & Levenson, R.W. (2017). Poor caregiver mental health predicts mortality of patients with neurodegenerative disease. *Proceedings of the National Academy of Sciences of the United States of America*, **114**, 7319-7324.

Question 2: Why do some caregivers get sick while others do not?



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Studying emotional functioning in the laboratory



~600 patients and 200 ADRD patient-caregiver dyads evaluated to date

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Behavioral “molecules”: Pathways to declining caregiver health

1. Lack of visual avoidance in patients
2. Lack of “we”-focused pronouns in patient-caregiver relationship

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Visual avoidance

Participants

- 86 PWD (50% with bvFTD, 50% with AD) and their familial caregivers

Procedure

- PWD view VERY disgusting movie

Measures

- PWD visual avoidance behaviors (e.g., head turn, look away, squint) rated by trained coders
- Caregiver mental illness symptoms measured with SCL-90R

Results

- Less visual avoidance in PWD associated with more mental illness symptoms in caregivers (controlling for dementia severity); ($\beta = -.26, p = .018$)

Meaning

- Declines in visual avoidance may be early indicators of more general declines in emotion regulation in PWD



Otero, M.C., & Levenson, R.W. (2017). Lower Visual Avoidance in Dementia Patients Is Associated with Greater Psychological Distress in Caregivers. *Dementia and Geriatric Cognitive Disorders*, **43**, 247-258.

Pronouns

Participants

- 58 PWD (37 FTD, 13 AD, 8 other) and their spousal caregivers

Procedure

- PWD and caregiver have 10-minute discussion of area of disagreement in their relationship
- Verbatim transcript prepared

Measures

Pronouns

- I-pronouns (I, me, my, etc.)
- You-pronouns (you, your, etc.)
- We-pronouns (we, our, us, etc.)

Caregiver distress

- Composite of depression, anxiety, strain, and burden (alpha = .84)

Loneliness

- UCLA Loneliness Scale

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C: When Max barks, do you sometimes squeeze him or um put him between your legs and squeeze him. You know, so that he's squeezed and...sometimes he squeals, right, because you're hurting him. OK. So I'm wondering are you doing that because you're angry with him or are you doing that because you're trying to get him to stop?

P: I try to get him to stop barking

C: Do you think there could be another way that you could do that, you know, by just...like sometimes you just talk to him and he does stop. You know, um, but you keep doing it that way. This is something that you and I have had an issue with...um..um. Do you think you could just talk to him and not squeeze him so that he squeals, do you think you could do that?

P: I don't know what you're talking about.

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C: When Max barks, do **YOU** sometimes squeeze him or um put him between **YOUR** legs and squeeze him. **YOU** know, so that he's squeezed and...sometimes he squeals, right, because **YOU'RE** hurting him. OK. So **I'M** wondering are **YOU** doing that because **YOU'RE** angry with him or are **YOU** doing that because **YOU'RE** trying to get him to stop?

P: **I** try to get him to stop barking

C: Do **YOU** think there could be another way that **YOU** could do that, **YOU** know, by just...like sometimes **YOU** just talk to him and he does stop. **YOU** know, um, but **YOU** keep doing it that way. This is something that **YOU** and **I** have had an issue with...um..um. Do **YOU** think you could just talk to him and not squeeze him so that he squeals, do **YOU** think **YOU** could do that?

P: **I** don't know what **YOU'RE** talking about.

<p>PWD Total words: 15 I: 2 you: 1 we: 0</p> <p>Caregiver Total words: 128 I: 2 you: 18 we: 0</p>

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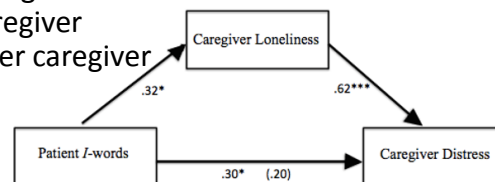
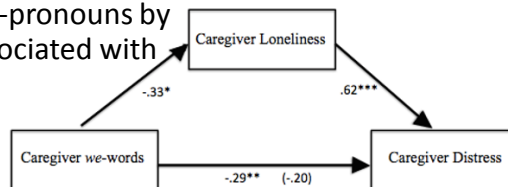
Results

Lower use of we-pronouns by PWD ($\beta = -.424$, $p = .001$) and caregivers ($\beta = -.324$, $p = .011$) associated with greater caregiver distress

Greater use of I-pronouns by PWD ($\beta = .310$, $p = .014$) and greater use of you-pronouns by caregivers ($\beta = .312$, $p = .014$) associated with greater caregiver distress

Meaning

Fewer we-pronouns and more pronouns referring to PWD associated with greater caregiver loneliness. Greater caregiver loneliness associated with greater caregiver distress



(Connelly, Verstaen, Brown, Lwi, & Levenson, under review)¹²

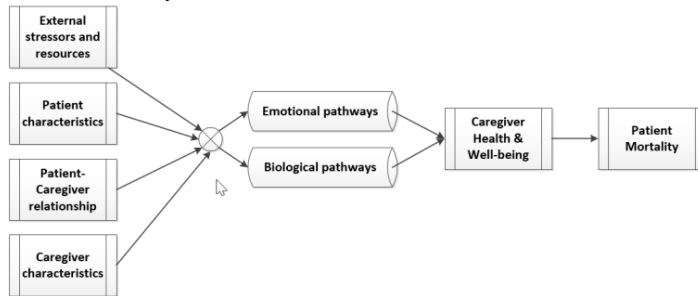
Behavioral molecules: Real world implications

For understanding why some caregivers get sick while others do not?

- Provide new ways of quantifying risk for health declines in caregivers

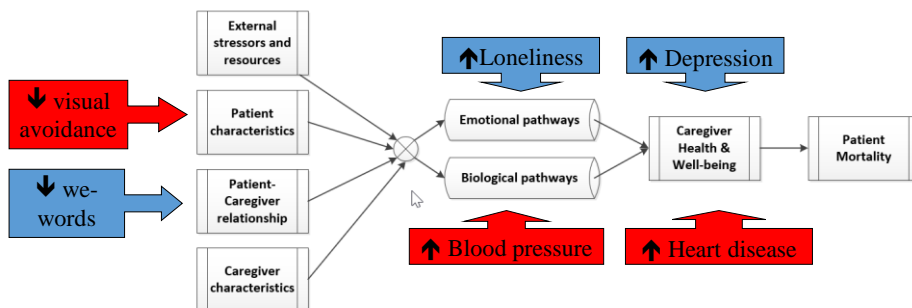
For protecting caregivers' health (and health of PWD)

- Guide development and evaluation of new interventions



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From molecules to pathways to mechanism-based interventions



Can design interventions that target established mechanisms
Interventions can be compact, focused, and minimize caregiver burden
Can evaluate effectiveness by monitoring pathways
Using “experimental medicine” guidelines for treatment evaluation

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The current state of caregiver interventions

A mixed track record in the real world (Gitlin et al., 2015)

- > 200 interventions have been proved to be efficacious in randomized clinical trials in past 30 years
- Only 6 have been translated into community trials
- Long-term effectiveness is not known

Challenges

- Scaling, fidelity, and dissemination
- Attrition associated with limited caregiver time and energy

Mechanism-based interventions and evaluations are extremely rare

Recent encouraging developments

- NIA research priorities
- Technology-based interventions

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- Berkeley Psychophysiology Laboratory
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- Our research participants and their families



From Left: Robert Levenson, Luma Muhtadie, Anna Sapozhnikova, Alice Verstaen, Yang Chien-Ming, Michael Simpson, Jim Casey, Marrele Otero, Claudia Heise, Scott Newton, Deepak Pavi & Sandy Liu



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