

Policies and Practices for Supporting Family Caregivers Working in Science, Engineering, and Medicine: Symposium 2



EMOTIONAL AND HEALTH IMPACTS OF END OF LIFE CAREGIVING AND BEREAVEMENT: IMPLICATIONS FOR FAMILY CAREGIVERS IN ACADEMIA AND STEM

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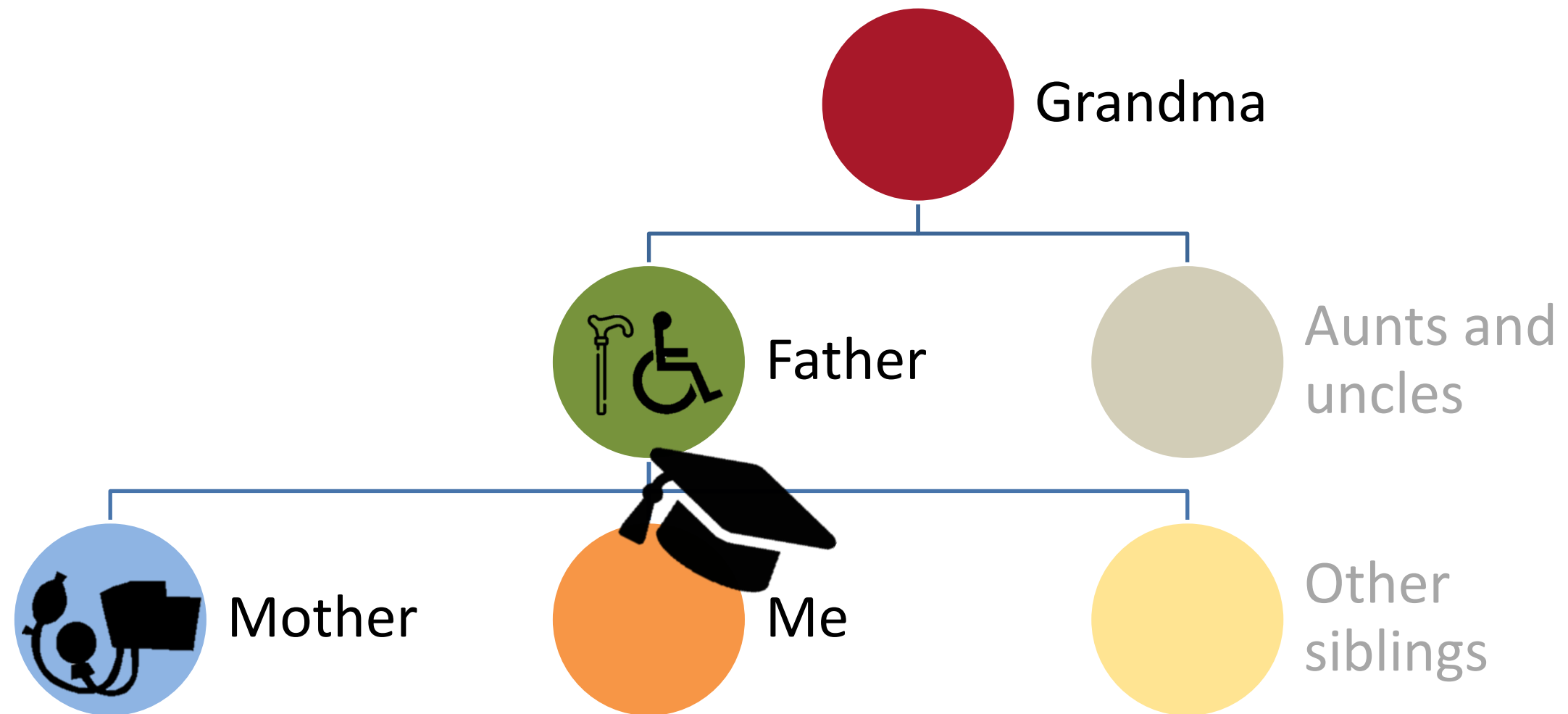
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DISCLOSURES: NONE

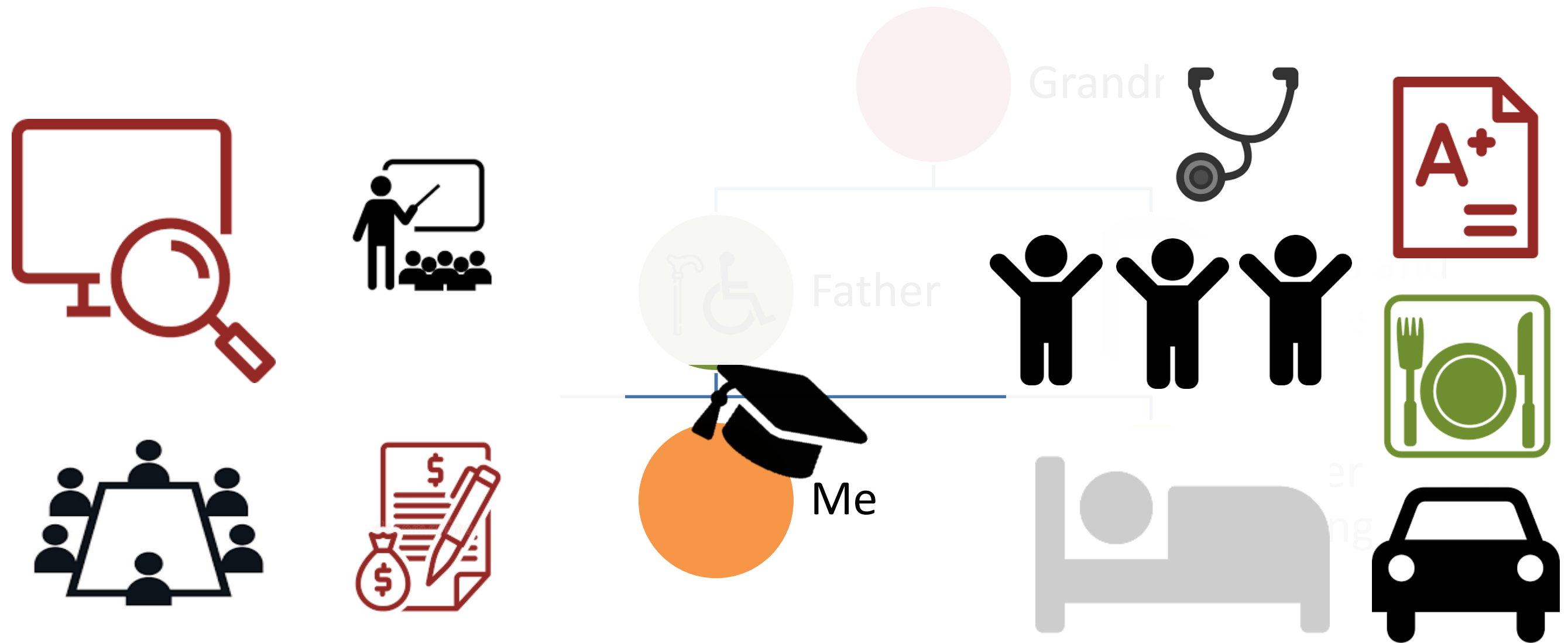
ACKNOWLEDGEMENT OF STUDY FUNDING:

Hospice Today study- NR016249 (PI: Ellington); **Denmark Population Register study-**nK01AG047923 (PI: Ornstein); **Utah Caregiving Population science** (Utah C-POPS): Consortium for Families and Health Research (mPIs: Stephens, Smith, Tay, Utz), Family Caregiving Collaborative (PI: Stephens); **ImmPETUS dataset:** Vice President for Research Seed Grant (PI: Tay); **HCI immunotherapy dyad study:** HCI supportive oncology and survivorship program seed grant (PI: Tay)

INTERSECTIONS OF ROLES



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OVERVIEW

- **Research in end of life caregiving**
 - Implications for policies and interventions
- **Research in bereavement**
 - Implications for policies and interventions
- **Research on spousal cancer caregiving**
 - Implications for policies and interventions

TIMELINE

- **Pre-post doc:** Hospice caregiving studies
(NR016249, PI: Ellington, Hospice Today Study)
- **Post-doc:** Population datasets to examine end of life health utilization and bereavement outcomes *(K01AG047923), PI: Ornstein, Danish Population Registers); Multiple intramural: Mt Sinai, C-FARH, FCC)*
- **Current (TT Asst Prof):** Population datasets to examine impact of cancer trajectory on spousal stress-related comorbidity *(Intramural VPR seed grant, PI: Tay)*

Anxiety, Depression, and Caregiving Burden



ANXIETY AND DEPRESSION IS PREVALENT IN CANCER CAREGIVERS

- Global prevalence of depression is 4.4%, anxiety is 3.6%.¹
- Among cancer caregivers the prevalence of depression is **42.3%** and prevalence of anxiety is **46.55%**.²
- Ongoing survey: N= 35 advanced head and neck and lung cancer patients, N= 20 caregivers; 15 dyads
- **Caregivers had greater anxiety than patients**
 - Caregiver anxiety (M=7.85, SD=3.96, 0-15); patient anxiety (M=5.60, SD=3.73, 0-14, $p=0.040$)
- In the **dyadic subsample of 15 dyads:**
 - **Caregivers** had lower optimism, greater anxiety, depression
 - Mean difference optimism=3.47, SD=3.96
 - Mean difference anxiety= -3.53, SD= 3.16
 - Mean difference depression =-2.73, SD=3.31
 - All $p<0.05$ (Tay, et al., manuscript in progress)



1. World Health Organization. Depression and Other Common Mental Disorders: Global Health Estimates. World Health Organization; 2017

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ANXIETY AND DEPRESSION IN HOSPICE CAREGIVING



- **Hospice Today Study:** $N=102$ cancer hospice family caregivers
- **Caregiving burden** was associated with:³
 - **Anxiety** ($B=0.18$ point, 95% CI = 0.009 – 0.27)
 - **Depression** ($B= 0.15$, 95% CI = 0.08 – 0.22)
- **Older Age** was associated with lower **anxiety** ($B= 0.12$, 95% CI= -0.18 - -0.05)³
- **Increased financial adequacy, social support** was associated with lower **depression** ($B = -1.19$, 95% CI= -2.07 to -0.32; $B = -0.04$, 95% CI= -0.06- -0.01)³



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IMPLICATIONS FOR STUDENT CAREGIVERS

- Prevalence of student caregiving⁴
 - Higher proportions of women, grad students, part-time enrollees, financial aid recipients⁵
- **Impact on student outcomes**
 - Anxiety and Depression⁵
 - GPA⁵
 - Dropout rates⁶

Potential Strategies:

- Frequent Assessment, understanding, flexibility from mentors
- Wellness supports
- Students helping students (Student hardship fund); caregiving focused scholarships



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Time strain



SELF-CARE IN HOSPICE CAREGIVERS



- Self-care deficits:
 - 47.67%- **Not enough time to exercise**
 - 47.67%- **Not enough time to rest**
 - 46.51%- Not being able to slow down and **get rest when sick**
 - 33.72%- **Missed at least one physician appt** in the past six months
- While caregiving burden not associated with self-care, better mental health associated with higher odds of
 - Getting enough time to **exercise** ($OR_{adj}=1.15$, [1.05, 1.26], $p=0.004$)
 - Getting enough **rest** in general ($OR_{adj}=1.11$, [1.01, 1.22], $p=0.031$)
 - Being able to **slow down when sick** ($OR_{adj}=1.16$, [1.04, 1.30], $p=0.010$)
 - Having enough time to go the **physician** ($OR_{adj}=1.12$, [1.02, 1.24], $p=0.02$)

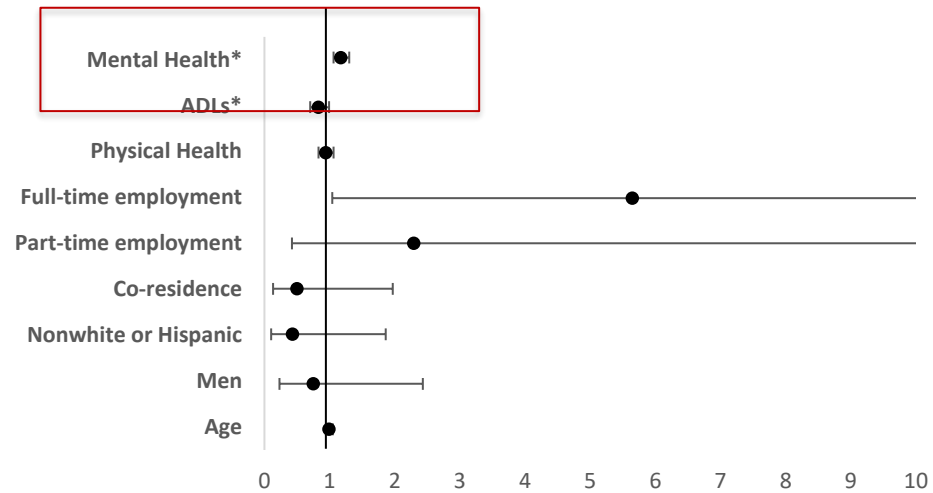


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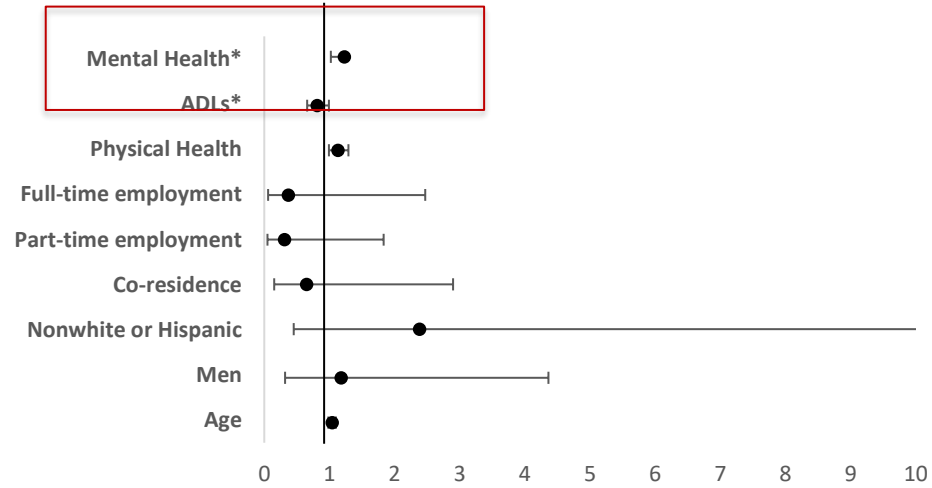
(Tay et al., manuscript under review)

ADLS & SELF-CARE

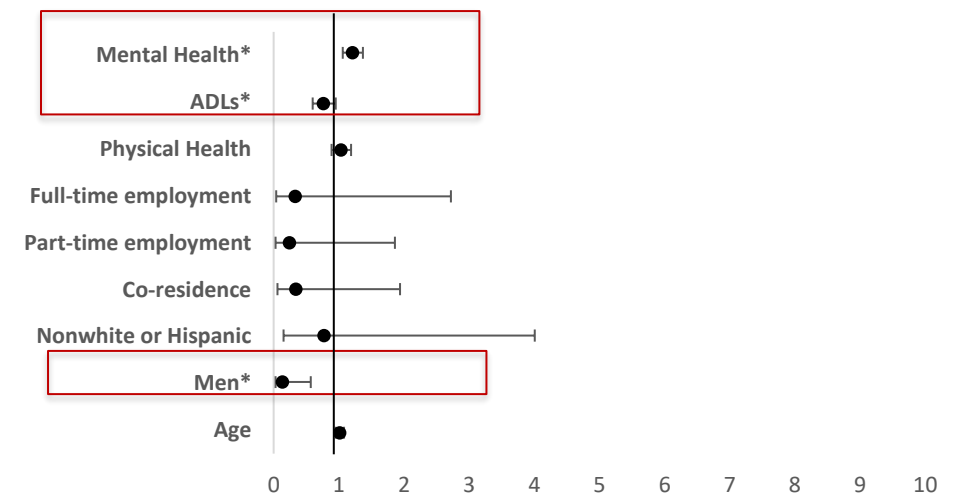
Time to Exercise (N=81)



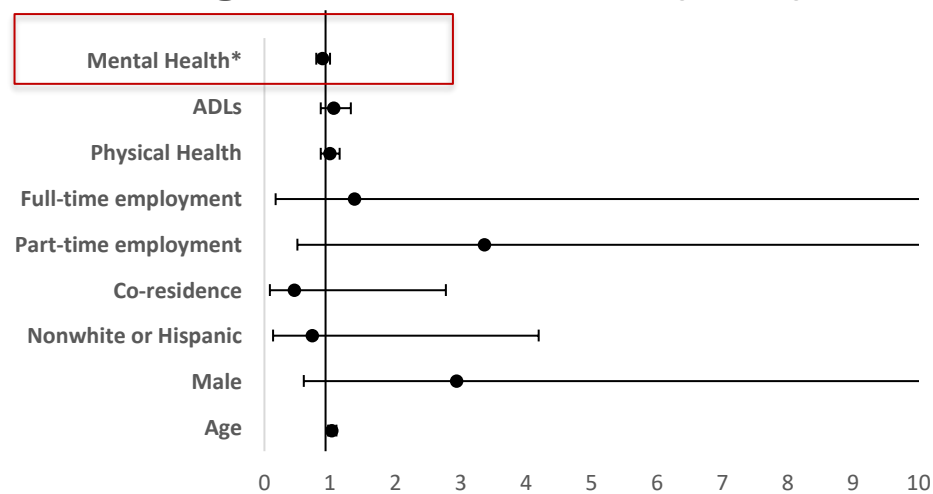
Enough Rest in General (N=81)



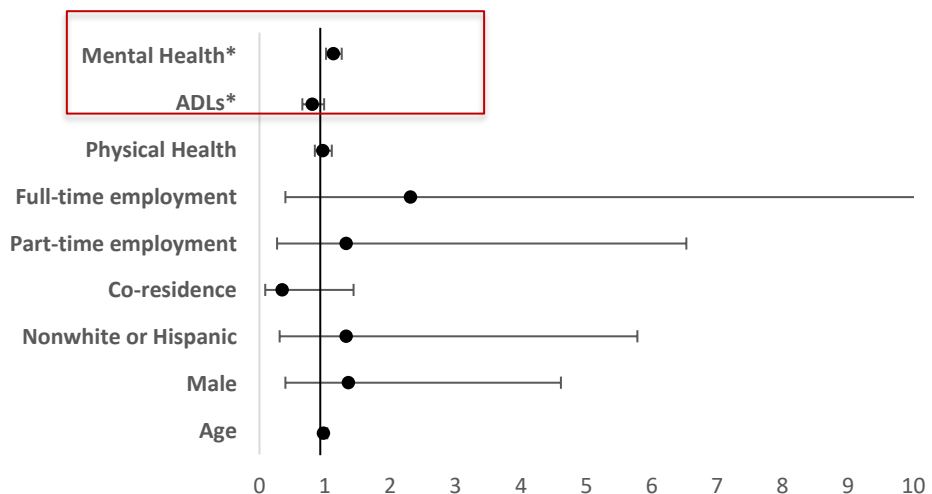
Slow down and get rest when sick (N=78)



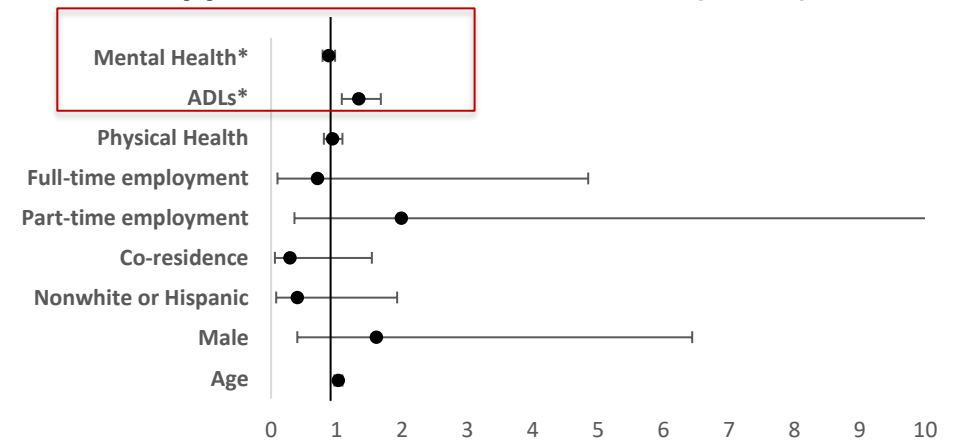
Forget to take medication (N=79)



Enough time to go to physician (N=81)



Missed at least one physician appointment in last 6 months (N=81)



(Tay et al. manuscript under review)

EMPLOYMENT AND OVERALL HEALTH, WORK PRODUCTIVITY LOSS, PRESENTEEISM, AND ACTIVITY IMPAIRMENT



- Caregiver burden was associated with poorer health⁷
- At greater levels of burden, working caregivers had better overall health⁷
- Yet other analyses suggest caregiving burden affects quality of work⁸

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IMPACT OF CAREGIVING ON WOMEN ACADEMICS - LESSONS FROM THE PANDEMIC



- **Working much less on research than planned:**
 - 50% of men versus 62% of women⁹
- **Difficulty **analyzing** quantitative and qualitative data:**
 - 24 % of non-caregiving faculty versus 41% of caregiving faculty⁹
- **Women were more likely to report difficulties in **grant writing**⁹**
- **Difficulties with **time management**:**
 - 48% of men, 63% of women⁹
- ****Balancing** family, household and work responsibilities**
 - 61% of men; 75% of women⁹

9. Skinner, M., Betancourt, N., & Wolff-Eisenberg, C. (2021, March 31). *The Disproportionate Impact of the Pandemic on Women and Caregivers in Academia*. <https://doi.org/10.18665/sr.315147>

ASSISTIVE TECHNOLOGIES AND PROGRAMS TO SUPPORT WORKING CAREGIVERS ROLE

Reduce time burden

- Telehealth

Alleviate caregiving burden

- Respite care
- Home healthcare
- Homemaker services
- Financial caregiving support

Improve ability to monitor and manage care

- Remote monitoring/ sensor technologies
- Electronic health record sharing

STRATEGIES TO SUPPORT CAREGIVING STEM PROFESSIONALS

Reduce Time burden

- Part-time enrollment for caregiving students¹⁰
- **Remote work** arrangements, including teaching¹¹
- **“Helping hand” grants**, editorial/manuscript support
- **Course reduction, research leave, sabbaticals, flexibility in workload**^{11,12}

Alleviate caregiving burden

- **Institutional:** Dependent care Benefits, compassionate leave, FMLA, and paid time off benefits
- Emergency funds for caregiving assistance, including childcare and eldercare¹³
- **Professional:** Conference stipends/grants for dependent travel/care

Improve ability to be productive and further career

- Writing and teaching groups¹¹
- No cost extensions¹¹
- National: Grants and NOSIs to support re-entry¹¹

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11. Schneider, M. C., Graham, L., Hornstein, A. S., LaRiviere, K. J., Muldoon, K. M., Shepherd, S. L., & Wagner, R. (2021). Caregiving, Disability, and Gender in Academia in the Time of COVID-19. *Advance Journal*, 2(3).

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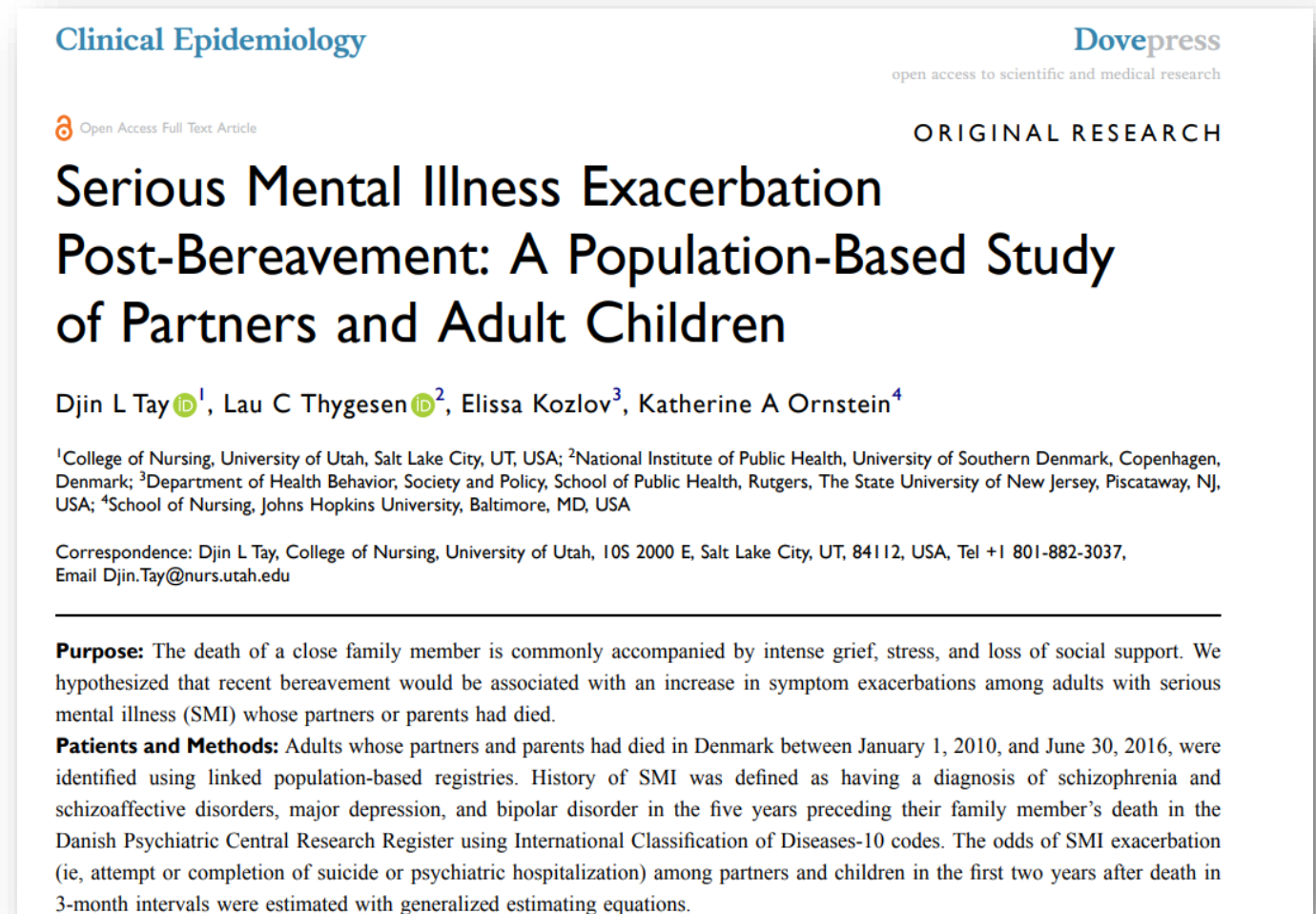
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Outcomes



WHICH FAMILY MEMBERS ARE AFFECTED IN BEREAVEMENT?

- **Spouses & Partners:** New antidepressant prescriptions¹⁴
- **Young and middle-aged siblings:**
 - Increase in psychological services¹⁵
 - New mental health diagnoses¹⁵
- **Partners and Children with Serious Mental Illness:**
 - Risk of inpatient psychiatric hospitalization, attempted, completed suicide¹⁶

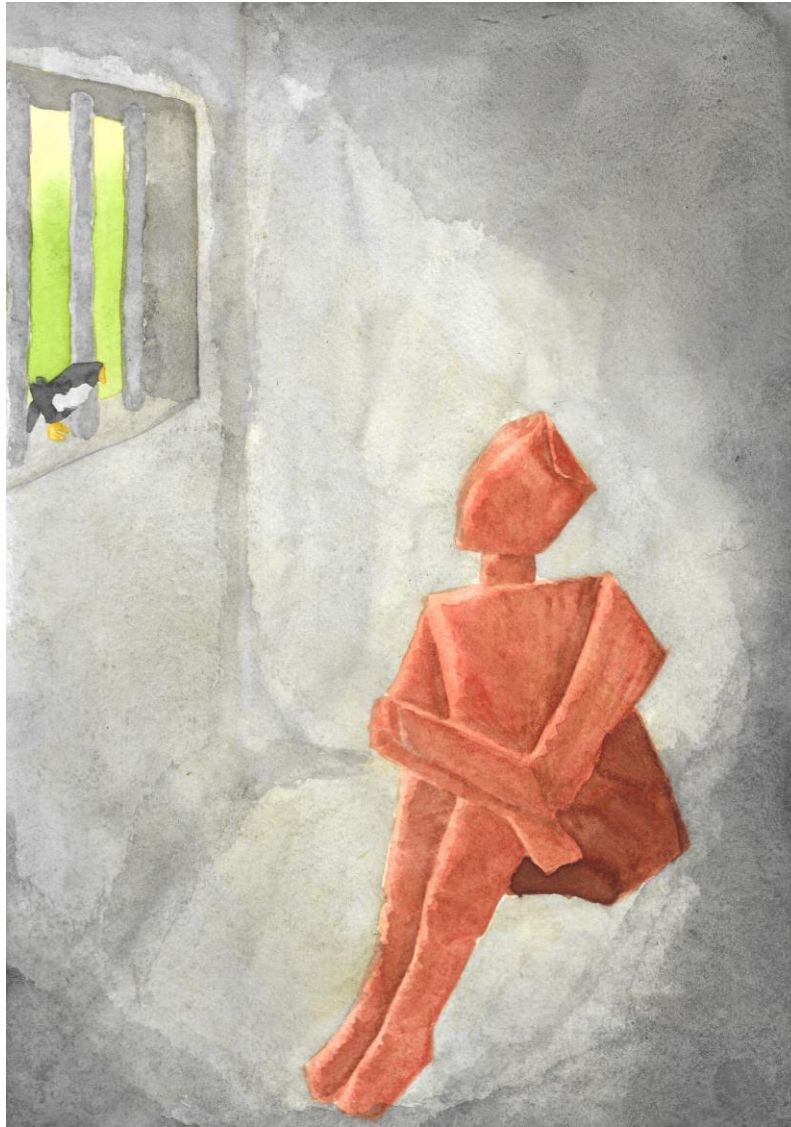


14. Ornstein, K. A., Aldridge, M., Gillezeau, C., Kristensen, M. S., Gazibara, T., Groenvold, M., & Thygesen, L. C. (2020). New antidepressant utilization pre-and post-bereavement: a population-based study of partners and adult children. *Social psychiatry and psychiatric epidemiology*, 55, 1261-1271.

15. Gazibara, T., Ornstein, K. A., Gillezeau, C., Aldridge, M., Groenvold, M., Nordentoft, M., & Thygesen, L. C. (2021). Bereavement among adult siblings: an examination of health services utilization and mental health outcomes. *American Journal of Epidemiology*, 190(12), 2571-2581.

16. Tay DL, Thygesen LC, Kozlov E, Ornstein KA. Serious Mental Illness Exacerbation Post-Bereavement: A Population-Based Study of Partners and Adult Children. *Clin Epidemiol*. 2022 Sep 20;14:1065-1077. doi: 10.2147/CLEP.S372936. PMID: 36164496; PMCID: PMC9508997.

MENTAL HEALTH- AN UNDER ADDRESSED ISSUE IN ACADEMIA



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- One in 3 graduate students are at risk of developing a mental health disorder¹⁷
- Bereavement is an acute stressor that can exacerbate preexisting mental health conditions

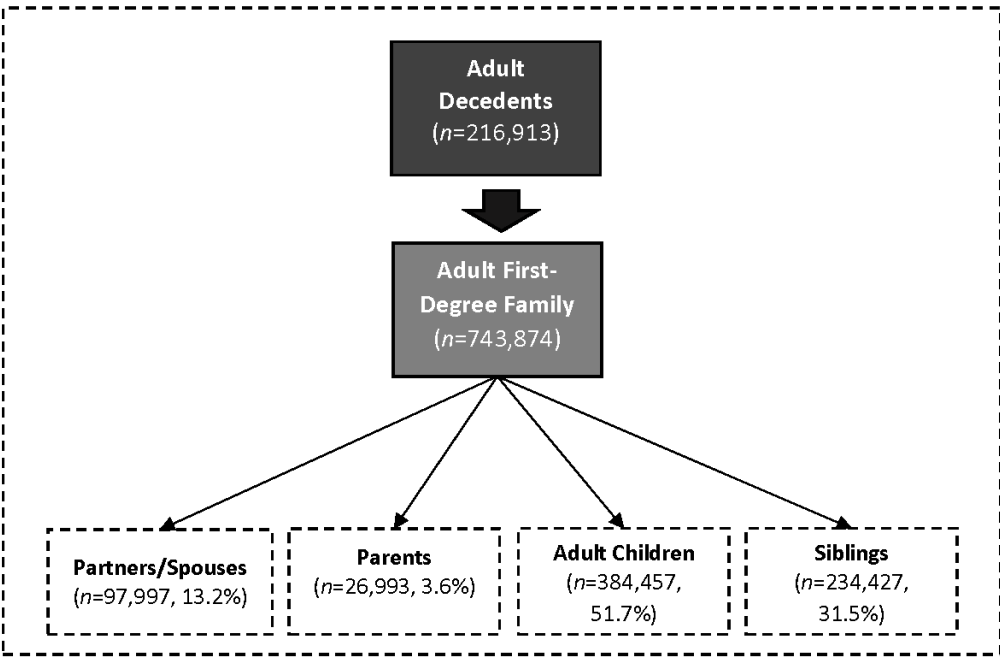
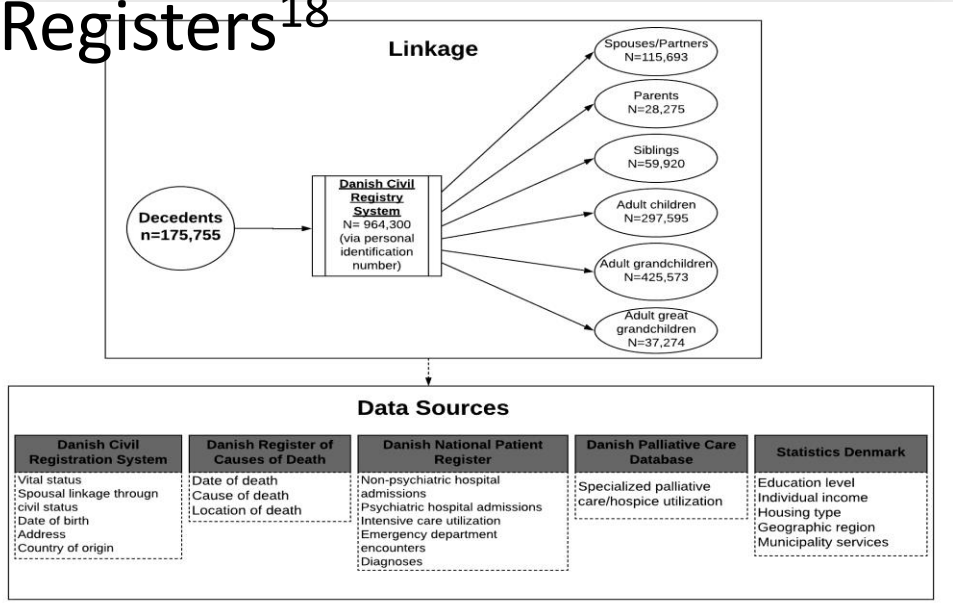
Recommendations from Council of Graduate Schools and the Jed Foundation:¹⁷

- Better training for mentors
- Increase availability and accessibility of counseling and mental health support
- Increase training for non-academic careers
- Revise graduate-leave policies
- Focus on individual rather than scientific output

FROM HOME BASED CARE TO POPULATION LEVEL PERSPECTIVES

Utah Caregiving in Population Science (Utah C-Pops)¹⁹

Denmark Population Registers¹⁸



Utah C-POPS Core team members: Caroline Stephens (Nursing), Katherine Ornstein (Johns Hopkins), Ken Smith (Nexus), Rebecca Utz (Sociology), Djin Tay (Nursing), Ken Hollingshaus (Demography), Eli Iacob (Nursing), Lee Ellington (Nursing)

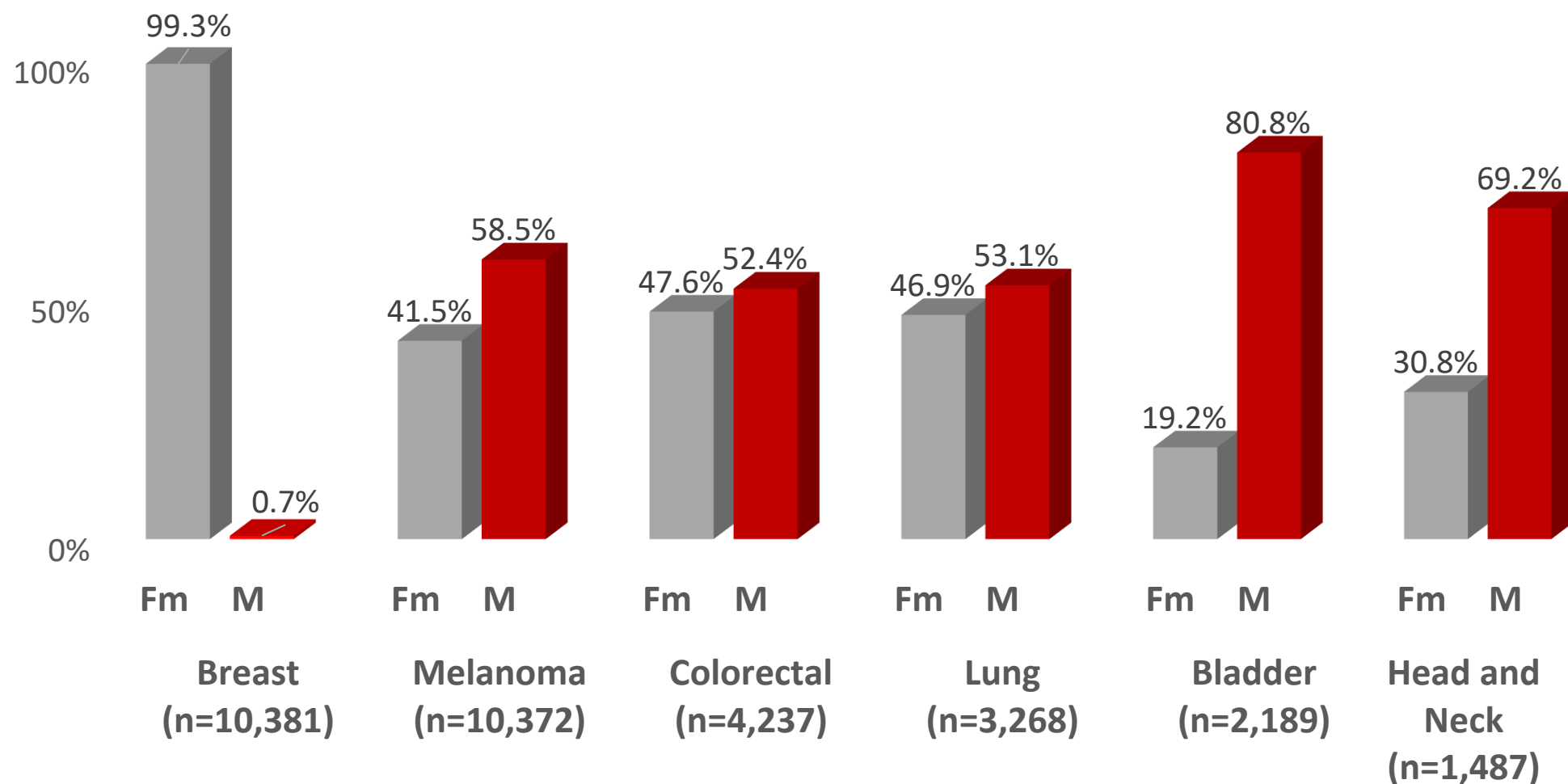


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Immunotherapy, Palliative, End of Life Treatment Utilization and Spousal Outcomes (*ImmPETUS*): A linked population dataset for dyadic cancer research

Proportions of cancers by gender (N=31,932)



Includes:

- All cancer patients with melanoma, colorectal, breast, lung, bladder, head and neck cancers
- Their spouses and partners

Initial cancer diagnosis 2013-2018

• Spouses/partners

(N=16,051)

- Ambulatory surgery encounters (n=25,382)
- Inpatient hospitalizations (n=26,690)
- ED encounters (n=14,828)
- Stress-related health diagnoses, e.g.
 - Depression (n=3,273)
 - Anxiety (n=2675)

IMPLICATIONS FOR TENURE

TENURE

- More women have doctoral degrees compared with men²⁰
- Yet women are less likely to earn tenure and promotion and earn less²¹

EXTENDING THE TENURE CLOCK

- Pausing tenure impacts earnings and salaries²², delays promotion and progression, and opportunities for leadership and grants²³
- Pausing tenure clock reduces pool of tenured women faculty while increases pool of male tenured faculty²⁴
- Women are less likely to stop the tenure clock²⁴

Equity implications

- Non-tenure-track faculty members have different needs
- Implications for diversity and equity– minoritized women are most concentrated off the tenure track²⁵



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25. Staniscuaski, F., Reichert, F., Zandonà, E., Soletti, R. C., Infanger, C., Mello-Carpes, P. B., ... & de Oliveira, L. (2021). Time to fight the pandemic setbacks for caregiver academics. *Nature Human Behaviour*, 5(10), 1262-1262.

Changing the culture



CHANGING THE CULTURE



- **Why students are leaving STEM research---**
- 69% of STEM students indicating disinterest in academia cite the stressful nature as reasons for leaving²⁶
- **Acknowledge and address** the role of gender bias in career progression²³
- **Increase visibility** of caregiving, distributing professional responsibilities more fairly²³
- Support/affinity groups¹¹
- Expand wellness supports¹¹

26. McGee et Al. (2019). Turned off from an academic career: Engineering and computing doctoral students and the reasons for their dissuasion. International journal of doctoral studies, 14, 277-305. <https://doi.org/10.28945/4250>

“There are only four kinds of people in the world.
Those who have been caregivers.
Those who are currently caregivers.
Those who will be caregivers, and those who will
need a caregiver.”

— **Rosalyn Carter**

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