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Caregiver Mental Health

Risk factors for caregiver mental health/suicidal thoughts and ways to improve caregiver psychosocial wellbeing

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Outline of Presentation

- Introduction
- Overview of Literature
  - Caregivers Broadly
  - Suicidal Ideation in Caregivers
  - Depression
  - Interpersonal Factors
  - Affiliate Stigma
- Findings of Dissertation Project
- Ways to help caregiver psychosocial wellbeing

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Introduction

Introduction

- Education
  - BA in psychology from Wheaton College, IL
  - Graduate School training at the Illinois Institute of Technology in Chicago, IL
    - MS in Clinical Psychology Science
    - PhD Candidate in Clinical Psychology with a Rehab Psychology Emphasis
- Clinical Training
  - Previous work in outpatient mental health, neuropsychology, and rehab psychology inpatient and outpatient settings
  - Current Behavioral Medicine and Rehabilitation Psychology Resident at Harborview Medical Center part of UWMC.

- Membership and special interests in American Psychological Association's division on Rehab Psychology ("Division 22")

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Literature Review

The Mental Health of Caregivers

1.1 Overview of Caregivers

52 million +
caregivers
(Houser & Gibson, 2008)

- Caregivers are America's "Super Helpers"
- Account for about 264 billion dollars in US healthcare costs

- **CHRONIC ILLNESS AND DISABILITY & TBI**(WHO, 2016; CDC, 2021)
  - ¼ persons lives with a disability in US
    - 1.5 mil sustain a new TBI every year
      - 80-90,000 PwTBI go on to have long term disability
      - Cumulatively ~5.3 million now live with TBI
  - Caregivers of PwCID → poor mental health (Sullivan & Miller, 2015; Miyashata et al., 2008)

1.1 Overview of Caregivers Cont'd

Characteristics of Caregivers

- Stansfeld et al (2014); N = 3,082
  - women
  - middle age
- NAC & AARP 2015; N = 201
  - 49% Child of care recipient; 10% spouses
  - 24.4 hr/wk caregiving
  - 46% help for ADLs (e.g. sit-stand, eating)
  - 72-78% for iADLs (e.g., driving, shopping)
- Middle adult age, female gender, spousal role, disability severity and more time spent caregiving associated with increased SI (Joling et al., 2019; Abbott et al., 2014; Triechel et al., 2019; O'Dwyer et al., 2016; Park et al, 2013).

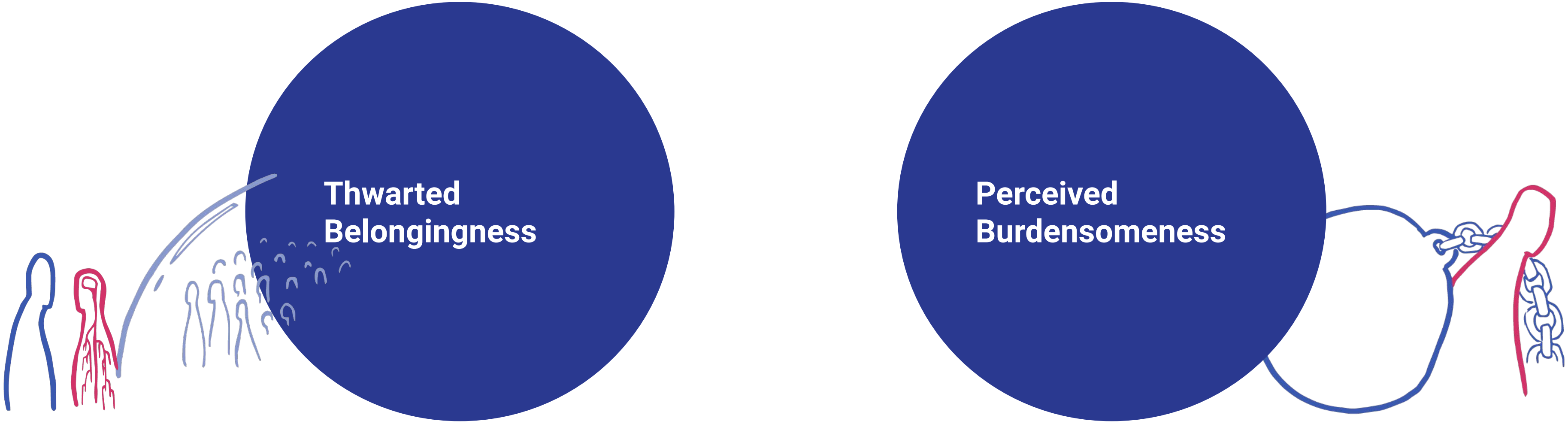
1.1 Overview of Caregivers Cont’d

- Caregiving associated with...
    - higher distress (Fujinami et al., 2015)
    - burnout (Gérain & Zech, 2019)
    - reduced social support (Bornstein & Weber, 2008)
    - discrimination experiences (McManus et al., 2009)
    - mental health problems (including depression) (Buchanan et al., 2010; Bostrom et al., 2006; Finlayson & Cho, 2008)
    - **Notably, elevated Suicidal Ideation (SI) .**

1.1 Overview of Caregivers

- **Joiner's (2005) Interpersonal Psychological Theory (IPT)**

Not yet applied to the caregiver population



Thwarted Belongingness

Perceived Burdensomeness

1.2 Suicidal Ideation (SI) - Caregivers of PwCID

- “Thinking about, considering, or planning suicide” (NIMH, 2019)

4%

US Population

(Piscopo et al., 2016)

0.6-2.0%

Globally

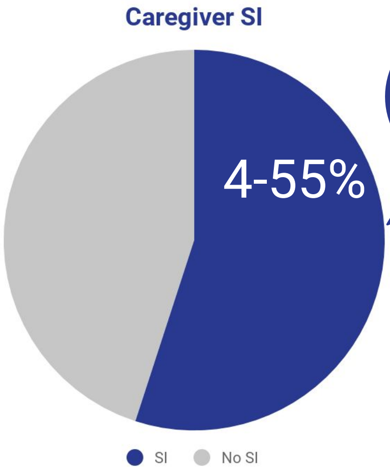
(WHO; Borges et al., 2010)

- Any lifetime SI: 30% probability of attempting (Nock et al., 2008)

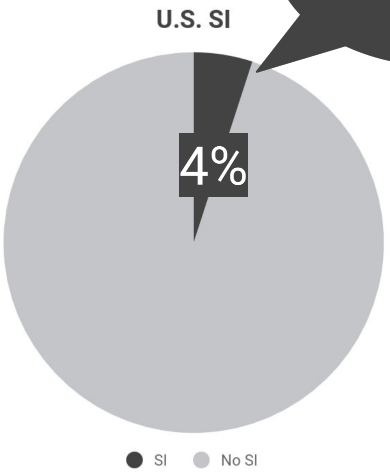
1.2 Suicidal Ideation (SI) - cont’d

Caregivers face risk for suicidal ideation

(Stansfeld et al., 2014, Rosengard & Folkman, 1997) (CDC, 2017)

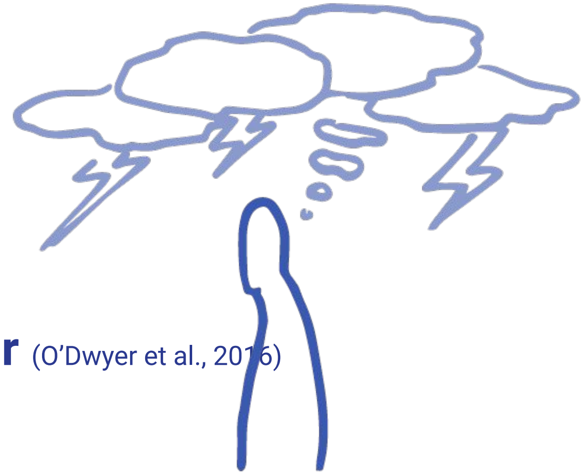


32.9-39.3%
(CDC 2021)



11%
(CDC 2021)

1.2 Suicidal Ideation (SI) - cont’d



- Range of SI in caregivers:
    - Gay men with HIV (US): **55% in 2-year period** (Rosengard & Folkman, 1997)
        - 24.84% lifetime
    - Cancer (SK): **17.7% in the past year** (Park et al., 2013)
        - 2.8% attempted in past year
    - Dementia/MND (Au, CA, US): **16% in the past year** (O’Dwyer et al., 2016)
        - 20% would attempt in the future
        - ½ disclosed SI
    - Psychiatric Conditions (BR): **12.5% in the past month** (Treichel et al., 2019)
    - Disability, Chronic illness, &/or “Frailty” (Au): **7.1% in past week** (O’Dwyer et al., 2014)
    - “Physical or mental ill health or disability” (UK): **4% in past year** (Stansfeld et al., 2014)
        - Twice as likely to have SI than noncaregivers

1.3 Depression in Caregivers

- Pinquart & Sorensen (2003) meta: higher depression and stress; $g = .58$, $p < .001$
- 58% more likely to have depression or anxiety than non caregivers (Stansfeld et al., 2014)
- ⅓ had depression or anxiety (vs ⅕) (Berry et al., 2020)

- **Depression in caregivers of PwCID**
    - Example: behavioral difficulties (Pinquart & Sorensen, 2007)
    - Dementia, TBI, and stroke (Choi et al., 2019; Chronister & Chan, 2006; Berg et al., 2005).

1.3 Depression in Caregivers

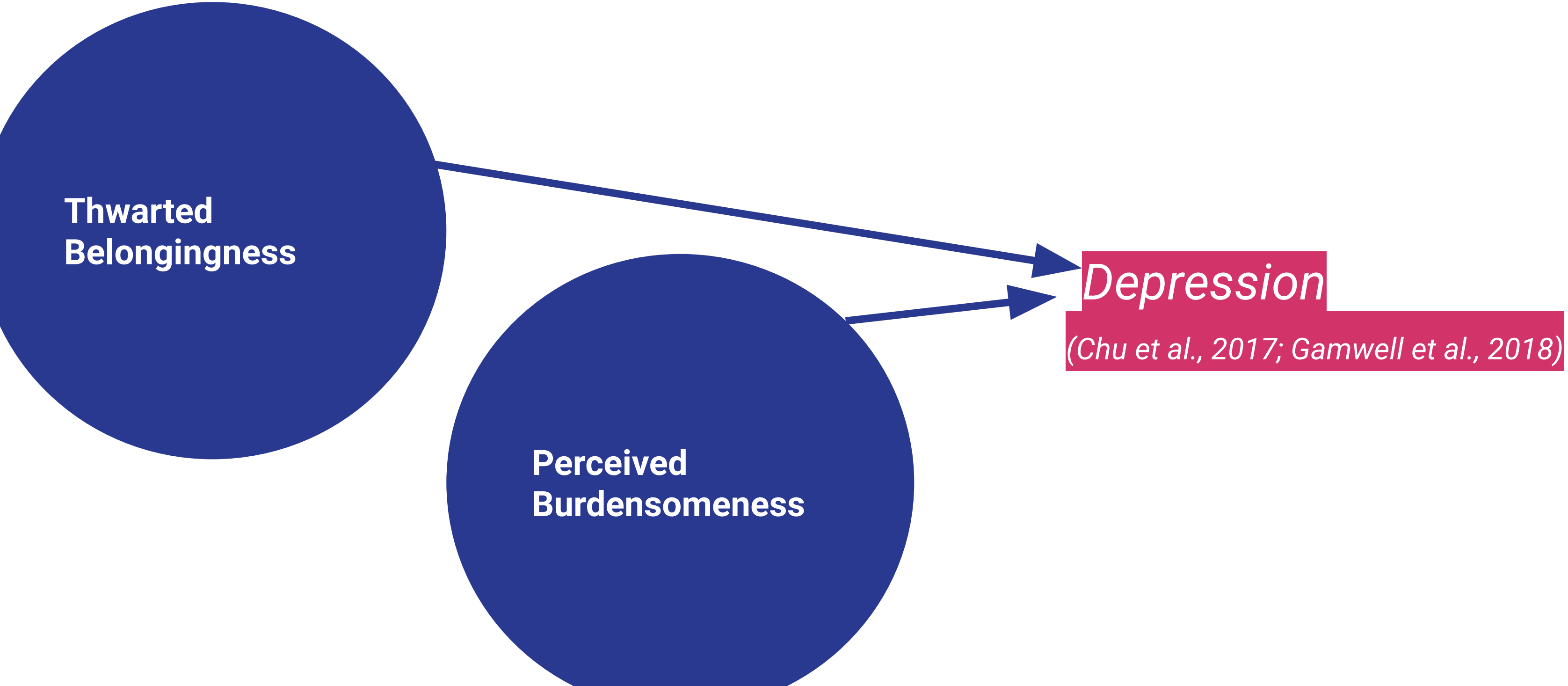
- Poor mental health → deaths by suicide
    - Arsenault-Paierre, Kim & Turecki (2004) autopsy meta: 87.3% of suicide deaths had psyc hx
- Depression and SI are distinct
    - 277 different symptom clusters of MDD
        - Not all include SI (APA, 2013)
    - SI least frequent symptom for those with MDD (Zimmerman et al., 2015)
    - SI can stand alone
        - Does *not* depend on depressive symptoms to describe itself

1.4 Joiner's (2005) Interpersonal Psychological Theory and Caregivers

Thwarted Belongingness

Perceived Burdensomeness

1.4 Joiner's (2005) Interpersonal Psychological Theory and Caregivers



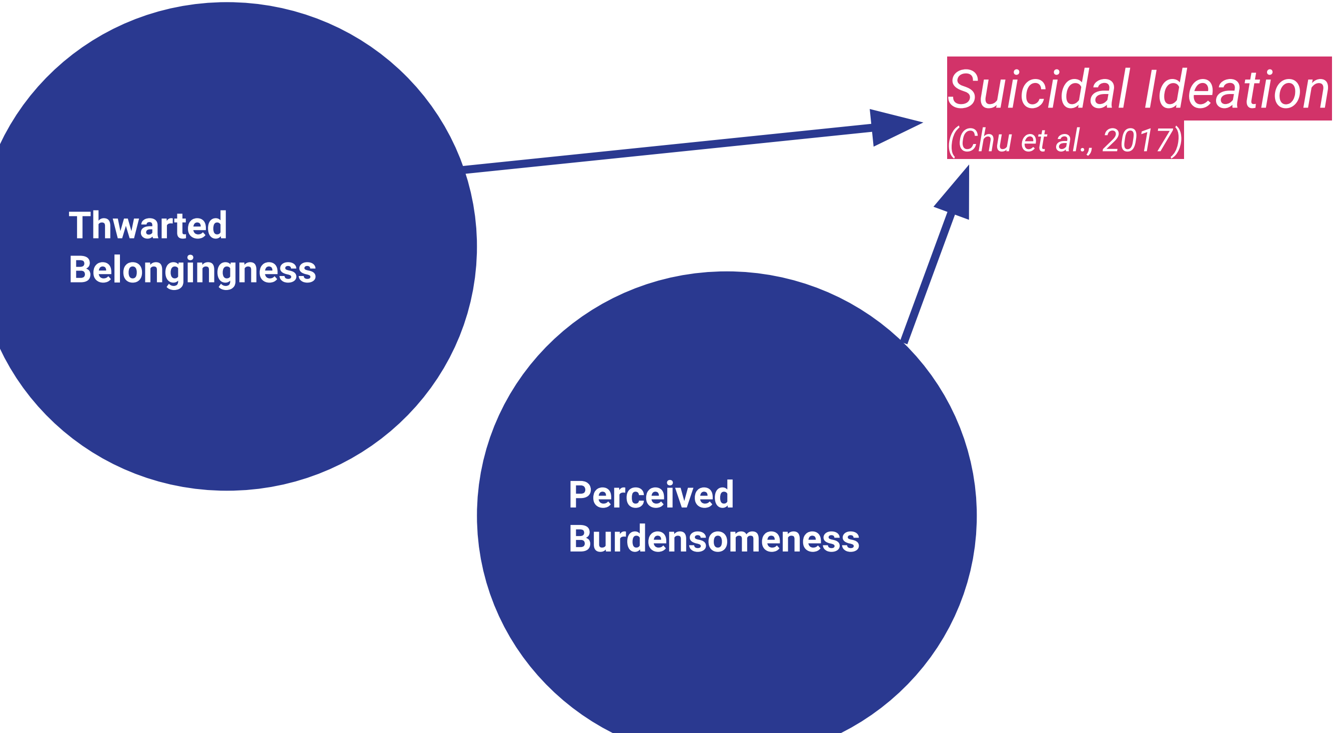
Thwarted Belongingness

Perceived Burdensomeness

Depression

(Chu et al., 2017; Gamwell et al., 2018)

1.4 Joiner's (2005) Interpersonal Psychological Theory and Caregivers



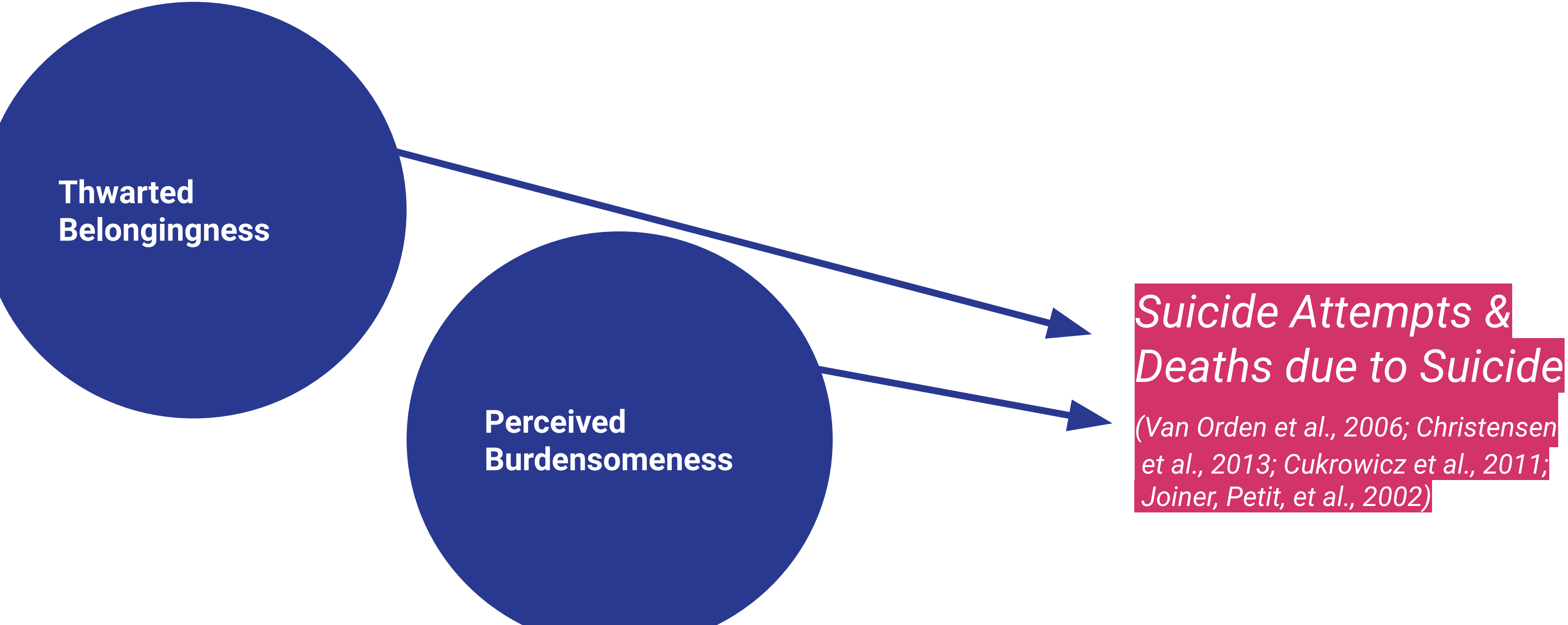
Suicidal Ideation

(Chu et al., 2017)

Thwarted Belongingness

Perceived Burdensomeness

1.4 Joiner’s (2005) Interpersonal Psychological Theory and Caregivers



Thwarted Belongingness

Perceived Burdensomeness

Suicide Attempts & Deaths due to Suicide

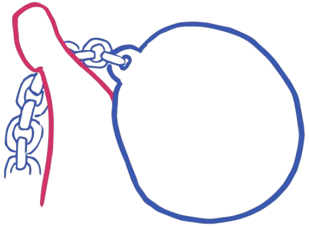
(Van Orden et al., 2006; Christensen et al., 2013; Cukrowicz et al., 2011; Joiner, Petit, et al., 2002)

1.4.a Caregivers and TB

- Loss of social networks, restricted social activities, less social supports, self-alienation, restricted social interactions (Blusi et al., 2014; Clark & Bond, 2000: Cunnuscio et al., 2004; Rokach et al., 2007)
- Example: dementia & reduced reciprocity (Shim et al., 2011)

- **Loneliness:**
    - ○ “We can’t do as much as we used to… you lose that person.” (Vasileiou et al., 2017)
    - ○ Higher loneliness, 80% felt lonely (Carers UK, 2015)
    - ○ Familial → caregiving relationship change (De Villiers et al., 2008; Beeson et al., 2000)
- **Social isolation:**
    - ○ 40% of caregivers of people with schizophrenia (vs 7%) (Hayes et al., 2015)
    - ○ Social isolation → caregiver burden (Leggett et al., 2011)
    - ○ Even with support, still isolation (Blusi et al., 2014)
    - ○ Caregivers of People with Parkinson's: 57% had isolation (de Villiers et al., 2008)

1.4.b Perceived Burdensomeness



- **Worthlessness and being a burden**

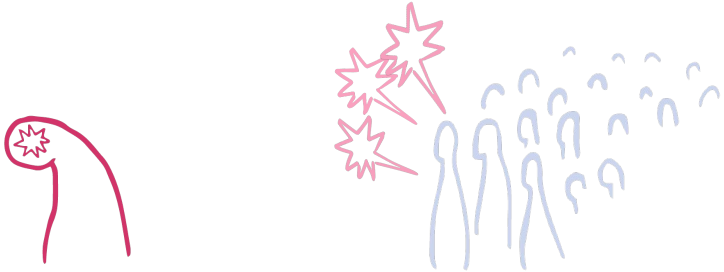
- **Stroke**: most stressful problem→worthlessness and being a burden (Haley et al., 2009)
- **Major Neurocognitive Disorders**:
  - 29.7% felt worthless or being a burden (Schulz et al., 2009)
  - “I thought about...bumping myself off…my insurance and all my stuff would’ve set [my wife; care recipient] up forever” (O’Dwyer, Moyle, & van Wyk, 2013)

- Too many responsibilities → SI
    - “Scarcity Hypothesis”: deplete energy and increase burnout (Mui, 1992; Cannuscio et al., 2004)
  - Caregivers of older adults: more responsibilities → hopelessness & SI. (Britton et al., 2008)

1.5 Stigma among Caregivers

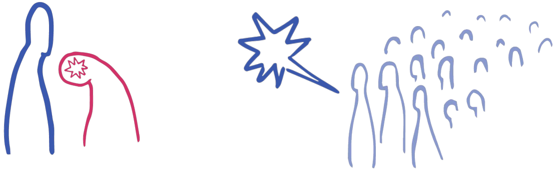
- **Public stigma** (Corrigan, 2000)

- **Self Stigma** (Corrigan, 2000)
- Stigma for PwCID (Rao et al., 2009; WHO, 2011)
    - Concealability
    - Incapability/Capability
    - Variable course/prognosis & cause/origin
    - Behavioral disruptiveness
    - Negative “visible aesthetics”
    - Peril/fear associated



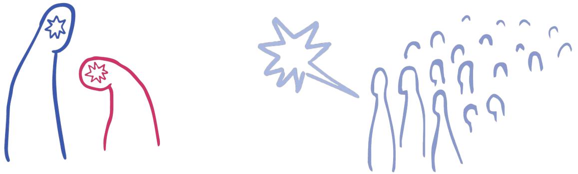
1.5 Stigma among Caregivers

- Stigma for PwCID → Stigma for the caregiver
- **Courtesy stigma/associative stigma**
  (Corrigan & Miller, 2004; Goffman, 1963; Mehta & Farina, 1988)



- **Vicarious stigma** (Corrigan & Miller, 2004)

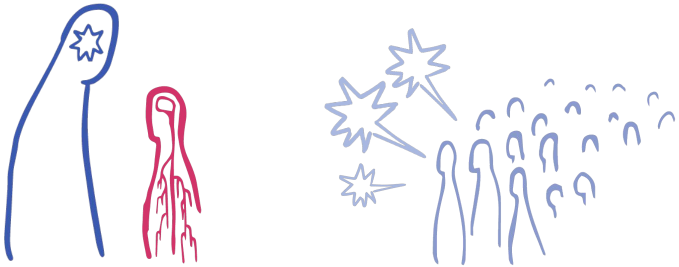
- **Affiliate stigma/self-stigma**
  (Mak & Cheung, 2008; Chan & Lam, 2018; Wong et al., 2016; Corrigan et al., 2006)
    - Shame, distress, marginalization



Courtesy Stigma vs. Affiliate Stigma? (Gray, 2002).

1.5.a Affiliate Stigma

- Internalization of stigma due to association to a stigmatized person (Mak & Cheung, 2008)
  - 1) Care recipient sx → public reacts to PwCID and the caregiver
  - 2) caregiver recognizes their own association to stigma
  - 3) caregiver emotional, cognitive, behavioral internalization



- Caregivers of PwCID: dementia & TBI (Kahn et al., 2016; Poritz et al., 2019)
  - Embarrassment & poor mental health (Liu et al., 2014)

1.5.a Affiliate Stigma

- Stigma internalization → SI in non-caregivers and caregivers of PwSMI (Ostman & Kjellin, 2002)
- Depression mediator between internalized stigma → SI (Zeng et al., 2018; Wang et al., 2017; Casale et al., 2019; Hottes et al., 2016)

- **Stigma might relate to IPT factors for caregivers?**
    - In PwIBD: TB mediator between stigma → depression (Gamwell et al., 2018)
    - In caregivers of ASD: affiliate stigma → reduced social activities (Werner & Shulman, 2015)

        Affiliate stigma → shame and worthlessness (Gray, 1993; 2002)
    - In caregivers of HIV: stigma → isolation & lack of social support (Herek, 1990; Rosengard & Folkman, 1997)
- **"Stigma → SI" relationship mediated by IPT then depressive sx?**: Durkheim Social Theory

2.1 Dissertation Examination of these factors

This study developed to:

- Extend the literature on IPT
- Help caregivers of PwCID identify resources and lessen risk

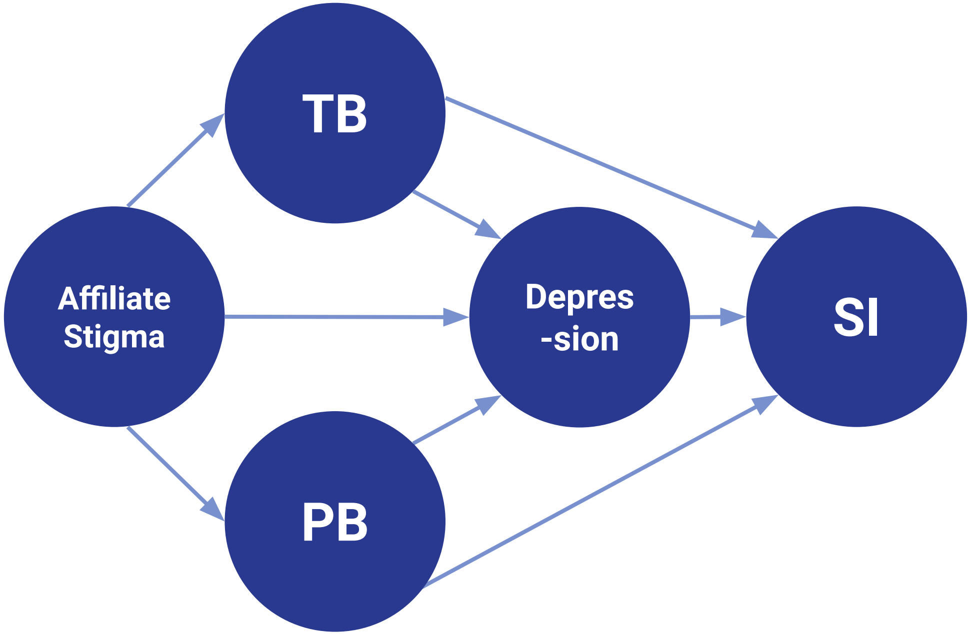
Study Rationale & Purpose

- IPT
- Affiliate stigma
- Depression

Must identify how these factors incur risk in caregivers of PwCID, create a better understanding of SI. *To test a serial mediation model with affiliate stigma, IPT factors, depression, and SI.*

- Study Aims:
    - (1) SI in caregivers of PwCID
    - (2) propose a serial mediation model predicting SI
    - (3) examine strength of associations among variables that influence SI

Study Model



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Methods

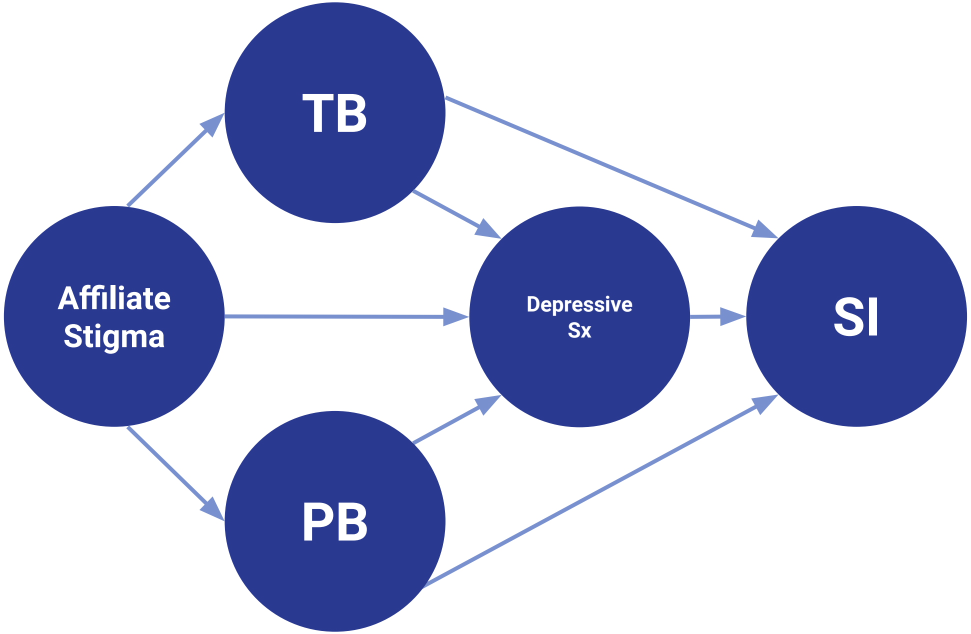
2.2 Participants (*N*=243, after data cleaning)

- After online recruitment, and survey completion on Qualtrics

- 18 y/o+
- Living in the US
- Able to read English
- Primary part- or full-time family caregiver
- Providing care to a person living with a diagnosed chronic illness or disability
- WHO (2011): an individual with a health condition who has “impairments, activity limitations, and participation restrictions,” that involves challenges for this individual to interact with their environment and people around them. ”
- Types of d/o and diagnostic examples provided → screener and demographics

2.3 Statistical Analyses

- Analyses all run on SPSS, SPSS PROCESS macro
- Pearson correlation matrix. $p < 0.05$ significant.
- Parallel-serial mediation bootstrapping analyses on SPSS PROCESS macro.
    - When zero (0) not between the CI’s = significant mediating effect.
    - $p < .05$ = significant direct effect.



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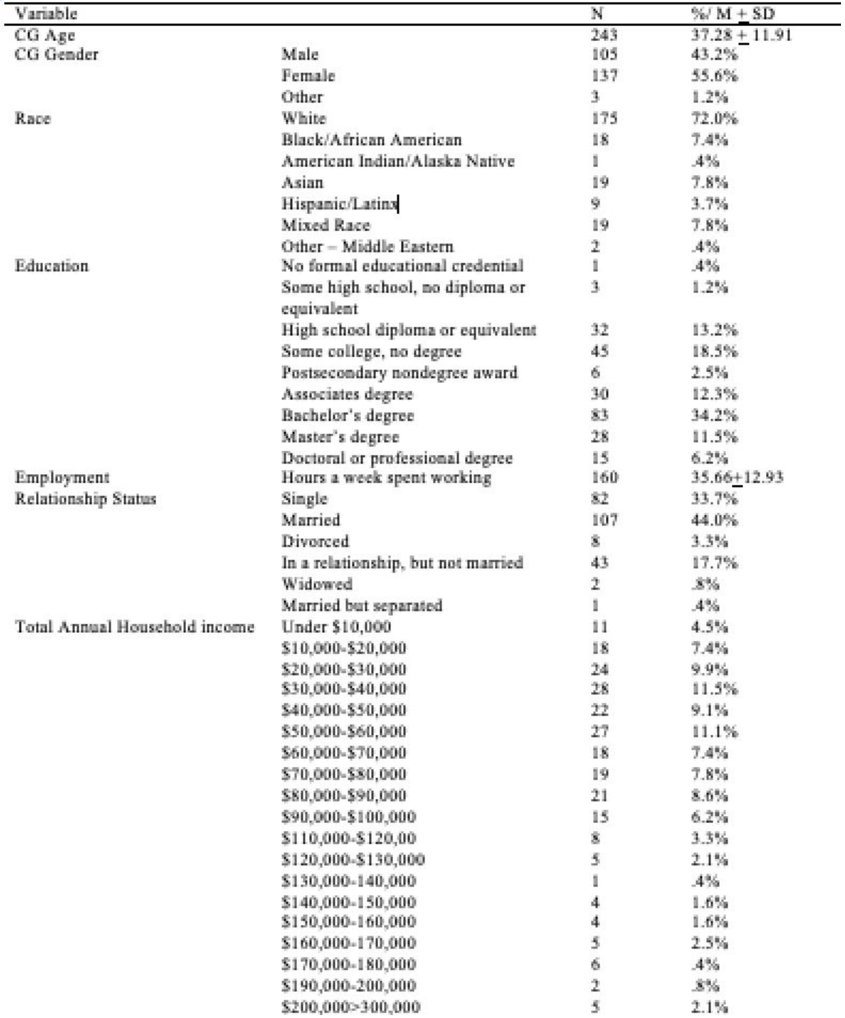
Results

Characteristics of Caregivers

- Young-to-middle adult range (M = 37.28 ± 11.91)
- Slightly represented more by women (n = 135; 55.6%)
- Spend avg of 34.54 hours a week providing care services (SD = 40.03)
  - majority of those services were unpaid (n=240) which was on average 33.10 hours a week (SD=23.68).
- Most were a Child or the child-in-law the care recipient (child: n=113, 46.5%, child-in-law: n=17, 7.0%),

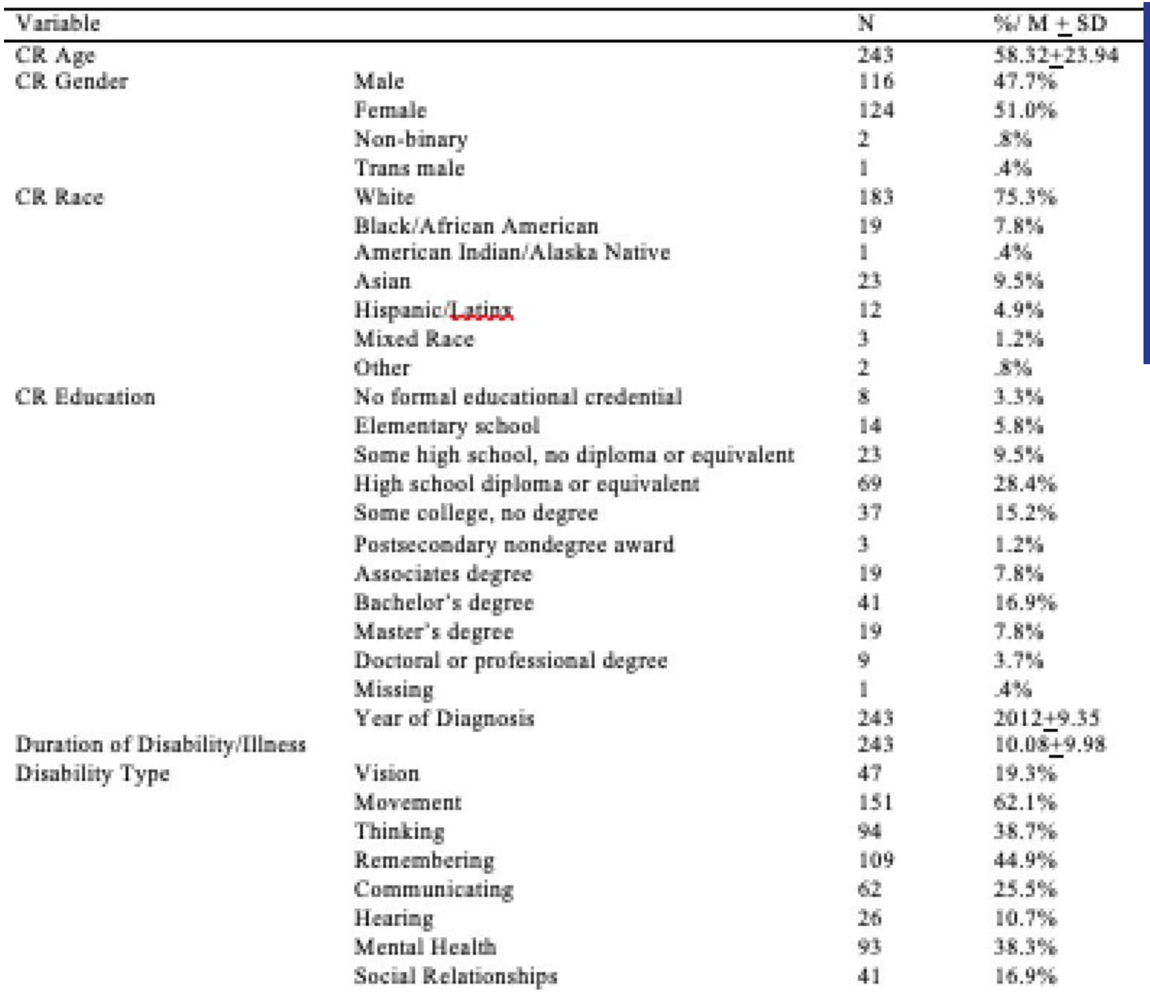


Variable		N	%/ M ± SD
CG Age		243	37.28 ± 11.91
CG Gender	Male	105	43.2%
	Female	137	55.6%
	Other	3	1.2%
Race	White	175	72.0%
	Black/African American	18	7.4%
	American Indian/Alaska Native	1	.4%
	Asian	19	7.8%
	Hispanic/Latinx	9	3.7%
	Mixed Race	19	7.8%
	Other – Middle Eastern	2	.4%
Education	No formal educational credential	1	.4%
	Some high school, no diploma or equivalent	3	1.2%
	High school diploma or equivalent	32	13.2%
	Some college, no degree	45	18.5%
	Postsecondary nondegree award	6	2.5%
	Associates degree	30	12.3%
	Bachelor's degree	83	34.2%
	Master's degree	28	11.5%
	Doctoral or professional degree	15	6.2%
Employment	Hours a week spent working	160	35.66±12.93
Relationship Status	Single	82	33.7%
	Married	107	44.0%
	Divorced	8	3.3%
	In a relationship, but not married	43	17.7%
	Widowed	2	.8%
	Married but separated	1	.4%
Total Annual Household income	Under $10,000	11	4.5%
	$10,000-$20,000	18	7.4%
	$20,000-$30,000	24	9.9%
	$30,000-$40,000	28	11.5%
	$40,000-$50,000	22	9.1%
	$50,000-$60,000	27	11.1%
	$60,000-$70,000	18	7.4%
	$70,000-$80,000	19	7.8%
	$80,000-$90,000	21	8.6%
	$90,000-$100,000	15	6.2%
	$110,000-$120,00	8	3.3%
	$120,000-$130,000	5	2.1%
	$130,000-140,000	1	.4%
	$140,000-150,000	4	1.6%
	$150,000-160,000	4	1.6%
	$160,000-170,000	5	2.5%
	$170,000-180,000	6	.4%
	$190,000-200,000	2	.8%
	$200,000>300,000	5	2.1%

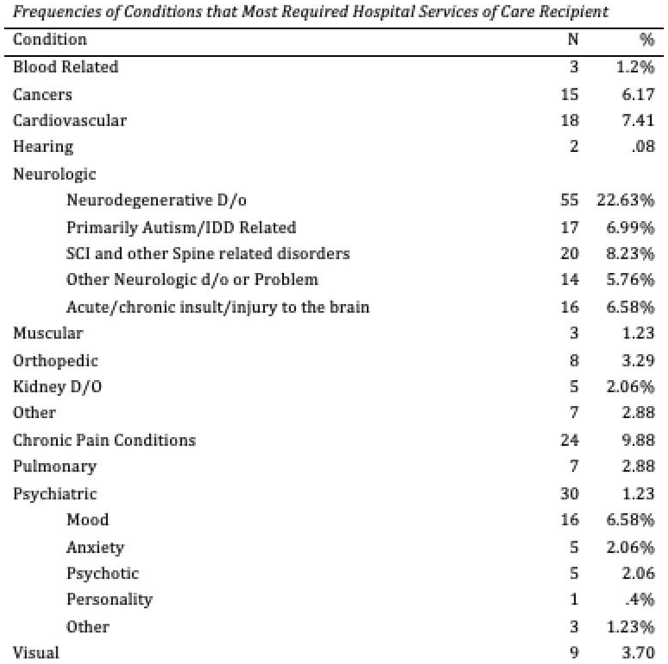
Time Spent Caregiving	Total	243	34.54±40.03
	Unpaid	240	33.10±23.68
	Paid	19	23.68 ± 25.81
Relation to Care Recipient	Parent	26	10.7%
	Parent-in-Law	2	.8%
	Child	113	46.5%
	Child-in-Law	17	7.0%
	Grandchild	29	11.9%
	Grandchild-in-Law	1	.4%
	Spouse	25	10.3%
	Ex-Romantic Partner/Spouse	1	.4%
	Sibling	19	7.8%
	Sibling-in-Law	2	.8%
	Aunt/Uncle	2	.8%
	Niece/Nephew	6	2.4%

Characteristics of People with Disability

- Large representation by neurologic conditions,~50%
- Mean WHO-DAS = 38.16 with 48 highest severity level, indicating high severity of functional impairment



Variable		N	%/ M ± SD
CR Age		243	58.32±23.94
CR Gender	Male	116	47.7%
	Female	124	51.0%
	Non-binary	2	.8%
	Trans male	1	.4%
CR Race	White	183	75.3%
	Black/African American	19	7.8%
	American Indian/Alaska Native	1	.4%
	Asian	23	9.5%
	Hispanic/Latinx	12	4.9%
	Mixed Race	3	1.2%
	Other	2	.8%
CR Education	No formal educational credential	8	3.3%
	Elementary school	14	5.8%
	Some high school, no diploma or equivalent	23	9.5%
	High school diploma or equivalent	69	28.4%
	Some college, no degree	37	15.2%
	Postsecondary nondegree award	3	1.2%
	Associates degree	19	7.8%
	Bachelor's degree	41	16.9%
	Master's degree	19	7.8%
	Doctoral or professional degree	9	3.7%
	Missing	1	.4%
	Year of Diagnosis	243	2012±9.35
Duration of Disability/Illness		243	10.08±9.98
Disability Type	Vision	47	19.3%
	Movement	151	62.1%
	Thinking	94	38.7%
	Remembering	109	44.9%
	Communicating	62	25.5%
	Hearing	26	10.7%
	Mental Health	93	38.3%
	Social Relationships	41	16.9%



Frequencies of Conditions that Most Required Hospital Services of Care Recipient

Condition	N	%
Blood Related	3	1.2%
Cancers	15	6.17
Cardiovascular	18	7.41
Hearing	2	.08
Neurologic		
Neurodegenerative D/o	55	22.63%
Primarily Autism/IDD Related	17	6.99%
SCI and other Spine related disorders	20	8.23%
Other Neurologic d/o or Problem	14	5.76%
Acute/chronic insult/injury to the brain	16	6.58%
Muscular	3	1.23
Orthopedic	8	3.29
Kidney D/O	5	2.06%
Other	7	2.88
Chronic Pain Conditions	24	9.88
Pulmonary	7	2.88
Psychiatric	30	1.23
Mood	16	6.58%
Anxiety	5	2.06%
Psychotic	5	2.06
Personality	1	.4%
Other	3	1.23%
Visual	9	3.70

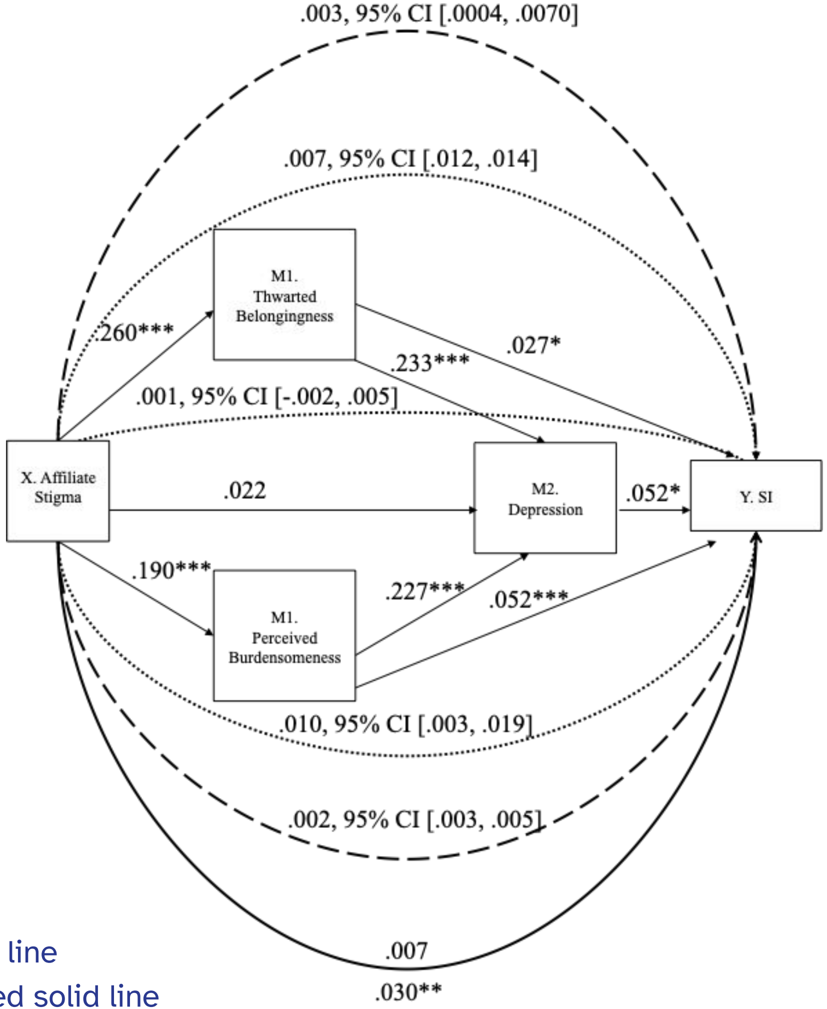
Suicidality Frequencies

- On total SI score, 32.9% indicated SI in last two weeks
    - On Frequency of SI
        - 25.9% had SI “sometimes”
        - 3.7% had SI “always”
    - On Control of SI
        - 21% “completely” under control
        - 6.6% “somewhat” under control
        - .8% “no” control
- 35.8% indicated SI in last year

- Plan in last two weeks
    - 3.3% “possible” plan
    - .8% “definite” plan
- Attempt
    - Single lifetime attempts: 15.2%
    - Multiple lifetime attempts: 6.6%

Figure Results: **Parallel-Serial Mediation**

(unstandardized effect values presented)



KEY:

*p < .05; **p < .01, *** p< .001

Simple mediation (1 mediator) = rounded dotted line

Serial Mediation (2 mediators) = rounded dashed line

Parallel-serial Mediation (3 mediators) = noted below rounded solid line

Direct effect (IV → DV, no mediators/cov) = noted above the rounded solid line

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Discussion

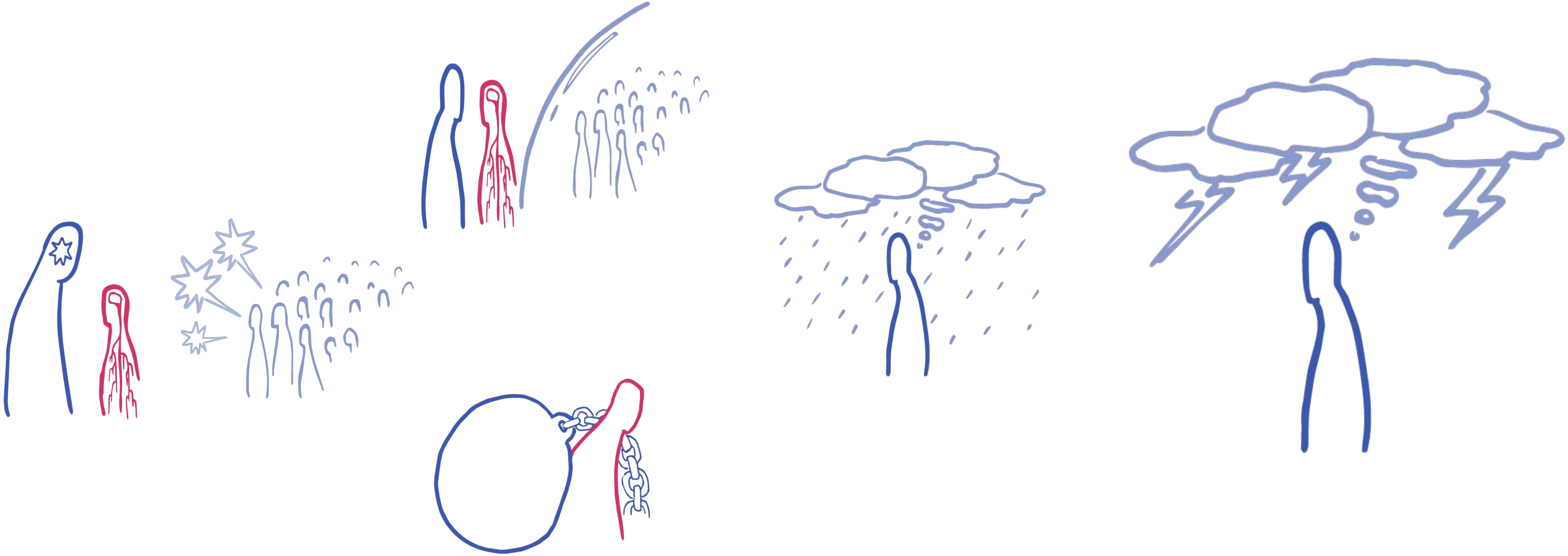
Discussion of study findings

Suicidality among caregivers:

- SI in last two weeks—worse in this study compared to past
  - Similar to current CDC studies on SI in caregivers
- SI in last year worse in this study compared to most past research
  - Less SI compared to 1990’s HIV/AIDS crisis
  - Comparable to current pandemic crisis as seen in CDC
- Frequency of SI and controllability is less described in past CG suicide research
- Reduced likelihood to attempt/plan to attempt in this study compared to past
- Attempt history higher than past research

The Theoretically Framework for Mediation Model of SI risk? Did I find Support?

- Yes! Similar pathways seen in past studies
    - Xu et al (2016) and Gamwell et al (2018): In Pt w/ Psychosis and IBD, TB and depression mediates stigma → SI
    - Bams et al (2015): in LGB youth, stigma → on SI mediated by PB and depression



Study Limitations

- Cross-sectional in nature
  - Need to observe these factors over time
- Overrepresented by white individuals and adult children of care recipient
  - Intersectional barriers face caregivers who have multiple identities
  - Spousal caregivers typically disproportionately show higher SI risk, given change of relationship and often shorter time to prepare.
  - Programs should be tailored to specific cultural factors of caregivers

Takeaways: Ways to Get Support

- How to help others with suicidal thoughts
    - It is OKAY to ask about suicide
        - It is a MYTH that asking about suicide triggers suicide
    - Provide support and listen without judgement
    - Offer to connect them to helpline resources when appropriate

Takeaways: Ways to Get Support

How to get help for suicidal thoughts

- **US National Suicide Prevention Lifeline**: 1-800-273-TALK (1-800-273-8255) or 988 - Languages: English, Spanish; https://suicidepreventionlifeline.org/ (Deaf & Hard of Hearing Options): 1-800-799-4889
- **US Samaritans**: 877-870-HOPE (4673) - registered charity aimed at providing emotional support to anyone in distress or at risk of suicide throughout the United States; http://www.samaritansusa.org/
- **US SAMHSA National Helpline**: - 1-800-662-HELP (4357) - free, confidential, 24/7, 365-day-a-year treatment referral and information service (in English and Spanish) for individuals and families facing mental and/or substance use disorders
- **US Trevor Project**: 1-866-488-7386 - an organization that provides a 24-hour phone hotline, as well as limited-hour webchat and text options, for lesbian, gay, bisexual, transgender and questioning youth within the US; text TREVOR to 1-202-304-1200 (available M-F from 3:00 pm to 10:00 pm ET)
- **US Veterans Crisis Line**: 1-800-273-8255 - 24/7 hotline that provides phone, webchat, and text options available to military veterans and their families. It provides options for deaf and hard of hearing individuals
- Call 911
- Go to an emergency department

Takeaways: Ways to Get Support

- How to figure out when to get mental health help
    - Is the problem going on for a long time?
    - Does it take up more space than usual?
    - Does it get in the way of your everyday activities?
- Finding a Therapist
    - Ask your PCP for a referral
    - PsychologyToday.com Therapy Finder tool
    - SAMHSA Behavioral Health Treatment locator
- Finding Emotional Support Resources
    - **Family Caregiver Alliance:** Virtual support groups for families, partners/spouses, and other caregivers who want a safe place to discuss stresses, challenges and rewards of providing care for adults with disorders such as Alzheimer's, stroke, brain injury, and other chronic debilitating health conditions https://www.caregiver.org/support-groups/
    - **US National Alliance on Mental Illness (NAMI)**: 1-800-950-NAMI - nationwide network and search function for support and education; https://www.nami.org/Support-Education/NAMI-HelpLine/Top-HelpLine-Resources

Takeaways: Ways to improve sense of belonging and social connectedness

- IPT interventions - developed originally for veterans
  - Dispelling myths
    - Instead of: “Sharing my problems with or being around others would be a burden them”
      - Reality: “Sharing my problems with or being around others is part of being in a community”
    - Instead of “I am alone and the only caregiver suffering” and “I can’t help my family member no matter what I do.”
      - Reality: share the commonality of care providers
      - Reality: you cover measurable health care for your family through your service
      - Reality: social iteraction is a critical need, just like food or water
  - Behavioral strategies:
    - Menu of options: talk with a friend, practice sharing your feelings with a trusted other, spend time volunteering
    - Opposite Action

Takeaways: Ways to tackle stigma

- Stigma reduction programs
    - Peer facilitated
        - Interact in pairs with those with low stigma
        - Family groups vs health worker led group
    - Education programs
        - Health worker provided education and coping strategies for caregivers
        - Telephone interventions on education and coping by researchers

Takeaways: Ways to improve society for caregivers and their families

- Policy
    - Improve policies that promote disability representation - Normalize caregiving and the experiences of people with disabilities
    - Credit for Caregiving Act (2021-2022) - tax credit for caregiving
    - Advocate for accessibility and equitable healthcare and society for people with TBI and other disabilities

In conclusion...

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Thank you!

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