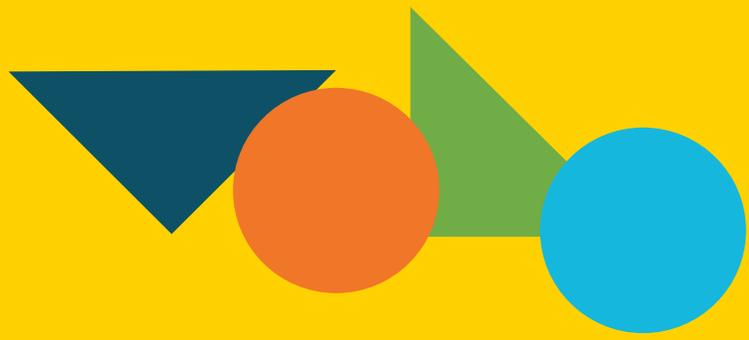


“What’s the Matter With Me?” Self-Care Advice for the Nonprofessional Caregiver

Olivia Jones & Dr. Elizabeth S. Parks



Welcome – a few things before we get started...

Expectations:

- Please keep yourself muted
- Feel free to reach out with any questions
- Ensure you are named how you wish to be addressed, and please add your pronouns to your name
- If you need to turn off your video that's fine but we still encourage participation
- If you need to leave early that's fine, but please fill out the evaluation for this session (link: <https://col.st/gqVnC>)
- Be mindful of and follow the the CSU Community agreements:
 - be present, open, honest, and authentic
 - speak from personal experience
 - monitor participation
 - listen actively and respectfully
 - be open to new and different perspectives
 - respect and maintain confidentiality

Land Grant Statement

Colorado State University acknowledges, with respect, that the land we are on today is the traditional and ancestral homelands of the Arapaho, Cheyenne, and Ute Nations and peoples. This was also a site of trade, gathering, and healing for numerous other Native tribes. We recognize the Indigenous peoples as original stewards of this land and all the relatives within it. As these words of acknowledgment are spoken and heard, the ties Nations have to their traditional homelands are renewed and reaffirmed.

CSU is founded as a land-grant institution, and we accept that our mission must encompass access to education and inclusion. And, significantly, that our founding came at a dire cost to Native Nations and peoples whose land this University was built upon. This acknowledgment is the education and inclusion we must practice in recognizing our institutional history, responsibility, and commitment.



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DIVERSITY
SYMPOSIUM

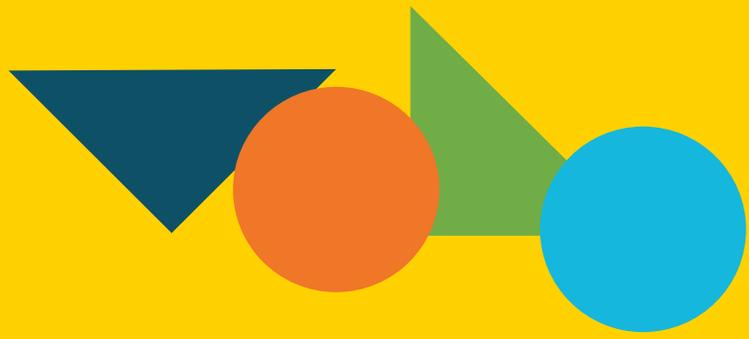
Who Are We?

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Poll – are you a caregiver or a care receiver or both?



Researcher Positionality for This Session

- Olivia Jones: Nonprofessional caregiver with experience looking for online advice for the nonprofessional caregiver role
- Elizabeth Parks: Listening across difference scholar passionate about individual and social well-being

Research Context: The Need

- Over 16 million people act as unpaid and nonprofessional caregivers in the United States, volunteering as friends and family with no professional caregiving training for over 18.6 billion hours of care (Alzheimer's Association 2020).
- As of 2020, Alzheimer's is the sixth leading cause of death in the United States and one-third of all seniors die with Alzheimer's or another dementia.
- Being a caregiver can have a negative impact on communication and relationships, employment, community, spirituality, and psychological and physical outcomes; ultimately, this can result in caregiver burnout (Lloyd et al. 2019).

Research Context: The Need

- Indeed, scheduling burden and social isolation can lead to health problems, decreased overall well-being, and mortality rates 63% higher than that of non-caregivers (Alpert and Womble 2014).
- Over 75% of caregivers report that “communication” with their patient or loved-one contributes to feelings of loneliness and isolation (Orange 1991; Rabins et al. 1982).
- While it has been established that the *process* of providing care to individuals is just as important as the outcomes of the caregiving process itself, increased positive communication and social support make a positive impact for everyone involved (Harvey, Faw, and Parks, in press).

Research Context: The Gap

- Supporting caregivers by equipping them with the needed information to decrease the personal costs of caregiving and contribute to more positive and satisfying relationships can come through a variety of mediums.
- Over the last few decades, the internet has become a central health information-seeking and social support space (Braithwaite et al. 1999; Dutta and Feng 2007; McGloin et al. 2016).
- Exactly how caregivers can care for themselves in the context of their communication with their cared-for is not widely discussed, and it is this extant scholarship we work to address.

Research Question & Approach

Research Question: What online information is available regarding how nonprofessional caregivers of people with Alzheimer's disease or dementia can practice self-care in their caregiver roles?

Research Approach: Thematic Analysis of online nonprofessional caregiver advice discourse in Spring 2019

Data: Online Caregiver and Communication Advice

- 332 distinct resources related to Alzheimer's and Dementia caregivers in general
- 39 English-based texts focused on nonprofessional caregivers of people with Alzheimer's and Dementia and verbal and nonverbal *communication* (11.7% of original sample)
 - **14 organizations:** *Aging Care, Family Caregiver Alliance, National Institute on Aging, Today's Caregiver, National Institute of Health, Alzheimer's Association, Alzheimers.net, Assisting Hands, Caregiver's Library, Daily Caring, Dementia Resource Center, Leisure Care, Medicare.com, and Take My Hand at Home*
- We analyzed 1,024 pieces of online nonprofessional caregiver communication advice

General Results

- Three categorical themes emerged in our thematic analysis of online communication advice to nonprofessional caregivers of people with Alzheimer's and dementia:
 - *Daily Routine of Care-Recipient* (n=737, 71.7% of advice)
 - *Care-Recipient Well-Being* (n=319, 31.2% of advice)
 - ***Caregiver Self-Care*** (n=118, 11.5% of advice)
- For the 118 pieces of ***Caregiver Self-Care*** advice found, three specific self-care subthemes emerged:
 - *Relational Well-Being* (n=83, 70.3%)
 - *Emotional Well-Being* (n=81, 68.6%)
 - *Physical Well-Being* (n=29, 24.6%)

Caregiver Well-Being Advice

- Don't give up when communication is difficult
- It's okay if you don't know what to say
- Set aside some time to discuss the tough stuff, when you are emotionally available
- Talk to other caregivers and find safe space for yourself
- Try to understand even if it's hard
- Recognize you won't always be able to convince them they are wrong
- Let them know it's okay that they are having trouble
- Be open to the person's concerns
- Make time to listen to your loved one
- Be patient with repeat storytelling
- Don't be discouraged if you get resistance when bringing up a new topic; try again another time
- Mourn the loss and meet your loved one in the present; it is a loss, and recognizing that can help you move on



Caregiver Well-Being Advice

- Don't argue if they are confused
- Use humor whenever possible, though not at the person's expense
- Give yourself permission to laugh
- Share your experience with others
- Keep the conversation soothing for your own benefit
- Being honest about your concerns and feelings can help both of you cope with a difficult diagnosis
- Be able to discuss with the loved one daily needs, both emotional and physical
- "No" is not your fault; respect their "no"
- Find common interests and, if you can't, talk about your own interests
- Recognize what you can't help them remember
- Recognize accepting the truth is difficult
- Give the person more attention and reassurance
- Remember that you cannot change the person but you can change your response to them
- Presence and friendship are the most important; grow closer to the person you are caring for by making time to talk; don't pull away



Caregiver Well-Being Advice

- Do not justify treating an elder like a child by comparing elders with children
- Watch for emotional contagion (e.g., agitation, anger, worry)
- Be flexible
- Be patient, it is the greatest skill caregivers can have
- Try to take nothing personally, including if they do not recognize you
- Don't feel guilty
- Try not to be surprised by what they are doing
- Try not to show your frustration or anger; find ways to cope; if you get upset, take deep breaths and count to ten; if it's safe, leave the room for a few minutes
- Painful emotions surrounding death can make honest, open dialogue difficult
- If you become frustrated, take a timeout for both of you
- Know that you play an important role in your loved one's well being
- When the person is aggressive, protect yourself and others from a safe space
- Think about the positive parts of your relationship
- Stress the meaningfulness of the moment together
- Don't beat yourself up if either of you struggle
- Love who your loved one is



Caregiver Well-Being Advice

- Learn to recognize when giving in and walking away is the best course of action
- Keep calm and carry on; you'll be better equipped to soothe and focus
- Caregivers must take time to connect in any way possible
- Be intentional about caring for yourself
- Explore new ways of spending time together
- Enhance feelings of personal control and make good use of time
- Set your own limits, and be clear about them with others
- Be realistic about what you can and can't do
- Define roles with your caregiving team
- Recruit family members / respite care providers for support, to get time away, sleep, help with health care visits, and companionship
- Remember this likely isn't the first time nursing home employees have been insulted; develop rapport with nurses, therapists, and physicians
- Begin showing a photo of a guest to the person a week before arrival each day, explaining who the visitor is while showing the photo. Arrange a pre-visit phone call so both become familiar with expectations
- Take precautions to provide a safe space for your loved one to sleep so you can get a solid night's rest



Caregiver Well-Being Advice

- Take catnaps during the day
- Take time for yourself, particularly when they keep saying, “I just want to die”
- Join a support group, counseling service, or other volunteer programs to help with the emotional impact and enable you to stay involved
- Choose what is easy for both the care receiver and you
- Do not try to live up to the expectations of friends or relatives; your situation is different now
- Celebrate holidays that are important to you; if you receive an invitation to celebrations that the person with Alzheimer’s cannot attend, go yourself
- Consider new ways to meet your sexual needs
- Try to find a way to take a break from caregiving
- Remind yourself that there will be bad days and good days
- Schedule time to pursue your own hobbies and interests
- Incorporate daily favorite activities into your shared daily routine at a similar time
- Make time for regular exercise to minimize restlessness
- Remember their mind has been hijacked by the disease and it’s the illness talking
- Let it go
- Ask for help



Call for More Engaged Scholarship

With growing numbers of nonprofessional caregivers at risk of isolation and eventual burnout through lack of necessary social support networks, it is crucial that information become more widely available to increase their bandwidth and ability to enact positive communicative relationships.

List of Resources in the Area

- [Family Caregiver Support Program – Larimer County Office on Aging](#)
- [Pikes Peak Area of Council of Governments Caregiver Support](#)
- [U.S. Department of Veteran’s Affairs Caregiver Support](#)
- [Colorado Respite Coalition: Colorado Caregiver Awareness](#)
- [Family Caregiver Alliance – Support Groups](#)
- [Alzheimer’s Association Colorado Chapter](#)
- [Powerful Tools for Caregivers \(Includes UC Health Chapter\)](#)
- [The Caregiver Space \(main, private Facebook group which is connected to numerous sub-groups for different needs and identities\)](#)

Q&A

- What specific questions do you have for us?
- What advice would you like to know more about?
- Are there particular scenarios you would like caregiver tips for?



*Resilience is the capacity to experience adversity and still maintain a **RELATIVELY** stable trajectory of healthy or goal-directed Functioning, Adaptation, and Attitude.*



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EMPIRICAL BENEFITS OF RESILIENCE

- Improved sense of well-being despite challenges, whether acute/chronic, physical or psychological
 - Increases the quantity and intensity of positive emotions
- Assists in self-regulation of “negative” emotions; decreased depressive symptoms
 - Improved problem-identifying and problem-solving skills under stress
 - Improved health care outcomes, with studies including oncology, spinal cord injury, chronic disease, PTSD, immune functioning.
 - Greater Resilience has been associated with Longevity
 - Associated with “hardiness” and finding work meaningful

ON RESILIENCE

The capacity to experience adversity and still maintain a relatively stable trajectory of healthy functioning, adaptation, and attitude.

RESISTANCE-Resilience

(stand firm)

RECOVERY-Resilience

(bounce back)

RECONFIGURATION-Resilience

(re-grow in new ways)

*To have practiced habits of Resilience
increases the possibility of POST-TRAUMATIC GROWTH

TRAITS
STATES
HABITS
~RX~

10 FACTORS FOR RESILIENCE

Choosing your Attitude

with hope and OPTIMISM for the future

Facing Fear with deliberate Courage
and a rallying of resources

Drawing on your Moral Compass
for what is valuable, good, right, altruistic

Seeing the World in New Ways
with cognitive and emotional flexibility

Caring for the BODY
physical strengthening and durability

Training for Brain Fitness and Emotional IQ
with mindfulness, self-regulation, love of learning

Shoring up Social Support Systems
and loving relationships of care

Identifying Role Models
for inspiration and guidance

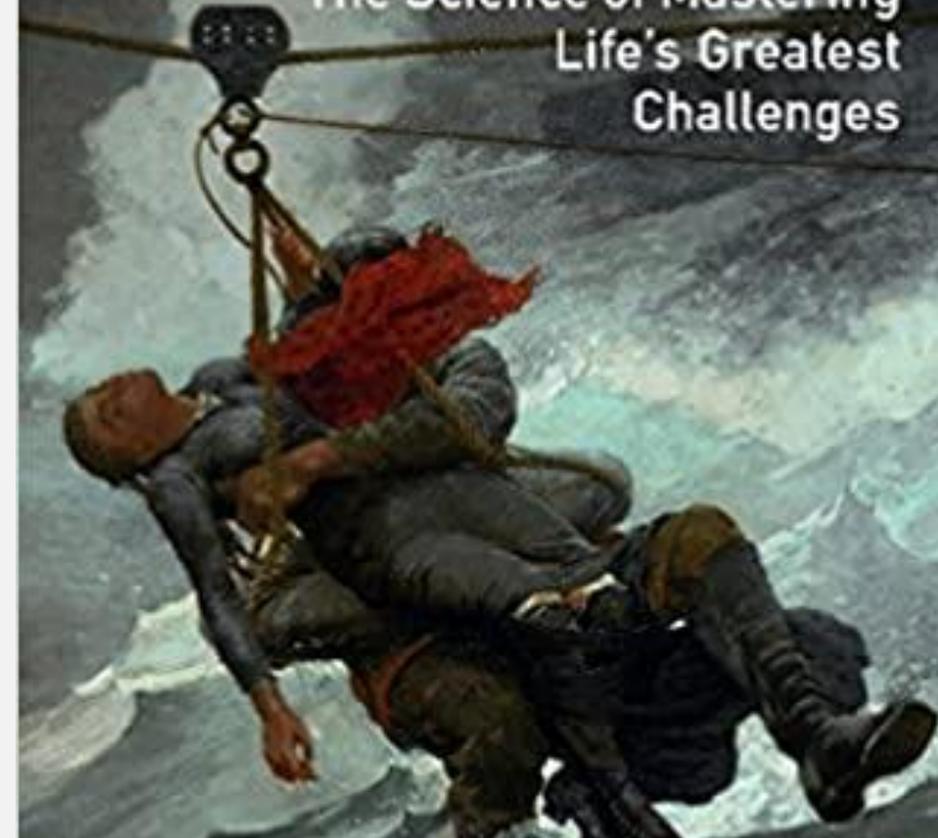
Engaging Life as having Ultimate Meaning
with spirituality, faith, a holistic world-view

Discerning personal Meaning and Purpose
towards GROWTH-possibilities

SECOND EDITION

RESILIENCE

The Science of Mastering
Life's Greatest
Challenges



STEVEN M. SOUTHWICK
& DENNIS S. CHARNEY

"Every parent, coach, and organizational leader should read this now,
and pass it on to those they care about the most."

Rear Admiral Wavy SEAL Scott Moore (ret/ret)



A Pause: Let's Build
Resilience Now

Supporting Our Caregivers

Informational Support

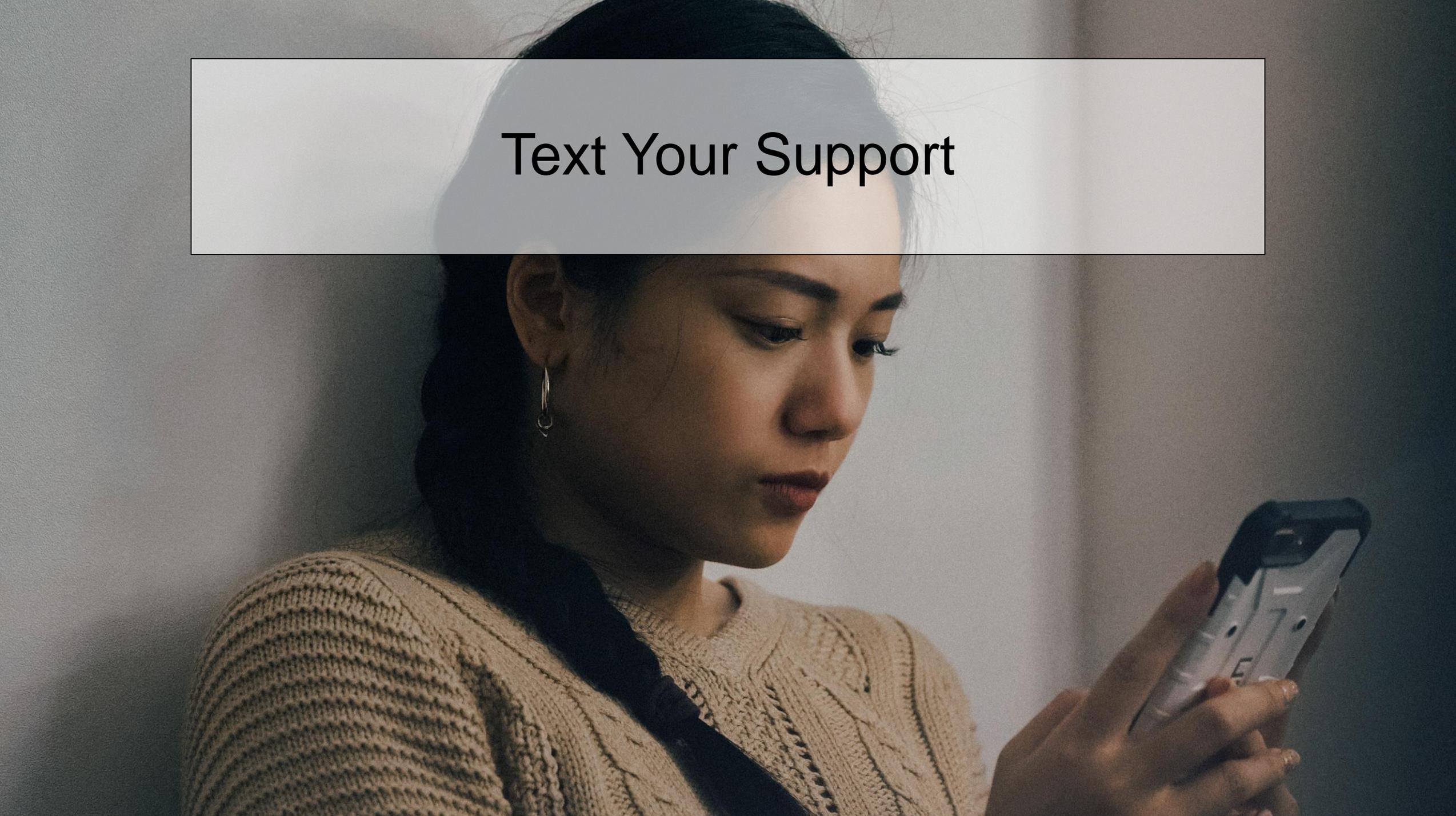
Emotional Support

Network Support

Tangible Support

Esteem Support





Text Your Support



To Nonprofessional
Caregivers:

*Why are you doing what
you are doing?*

Caregiver Commitment: A Simple Equation to Think About

Commitment

=

Satisfaction (Rewards – Costs)

–

Availability of Attractive Alternatives

+

Resources invested in the relationships



Willingness to Rely on Others

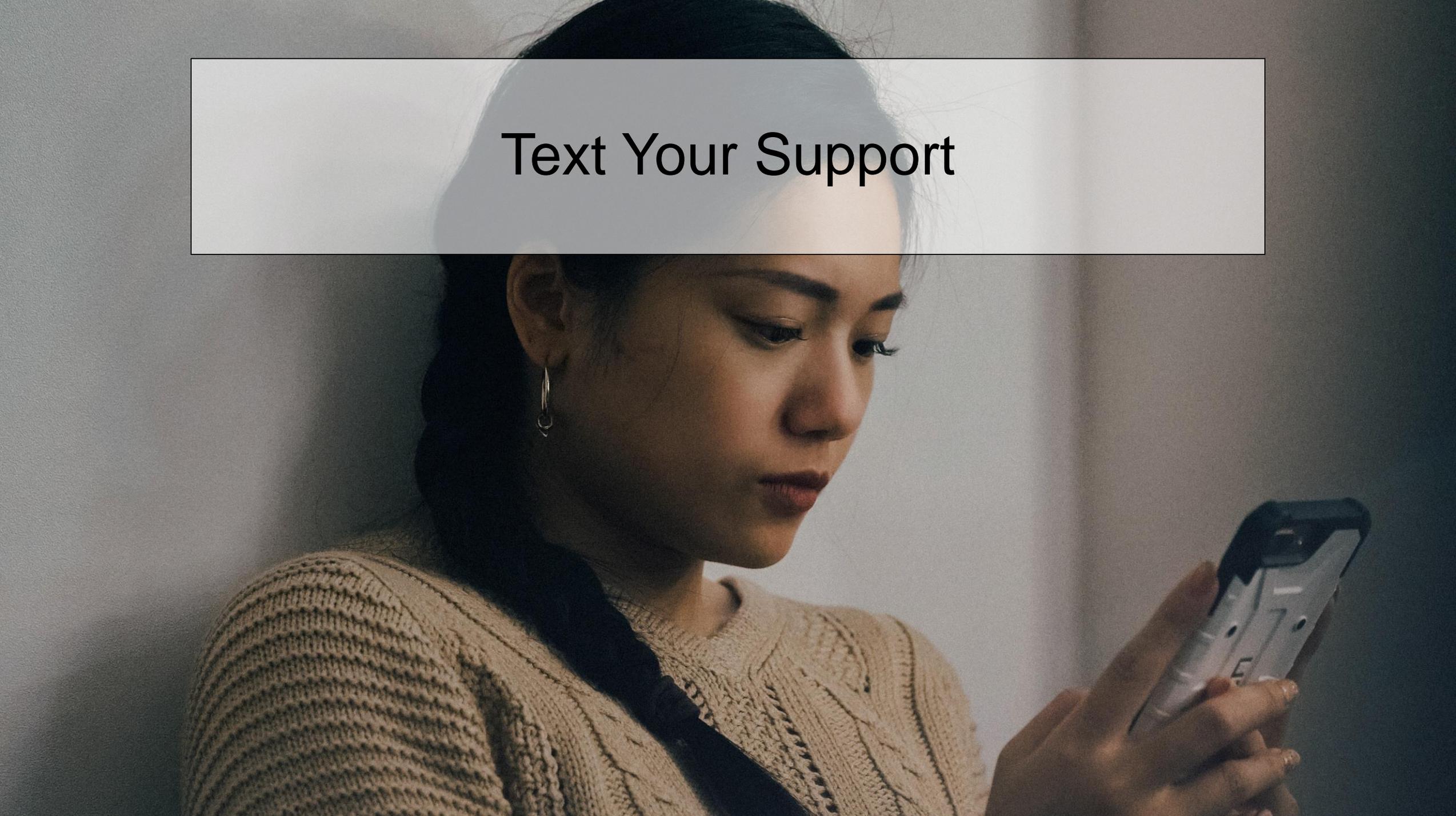


HOW WILLING ARE YOU TO RELY ON YOUR NETWORK?

ON A SCALE FROM 1 (STRONGLY AGREE) TO 5 (STRONGLY DISAGREE)

I WOULD TURN TO A FRIEND IF I WERE:

1. ALONE OR DEPRESSED
2. ANXIOUS OR SCARED
3. HAPPY OR HAD GOOD NEWS
4. EXPERIENCED A TRAGEDY
5. OVERWHELMED BY RESPONSIBILITIES AND COMMITMENTS
6. DISAPPOINTED
7. PROUD OF MY ACCOMPLISHMENTS
8. CONFUSED OR INDECISIVE



Text Your Support



EVALUATIONS

Tuesday, October 20 Sessions:

<https://col.st/gqVnC>



COLORADO STATE UNIVERSITY

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