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Tonight's Goals:

- **Identify at least one way you can take care of yourself**
- **Understand how your rules and expectations create stress for you**
- **Think about the role faith has in your caregiving journey**

My Story

- Professor Emeritus with UW-Extension
- Content specialization was family caregiving and grandparents raising grandchildren
- Primary caregiver for adult son
- Raised in Christian home and active in UMC for over 40 years



Caring for son with colon cancer (Stage four)

- 38 years old
- Single
- Lives in Tampa, Florida
- Recently broke up with girl friend
- Avid golfer
- Nonbeliever
- Had recently moved into temporary housing
- Two chemo treatments failed, radiation failed and wasn't expected to live







Sharing how my:

- Caregiving **knowledge** helped me
- Need to **care for myself** was essential
- **Faith** became an interictal part of my caregiver journey



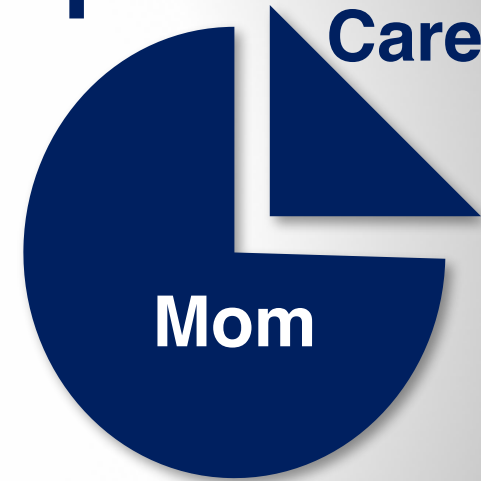
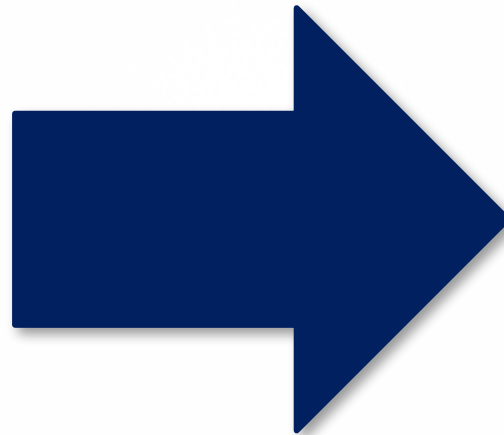
Knowledge from Research

- Taking on the role of caregiver would impact my role as Will's mom and could result in stress
- Realizing how my rules and expectations could create stress
- Finding resources would be key to reducing stress
- Taking care of myself needed to be a priority for me

**I became a caregiver
because
of my
relationship to Will
Caregiver**



Relationship




Caregiver



**Becoming
a
caregiver
changes:**

- who you think you are (*identity*)
- your *relationship* with your care receiver
- what you do (*actions*)



**Who
“you” are
depends
on:**

Life experiences

- When & where you were born
- Education
- Culture and heritage

Relationships

- Wife, parent, sister, friend, employee, friend, etc.

Life events

- Financial situation
- Life trials
- Family situation
- Losses in life
- Other events



Relationship Changes

Varies depending on:

Your caregiver situation

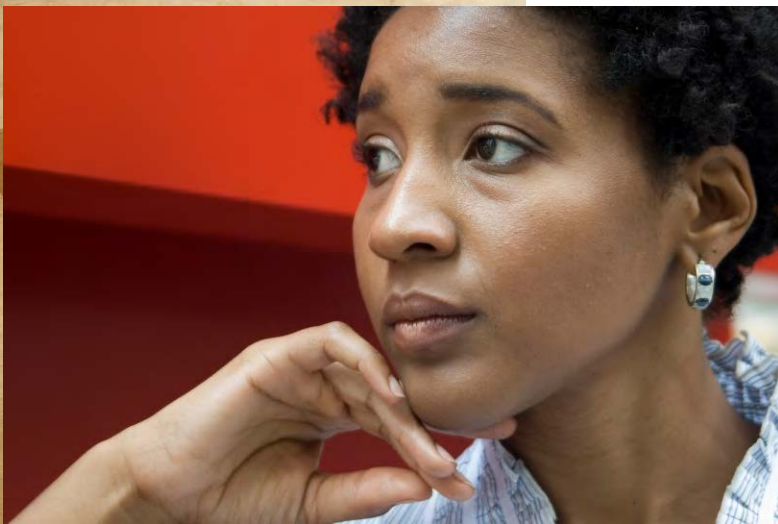
- Disability or illness of care receiver
- Living arrangement
- Your health
- Your skills and knowledge
- Your other obligations
- Resources and supports

Your rules and/or expectations

- Guides actions
- Are internalized
- You don't think —you just do
- Respond to what is needed

**Know there
are rules
because
you
experience:**

- Guilt
- Frustration
- Anger
- Depression
- Uncertainty
- Worry





Rules are Developed From...

Society

- A good spouse/partner:
 - Doesn't cheat
 - Loves their partner
 - Is there for each other
- People don't go out in the public naked

Communities you interact with

- Geographic communities
- Faith communities
- Ethnic communities
- Other communities such as a military community, fraternal group, etc

Your family

- We don't talk about money
- Women provide care
- We don't need/use outside help
- It's no one's business what happens in our family
- Others...



What you do..

**Its not what you do
but what you are doing
relative to what you think
you should be doing that
creates your stress.**

**Reactions to Caregiving Can
Create Identity Discrepancy**



Activities of Caregivers

ADLs (Activities of
Daily Living)

Bathing
Toileting
Feeding
Dressing

IADs (Instrumental Activities
of Daily Living)

Transportation
Finances
Housework
House maintenance
Yard work

Vigilance:

Never getting away; feeling like you are
on call 24/7

**If one of
these are
out of
balance
you will
experience
stress**

- who you think you are (*identity*)
- your *relationship* with your care receiver
- what you do (*actions*)

**Identity
Discrepancy
is expressed
as:**

Emotional Stress

- tasks and responsibilities of caregiving make you upset, anxious or worried

Workload Stress

- tasks of caregiving are interfering with other parts of your life

Relationship Stress

- tension between you and your care receiver because of caregiving

Three-Legged Stool

**Decision
Time to
Achieve
Balance**

1. Personal Rules

2. What you do
(actions)

3. How did you do? (Self-
appraisal)



Use Rules To Achieve Balance



- Accept your rule(s)
- Tweak or adjust your rule(s)
- Reject or throw out your rule(s)
- Create new rule(s)

Possible Supports to Help with Rule Balance

- Counseling
- Support groups
- Social media-blogs, networks, etc.
- Educational class
- Other supports



**Use
Actions
to
Achieve
Balance**

- Stop doing
- Have someone else do it
- Have care receiver do it
- Find ways to make action easier



Possible Supports to Help with Actions

- Assistive technologies
- In-home care assistance
- Family/friend
- Respite
- Turn task over to soldier



**Use
Self-
Apprais
al
To
Achieve
B**



- Change self appraisal
- Get rid of negative messages
- Find reinforcement for positive messages

Possible Supports to Help with Self Appraisal

- Support group
- Counseling





Example

Daughter (Rachel)

- Works full time and planned to retire in two years
- Has three children with one in high school
- Husband works second shift
- Only child and her relationship with her father isn't great

Father(Andy)

- Lives in his home alone as his wife died three years ago
- Has high blood pressure, heart condition, and some memory loss.
- Needs assistance with personal care, house maintenance, finances and transportation
- Can be difficult at times and feels he doesn't need assistance



Sources of Stress

Rachel stressed about:

- Having to take off work to care for her father
- Doing personal care for her father
- Taking care of her own family
- Conflict between them because of previous relationship



Identity Discrepancy & Types of Stress

Yes—identity discrepancy

Type of Stress(es)

Workload stress

Relationship stress

Emotional stress

Three-legged Stool

Rules out of balance

- a. Being a good employee means being at work
- b. Daughters don't bath their father
- c. Good daughter's take care of their parents
- d. Good wife's and mother's should be there for family members when they need her



Three-legged Stool

Rules out of balance with actions and self appraisal

A. Possible Supports:

1. **Hire** in home help to do housekeeping & other tasks
2. **Explore** with employer work options such as work at home, flex time, change hours, etc.
3. Change her **appraisal** about being a good employee to recognize that her work gets done, she communicates with employer, employer hasn't complained about her missing work or her performance
4. Change her definition (**rule**) of what a good employee is to include longevity; how she has helped others, etc.



Three-legged Stool

Rules out of balance with actions

B. Possible supports:

1. **Hire** someone to bath father
2. **Have someone else (her husband /his friend)** bath her father
3. **Secure** assistive technologies so father can bath himself
4. **Educational class or counseling** about identity change so she can expand her identity to include caregiving so bathing doesn't create stress



Three-legged Stool



Rules out of balance with actions

C & D. Good daughter's take care of their parents and Good wives and mothers should be there for family members when they need her.

Possible Supports:

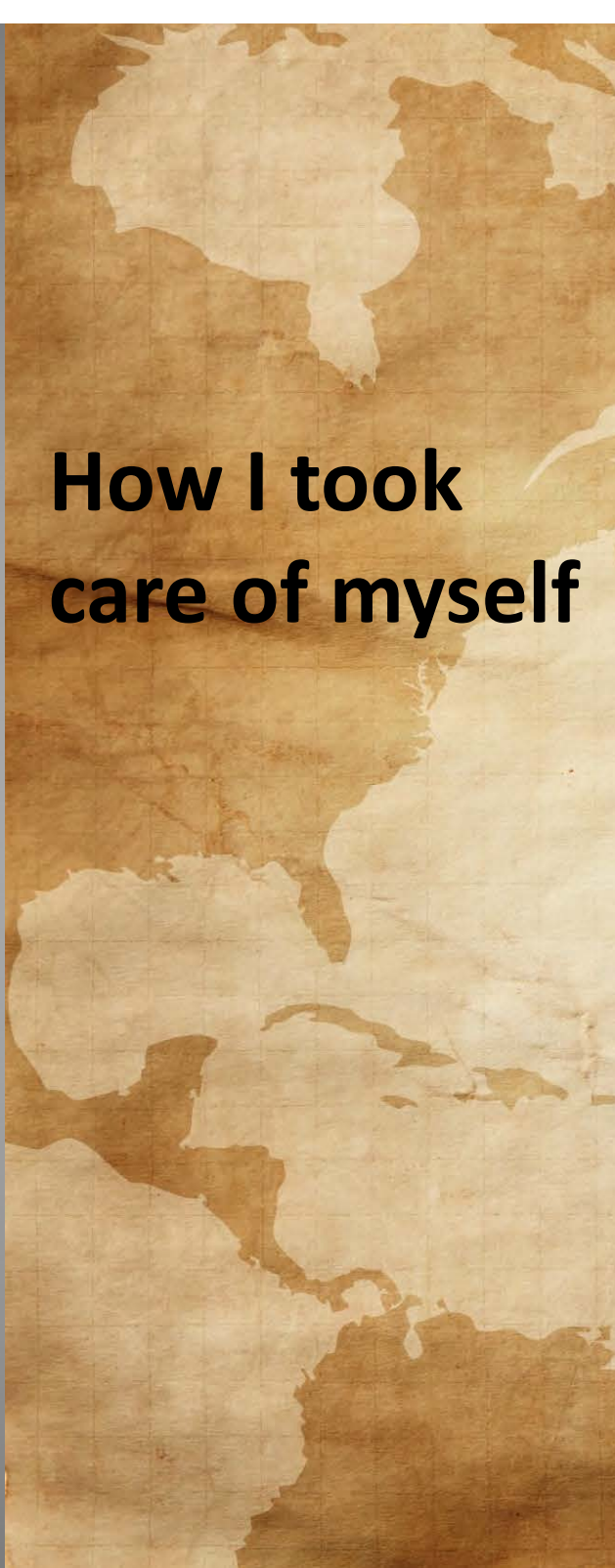
1. **Counseling**
2. Educational **class** about caregiving
3. **Support group** for caregivers



How I took care of myself

Identified what made me happy or provided comfort

- Nightly glass of wine
- Thinking of others
- Friends and family
- Reading romance books
- Cooking for Will and/or others
- Expressing love for Will by doing for him
- Spending time with Will
- Sharing my caregiver journey with others
- Prayer



How I took care of myself

Identified Rules

- When upset, conflict, etc. stepped back and tried to see if a “rule” was involved
- Looked for how “rules” were guiding my caregiving journey



How I took care of myself

Shared my journey

- Realized others truly wanted to help
- Asked for help
- Prayer
- Participated in church educational programs
- Sought out assistance and resources
- Wrote articles on emotional aspects of caregiving
- Held benefit(s) for Will



Faith Grew

Christian beliefs and practices

God provided for us:

- He opened doors when we saw no options
- Provided a sense of calm
- Guided us through the journey

Faith community:

- Knowing people were praying for us
- Local church support
- Tampa church support
- Pastoral support



Faith Grew

Christian beliefs and practices

Prayer

- Became active part of my life
- Prayed for calmness
- Prayed for a “miracle”
- Prayed for calm and peace

Out Reach

- More sensitive to others in need
- Realized I could ask for help and people would be there for us



Can You:

- **Identify at least one way you can take care of yourself**
- **Understand how your rules and expectations create stress for you**
- **Think about how your faith is supporting you**



Key Points

- Every caregiver journey is different but there are lots of similarities
- Your body tells you when you are under stress
- Our rules can create stress for us as caregivers
- Taking care of yourself is essential
- People want to help so ask!
- Your spiritual life or religious beliefs can be helpful



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