



# DEMENTIA CAREGIVERS AND COPING: THE POWER OF NARRATIVES

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# Our time together today

To talk about:

Paths to caregiving

Responses in walking up to caregiving

Use of narratives as a way of coping

Questions/comments



# PATHS TO CAREGIVING





# Examples of responses

Caregivers give something up to take on the role

Add the role on top of everything else

Take on the role accepting it for what it is and assuming they will be able to go back to their former lives and former selves once caregiving responsibilities end

Accept the role and go wherever it leads

Take on the role accepting it for what it is and realizing that they may not or will not be able to go back to their former lives and former selves

# Caregiving: a loaded experience

It involves learning new things

Transitions in relationships

New purpose; new meaning; new role; new self

Losses

One of the biggest losses is loss of self and selfhood



# CAREGIVER NARRATIVES





# In the words of caregivers

" My wife took care of me and our family for all those years while I was working. She did everything. And now it's my turn to care for her and I will not turn this responsibility over to anyone else. She never asked for help and neither will I. This is what husbands and wives do for each other."

" Can you tell me if my husband's dementia was caused by his years of heavy drinking in the past? If it wasn't I would have no problem caring for him but if it was..."

“ Every family has something to bear and this is our family's thing. I'm not looking for pity.”

Amy was 42 when she was diagnosed in Atlanta with early onset Alzheimer's disease.

# Brian continued

I once asked Brian to identify the first time he felt like a caregiver more than a husband to Amy. To my surprise he responded, "I never have." He continued to see Amy as his wife until her passing. He found comfort in sitting with her every evening even though she didn't acknowledge his presence and couldn't speak.

Here are some excerpts from Brian's chronicle of their journey with Alzheimer's disease.



# Brian continued

Amy died at 48, 5 years after her diagnosis.

" I feel like I'm getting a master's degree in life."

Sarah is an 80 year old woman whose husband, David, was diagnosed with Alzheimer's disease after a noticeable progressive loss of speech (aphasia).

David had a successful career in the insurance business before he retired at age 70.

Sarah had been a stay-at-home mother whose primary responsibility was raising their two sons, now both married and with children of their own. When their sons went to college, with David's financial support and business savvy, Sarah opened up a small gift shop because she "loved pretty things" and "loved creating beautiful displays" and wanted to give it a try. She closed the shop when David retired but felt a sense of satisfaction that she had done something she always wanted to do.

By Sarah's own admission, she felt that David had always "treated her like a princess" in that he held the responsibility for all of the "tough stuff" - the legal and financial decisions, investments, college tuition bills, etc.

# Sarah continued

As David's cognitive function started to decline, she realized that she was going to have to take on responsibility for those things - filing income taxes, annual Medicare enrollment decisions, and finding a plumber when the hot water heater broke.

Sarah became overwhelmed with anxiety because she had never done these things before, she didn't want to disappoint David, she didn't want to burden their sons knowing that dementia lasts a long time and she would need them later. She also wanted to "include" David in as many decisions as possible so as not to marginalize him.

She slowly began to tackle one thing after another. She was not afraid to ask for help or opinions from others. She connected with the professionals David had used in the past whenever possible.

She came in one day beaming with pride that she had filed the taxes! She then shared that she felt that she was "getting a master's degree in life." She acknowledged that she would never do things the way that David did but that if she could get the tasks done, that would be good enough and that sometimes "good enough is good enough"

She has since gone on to make other decisions on her own, including hiring a companion for David so that she can have some time to herself. Her symptoms of anxiety over legal and financial affairs are no longer causing her great distress.



"As a Catholic, I love my husband as a child of God and as the father of my children, and I will care for him throughout his illness. But... I will not give up my life for him. I will continue to golf and swim at the club and take short vacations because I need them."

Theresa first came to me as a 67 yo woman whose husband, Glenn, was diagnosed in the early stages of Alzheimer's disease. They had four adult children all of whom lived out of the area. She had one sister in the area and they had a very close but somewhat conflictual relationship. Her husband had been a prominent local athlete and went on to have a successful coaching business for athletes. She was also athletic and was a swim coach for athletes training for the Olympics tryouts. They had been married for 45 years and she had learned within the past year that her husband had been having an extramarital affair for the past 30 years. She was upset not only about his diagnosis and the affair, but she also had learned recently that he had given power of attorney to his brother and that she had no authority over their retirement funds.

She struggled for months with all of these feelings. She had little insight into her emotions as she had learned to "ignore and move past them" as a child when, at an early age, she became the "woman of the house" when her mother was hospitalized for a psychiatric illness. Theresa was in touch only with the emotion of anger, which she tempered with her faith. Being a devout Catholic was a check on her impulsivity.

# Theresa continued

Theresa eventually hired an attorney and got POA and authority over their retirement accounts. Glenn continued to decline cognitively but had little insight that anything was wrong with his brain for a few years, which made things difficult for them.

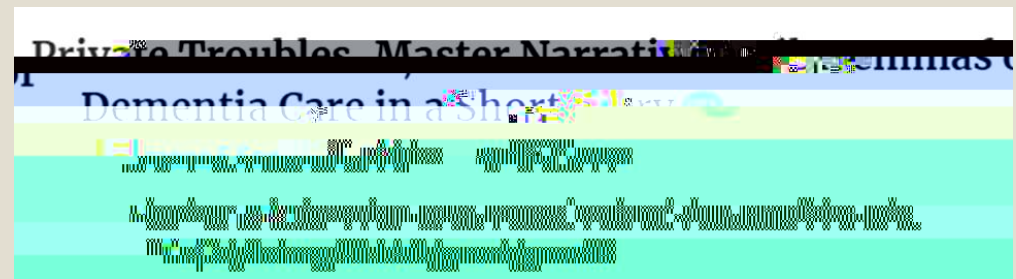
After a number of illnesses and economic turns, Theresa and her sister decided to sell their homes and buy a larger home where both couples could live and help each other. They have lived together now for about three years. Glenn is barely ambulatory at this point but Theresa continues to provide him with the best care possible.

I realized that Theresa's initial narrative was only partially true. While she does continue to play golf and take weekend getaways, she has become one of the most devoted caregivers I've ever seen. She has some outside help and holds them to very high standards for care. Her original underlying motivation to care for Glenn was her vows and the acknowledgment that he was a child of God. The motivation that sustained her as a caregiver was the one she got from being a coach – that of competition.

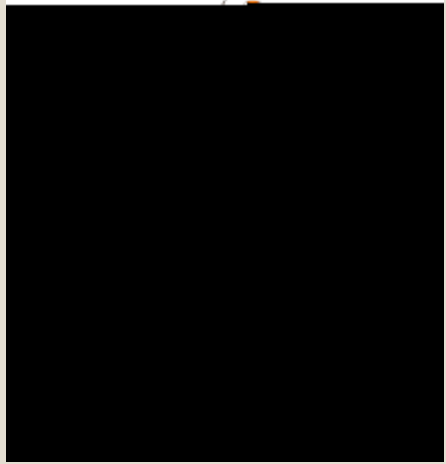


# The pain and stress of conflicting narratives

I once again chose the story partly because ... On one level it is "about" resistance to using formal services and illustrates the way that moral reasoning may be a more powerful influence on decision making than calculations of the emotional and other costs of continuing to provide care. I chose it as well because it is not about the cliché of caring for a "loved one", and it illustrates the tension between the socially constructed public meanings of the experience (Gubrium, 2000), and Mr. Cassidy's private, inexpressible emotions, exemplifying what Lionel Trilling observed of modern literature—that it is "shockingly personal ... [asking] every question forbidden in polite society" (1979, p. 7).



Loss of self and/or transformation of self





# FOUNDATIONS OF A NARRATIVE

# Finding elements of narratives

Tretteteig, Vatne, & Mork Rokstad.

2017

Sample question	Themes/Abame codes
<p>1. Introduction</p> <p>How has your social network changed over time?</p>	<p>How are you doing as a friend? Are you as close as you were before?</p>
<p>How do you consider your relationship with your relative?</p>	<p>2. Relational emotional changes</p>
<p>3. Positive experiences in the job</p>	<p>3.1. Positive experiences in the job</p>
<p>4. Negative experiences in the job</p>	<p>4.1. Negative experiences in the job</p>



Box 1 Narrative steps-by-step analysis

2. Searching for the narrative's overall theme What is the core content of the narrative?

3. Searching for the narrative's three main themes

Are there any conflicts or dilemmas related to who I am and who I want to be?

Relationship:

Are there any conflicts or dilemmas related to the need of belonging and/or separation?

Who I want to be in this situation?

Needs for belonging/separation/proximity and

Are there any conflicts or dilemmas?

Are there any conflicts or dilemmas related to the need of belonging and/or separation?

What separation did I take to reach that on regular days?

The influence of day-care

How does the day-care service influence who I am

How does the day-care service influence my need

How is the family caregivers' role

How is belonging described?

Are there any conflicts or dilemmas?

How day-care can support him or her to cope

Write down a short version of the narrative

The short version of the narrative should

Give a characteristic view of the family caregivers

Name the narrative with a short

# The study narrative findings

Family caregivers reported that day care positively influenced their "relationship-oriented coping" and experience of meaning

Finding meaning in the role of a family caregiver for persons with dementia is closely connected to the caregivers' own values and goals

Finding a balance between attending to their own needs and the needs of the person with dementia is crucial.

Day care has the potential to increase family caregivers' motivation to care by supporting their capacity to meet their own needs



# PROFESSIONAL'S ROLE

# Professional's role

To support and advance a useful narrative

To challenge a destructive or unhelpful narrative

To help to create a narrative if it would be helpful



# AN ACKNOWLEDGMENT

...

# The value of sharing

