

DEMENTIA CAREGIVERS AND COPING: THE POWER OF NARRATIVES

Carol Podgorski, PhD, MPH, LMFT
University of Rochester Department of Psychiatry-- Institute for the Family
Finger Lakes Center of Excellence for Alzheimer's Disease
July 20, 2020

Our time together today

To talk about:

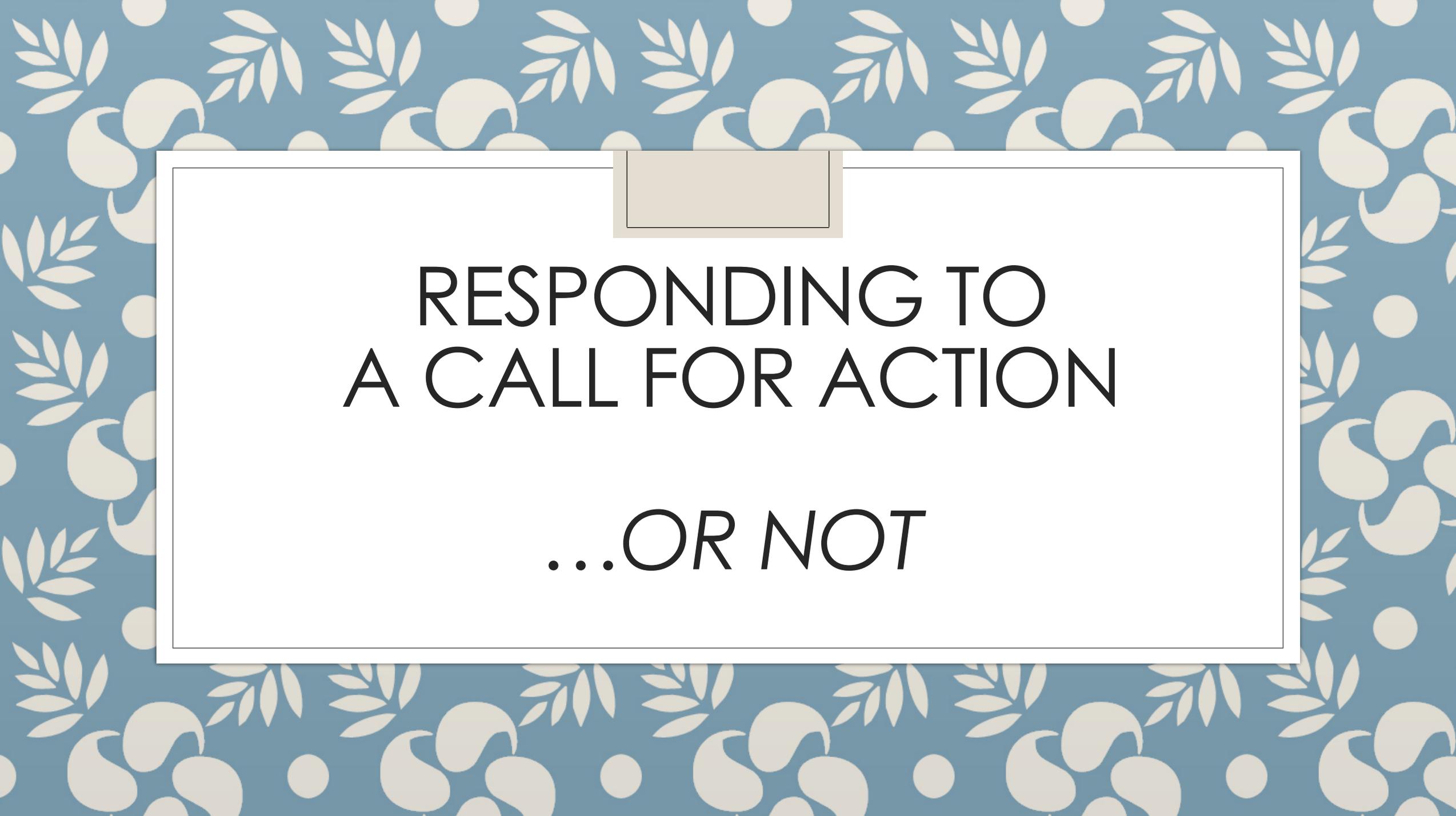
- Paths to caregiving
- Responses in walking up to caregiving
- Use of narratives as a way of coping
- Questions/comments



PATHS TO CAREGIVING

Paths to caregiving

- Onset of responsibilities
 - Sudden
 - Gradual
 - Expected and natural
- Accommodation versus choice
 - Acceptance
 - Responsive
 - Ambivalent
 - Avoidant
 - Rejection
- Relationship to role of “caregiver”
 - Conscious acceptance ←-----→ Conscious rejection



RESPONDING TO A CALL FOR ACTION

...OR NOT

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
 - Responses:
 - Define new role and strategy
 - See where it leads without proactive strategy
 - Minimize or deny that it interferes



CAREGIVER NARRATIVES

A planful, strategic approach

My purpose as a caregiver is

- To do what...
- In a way that...
- So that...

My purpose as a daughter caring for her aging and widowed 80 yo father was:

- To provide social, emotional and instrumental care for him, including at least one weekend visit every month and at least two phone calls per week
- In a way that preserves his independence and dignity while showing him that I love him and am available to him despite our geographic distance; and by connecting to his comfort and pride in our shared past
- So that he will feel cared for, safe, and connected and I will be able to give back to him and have no regrets of not being there for him

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. After the diagnosis, her husband, Brian, decided to move Amy and their two young children to Rochester to be close to his family for support. He took a demotion with the company that employed him when he relocated but was able to remain employed. Amy’s decline was quick.
- When I first met Brian he looked me in the eye and made the statement above. I had heard him repeat that statement many times.
- Brian has a planful coping style and has little tolerance for uncertainty and things he cannot control. He immersed himself into attending classes and reading everything that he could on Alzheimer’s disease and caregiving. He put a plan in place for everything he could anticipate. He joined a support group and took great satisfaction from being able to share things he had learned along the way. He found satisfaction in being helpful to others.

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.

*Despite the losses that continue to mount, Amy still understands quite a bit of what we say, even if her memory does not retain it. **There is an interesting mix of ability and loss and I realize the need to continue living and interacting with Amy as though she was healthy.** The moments may be fewer than before and this journey continues to grow harder but knowing Amy feels safe and perhaps happy brings some level of comfort.
(12/17/16)*

Brian continued

We are coming up on the 4th anniversary of Amy's diagnosis but it was a good 2 years prior to that date that Amy began showing signs of the disease and our lives began to change...*I quickly came to accept Amy's diagnosis and what it meant and immediately developed a plan* that I thought would protect Megan and Justin and enable us to stay strong as a family while the disease progressed. While I no longer regret my decision to move and give up my prior job, winter snow and cold are not my friend and I often find myself wishing for the life we had back in Georgia this time of year. ... Although it was hard to be far from family, we were happy and made many great friendships. Justin was going into 6th and Megan 9th when we moved and looking back I'm amazed how fast the time has gone. They are both in HS and Megan is awaiting college acceptance letters. They have demonstrated an incredible level of resilience with new friendships formed and active in sports they enjoy. They have adjusted to new schools and seem happy despite the losses they witness every day. I believe the move north was worthwhile but *I still worry every day and just hope they make it through this part of their lives with as little damage as possible.* (12/18/16)

Brian continued

Between the needs of work, the kids, our house and Amy there are many days where I feel overwhelmed and exhausted. I have seen my short, morning workout routine become continually less intense and not as consistent as I would like. I find it difficult at times to focus on certain tasks and some days it is impossible to even make a decision on simple things like meals. Caregiver burnout is real. *Over time my characterization of this journey has evolved from the hopeful "championing the cause" and "one day at a time" to the sober "just focus on today" and recently "just keep moving forward, it doesn't matter how small the steps".* This disease hits the caregivers hard, physically and emotionally. I know the journey will not last forever and *I tend to be stubborn so I wake up each day and keep going as I will not give up or give in. But, to be honest, there is something else that drives me and it is more than love, loyalty or obligation.* I have come to realize it is faith and God's strength. Attached is a photo I took on our second visit to the Univ of Scranton in August. It is a Jesuit school and we stopped in front of this statue during the tour. I have great respect and appreciation for the Jesuits, and this statue of St. Ignatius Loyola and the words written on the stones captured my attention. Not too long ago I found the photo on my phone, read the words again and *realized that I am doing what I've been called to do.* (12/21/16)

- 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.

Theresa continued

- She has been driven by making sure that Glenn “beats the odds” and that he manages to “surprise his doctors” every time with how well he is doing. (And he is!). She has hired PTs to keep him as mobile and strong as possible and to keep his mind sharp. She often shows me videos of him playing catch with a tennis ball with the PT. She only allows him to eat healthy foods and “encourages” him to eat even when he is not interested. She sings love songs to him and has come to obtain “evidence” that the affair was “not really a big thing.”
- She is motivated by a narrative that affirms that she provided the “best” care for him by the “best” people and that she knew best what he needed and that is why he defied the odds and lived so long with a good quality of life.

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).

Private Troubles, Master Narratives: Dilemmas of Dementia Care in a Short Story FREE

[Suzanne E England, PhD](#) ✉ [Author Notes](#)

The Gerontologist, Volume 57, Issue 5, October 2017, Pages 963–968,

<https://doi.org/10.1093/geront/gnw086>

Loss of self and/or transformation of self





FOUNDATIONS OF A NARRATIVE

Finding elements of narratives

- Tretteteig, Vatne, & Mork Rokstad. *Journal of Multidisciplinary Healthcare*, 2017
- Study to understand what influences how caregivers perceive use of day care services
- Their 3 research questions:
 1. What motivates family caregivers to provide care?
 2. How do family caregivers find meaning and develop a sense of coping in their role?
 3. How does day care influence family caregivers' sense of coping and motivation in the role?

Table 2 The interview guide

Themes/theme areas	Sample question
1. Introduction	How are you doing, as a family caregiver? How has your situation changed lately?
2. Relational emotional changes	How do you consider your relationship with your relative?
3. Positive experiences in the role	Is there anything about your situation now that you consider to be good? <ul style="list-style-type: none">• What contributes to these good times?• Why do you think you handle this difficult situation so well?• What is important in order for you to help and support your relative?• Is there anything health care workers can do so that you have more good times together?• Have you ever thought that you have to give up or “drop out” of caregiving?• What keeps you going when things are difficult?
4. Own needs	What do you think about taking care of yourself? <ul style="list-style-type: none">• Is it important to prioritize your own needs in your current situation?• Can you prioritize your own needs or those of others?• Are there any conflicts associated with your needs or those of your relative?
5. Conclusion	How does your relative attending a day care center impact on your everyday life? In general, what do you think is important in order for you to do well in your current situation?

Note: The interviews were conducted and analyzed in Norwegian and then the quotations were translated to English by the research group.

Box 1 Narrative step-by-step analysis.

1. Transcription	From oral speech to text
2. Searching for the narrative's overall theme	What is the core content of the narrative?
3. Organizing the narrative in three main themes as described by the study objective	Identity Who am I? Why am I/are we in this situation? Are there any conflicts or dilemmas related to who I am and who I want to be? Relationship To whom did I belong? To whom do I belong? How do I experience belonging to a person with dementia today? Are there any conflicts or dilemmas related to the need of belonging and/or separation? What position do I take toward the person with dementia? The influence of day care How does the day care service influence who I am/who I want to be in this situation? How does the day care service influence my needs for belonging/separation/proximity and distance?
4. Searching for the narrative's plot	Write down one or two sentences describing the narrative's plot/main content
5. Organizing the narrative into meaningful stories. Analyzing these stories through questions aimed to concretize and complement the main themes (point 3)	Ask the questions: <ul style="list-style-type: none">• What is distinctive in the story?• How is the family caregivers' identity described?• How is belonging described?• Are there any conflicts or dilemmas?• How are their choices of position described?• How are their stories told?
6. Summing up the analyses of the meaningful stories in 5–10 sentences to describe the condensed content	Are there any repeating themes? Are there any relationships between the present and past?
7. Write down a short version of the condensed narrative based on the analyses and the adjusted plot	The short version of the narrative should give a characteristic view of the family caregiver's identity, his or her experience of meaning and the relationship to the person with dementia, and how day care can support him or her to cope
Name the narrative with a short descriptive sentence	

Note: The interviews were conducted and analyzed in Norwegian and then the quotations were translated to English by the research group.

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

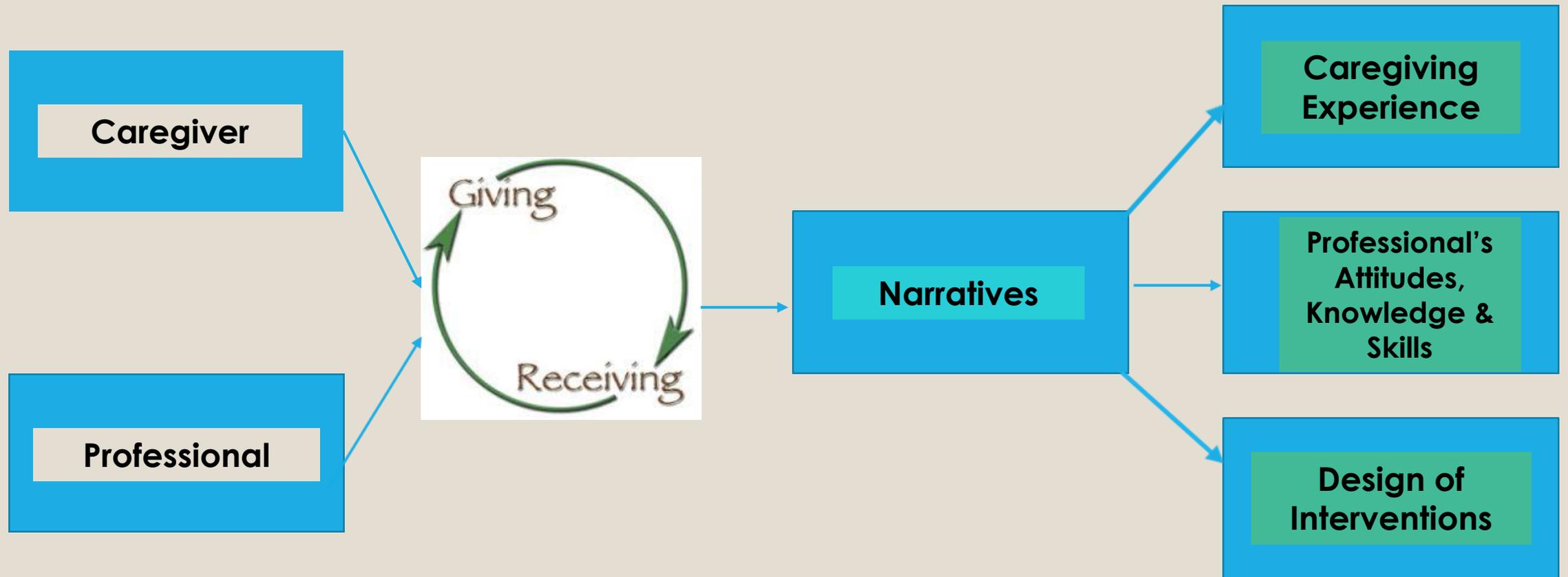
- To support and advance a useful narrative
- To challenge a destructive or unhelpful narrative
- To help to create a narrative if it would be helpful



AN ACKNOWLEDGMENT

...WITH GRATITUDE

The value of sharing





THANK YOU