

2018

Dementia: Shifting Mystery to Meaning and Management

Daniel and Beverly Egley

University of Minnesota Duluth, degley@d.umn.edu

Follow this and additional works at: https://repository.stcloudstate.edu/survive_thrive

Recommended Citation

Egley, Daniel and Beverly (2018) "Dementia: Shifting Mystery to Meaning and Management," *Survive & Thrive: A Journal for Medical Humanities and Narrative as Medicine*: Vol. 4 : Iss. 1 , Article 11.

Available at: https://repository.stcloudstate.edu/survive_thrive/vol4/iss1/11

This Article is brought to you for free and open access by theRepository at St. Cloud State. It has been accepted for inclusion in *Survive & Thrive: A Journal for Medical Humanities and Narrative as Medicine* by an authorized editor of theRepository at St. Cloud State. For more information, please contact rswexelbaum@stcloudstate.edu.

Dementia: Shifting Mystery to Meaning and Management

Cover Page Footnote

Cover info already uploaded

Dementia: Shifting Mystery to Meaning and Management

[Editorially Reviewed Submission for *Survive and Thrive*]

Dementia: Shifting Mystery to Meaning and Management

Introduction

Soon after my mother completed her eightieth year on this planet, we moved her and her downsized number of belongings into our house. Even though her household items eventually fit comfortably into one rented truck, the move from Central Missouri to Northern Minnesota was an adventure to say the least. We recently recognized the first anniversary of her change of residence. During these months, we noticed a variety of habits and quirks that are the result of Mom living by herself after she was widowed over 30 years ago. Some of those habits have naturally aligned themselves to living with more than one person in the house, like wandering through the house in various states of dress. However, some idiosyncrasies tend to provoke more thought than others. One of those oddities includes an incident that occurred early during this season of caretaking.

As my wife helped Mom prepare for her bath, Mom stood in front of the open door of the linen closet. She did not say anything. She just stood. After several minutes, Beverly asked, “What are you looking for?”

“A towel.”

The closet was full with fresh laundry completed the day before. As Beverly looked in, she could not figure out what Mom was not seeing. “Right here, Mom.”

“Oh, I was looking for the white one.”

This incident and Mom’s perspective surrounding it has manifested itself in her apparent inability to find towels, housecoats, and blouses in any color other than white. We noticed during the two years before her relocation that she always wore the same worn, ancient, tattered shirt when we arrived on her doorstep for a visit. When we took her to a restaurant, she always changed it, but around the house, she always, always, always wore the same almost-see-through, sleeveless shirt. After Mom was standing at linen closet, the first questions we asked ourselves were natural. “Why did she wait so long to choose a towel? Why didn’t she notice that the closet was full? Why did she want *only* a white towel?”

Looking at Dementia in the Medical Humanities Literature and by Looking at Scripture

We are now a part of a community of caretakers who find themselves asking, why are you doing that? Why are you saying that? Whatever the reason, our elders are not who they used to be. There is a struggle as one takes care of them to understand why they are so different now. Why does Mom appear to be

Dementia: Shifting Mystery to Meaning and Management

[Editorially Reviewed Submission for *Survive and Thrive*]

less intelligent? Why can't I get Grandma to understand? Why doesn't Dad recognize me? Why is Auntie more emotional? Why is Granddad stressed when he was a low-key person his whole life? Why, why, why?

The questions of "Why" can be answered in the physiological degeneration of the brain. According to the Alzheimer's Association (2018), "The main cause of behavioral symptoms in Alzheimer's and other progressive dementias is the deterioration of brain cells which causes a decline in the individual's ability to make sense of the world." Having the physiological answer to "Why" helped us understand what is going on in Mom's brain. However, it did not help us in our daily activities. Since Mom cannot make sense of her world, it leaves her in confusion. She cannot express herself. She cannot share her life.

Similarly, in her article on Narrative Collapse, Robillard (2014) said, "Narrative resides in the background of so much of our day-to-day lives, the often invisible explanations for the ways we think, the things we do." For us, the medical humanities includes the creation of the picture or story within our experiences. As a result, we can treat Mom as a whole person. Robillard described stories as support beams for a relationship. We live our lives as a series of stories. Without that narrative, the relationships might collapse.

Narrative involves your whole being. Therefore, we turned our thoughts to biblical principles. We noticed that the question "Why" in scripture was seldom, if ever, answered. This was congruent to our experience. In the example above, we eventually discovered the reason Mom needed a white towel. When the other towels she owned were wet or damp, the extra weight made them difficult for her frail frame to handle. However, the white towels were smaller, lighter, and easier to manipulate. Unfortunately, when Mom was standing in front of the linen closet, she could not articulate that idea because she could not recall the reasoning, just the feeling that she liked them. Months later, we discovered why by asking, "What is it about the white towel you like best?" From our experience and perspective, "Why" seemed to be the wrong question. We began to search for the correct questions.

Our heart is to help Mom enjoy the sunset years of her life and to make them as comfortable as possible. However, we needed to figure out our response mechanism so that we could assist her as she moves forward. As we prayed and read, we came across two questions in the New Testament.

At Pentecost, many people from many nations heard the sounds and saw the effects of the original manifestation of Holy Spirit in the disciples. A question bubbled up from their perspective, "Whatever could this mean?" (Acts

Dementia: Shifting Mystery to Meaning and Management

[Editorially Reviewed Submission for *Survive and Thrive*]

2:12) Saint Peter told them what it meant. Shortly afterward, they asked another question, “What shall we do?” (Verse 37) Again, Peter told them exactly what to do. As we have applied these questions to our experiences, they became especially helpful as we worked with Mom. Whenever we were particularly troubled or confused with her responses, reactions, or routines, we wanted to ask, “Why are you doing that?” We wanted to understand the logic. Asking “Why” tries to find the rationale behind current behaviors.

With dementia, reason falters with the breakdown in the normal brain activity. These new questions were catalysts to taking care of Mom’s needs and emotions. We began to change our questions to “What does this mean? What must we do?” For example, when she was searching for the white towels in the closet, we needed to ask, “What does this mean? What must we do?” In this case, we had to find out her need for a smaller towel by asking better questions. Also, we found out that the white shirt she wore every day for two years was comfortable. The buttons were bigger and easier for her crooked fingers to manage. She did not have to “think” about what to put on. It was easy.

On another morning, Mom emerged from her bedroom wearing pajama bottoms and the dress blouse she had worn to church the day before. Once again, our initial reaction was to ask, “Mom, why are you wearing a blouse with PJs?” However, we needed to respond with correct questions. “What does this mean? What must we do?” It means that Mom was tired last night before bedtime. It had been an eventful day as a family and with other people. By bedtime, she was too tired to put together her customary sleeping attire. We needed to help her and set out her pajamas before saying goodnight.

Putting the Right Questions into Action, in Communication

These questions relate to more situations than just towels and blouses. Mom’s conversation changed as she struggled with short-term memory loss. She remembered events that happened decades ago as perfectly as if they occurred yesterday. However, she could not seem to remember this evening that she received phone calls today from her three eldest sons for her birthday. Furthermore, this phenomenon affected her ability to create relevant conversations with us and others. She did not say anything related to the topic (birthdays, family visits, worship experience) because she struggled to remember anything appropriate to say. In an effort to join the conversation, she strived to recall something, anything from her experience, to add to the discussions. Unfortunately, the only thing she remembered were bromides. When we noticed this shift in Mom’s phrasing, once again, we were troubled. We asked ourselves, “Why does she do that?”

Dementia: Shifting Mystery to Meaning and Management

[Editorially Reviewed Submission for *Survive and Thrive*]

Mom was the Valedictorian in her class. She worked for a university extension center and two county governments. She spent a lifetime completing crossword puzzles in ink. She raised five boys, lost two husbands and her youngest son, and still proclaims that she has lived a great life. She has always been intelligent, hardworking, creative, and witty. So, why was this smart, funny, world-wise woman suddenly using clichés in everyday conversation instead of just speaking her mind? Again, “Why” is the incorrect question. In this situation, it does not resolve the issue she has in carrying on a conversation. For the sake of Mom’s health and wellness, we needed to ask the two questions from Acts Chapter Two.

First, “What does this mean?” Mom struggles with short-term memory loss. She tends to forget what she said five minutes ago and then makes the same statement again. Second, “What must we do?” We need to talk about experiences in her distant past. She can tell the story and hold a conversation about those. We need to turn the conversation to what we are experiencing in the moment. The beauty of the day, trees, sky and not focus on the events leading up to that point. When all she can think of are bromides, we need to let the bromides flow! We can even try to connect them to a distant memory of when she first heard it.

Robillard (2014) described our need to connect our stories with the stories of others. We need to help Mom converse so that her stories are intertwined with ours and those around her. We cannot let her just “disappear” because her ability to articulate her story has been affected by dementia. The famous quotation from Maya Angelou and others states that people may not remember what you said or did, but they will remember how you made them feel. Our Narratives bind us together in relationships. Mom once said, “Communication is *not* the backbone of a relationship; communication holds the backbone together.” (Little, 1987)

Putting the Right Questions into Action, Looking Forward

As we look forward, our perspective about *our* future is changing. We are looking at our current habits to see how our son might perceive them in three decades. If he ever becomes our caretaker, what behaviors can we change now to help him avoid the “Why” questions? As stated above, everyone has quirks and idiosyncrasies. They make up the flavor and humor of our lives. No one’s peculiarities are better or worse than anyone else’s. However, to a caretaker, have those characteristics become simple eccentricities? Or rather, do they present as confusion and senility to create the evidence of faulty neurological functions?

Dementia: Shifting Mystery to Meaning and Management

[Editorially Reviewed Submission for *Survive and Thrive*]

As we continue assist Mom, we are looking to avoid these pitfalls when we are 80. For example, we tend to talk in random phrases from movies we have watched. As a couple, this is fun, and we know what we mean. To those around us, it creates confusion or, worse, it shuts them out of our own little conversation. Thirty years from now, we will need to be able to converse in more than movie phrases. We need to begin now to reduce the frequency of this practice.

Humans are creatures of habit, and that is not a bad thing. However, when the habits create hazards, we need to try to remove them. We need to begin journaling the events in our lives. As we get older, we may not recall the details, but we can still share our story with our future generations through our journals. As a result, we can continue our relationships through our written narrative.

Conclusion

The framework for Mom's care is various and thrilling. We love having her in our home. We know that she is well cared for, and we know that she is receiving the individualized care that is impossible elsewhere. We have lives filled with love, humor, and joy. However, from time to time, we experience some confusion. We have tried to resist the "Why" questions since they lead to frustration and irritability when left unanswered. Even when the question of "Why" is answered, the issues remain. We prefer to ask, "What does this mean? What must we do?"

The answers to these questions are more practical and valuable. These questions will honor the woman Mom has always been. They will help others see the person she was before dementia. These new questions help us to care for Mom's whole being: Body, Soul, and Spirit. Simultaneously, they heal *our* Body, Soul, and Spirit because we are able to help Mom. As a result, we are learning to care for the whole of Mom in her day-to-day life. Furthermore, we can maintain our relationship with her as a mom and keep her from becoming patient "M."

Dementia: Shifting Mystery to Meaning and Management

[Editorially Reviewed Submission for *Survive and Thrive*]

References:

Aims & Scope. (n.d.). *Survive and Thrive: A Journal for Medical Humanities and Narratives as Medicine*. Retrieved June 16, 2018, from http://repository.stcloudstate.edu/survive_thrive/aimsandscope.html

Little, V. D. (1987). [Interview by D. D. Egley]. Monticello, Missouri. (We chatted together while she was washing silverware at the dish sink.)

Alzheimer's Association. (2018). Repetition. Retrieved July 18, 2018, from <https://www.alz.org/help-support/caregiving/stages-behaviors/repetition>

Robillard, Amy E. (2014) "On Narrative Collapse: Dementia, Depression, and the Significance of Narrative Resources," *Survive & Thrive: A Journal for Medical Humanities and Narrative as Medicine: 1(1)*, Article 8. Available at: http://repository.stcloudstate.edu/survive_thrive/vol1/iss1/8

The Holy Bible: New King James Version. (1985). Wheaton, IL: Thomas Nelson Publishing.

Dementia: Shifting Mystery to Meaning and Management
[Editorially Reviewed Submission for *Survive and Thrive*]

