
10-10-2020

Defying Dementia: An Exploration of Recovery


Deb Miller

City Seattle University, debmiller@cityu.edu

Corey W. Johnson

University of Waterloo, corey.johnson@uwaterloo.ca

Follow this and additional works at: <https://nsuworks.nova.edu/tqr>

 Part of the Development Studies Commons, Disability Studies Commons, Family, Life Course, and Society Commons, Quantitative, Qualitative, Comparative, and Historical Methodologies Commons, Social Statistics Commons, Social Work Commons, and the Sociology of Culture Commons

Recommended APA Citation

Miller, D., & Johnson, C. W. (2020). Defying Dementia: An Exploration of Recovery. *The Qualitative Report*, 25(10), 3627-3640. <https://doi.org/10.46743/2160-3715/2020.4460>

This Article is brought to you for free and open access by the The Qualitative Report at NSUWorks. It has been accepted for inclusion in The Qualitative Report by an authorized administrator of NSUWorks. For more information, please contact nsuworks@nova.edu.



Defying Dementia: An Exploration of Recovery

Abstract

Exploring the human side of dementia helps put a face on this fast-growing affliction. This study reflects one elderly woman's story of recovery from dementia that arose following a stroke. Painting a portrait of life with dementia can help us conceptualize the experience, how people live and how they would like to live. The woman is Marcia, my mom, and this is a qualitative inquiry with a collaborative narrative design to explore her experiences and to document my own. This study may help dementia patients and their support teams better understand the process of living with dementia and can perhaps lead to a more informed and supportive environment to optimize recovery for all concerned.

Keywords

Dementia, Dementia Recovery, Quality of Life, Qualitative

Creative Commons License



This work is licensed under a [Creative Commons Attribution-Noncommercial-Share Alike 4.0 International License](https://creativecommons.org/licenses/by-nc-sa/4.0/).

Acknowledgements

We would like thank Marcia for her willingness to share of her lived experience and her resilient life.

Defying Dementia: An Exploration of Recovery

Deb Miller

City University of Seattle, Washington, USA

Corey W. Johnson

University of Waterloo, Ontario, Canada

Exploring the human side of dementia helps put a face on this fast-growing affliction. This study reflects one elderly woman's story of recovery from dementia that arose following a stroke. Painting a portrait of life with dementia can help us conceptualize the experience, how people live and how they would like to live. The woman is Marcia, my mom¹, and this is a qualitative inquiry with a collaborative narrative design to explore her experiences and to document my own. This study may help dementia patients and their support teams better understand the process of living with dementia and can perhaps lead to a more informed and supportive environment to optimize recovery for all concerned. Keywords: Dementia, Dementia Recovery, Quality of Life, Qualitative

Background and Objectives

While dementia is a growing global public health problem, dementia *recovery* is achievable, within a range of possibilities. I know because I witnessed it with my own mom. Using narrative inquiry, we explore my mom's experiences after being diagnosed with dementia - hearing in her own words about the memories of her journey, what drove her recovery and how she wishes to live her life going forward.

It is challenging for a child to become the chief caregiver for their parent, let alone to tackle roles as researcher and parent participant. Relationships between mothers and daughters can be complex, but sometimes new roles can evolve from these experiences and do so in all the right ways.

Dementia is Scary

Approximately five to seven percent of our worldwide population is affected by dementia with the number doubling approximately every 20 years (Djukic, Wedekind, Franz, Gremke, & Nau, 2015). The American elderly population (defined as persons age 65 years and older) is expected reach to 70 million by 2030. As the elderly U.S. population grows, the number of individuals suffering strokes and/or dementia is predicted to increase (Plassman, Langa, Fisher, Heeringa, Weir, Ofstedal, & Steffens, 2007). Dementia is the most common reason to place the elderly in nursing facilities, and the demands for nursing home care are predicted to quadruple for those aged 85 and older (Feil, MacLean, & Sultzer, 2007). Learning more about what dementia is and what the best approaches are to possible recovery is likely to be of interest to growing numbers of people. The topic caught my attention last year.

¹ When first person is used, it refers to the first author, Deb Miller.

The beginning of my mom's story. Marcia (pronounced Mar-SEE-uh) is my mom. This is not her life story, but rather a story about her recent experiences. A year ago, she was living independently at age 90, still proudly driving her Chrysler Milano, taking care of her beloved dog, Snowy, going to church on Sunday and managing her own finances without any signs of dementia. Then, she suffered a massive stroke. She needed to learn to speak again, how to eat, to sit up and to walk. Her brain function seemed generally fine in the beginning, although depression quickly set in as she sat in the hospital and began to realize her independence had been drastically altered. She clung to the idea of at least being reunited with Snowy, so she asked me, her youngest daughter, if she and her dog could join us in Florida. This dream became a reality after about two months of initial therapy in her Indiana hometown.

We enjoyed a couple of happy but hectic months making continued physical progress until she suffered a second stroke. While this mini-stroke was barely perceptible on one level, the impact was major on the cognitive side. Suddenly, she no longer recognized me, she started to open outside doors randomly in search of long-lost destinations, incontinence took over and she would frequently forget to don any clothes. She dozed in and out of reality during the day and experienced vivid hallucinations at night. Marcia's hard-earned physical improvement following the first stroke rapidly declined and she ended up back in a wheelchair much of the time.

We turned to a neurologist who reviewed Marcia's magnetic resonance imaging (MRI) and spent time reviewing her current medications, blood work and history. She dozed in and out as his staff conducted initial cognitive screening tests (which she failed miserably) and some physical tests for gait and mobility. She was brought back a few days later for a lengthy brain scan and ultrasound, but it was not until the third visit when he diagnosed her with vascular dementia and delirium.

He gently suggested we move her from our home to a nearby memory care facility with 24-hour nursing and cognitive activities to routinely stimulate her, which could possibly aid in her recovery. The family all agreed. The neurologist said she had a chance at recovery, but the memory medication would take months to ramp up and to take full effect. This was a lot of information for me to process. For Marcia, this was the culmination of a tumultuous six months. I realized I didn't really know what dementia was - let alone what to expect. At that stage, given Marcia's recent rapid decline, recovery seemed impossible. I turned to the research for answers (see Figure 1).



Figure 1. Source: Author. *Marcia when diagnosed with dementia*

Dementia

Dementia is defined as an *acquired, persistent impairment in two or more cognitive areas* (language, memory, problem solving) and is a leading cause of disability in the elderly

(Feil et al., 2007). According to dementia.org (2020), vascular dementia may set in following a stroke and patients can experience a sudden onset of these symptoms: confusion, trouble speaking or concentrating, difficulty solving problems, or completing tasks, problems with bladder and bowel control, hallucinations or being easily agitated or upset. Marcia had every symptom.

Dementia Recovery

Dementia reversibility is a rare event. While possible, it is estimated that only 1-20% of all cases can be reversed (Clarfield, 2005). The wide range is due to many factors, including whether or not to include Alzheimer's disease (AD) patients or not in the numbers as AD is considered irreversible and can distort the picture for those patients with a true shot at recovery. AD accounts for 55% to 77% of all dementias and vascular dementia (my mom's diagnosis) accounts for 15% to 25% (Djukic et al., 2015). Prokopov (2010) reports about 10% of dementia cases can be reversed – all vascular.

Although the odds of reversibility are slim, especially for older adults, dementia reversal is not a myth and Harisingani (2005) encouraged physicians not to give up the effort; testing, which can be rigorous, should only be considered on a case by case basis. Early recognition of cognitive impairment and dementia, followed by intervention, can offer patients and caregivers the opportunity for better quality of life (Feil et al., 2007). As there is much variability associated with vascular dementia, there is no specific treatment. Rehabilitation and accommodations can help improve an individual's functioning post-stroke, and prescriptions for cognitive difficulties following stroke can be effective (Pinkston, Alekseeva, & González Toledo, 2009).

One major obstacle to recovery is typically the stigma associated with dementia in older people. This negative image of being viewed as "different from others" significantly disadvantages older persons with dementia and contributes to a loss of status in society (Gavan, 2011). As dementia symptoms often appear during hospital stays, knowing the right way to support older adults at the hospital is a starting point and could prevent the progression of dementia (Komatsu & Hamahata, 2014).

Researchers report that older people with dementia prefer to be informed of the diagnosis, because they can more effectively manage their condition when they are aware. They feel hopeless and worthless without the ability to exercise some degree of control over their lives (Gavan, 2011). The concept of recovery within the recovery-based approach describes how people become empowered to manage their lives in a manner that offers meaning and purpose (Martin, 2009). This idea of recovery guides the dementia support team to create opportunities for empowerment for the person with dementia to choose how they manage their lives. The pursuit of empowerment means challenging the paternalistic approach traditionally taken in care of people with dementia (Gavan, 2011).

The recovery-based approach means the support team maintains a positive attitude in a sharing of information within the reciprocal relationship. The staff brings expertise about dementia and health, while the person with dementia brings expertise about their life circumstances. The shared information results in customized care going beyond mere maintenance of people with dementia and offering them the possibility of recovery and hope (Gavan, 2011).

The Tidal Model by Barker and Buchanan-Barker (2005) is one variation of the recovery-based approach and is used for dementia patients and more broadly for other areas of mental health nursing. The model was developed in the 1990s and focuses on empowering the person in care. The Tidal Model suggests treating others as we would want to be treated. Instead of the support team trying to mold the patient into a specified format for recovery, the model

uses the life experiences and everyday living of the person in care to shape his or her own recovery. The team listens and learns instead of directing (Kilmer & Lane-Tillerson, 2013).

The Family Role

Family members can provide significant support for older relatives in long-term residential care (Barken & Lowndes, 2018). Yet, while family members and friends may be considered “part of the team,” care facilities often lack the ability to facilitate their integration and engagement over time (Baumbusch & Phinney, 2014, p. 88). There are two primary theories about the role of families with respect to the elderly in long-term care settings. One theory is about the family’s shared function and balanced coordination with a facility, and the other theory views family roles in terms of providing meaning or purpose, such as the maintenance or preservation of the older relative's dignity and sense of self (Dupuis & Norris, 2001).

A study about the roles of adult daughters, who make up the majority of familial caregivers in the long-term care setting, looked at the daughters’ roles in caring for a parent with cognitive impairment living in a long-term care facility from the daughters’ perspectives. While family members are typically viewed as one homogeneous category, the researchers subdivided the daughters into five caregiving roles: active monitors, regular visitors, accepting relinquishers, unaccepting relinquishers, and indirect supporters (Dupuis & Norris, 2001).

The active monitor role was consistent with the “role meaning” theory outlined above. These daughters believed their role served a purpose within the facility to maintain some sense of normalcy in their parents' lives, to monitor their care through regular communication with and observation of staff, and to maintain their parent's sense of personhood - by trying to maintain as much of the parent as possible. They also ensured that their parents were treated as adults, with dignity and respect. Adult daughters with this role felt some “pressure” to “being there,” a sense of obligation or duty to be involved in their parents' care. In some cases, this pressure seemed to be come from the adult daughters’ dissatisfaction with the care provided at the facility or in the women's perceptions of what their parents expected of them (Dupuis & Norris, 2001).

While all five roles mentioned the “sense of duty” as a reason for their involvement, the less involved adult daughters in the study did define their roles differently than the more active women. These perceptions ranged from: their parent’s cognitive impairment meant their involvement wasn’t needed at the facility or that the facility could handle it better, they may have been more focused on the parent *not* in the facility or they were struggling with their own emotions about their parent’s impairment (Dupuis & Norris, 2001). The study concluded that the adult daughters' perceptions of the *degree* of cognitive impairment of their parent, and particularly their perception of the parents' psychological presence, were most important to the daughters’ experience and to their perceptions of what their role should be in the care of their parents (Dupuis & Norris, 2001).

Purpose

The purpose of this study was to understand the lived experiences of my mom, myself and our relationship through the context of Marcia’s dementia. Dementia can be a difficult illness to accept and to manage for the individual, and for their support team. Recovery from dementia is a process that can require a great deal of effort, yet without any guarantees of success or even any progress.

Research Design and Methods

A narrative design portrays the experiences of others through vivid description and allows the researcher to “re-story” the narrative to focus on certain aspects of the experience and code for themes, context or setting which can be valuable to determining how and why the experience occurred (Patton, 2015). According to Gibbs (2015), data for narrative inquiry is obtained primarily from interviews, chronology is important and narratives are temporal, with a causal sequence. Clandinin and Murphy (2007) point out that narrative inquiry, unlike other methods, such as phenomenology, with its focus on observation, is not only about the experience, but is also about the human side that combines with the chain of experiences to create a narrative. With the story as a basis, the researcher seeks contexts and is part of the meaning-making process, as opposed to being a separate observer of it (Lacy, 2017).

This qualitative study sought answers to the following specific research questions:

- How can this narrative be interpreted to understand and illuminate the life of a dementia patient as they seek to recover and optimize their life experience going forward?
- What does this narrative reveal about the person and the community they live in?
- What can supporters learn from the narrative to aid in the recovery of dementia patients?

In addition to the research questions, I also had my own questions. I felt like I had been a witness to a miracle. My mom *had* recovered. I wanted to know how this recovery could be explained. My own mom didn't even know who I was for about three months before she regained 91 years of memory - except for pieces permanently lost in the immediate aftermath of the stroke and during the severe dementia portion. But now I had my mom back! I was grateful for the opportunity to pour over the research and to compare with my own observations and experiences – before I asked for my mom's thoughts. I wondered if she blamed me and the family for placing her in a memory care facility? More importantly, was she sincerely positive now about her life in general? If so, what was the secret for finding this inner peace and joy in life at age 91, post-stroke and post-dementia? I looked forward to learning her perspective on the recovery.

Data Collection

The data were primarily collected via interviews with Marcia, supplemented by my own observations. Many of these observations were captured on a daily basis in a journal I kept about Marcia in the year following her stroke. Some of Marcia's hand-written notes and drawings from this period were also collected as artifacts.

After the first interview, Marcia became fully engaged in the project. She inquired daily about my progress with the manuscript. I explained how her recent interview was only one piece of the overall study and she seemed genuinely interested to learn about the entire process. Later, I offered for her to read it (member checking) and she did. Having obtained institutional ethics approval and by fully explaining the study to her at the onset and involving her throughout the process, it increased my understanding and importance of her consultation in a process attempting to capture her experience and represent it in an authentic fashion,

However, I still wondered why Marcia was so interested to tell her story. Was it her sense of duty to help her adult child write an article? Did she want to share the hope of recovery for other elders or their families and caregivers? Was she using the platform to leave behind a

message to her family? Gubrium and Holstein (2009) report that speakers not only tell stories, but what they *do* with their stories can shape the consequences of sharing their stories. So, finally I asked her, and she replied, “I was afraid to be interviewed at first - that you (Deb) might not like what I had to say - but once we got going and asked [me] questions I thought it was fine. Now, I’m happy about it.” You know what? I’m happy too, mom. And sharing your story has resulted in some important consequences for both of us.

Data Analysis

I chose line-by-line coding and supplemented the analysis by adding keywords-in-context and word count analyses based on the transcripts. There were four interrelated themes that emerged from the coding process. The first theme was about her memories of the recovery, as well as her lack of memories. Other themes described her recovery, her strong desire for independence and her dreams for the future – all of the themes were underpinned by relationships she enjoyed with God, her doctor, her dog, family, friends and trained support personnel.

The themes were derived from 27 categories identified from nearly 300 focused codes that resulted from the concrete analysis of data from the transcripts of interviews and from the observations made in my journal. There was also a review of artifacts from Marcia, such as notes she wrote, and clock images drawn for the neurologist at different stages of her recovery.

Results

Marcia’s road to recovery from dementia defied the odds. Without a road map for mother or daughter to follow, we discovered dementia recovery *is* possible with support along the way. There is broad research about dementia from a scientific lens, however, there is little attention given in the literature to exploring how a person that has been diagnosed with dementia feels about the journey to recovery, how they believe others treat them and how they define a successful recovery. The themes that emerged from the data were enlightening.

Memories: Surprise, Surprise

Memories and lack of memories were noted frequently in the transcripts. I was so surprised to hear her first interview response. When asked how she felt about her recovery from *dementia*, she replied “I didn’t know I had it.” As I later processed this response, it occurred to me that neither her neurologist, staff nor family had ever used that term, although they did discuss the temporary loss of her memory on many occasions. Perhaps this was a good thing – that no one had attached a label or implied the stigma of a mental disorder.

I experienced a similar feeling of surprise later in the interview, when I realized Marcia didn’t remember much about the months she suffered from dementia. “I feel...I feel that I don’t even remember having it.” And while she regained a lifetime of memories, there were some distant memories she claimed she would rather forget: “I don’t even want to talk about it...It’s things in my past that I’d just as soon forget...” She certainly didn’t recall many of the experiences she had during her period of dementia. But that made sense as I mulled that over. If Marcia didn’t recognize her daughter at the time, why would she suddenly remember months after the fact, that she didn’t know who I was for three months?

Bold (2012) suggested any narrative is only a representation of actuality – that a participant’s memory can impact how they tell their story, which then becomes the basis of analysis for the narrative. This narrative was not about the reality of Marcia’s recovery, but

more about interpreting the story she told, and determining if the research questions were answered.

Recovery: Keeping the Faith

After the first month of memory medication was in effect, she was gradually regaining her healthy mental state and she began to recognize her neurologist and place faith in him about her recovery. She listened very carefully as he tried to explain what had happened to cause the cognition challenges. He told her that the stroke had caused some damage to her brain, and that with therapy and medicine she could expect to recover, but it would take time and hard work. I believe it was important he offered her hope; from that moment she seemed inspired to work hard, and she set both small and large goals. But it started with her ability to make sense out of what had happened to her.

He said there were little veins up in my head that had to grow back together. (Demonstrating by moving her fingers) and he said once they get back together, you'll never know that it happened. He said they had to go back together. And he gave me some medicine that would help me.

When asked if the medicine helped, she responded "My daughter said it did. And evidently it did, because I don't have any of that up there and it has all healed." Numerous times I've observed Marcia mimicking the doctor's visual demonstration with her own hands as she explained to people how her brain was recovering. She seemed to need some sort of logical explanation about what had happened to her and to know that there was a recovery plan. Later, when her memory had returned, many staff members at the Coronada (the facility) remarked to her about her miraculous recovery. She appeared to accept this feedback as a compliment to her own efforts, but also as reinforcement that the doctor's plan (fingers again visually demonstrating) had worked to repair her brain. Marcia seemed to view the recovery as a team effort, with contributions of her own combined with that of her doctor, daughter and staff.

With reference to the Barker and Buchanan-Barker (2005) Tidal Model of recovery, I observed that the "Red Coats" (Marcia's term for Coronada's aides who wore red uniforms) provided a safe haven for Marcia by treating her like family. My all-important daily visits reinforced to Marcia that she was loved and not abandoned. The memory medicine from the neurologist helped her regain her sea legs along with therapy, cognitive activities, frequent visits from her dog and support from her friends – new and old. Regaining her memory was a gradual process, not an event; and it did "take a village."

Independence: Fuel for Recovery

Marcia was raised as the only child of a single mother during the Great Depression. As a latch-key child, she developed a powerful sense of independence. This trait was reinforced later in life as she raised four children with little support from an executive husband who was at the office much of the time. More recently, she lived on her own, as a widow, for decades. However, Marcia's sense of independence was challenged soon after the stroke as she faced a dramatically different lifestyle.

I went through a lot of depression...I didn't have anything of my own. Everything was taken from me. I had no longer a car or my dog. Everything. I wasn't allowed any money...

Well, they never let me drive anymore. I can still drive. I could have still driven. I only drove 2000 miles a year. I only went to the grocery; I went to the church and I went to get my hair done and that's about all. And the doctor to get my shots...

Losing independence can trigger symptoms of depression, while negatively impacting self-esteem and well-being (Calkins & Cassella (2007). Marcia admitted her own depression, and her reasoning for that condition seemed related to her lack of independence.

Dreams for the Future

Depression and hope are highly interrelated in the elderly population. Those with hope about the future report far less symptoms of depression (Chimich & Nekolaichuk, 2004). Marcia's fierce desire for independence seemed to explain the reasons for her dream to return home to Indiana.

I can walk without it (the walker) cuz I've done it. I can do it...I get myself dressed. I get my nails done every other week and I get my hair done every week...

And also, the reason I want to go home cuz I want to be near my husband where he's buried and my mother and my son that died and that way...cuz I know that's where I will be. And I just want to be close to it and I know that I don't have many years left too. So that's the main reason I want to be home. And I have a lot of friends back home, so I just want to go home.

Chimich and Nekolaichuk (2004) also found that having a sense of hope may offer a resilient or protective factor against depression in the elderly. For Marcia, her dream to return to her home and her husband's gravesite seemed to do just that.

Relationships

Relationships were at the foundation of all the themes. Memories about relationships supported Marcia's recovery, sparked her independence and were at the heart of her dream to return home. Marcia credited support from friends during her recovery. "They are still my close friends. Janet. Ruby. Barbara...Roselyn is my oldest...she's 95 going on 96 and she still alive and she still has most of her cookies. They kept calling me when I was down..."

Marcia also used one of the biggest tools she had in her tool chest of resources - her relationship with God - to help fuel her recovery. "Because God is the one that helped me through. I am a strong believer in God, my Lord. He kept me through." Relationships with family and especially her dog, Snowy, also contributed to her recovery, as seen in her recent Christmas card shown in Figure 2.



Figure 2. Source: Author. *Marcia when recovered from dementia, with Snowy.*

As her daughter, I tried to make Marcia's time in Florida feel like home, in part by driving her furniture 1,000 miles from Indiana. I believe we achieved that.

(I have) the same furniture. My headboard. My lamps. Here are photographs of my family (pointing) and over there is my curio and what's inside is a little bit of everything. My memories. On top of my curio are all my babies...my little dogs. (pointing at stuffed animals) The dog in the front is my Beau. I lost him. But I look at him every day. My little Snowy over there.

I believe the staff at Coronada and myself were practicing the Tidal Model without knowing it. We allowed Marcia to experience the emotions of being tossed in a storm but didn't make a fuss over it. She was shipwrecked, but we worked with her to repair her ship. We listened, and she was always valued and respected, hallmarks of the model (Barker & Buchanan-Barker, 2005). Marcia commented about getting along with the Red Coats. "They ask me what I think...I tell them what I think, and they listen to me." This type of support was one piece in the puzzle that led to her recovery. When asked about how she thought people have helped with her recovery, Marcia responded "Just being with me, and you know, be nice to me."

Marcia developed strong bonds with the staff at Coronada.

Redcoats - I love 'em all. They are very sweet and very kind, and they are very helpful. They've helped me a lot...I certainly like them. They have gone out of their way to help me if I ask for it.

Jorge, the manager - he always made sure I'm taken care of. He knows how to fix my TV. I call him "Dimples" because he has them when he smiles, and he likes that.

Francois, the activities leader - She's very sweet and very giving and tries to please everybody which is almost impossible to do but she does it.

Coronada has small clusters of residents unlike many large-scale memory care facilities for the elderly. The size offers an opportunity for capable residents to get to know each other quickly, while the more severe memory-challenged residents still have a lot of familiar faces around them and smaller common spaces that feel more like family rooms than a facility. When

her recovery became obvious, there was talk of moving Marcia to a minimally assisted living building, as she no longer really needed special memory care support. Marcia dismissed that notion by saying, “I have friends here and I’m not moving across the way.” In the interviews, Marcia commented about one dear new friend from Coronada, whom she fondly nicknamed “New York.” “She just wears you out talking about New York, but yet we’re more like sisters. We can argue but we still like each other.” There was another resident, Miss Margaret, who doesn’t speak at all. Marcia watched over her with care and encouraged her to hold my own small dog (Figure 3) when he occasionally visited instead of Snowy.



Figure 3. Source: Author. *A dementia patient happily hugging a chihuahua.*

Marcia continued to build relationships. Recently, while visiting Marcia during bingo, I asked the newest Coronada resident, Sam, how old he was. I’d read his birthday was in December but was amazed to learn he was nearly 99. Marcia questioned if he served in WWII and Sam nodded and told us all about it - including how his command of four languages landed him a unique position in the military. I asked if he could still speak German, French or Italian and Sam proceeded to dazzle us. We had an enjoyable conversation (mostly in English) over several rounds of highly competitive bingo. The staff said Sam had not revealed much of anything since his arrival a few weeks ago and they were amazed as they listened in to the conversation. Marcia, of course, was delighted to have acquired yet another new friend.

Discussion and Implications

Not every 91-year old can recover from dementia like Marcia and not every 99-year old can still speak four languages. Living with any level of dementia does not have to mean a death sentence. I discovered if you take time to say “hi” or ask the residents questions, those who are able are delighted to answer and often have some fascinating stories to share. There’s nothing quite like seeing a sad, blank stare transform into a beautiful smile at just being greeted by name, being asked a question or by hugging a chihuahua.

For me, the overarching message from the analysis became clear. Recovery from dementia *is* possible *if* the person has a strong drive, the right support, and some luck. With only 1 to 20% of those diagnosed with dementia likely to recover and decreased odds for the elderly (Clarfield, 2005), my mom faced slim chances. Consistent with the literature, her recovery was aided by early diagnosis and intervention, rehab, accommodations, and medical treatment. While these factors helped to jump-start her recovery, it seemed her strong drive to regain as much of her independence as possible and her dream to return home to Indiana in the future sustained her recovery. Specifically, her recovery seemed to result from a combination of: the medication; her faith in God; her love for her dog; therapy; regular cognitive activities; socialization; a neurologist and also a care facility staff that respected, empowered and believed in her; new and old friends; and family, including me - her “active monitor” daughter who listened and learned while serving as her chief advocate. Marcia’s recovery truly feels like a miracle.

The Future - Conclusions

It is hoped that the study provides an example for dementia support teams to understand something new and/or helpful about the experiences of living with dementia from the unique perspective of a patient...or just to offer some hope. Educating people with dementia along with their families and broader support teams about experiencing dementia may help them better understand the process so they can adjust their expectations and approach to care and recovery. A recovery-based approach can mean a more optimistic outlook for older persons with dementia, by increasing the likelihood of living as valued and respected individuals in their community no matter what level of recovery is possible (Gavan, 2011).

Narratives help us to learn about specific individuals and society and culture more generally (Patton, 2015). My mom felt as though her life had been taken from her when she suffered from dementia and began the uncertain road to recovery. Her story touches on society and its acceptance and treatment of those diagnosed with dementia. Frequently, in the end, the narrative combines views from the participant's life with those of the researcher's life in a collaborative narrative (Clandinin & Connelly, 2000). That is exactly what happened in this study.

A *good* narrative analysis encourages the reader to think beyond the surface message and towards a broader concept (Riessman, 2008). The process of capturing Marcia's story, reviewing the research and thinking about what it all meant certainly moved me to think about the bigger picture...how society treats people with dementia versus how they would like to be treated.

We did make changes to the *little* picture - for my mom. The takeaway from listening to her interviews was learning just how much she values her independence and the recognition that she has recovered mentally and has earned more freedom in her life. I realized there were changes we could make or already have made to safely return more ownership for various aspects of mom's life.

We are happy to report Marcia once again has a checking account (for "fun" money) that can work around the "no cash" rule at her facility. Just yesterday, Coronada issued a rare resident key to Marcia that she now proudly wears around her wrist. As a result of her being able to lock the door, her room feels more like an apartment of her very own. Most importantly, I've worked with her doctor to set a timetable for Marcia to move back home to Indiana next spring to another facility. And yes, they will figure out a way for Snowy to make the move right along with Marcia, so they can continue their mutual joy of frequent visits. I'm confident the return home will bring Marcia peace and she will revel with pride that comes from conquering recovery, regaining more independence and achieving her dreams.

As for me, while I'm proud of my mom, I'll miss those daily visits, with Snowy tugging on the leash to race down the hallway to Marcia's door, fixing her TV remote (again) and seeing what stylish outfit she chose to put on that day. Instead, I'll go back to calling by phone to hear about her day and then visiting every few months as I did before the stroke. As for the Coronada residents...I've promised to keep in touch. I'll stop by at least monthly to play some bingo and enjoy conversations about WWII, the darn weather or the dessert they served at lunch that day. Maybe we can Facetime Marcia.

References

- Barker, P. J., & Buchanan-Barker, P. (2005). *The Tidal Model: A guide for mental health professionals*. Psychology Press.
- Barken, R., & Lowndes, R. (2018). Supporting family involvement in long-term residential care: Promising practices for relational care. *Qualitative Health Research, 28*(1), 60-72.
- Baumbusch, J., & Phinney, A. (2014). Invisible hands: The role of highly involved families in long-term residential care. *Journal of Family Nursing, 20*, 73-97.
- Bold, C. (2012) *Using narrative in research*. Thousand Oaks, CA: Sage.
- Calkins, M., & Cassella, C. (2007). Exploring the cost and value of private versus shared bedrooms in nursing homes. *The Gerontologist, 47*, 169-183.
- Chimich, W. T., & Nekolaichuk, C. L. (2004). Exploring the links between depression, integrity, and hope in the elderly. *The Canadian Journal of Psychiatry, 49*(7), 428-433.
- Clandinin, D. J., & Connelly, F. M. (2000). *Narrative inquiry: Experience and story in qualitative research*. Wiley.
- Clandinin, D. J., & Murphy, M. S. (2007). Looking ahead: Conversations with Elliot Mishler, Don Polkinghorne, and Amia Lieblich. In D. Jean Clandinin (Ed.), *Handbook of narrative inquiry: Mapping a methodology* (pp. 632-650). Sage.
- Clarfield, A. M. (2005). Reversible dementia—the implications of a fall in prevalence. *Age and Ageing, 34*(6), 544-545. doi:10.1093/ageing/afi203
- Dementia.org. (2020). Retrieved April 19, 2020, from <https://www.dementia.org/vascular-dementia>
- Djukic, M., Wedekind, D., Franz, A., Gremke, M., & Nau, R. (2015). Frequency of dementia syndromes with a potentially treatable cause in geriatric in-patients: analysis of a 1-year interval. *European Archives of Psychiatry and Clinical Neuroscience, 265*(5), 429-438.
- Dupuis, S. L., & Norris, J. E. (2001). The roles of adult daughters in long-term care facilities: Alternative role manifestations. *Journal of Aging Studies, 15*(1), 27-54.
- Feil, D. G., MacLean, C., & Sultzer, D. (2007). Quality indicators for the care of dementia in vulnerable elders. *Journal of the American Geriatrics Society, 55*(s2), S293-S301. doi: 10.1111/j.1532-5415.2007.01335.x.
- Gavan, J. (2011). Exploring the usefulness of a recovery-based approach to dementia care nursing. *Contemporary Nurse: A Journal for the Australian Nursing Profession, 39*(2), 140-146. <http://proxy.cityu.edu/login?url=https://search-proquest-com.proxy.cityu.edu/docview/1022983997?accountid=1230>
- Gubrium, J. F., & Holstein, J. A. (2009). *Analyzing narrative reality*. Sage.
- Harisingani, R. (2005). Where are the reversible dementias? *Journal of the American Geriatrics Society, 53*(6), 1066-1068. <https://doi.org/10.1111/j.1532-5415.2005.53337.x>
- Kilmer, D. L., & Lane-Tillerson, C. (2013). When still waters become a soul tsunami: using the Tidal Model to recover from shipwreck. *Journal of Christian Nursing, 30*(2), 100-104.
- Komatsu, M., & Hamahata, A. (2014). Relocation of older people to recovery phase rehabilitation wards: Adaptation patterns according to the presence of dementia. *Working with Older People, 18*(4), 205-213. <http://proxy.cityu.edu/login?url=https://search-proquest-com.proxy.cityu.edu/docview/1634008884?accountid=1230>
- Lacy, M. (2017). *Phenomenology or narrative inquiry methodology?* [Blog post]. Retrieved from <http://www.marvettelacy.com/phenomenology-or-narrative-inquiry-methodology/>
- Martin, G. (2009). Recovery approach to the care of people with dementia: Decision making

- and 'best interests' concerns. *Journal of Psychiatric and Mental Health Nursing*, 16(7), 654-660.
- Patton, M. Q. (2015). *Qualitative research & evaluation methods* (4th ed.). Thousand Oaks, CA: Sage.
- Pinkston, J. B., Alekseeva, N., & González Toledo, E. (2009). Stroke and dementia. *Neurological Research*, 31(8), 824-831.
- Plassman, B. L., Langa, K. M., Fisher, G. G., Heeringa, S. G., Weir, D. R., Ofstedal, M. B., & Steffens, D. C. (2007). Prevalence of dementia in the United States: The aging, demographics, and memory study. *Neuroepidemiology*, 29(1-2), 125-132.
- Prokopov, A. F. (2010). A case of recovery from dementia following rejuvenative treatment. *Rejuvenation Research*, 13(2-3), 217-219.

Author Note

Dr. Deb Miller is an Associate Professor in the School of Management of City University of Seattle, USA teaching MBA courses to future leaders. Beyond the academic world, she has extensive industry experience having served as the vice president of global marketing and communications for multiple Fortune 500 firms for more than 20 years. She is recognized as a brand innovator for conceptualizing and executing B2B global experiences across audiences, an award-winning visionary with a unique combination of financial, business, communication, and marketing expertise. Her general research interests are related to organizational branding, rebranding, corporate identity, corporate brand management and corporate marketing. She holds a D.B.A, M.B.A, B.S. and is a certified public accountant (C.P.A.). Please direct correspondence to debmillier@cityu.edu.

Dr. Corey W. Johnson is a Professor in the Department of Recreation and Leisure Studies at the University of Waterloo. He teaches courses on inclusive recreation, social justice, gender and sexuality, qualitative research methods, and the philosophy of science. Dr. Johnson's theorizing and qualitative inquiry focuses its attention on the power relations between dominant (white, male, heterosexual, etc.) and non-dominant populations in the cultural contexts of leisure. This examination provides important insight into both the privileging and discriminatory practices that occur in contemporary leisure settings. He sees this research as complimentary to both his classroom instruction and his professional service, and he uses advocacy, activism, civic-engagement, service-learning, and community partnerships to create unique learning opportunities for individuals and institutions. His research has been published in journals like the *Journal of Leisure Research*, *Leisure Sciences*, *The Journal of Homosexuality*, and the *International Journal of Qualitative Studies in Education* just to name a few. He has co-written the seminal text *Fostering Social Justice through Qualitative Research: A Methodological Guide* and is currently writing *Collective Memory Work: Learning with and from Lived Experience* and co-editing *Digital Dilemmas: Transforming Gender Identities and Power Relations in Everyday Lives*. He has received substantial financial support in his efforts to create safer environments for lesbian, gay, bisexual, and transgender youth in institutional settings such as camps, secondary schools, universities, and detention centers. He has also co-produced two documentaries, "be there for me": collective memories of LGBTQ youth in high school, and "We exist": collective memories of transgender, queer and questioning youth; distributing the films with a resource binder to +1000 schools in the state of Georgia. He was selected as one of the top ten educators (P-16) in Georgia working for equality by the Georgia LGBT Pride Committee and in 2012 he received the UGA President's MLK Jr. Achieving the Dream award for his efforts. Please direct correspondence to corey.johnson@uwaterloo.ca.

Acknowledgements: We would like thank Marcia for her willingness to share of her lived experience and her resilient life.

Copyright 2020: Deb Miller, Corey W. Johnson, and Nova Southeastern University.

Article Citation

Miller, D., & Johnson, C. W. (2020). Defying dementia: An exploration of recovery. *The Qualitative Report*, 25(10), 3627-3640. <https://nsuworks.nova.edu/tqr/vol25/iss10/9>
