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Alzheimer's Talking: Stories from the St. Mary's Alzheimer's Day Treatment Center

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UNIVERSITY HONORS PROGRAM

SENIOR PROJECT - APPROVAL

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College: Human Ecology Department: Child & Family Studies

Faculty Mentor: Dr. Julia A. Malia

PROJECT TITLE: Alzheimer's Talking: Stories from the

St. Mary's Alzheimer's Day Treatment Center

I have reviewed this completed senior honors thesis with this student and certify that it is a project commensurate with honors level undergraduate research in this field.

Signed: Julia A. Malia, Faculty Mentor

Date: May 6, 1999

Comments (Optional):

Wonderful, creative work! You have used your internship experience for careful observation as well as heart-to-heart interaction. And now you have distilled both facets into a vintage collection of stories framed in the patterns your observations have identified. It has been a true pleasure to supervise you in both the internship itself and this senior project.

**Alzheimer's Talking:
Stories from the St. Mary's Alzheimer's Day Treatment Center**

Melanie R. Wynn

Senior Honors Project

May 7, 1999

ABSTRACT

I have spent this semester as an intern at St. Mary's Health System Senior Services in the Alzheimer's Day Treatment Center. When people ask me what I do there, I have trouble coming up with a concise answer. My responsibilities thus far have been many and, for the most part, fun. I have been a student, a teacher, a waitress, a referee, a caregiver, and, most importantly, I have been a listener.

I have not been in many work environments where one truly has an opportunity to learn something new every day, but this is one of them. All I have to do is listen. Some of our patients have lost most of their verbal ability, but there are some who have not progressed far enough into the disease to be easily identifiable as Alzheimer's patients. The latter group is always eager to share life stories, which vary from life on the farm to life on the stage as a Broadway dancer. The less verbal patients have had lives just as full, but for them it may take a certain song or topic of conversation to spark their memories. For others still, there are no memories left to spark. It is for them that I have chosen to make my senior honors project a collection of stories from the Alzheimer's center.

Most of these stories are funny, some are sad, but all are fascinating to me. There are contributions from patients at all levels of functioning, from the ones who still keep up with the news to the ones who no longer remember how to use the bathroom. I hope that you will be touched and charmed, as well as mindful of the daily struggle of these people and their families as they face the imminent decline that this disease brings.

Introduction

Baptism by Fire: Day One in the Alzheimer's Day Treatment Center

I was a nervous wreck my first day in the ADTC. I knew next to nothing about Alzheimer's disease, and I knew even less about the people it affects. It would take a little while for me to learn that the disease and the people affected by it are two separate entities.

I had visited the ADTC once before, met my supervisor and a few staff members, and had even peeked into the day room for a few minutes. Entering the day room as an intern, however, was an entirely different experience. Before I only had to appear professional and competent under normal circumstances. Now I would have to convince my fellow staff members and, more importantly, myself that I knew how to deal with a population with whom I had no real prior experience--a population of whom I was terrified as a child.

As I looked around the day room, I saw some people watching television and chatting with one another. I saw people wandering around for some purposes known only to them. There were also people sleeping, some slumped over like limp dish rags and others sprawled out with their mouths open.

The sleepers were the ones who bothered me. I was instantly reminded of childhood trips to the nursing home to visit my great aunt. As I walked down the hall holding my father's hand, I was right at eye-level with the people asleep in wheelchairs out in the hallway. Their slack, toothless faces looked dead to me. Perhaps even more terrifying were the flat, gray, watery eyes of the ones who were awake. I thought they

were zombies. Even now, years after those hated trips down that hallway, I was still afraid of that empty, lifeless look.

Standing there in the day room, I came to the stark realization that I had no clue what to do next. Fortunately for me, a sweet lady named Alma took care of that for me.* She walked up to me, stuck her hand out, and said, “Hey, there. I’m Alma. I have two sets of twins, and I’m the oldest lady in the choir at church. They call me the Sweetheart of the Choir.” We talked for several minutes, which gave me some much-needed confidence. I could have just hugged her!

After my success with Alma, I got a little braver. I sat down between Alma and another lady named Trina. I introduced myself to Trina and extended my hand to her, not knowing that she was nearly deaf. I scared her to death. She and I both jumped, and she laughed the most contagious laugh I believe I have ever heard. I couldn’t help but laugh, too. When she finally caught her breath, she said, “Goodness, girl! When did you get here? I thought you were up at High Point visitin’ your mama?”

I had been in the day room for five minutes, and I was already stuck. There was nothing more I could possibly discuss with this lady. She was just too far gone for me to have a conversation with her. As she looked at me, patiently awaiting an explanation for why I was not at this High Point place, wherever that is, I learned my first lesson in talking to a person with a cognitive impairment. I did not have control of the conversation. This lady was talking on her own terms, reality-based or not, and it was my responsibility to follow her lead.

*All names have been changed to protect patient confidentiality.

I decided to exercise my creative license (i.e., lie like a dog and have fun doing it). “Well, Miss Trina,” I responded, “I decided to wait until it warms up a little before I go see Mama. It gets awfully cold up at High Point.”

Trina and I continued talking this way for a little while, and she told me all about how sweet my mama is and how they were best friends as little girls. It was fascinating to hear her describe this invisible world in which she was living. It may well have been some memories from her childhood that she was experiencing as current reality.

As I talked to Trina and the other patients that day, I found myself wanting to tell other people all about these incredible conversations. Some of them were just fascinating life stories told by people who you would never know had a cognitive impairment. Others were like the conversation with Trina. They would not make a lot of sense to an observer, but they reveal so much about the reality that Alzheimer’s disease can create for a person.

The following stories are merely a series of snapshots of Alzheimer’s disease. Because there were only a few men attending the ADTC during the time I worked there, most of the stories are about women. They have been collected and related with the utmost respect and love for the people in the ADTC. I hope that you will read them with the same love and respect. Some of the stories are funny, some are sad, but I think you will find all of them fascinating. Enjoy.

The Things That Change

When I first began my internship in the ADTC, the staff held an in-service training session for the new interns. It was very valuable in that it helped prepare us for the things we might encounter while working with the Alzheimer's patients. Incidentally, I witnessed almost everything mentioned as a possibility during my four months there. I can only imagine what the full-time staff members have seen in their years of experience. I have provided some of my favorite and most memorable examples of these "common" Alzheimer's behavior patterns.

Reactions to Changes in Structure

One of the things stressed in the training session was the need for structure in the ADTC. Because it is very easy for a person with Alzheimer's disease to become disoriented, structure is a very important tool. Developing and maintaining a routine gives people a comfortable, reliable way of doing things. It also helps them remember what is happening next.

The importance of structure for Alzheimer's patients is not really apparent until something happens to disrupt that structure. It is a mistake to assume that one can slide something new into that routine. For some Alzheimer's patients, a change in routine can cause a catastrophic reaction or "sensory overload." They just cannot handle the stress of the change.

The funniest example of this for me was when I helped set up the lunch tables in the ADTC for the first time. A lady named Glenda was watching me like a hawk. The patients generally sit in the same spot every day, and I had evidently set up her lunch table about three feet to the right of where it usually sits. Well, she noticed and wasted

no time correcting me. “I know you’re new at this dear, but this is just not in the right place,” she said in the same patient way a woman would let a cashier on her first day of work know that she had rung up the receipt incorrectly. And, just like the new cashier would, I promptly apologized and moved the table where she wanted it. After all, the customer is always right.

In another example, the transportation system for the ADTC underwent some changes during my internship. There were some new drivers taking people home an hour later from the ADTC on different vans. These changes presented a major rift in the structure for the people who rode the vans to and from the ADTC.

First of all, the new driver and different vehicle caused many patients to think that they were on the wrong van. Some even refused to get on the vans. The lady I just mentioned, Glenda, experienced what I would call a catastrophic reaction. She was in tears when she got off the van on the first morning of the changes. She reminded me of a scared little girl who had gotten lost in a department store, one of those who comes up to the service desk in tears and begs the cashier to help find Mommy. All morning long she kept saying, “I think I’m in the wrong place.” By then she had long since forgotten the changes in driver and vehicle, but the feeling that something was not right lingered on with her. We tried to comfort her as best we could, but it took a few days for her to become comfortable with the changes.

Wandering and Repetition

The later departure time for the patients who rode the van home enhanced another phenomenon in the ADTC, a phenomenon I call afternoon wandering. The most successful group activities in the ADTC usually occur in the morning, typically from

10:00 A.M. to 1:00 P.M. The patients participate pretty well during the morning orientation and perception group, exercise, and lunch, which ends around 1:15 P.M. After that, people are pretty much ready to go home.

The most common concerns about going home are not what time someone will come to get them but if someone will come to get them and who that person will be. They are so afraid of being stranded there and have to be reminded every day of how they are going to get home. From the time lunch ends people begin to ask, “Does my daughter know I’m here? Do you have a phone I can use to call my son? Did my daughter say what time she was coming? Have you seen her? Does she know how to get here?”

This is the time of day when the symptoms of Alzheimer’s disease seem to become the most apparent. Patients repeat these questions over and over again, having no clue that they have just asked the same thing only minutes earlier. They wander around the room and have to be watched closely to make sure they do not wander down the hall of the hospital. People get cranky, and tempers run short. It is a very anxious time for the patients and a very trying time for the staff.

One lady in particular is, in my opinion, the poster child for afternoon wandering. Nan repeats everything and is ready to go home long before lunch. She is extremely disoriented. She and I go through the following dialogue constantly from 10:00 A.M. until she leaves at 5:00 P.M.:

NAN: Did they say if my brother is coming to get me?

ME: Yes, Don’s coming to get you at 5:00.

NAN: Don Kinsley?

ME: Yes, Don Kinsley’s coming to get you at 5:00.

NAN: 5:00?! What time is it now?

ME: It’s (insert time). Don Kinsley’s coming to get you at 5:00.

NAN: He’s my brother. He’s a good brother, and I need to take care of him. Do you think he’ll know where to find me?

ME: Yes, he'll come right in here where he dropped you off this morning.
NAN: Are you sure?
ME: Yes, I'm sure. I talked to him, and he said he will see you here at 5:00.
NAN: Okay then.
(30 second time lapse)
NAN: Did they say if my brother's coming to get me?

This little script has become so routine that I stopped getting annoyed after a while, but I have to admit I am probably even happier than she is when 5:00 arrives! Nan is especially fond of trying to leave the ADTC before her brother comes to get her. The staff must watch her constantly to make sure she does not wander away, a task which can get extremely old very fast.

The more resourceful patients try to come up with different ways to get home. One lady used to ask me every day where I live. When I would tell her, she would say, "Well, I think you go right by my house on the way. Would you mind giving me a ride home? I've got money." I would always smile and tell her what time her daughter was picking her up, but I would also offer to give her a ride if no one showed up for her. That made her feel better, but the fact that she would take a ride from a stranger scared me for her.

There was one lady, Ina, who had a habit of taking rides from strangers. She used to go visit people in the nursing home with a friend of hers. On one occasion her friend left her for a few minutes and told her that she would be right back. While her friend was gone, Ina decided that she would have to find a way home herself. She asked some man for a ride, and he actually gave her a ride home. Imagine the look on her daughter's face when her cognitively impaired mother came rolling up with some strange man. It scared her and her mother's friend to death, and Ina has not been left alone since.

Hostility and Violence

An alarming symptom of Alzheimer's disease is violence. Some Alzheimer's patients have a tendency to become violent when they get upset. While I never witnessed any violence first-hand in the ADTC, I have heard stories from staff members about patients who have just snapped and started hitting. The interns were told never to try to restrain someone who becomes violent, but we should simply step out of the way and defend ourselves and the other patients if necessary.

The family of the violent person is called immediately on the first offense, and the violent offender is on probation from that point forward. Any further violence typically warrants expulsion from the program. As one might imagine, this is both an embarrassment and a major challenge for the family. The patient is just as likely, sometimes even more likely, to strike out against a family member rather than a friend. It is extremely hard to keep a positive attitude when caring for a patient who is violent or hostile.

Interestingly enough, the violent people are often people who have never hit anyone in their lives. For example, one lady became violent on a day I did not work and struck another staff member twice. She was one of the sweet little grandmotherly types, but she was evidently upset by something the staff member said or did. There is really no predicting who has the capacity to become violent in the ADTC.

A more common symptom of Alzheimer's disease is a general hostility, which can be directed toward particular people or sometimes the world in general. Patients who are prone to hostility are typically very anxious and disoriented. Nan, the lady I mentioned previously, is a hostile person. I have been around many times when she

seemed to be doing fine, but then she would become very agitated over what seemed to be nothing. For example, we were preparing lunch for the patients one day, and I evidently was not bringing her food out fast enough to suit her. She muttered under her breath for a while and, when I finally brought her the food, got very animated and said, “I don’t need this! I’ll just go somewhere else! I won’t come back to this place another day!” I simply told her that we would miss her and that I hoped she would enjoy her lunch. I was truly upset by this episode, but I realized on about the third day of the same thing that this was simply a behavior pattern.

Language

Just like an Alzheimer’s patient who is not hostile by nature can become hostile, it is not uncommon for Alzheimer’s patients to use language they have never used before. This is why there are people in the ADTC who sometimes use a lot of profanity when they might never have sworn in their entire lives before the onset of Alzheimer’s disease.

We have a textbook example of this behavior in the ADTC. Her name is Lynette. She is a sweet-looking, churchgoing grandmother with faultless manners. She prays throughout the day under her breath, little prayers like “Dear God, deliver me a fork” or “Dear God, please deliver me a Kleenex.” She often comments on how fortunate we are to have what God has provided for us. She is just an overall nice little lady.

On one of my first days in the ADTC, however, Lynette gave me a shock. While we were working on an art project one afternoon, another lady borrowed one of Lynette’s markers. Upon glancing around and realizing that her marker was gone, Lynette, with no apparent vehemence, remarked under her breath, “Well, shit a monkey. That old bitch took my marker.” I burst out laughing, and she just smiled at me sweetly.

There are times, however, when Lynette's profanity has no small amount of feeling behind it. I have heard her call people bastards, bitches, and shitasses, sometimes to their faces. For the people who cannot process what she is saying anyway, this is not a problem. The people who do realize what she is saying, however, do not appreciate it at all. When they confront her about her profanity, she denies that she has even said anything. I believe that she truly may not realize what she has said.

I am sure that Lynette's family has experienced and perhaps been recipients of her profanity. While we in the ADTC understand that this is part of her disease, the general public may not be as understanding. I am sure that it is hard for them to explain and hard for them to hear their sweet, genteel mother talking that way.

Paranoia

Paranoia is often one of the early signs of Alzheimer's disease. Because they fear that people are trying to steal things from them, it is not uncommon for them to hide things under their mattresses or in various other secret places. They sometimes become paranoid that their own family members are stealing from them, which can be very painful for their family members to know.

In the ADTC, paranoia is pretty common. People who do not carry purses or wallets often come up and tell us that they think someone has stolen their purse or wallet. An example that I find particularly endearing is the way that some of the women hold on to their purses all day long. Although we have a place to store coats, hats, and other personal items, they will not even consider letting go of their purses. Some of them will not even set their purses on the floor beneath their chairs. It is funny to watch a little old

lady trying to participate in our group exercise session while maintaining a death grip on her purse.

Delusions

A delusion is something a person has fixed in his or her mind that is not true. When I first heard this described in our training session, I got a little nervous. We were told not to even attempt to convince a person that a delusion was false because it is impossible. Before I worked in the ADTC, I reserved the term delusional for people who were severely mentally ill. It did not take long for me to change my mind. Even though Alzheimer's-induced delusions are usually experienced only by people in the middle to later stages of the disease, I can honestly say that I never encountered a delusion whose origin did not make sense to me.

Trina, who I mentioned earlier, is delusional. Her delusions are typically based on thinking that people in the ADTC are various other people she has known throughout her life. For example, she is absolutely convinced that Lynette is her sister-in-law, Esther. She never addresses her as anything else. Trina is forever asking "Esther" how her mother is doing, when the baby is due, and occasionally if she wants some turnip greens out of her garden. Meanwhile, "Esther" is cursing Trina under her breath the whole time, which does not really matter because Trina is nearly deaf anyway. It is truly something to see.

Another lady with many interesting delusions is Flossie. Flossie is just a good old mountain woman, as country as can be. She provided one of my funniest memories from the ADTC. One day after lunch, Flossie and I were sitting at a table. She began rubbing her stomach and complaining of abdominal pain.

“Man, it hurts down thar,” she said.

“What do you think it is, Flossie?” I said with genuine concern.

“Well, I ain’t had a period in a right smart while. I reckon I’m a gonna have another’n,” she said with frustration.

“Another what?” I asked of this woman whose last period was thirty years ago.

“A young’un,” she answered. “I ain’t even done nursin’ the first ‘un and here comes another’n.”

I could not believe I was talking to a lady in her eighties who actually believed she was pregnant. I was absolutely amazed and not a little amused.

Some of Flossie’s delusions, however, are not so funny. For example, there is a tiny lady in the ADTC named Minnie. She is about four feet tall, child-sized, with short, straight hair. Flossie is quite fond of Minnie and, on one particularly day, decided that Minnie was her little boy. She led Minnie around by the hand all day and was very sweet to her. It all seemed harmless.

The problem came when Minnie’s daughter came to get her that afternoon. Flossie had a fit. She followed them out into the hall yelling, “That’s my little boy! Come back here! You can’t take him! He’s mine!”

She had tears streaming down her face and was feeling all the same emotions as a mother who could only watch helplessly as her son was taken away from her right before her eyes. It was heart-wrenching to see her that way, but there was no way to change her mind. We just had to comfort her as best we could until the delusion passed.

The Things That Stay the Same

Although the patterns I have mentioned are mostly negative, there are many positive indications that the real personality of the Alzheimer's patient remains very much intact. There seem to be some parts of a person's character that are so deeply ingrained that no disease, no matter how powerful, can take them.

One of my favorite examples of this is little Minnie. She has lost most of her verbal ability and can no longer participate in a conversation. She has forgotten how to use utensils to eat and is completely dependent on other people to take care of her bathroom needs. When we have music therapy, however, she knows every word of every song on all the music tapes. She sings along happily without a songbook because she knows the words by heart. If not by heart, how else? She has no memory on which to rely.

Minnie is also an avid ball player. In the afternoons we often pop in a Chubby Checker tape, put the chairs in a circle, and kick a beach ball around to one another. This is Minnie's time to shine. She often gets in the middle of the circle with the ball and does the Twist for us. She then makes a big production out of deciding to whom she will throw the ball. It is an incredible transformation from a tiny, quiet elderly lady to a little old fireball doing the Twist with a beach ball in her hands. No one can tell me that, in that moment, her soul is not shining.

Glenda is another lady who begins to shine as soon as the music starts. While she is at a much higher level of functioning than Minnie, her transformation is no less amazing. Glenda was a Broadway dancer in New York, which she proudly tells anyone who will listen repeatedly throughout every day. She is still a wonderful dancer and

loves to be told so. I will always remember her beautiful face, lost in memories she can no longer express, as we danced across the day room.

Lynette has not lost a bit of her grace and charm, despite her behavioral changes. As a prominent socialite, her life has consisted of brunches, bridge parties, and shopping trips. I always smile when I hear her making small talk about the weather or complimenting another lady on her lovely sweater.

When lunch time comes, she sits politely at her table as if she were at the Regas awaiting a deliciously expensive meal. As I approach her with her plate of hospital food, I become her waitress. She is always ready with a “please, if you don’t mind,” a “thank you, angel,” or an “everything’s delicious, dear.” I watch her, sitting there in her perfect little outfits reapplying her lipstick for the hundredth time, and know that she is in her element. There is no reason to be sad for her.

From Lynette I move to Flossie, her polar opposite in upbringing and character. Flossie is just as sweet as Lynette, but her mannerisms are as rough as the callouses that hard work has put on her hands. Her big, toothless smile, however, is enough to charm anyone.

The first thing Flossie ever asked me was, “You don’t have any bakker, do ya? I’m just dying for a little something to chew.” I was in love from the start and was delighted to realize that she was still very much able to tell me about her life. She was a farm girl who knew how to do it all, from making her own soap to cooking collard greens. She loved and respected her family and, due to her disease, often speaks about them in the present tense from a child’s perspective. I remember one conversation in particular.

"I have to go home now," Flossie said. "I'm sure Mama's worried to death wanting to know where I am. I have to help out a lot now that Grandma's down sick."

"Wow, Flossie. That's an awful lot for one person to do. How old are you?" I asked.

"Twelve, I reckon. I'll turn thirteen in December," she replied.

One of the most charming things about Flossie is that she is always willing to help in any way she can. She sometimes goes out onto the ADTC patio and pulls weeds out of the flower beds just so she can get her hands in the dirt. She loves to garden. Sometimes when she gets nervous and anxious to leave, we give her a stack of dish towels to fold just so she can feel useful. She is always so proud when she gets them done. It is then, as I watch her folding those towels, that I see her character shining through. She is at her best when she feels that she is doing something for someone else. That is a habit that no disease can ever break.

I look at Byron, a sweet and polite gentleman, and see my father. His subtle sense of humor and quiet Southern drawl are just so comfortable to be around. He loves to visit with our pet therapy dog and often tells stories about dogs he has had in the past, especially that one that was "so good with the children." Although he is becoming more disoriented, his sweetness and sense of humor keep him grounded in himself.

Daisy is another charming and funny lady. She loves to tell us about all the pranks she pulled as a child, from locking schoolmates in the outhouse to throwing snakes on people. Her mischievousness is still very prominent. If the person next to her is sleeping, she loves to cry "Boo!" or pinch the person to wake him or her up. She is a ray of sunshine.

Some of the most powerful testimonies to the character of our patients are the visits from the children at the St. Mary's Day Care Center. They usually come by once a month so that we can all do a simple art project together. Then the children have juice and cookies with our patients. Watching even our patients on the lowest level of functioning, I find one thing very apparent: Children still make them smile.

As I watch the two generations enjoying each other's company, I am convinced that the true essence of a person cannot be contained in something as small as a human brain. If our emotions are really just a sum of chemicals and circuitry, how can these people, whose brains are being ravaged by a terrible disease, still get caught up in the light of a child's smile?

I submit that, even after Alzheimer's disease has robbed a person of his or her memories, thoughts, and ability to function independently, there is still a spark of that person that will shine forever, perhaps even after death. I consider myself lucky to have had an opportunity to become acquainted with the sparks that make up the true personalities of the patients in the Alzheimer's Day Treatment Center.