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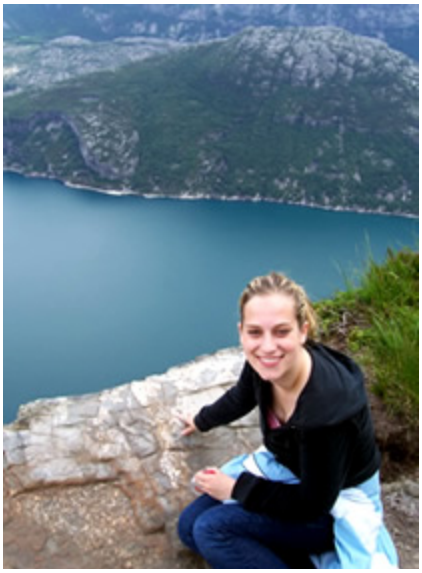
research ARTICLE

"My Mind Is Like a Dark Storm Cloud": Observations and Experiences in Norwegian Dementia Care

—Cristina Joseph

"Is that me?" says the elderly woman, as she stares at herself in the mirror. She appears frightened, and then her concern quickly fades as she continues to shuffle down the hallway. To the average person, forgetting who you are and what you look like is not a daily occurrence. However, for millions of people around the world, thinking is like trying to find their way out of a dark storm cloud. Things that happened in the last thirty years are wiped from their memory and their most formative years play over and over in their minds. They don't remember who the president is, or what season or year it is, but they might remember everything about their parents, their children or what Norway looked like in 1920s. These memories of the past are selective. One day they may be able to dredge them up, but days, weeks or even hours later they are gone.



The author at Pulpit Rock. Located outside the Norwegian city of Stavanger, Pulpit Rock soars 604 meters above Lysefjorden. It is about a two-hour hike both ways.

Dementia in the United States and Norway

Dementia is poised to become a major public health issue in the future; today it affects 4.5 million people in the United States alone (1). With the baby boomer population beginning to age, by year 2030 there will be seventy million Americans aged sixty-five and over (2). Inevitably, a considerable portion of this population will experience dementia at one time in their life span.

Dementia is a disease that can develop in a myriad of different ways: lack of oxygen to the brain, vascular issues and neurochemical issues can all cause dementia. This makes prevention a difficult issue to approach. Many families watch their loved ones progressively decline and are helpless to stop the progress. Certain pharmacological interventions are being used but their effectiveness and dosage is arguable (3). In addition, the effects of the disease vary widely, which necessitates, according to Norwegian nurses, an individualized, personalized approach.

The nature of dementia usually requires 'round the clock care, which will put a continued strain on an already understaffed and chaotic health care system. The disease process often necessitates hospitalization in long term care facilities or nursing homes.

However, this is not the case all over the world. In southern Europe, where the family is a very cohesive unit, care of demented elders is done more in the home (4). This is not exactly the norm for many other countries.

In the fall of 2006, inspired by an after-school job caring for a woman with progressive dementia in Durham, I wondered how other cultures coped with this daunting problem. With the help of my faculty mentor, Professor Gene Harkless, we set out to write a research proposal to submit to the International Research Opportunities Program.

First, the topic of where best this phenomenon could be studied was discussed. Norway, a country I knew very little about, was one of the safest, American-friendly and potentially interesting places to travel to study dementia care. *But Norway?* All I could remember was a PBS special I had seen about it with endless miles of tundra and wild reindeer. In actuality, Norway has to be one of the most untouched, unspoiled places on earth. Everywhere you go, even urban areas, there is beautiful scenery where you can feel one with nature. There are soaring mountains, glaciers, uninhabited islands, breathtaking fjords, the open ocean, and unique vegetation and wildlife the likes of which a North American has never seen.

Norway is an interesting place to study health care for several reasons. The inhabitants of Norway have enjoyed one of the highest standards of living, socialized health care and considerable wealth since they started pumping oil out of the North Sea (5). It is interesting to see how this country in particular, as opposed to the U.S. health care system, can provide for its residents with dementia. Since it is a disease with little treatment or prevention, any insight we can gain from the Norwegian approach to dementia care will be helpful.

Preparing for Research Overseas

To prepare for my research experience, I needed to learn Norwegian and become knowledgeable about ethnographic research. I met weekly with my mentor to discuss techniques I could use and to make further arrangements. In addition, I read several texts that discussed ethnographic research and its various methods of data gathering. Learning Norwegian, however, proved to be much more difficult. Norwegian, as the natives explained to me, is a combination of French, German, and English. Most likely, the only people who are truly fluent in Norwegian are native Norwegians. For English speakers the vowel sounds prove to be incredibly hard to pronounce, and the pronunciation of many words changes depending on the indigenous dialect of each region. Thankfully, even if you do not speak Norwegian, it is quite easy to get along in most daily activities knowing only English. Currently, almost all adults and children have received some degree of English instruction in their education. In the end, I traveled to Norway with just a very basic vocabulary of Norwegian and primarily depended on my English.

My goal was to interview and observe nurses at work in three different study sites in Norway: Trondheim, Oslo and Tromso. My main place of study was Trondheim, a city of 165,000 people and the third largest city in Norway (6). Trondheim is the home of approximately 10,000 students and to Nidaros Cathedral, one of the most impressive cathedrals in Scandinavia (6).

Observations of Norwegian Dementia Care

In Norway, care for those with dementia is usually provided in small, specialized wards. This has been the established movement for quite some time, inspired by certain literature proposing that psychological facilities were poor environments for people with dementia (7). From my observations, these wards typically hold six to eight residents; the maximum I have seen is ten. Usually, there are one to two nurses in every ward and also a nurse's aid who has received considerable education and has the authority to pass medications. These nurses have spent years working with those with dementia and, therefore, are very valuable resources.

The actual physical environment of the nursing home is conducive to remembering. For example, the décor of the nursing homes usually includes things that the residents could identify with, such as photographs of the city from the 1920s to 1930s. The look of the nursing home is deliberately "homey," and the patients' rooms contain furniture and other items taken from their former homes. Great pains are taken to make the environment non-institutional by the use of formal furniture, potted plants, gauzy window treatments and assorted knick knacks.

The nurses stressed that the environment of the nursing home needs to cater not only to the residents but to their families as well. Many nurses described the transition from a family member's home to the nursing home to be one of the hardest times in the course of the patient's disease. Nurses provide support and have caring interactions with the families in formal and informal meetings to facilitate this transition. At a facility in southern Norway, it was customary to serve coffee to any visiting family member. In addition, all the nursing home facilities I visited stressed having at least one annual meeting with family members.

This welcoming and caring environment extends beyond the client's admission and continues until the client leaves the facility. An average stay at the nursing home lasts about five years and usually ends with the patient passing away. Many facilities forewarn that they provide mostly dementia care and are looking for residents who are mobile and without any serious medical issues. If the resident's health should drastically change, the facility reserves the right to transfer the patient to another facility.

The common practice in dementia facilities is to do tasks in the same exact way every day. This allows the patients to become secure in their environment and maximizes the likelihood that residents will remember certain tasks. At one facility, the morning routine for a certain group of patients is always performed by the same staff to ensure continuity of care. In other words, the same staff does the same actions over and over with the hope of promoting remembering in the patients. One nurse I met from southern Norway is a firm believer that patients can remember with this continuity of care: "Never think they don't remember. Everyday you must do the same things." This nurse maintains a uniform appearance in hopes of promoting remembering: she always wears a cross and puts her hair up in the same way so that she is easily distinguished from the other caregivers.

Part of the challenge of caring for people with dementia is dealing with behavioral issues such as jealousy, paranoia and combativeness. Some of these behaviors are present all the time, but usually they are brought out when the caregiver must do something for the patient. This creates the necessity for a certain approach to dealing with patient interactions. In Norway, when nurses need to give medication or get a patient up in the morning, they approach these tasks in a slow-paced, easy-going manner. One nurse explained, "You will not get anything done quicker…rushing the patient only overwhelms them."

Overall, redirecting and attempting techniques are used instead of forceful actions. "Attempting" means that the nurses try multiple times to get a patient to do something. For example, a nurse will repeatedly offer a patient his medication even if he refuses initially. A special order from a doctor must be obtained to force the client to take any medication against his will. Nurses said that obtaining this order is usually a last resort and occurs only after many attempts.

"Redirecting" involves refocusing patients on a certain task, such as eating. If a patient stops eating, the staff will redirect her to her spoon or plate rather than start feeding her. If a patient begins to act violently, refusing to move from a chair, the staff keeps trying to get this patient up of his own free will and uses force as a last resort. Redirecting may seem an obvious intervention, but in an environment like a nursing home, where many tasks need to be accomplished in a set period of time, force would be an easier, more efficient way of doing things.

Nurses feel that engaging their patients in certain activities can be helpful even for those with serious limitations. Music is thought to be especially useful, in that many patients with poor communication skills can become very responsive through music. Some nurses believe that music therapy also helps patients reminisce, as certain songs can be associated with times, occurrences, and specific holidays.

Another way the nurses engage their patients is by talking about their past. The nurses I interviewed overwhelmingly felt that knowing a patient's personal history was helpful. Most nurses said that it was routine for the institution to gather personal information upon admission. One nurse said that gathering personal information was "important for all but more useful when the patient has more severe dementia." Another nurse, specializing in working in the community and with families, said this about learning patient histories: "It helps you know if what they are saying is true. It is important to know hobbies or music they like. It is important to know if they have been a POW or served in the army, or if there have been any traumas in their lives…"

I also observed nurses routinely performing caring interactions with their patients. Caring actions varied widely but included holding a patient's hand while removing sutures, sitting with the patient for a period of time in silence, and simply asking the patients how they are feeling. All of these actions demonstrate that the nurses truly care about the residents and help to create a positive rapport.

How Dementia Care in Norway is Different from the United States

American nurses address behavior problems in a similar way, but certain things are allowed in dementia care in Norway that would not be allowed in the United States. For example, in some facilities in Norway, the mildly demented are allowed to walk unaccompanied outside. If the patient does not return in a certain amount of time, a staff member begins to look for him. Only some of the dementia wards are physically locked in Norway; many have mechanisms on the doors that make leaving difficult, but not impossible, for the residents.

The motivation behind this greater degree of freedom is the belief that dementia patients possess free will and should not endure such forceful intervention as being physically locked in one space. In many Norwegian facilities, families can take patients off the nursing home grounds. Residents may even smoke in their rooms as long as they have staff supervision, have alcohol if they request it, and have a candy bar every day if they wish. In the United States, patient activities are largely restricted. You will not see dementia patients going for walks

unaccompanied, nor can family members easily take patients for outings because of liability reasons. The United States is a far more litigious society, which is becoming increasingly suspicious of health care providers, whereas Norwegians are extremely trusting. In Norway, according to interviewees, lawsuits are rarely brought against health care professionals.

In several profound ways I believe that the Norwegian approach is a more personalized, individualized, involved and holistic approach to caring for people with dementia. In the United States today, the common thinking towards long-term care is that the care is sub-par, expensive, and offers an undignified experience where patients totally lose their ability to care for themselves. In American nursing homes, meals are brought on trays at set times in the day and the furniture is hospital-issue. In Norway, even though access to the specialized dementia wards is competitive, the actual facility looks and feels more like a home than a hospital.

In Norway, all care providers read a detailed history of each patient and use that information in everyday activities. The nurses and nursing assistants have a manageable workload and are able, even though it is hard at times, to tend to basic needs and stimulate the patients both emotionally and mentally. This differs from ethnographic studies done in the United States that reported demented patients were often the first population in nursing homes to be neglected (8). In the United States we talk about providing individualized care to our patients, but in actuality the care is pressured, focusing on doing tasks in order to provide just the basics, and simply managing the disease rather than getting to know the person (8).

In conclusion, much thought and action should be taken in upcoming years to prepare for the influx of demented baby boomers. Even though some specialized wards exist in the United States, many demented elders are being cared for in regular, institutionalized nursing homes. The holistic approach that Norway offers could yield a different, more liberated way for the demented to live.

Thanks to Gene Harkless, for her consistent and appreciated guidance from the project's conception to completion. To Anne Visnses Ph.D, my Norwegian mentor, for help in data collection and asking all the hard questions. To Mr. Hamel, Mr. Noonan, Sam and Sally Paul, and the class of '59 for their generous contributions. To Britt Hansen, who helped me acclimate to Norwegian life. To Raelene Shipee-Rice for her help in getting the project off the ground. To Georgeann Murphy and the IROP department for their guidance and help in coordinating travel to Norway. And finally, thanks to all those at the long-term care facilities in northern and southern Norway who were gracious enough to give me a tour and to explain to me what they do and how they do it.

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Author Bio

Cristina Joseph*, of Rehoboth, MA, is a senior nursing major at UNH. She completed her research through the International Research Opportunities Program (IROP) after a part-time job caring for a woman with progressive dementia inspired her to learn how other cultures care for patients with dementia. She says, "I really had no idea what to expect when traveling to Norway. I thought I might be dropped out of a plane and living in the woods in a log cabin. It certainly looked that way when the plane landed….but I quickly learned that I was in a city, and there was plenty to do and plenty of people to socialize with who were my age." Conducting interviews in English with non-native English speakers did prove to be a challenge, even when the interviewees' language skills were strong. Cristina also learned that "Qualitative methods can be more difficult than quantitative research. With quantitative research you crunch the numbers and Bam! you have your answer, whereas with qualitative research you are always trying to think, 'Is this a theme? Have I captured the essence of the experience?'" By publishing her article in Inquiry, Cristina hopes to show other families affected by Alzheimer's disease and dementia that there is a different approach to care than what is found in the United States, and to inspire them to reconsider how to best care for their loved ones. Upon graduating in May 2006, Cristina plans to work in a hospital where she can gain experience in medical-surgical nursing—she hopes that hospital will be in San Francisco.*

Mentor Bio

Gene Harkless*, DNSC, ARNP, is an associate professor in the nursing department. She is a family nurse practitioner who has taught at UNH for twenty years, focusing her research on evidence-based practice and clinical decision making. Her experience working with a Norwegian nursing colleague on a study of nursing home residents led her to suggest Norway as an interesting place for Cristina to pursue research on dementia. Professor Harkless points out that the outcome of Cristina's research was not totally unexpected: "The questions she raised in her research left her with many more questions to answer. Now she lives in that uncomfortable professional space of knowing how much we do not know." Harkless is grateful for "the international scholarly connections that are fostered and nurtured by those involved in the International Research Opportunities Program," and explains that her respect "for the generosity and helpfulness of the international nursing community continues to deepen."*