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On Living Alone with Alzheimer's Disease

E. PORTACOLONE

Abstract

A sociologist's encounters with a retired executive living alone with Alzheimer's disease reveal gaps in the U.S. healthcare system. These gaps emerge during eight ethnographic interviews and participant observation between 2014 and 2017 with Ms. Judith Banks, 79. Ms. Banks' perspective offers an inside-view of the challenges of living alone with cognitive impairment. Receiving a diagnosis of Alzheimer's disease was "brutal" for her and the support to continue living in the community almost non-existent. Gaps in the U.S. healthcare system further emerge from the contrast between Ms. Banks' case study and the examination of the Danish system of care for non-institutionalized persons with dementia. Given that one third of people with dementia live alone in the U.S. and that they are likely to experience poorer health outcomes than counterparts living with others, it is critical to ensure that they receive appropriate health services upon diagnosis of cognitive impairment.

Keywords

Living arrangement; Alzhemer's disease; health care services; diagnoses

Introduction

In her elegant living room with Persian rugs and spectacular views of the California coast, Ms. Judith Banks (a pseudonym), 79, a retired executive, welcomes me with a smile. Ms. Banks and I sit on a comfortable leather couch, a vase with a white orchid sitting on the coffee table facing us. Classical music fills the room. Ms. Banks is wearing the same cashmere sweater that I bought at Macy's. Mine is red; hers is navy blue.

Ms. Banks is keen to help me with my investigation of people living alone with cognitive impairments such as Alzheimer's disease or mild cognitive impairment, the intermediate stage between healthy aging and Alzheimer's disease. To help me, Ms. Banks and 45 other Americans living alone have opened their doors to me several times, for a total of 195 interviews. As an ethnographer, my goal has been to spend time, mostly afternoons, with people like Ms. Banks to deeply understand the experience of living alone with cognitive impairment in this country.

Corresponding to: Elena Portacolone, MPH, MBA, PhD, Institute for Health & Aging, University of California San Francisco, 3333 California Street Suite 340, 94118 San Francisco, CA USA, Tel.: +1 510 830 9309, Fax: +1 415 476 3915, elena.portacolone@ucsf.edu.

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This privileged inside view is essential to understand if and how our healthcare system may be ready to support an increasing number of people living alone with cognitive impairment. In the United States, estimates indicate that one third of people with dementia live alone (1). Furthermore, at least one in seven individuals with Alzheimer's disease lives alone, a total of 800,000 individuals (2). The number of people living alone with cognitive impairment is likely to increase, as we project that baby boomers (in 2017, those aged 53–71 years) are more likely than ever to live alone in old age, as they have fewer children and higher divorce rates than prior generations (3).

A special issue of the annual report of the Alzheimer Association was devoted to people like Ms. Banks, living alone with Alzheimer's disease (2). These older adults have poorer health than those living with others. Comparisons between older adults living alone with cognitive impairment and counterparts living with others pointed to the higher unmet needs in self-care (4), nutrition (4, 5), and management of medications (6) of those living alone. Furthermore, older adults living alone with cognitive impairment are more exposed to self-harm (4) and they are less likely to participate in clinical trials (7) or to receive a diagnosis for their cognitive impairment (1, 8). Despite these concerning findings, very little is known about the subjective experience of people living alone with Alzheimer's disease or other forms of cognitive impairment. That was the reason for my attentive listening to Ms. Banks and other study participants recruited through healthcare organizations (9, 10).

From the beginning, Ms. Banks was enthusiastic about talking to me. "I'm not one to start chatting easily with people. That's not my character. But I'm very talkative when I get going." She was so hungry for company that sometimes at the end of my visits, with me at the door, to stretch our time together she asked question after question about my family, work, and plans for the weekend. Each visit gave me a deeper understanding of her experience of living alone with Alzheimer's disease. Overall I visited her on eight afternoons between October 2014 and July 2017.

Ms. Banks told me how she discovered that she had Alzheimer's disease. A few months after her husband died, she noticed that she had trouble performing tasks that were usually very easy. At first her primary care physician minimized the problem. However, at Ms. Banks' insistence, he referred her to a neurologist. About that visit, Ms. Banks recalls spending 25 minutes answering some cognitive tests which led to the diagnosis. "It was brutal," she recalled. In her words,

> I was very upset by this woman [the neurologist]. She told me right off the bat I had Alzheimer's, dementia…But the lady never explained anything. I was so shocked that I had no idea – and the first thing she said after that, "I have no choice but to inform the DMV because that's the law. The law requires it."

The diagnosis of Alzheimer's disease was upsetting at many levels. First, Ms. Banks was distressed that she had Alzheimer's disease. Second, the lack of explanations upset Ms. Banks to the point that she stopped taking a prescribed medication for Alzheimer's disease because she did not know why she was taking it. Third, suddenly being unable to drive transformed her life. In the throes of grieving her husband's death, and with this new diagnosis, Ms. Banks sold her house in the countryside and purchased an apartment in a beautiful city in California so that she could use public transportation. To understand her options, during this transition, she hired a case manager for older adults: “The whole thing cost nearly $2,000.” The case manager organized the visits to three continuum of care facilities, which are places that offer daily living assistance to their residents, if needed, as well as meals and entertainment, all of which cost at least $48,000 per year plus an entrance fee of at least $100,000. Repelled by the visits of these facilities, Ms. Banks preferred to move into a conventional apartment complex. She explained:

> If you look at the units that you live in, they are like a little rat box. They are very small… And I don’t like to be totally surrounded with people my age either. You know, there’s a limit to that.

But life in her apartment was trying. A former executive, used to managing personnel and handling complicated matters, Ms. Banks explained, “everything I do is difficult because I can’t remember things. I can’t remember that hour that I said I would be there or the hour that my brother said would be here.” To keep abreast of today’s date, she checked the date in the newspaper. “I try to find something that helps me prove the right date,” she explained. And when she wrote checks, she often used a dictionary to remember how to spell numbers. “Sometimes I have to do three copies before I can get one that I know is right.”

There were other difficulties as well. Five falls in the first five months in the apartment, an inflammation of the joints, and a sense of imbalance thwarted her original plan to use public transportation. The unpredictable and intensifying course of her impairment also isolated her. A “fairly private” woman, Ms. Banks shied away from social interactions to avoid feeling embarrassed:

> I’m not comfortable talking to people that I don’t know, for instance, because sometimes my speech stops, just stops. So I don’t know how to pick it up and start again and I get agitated, which means that I cannot talk at that point.

Some interactions were downright hurtful. For example, after she told an old friend about her condition, he avoided her. “I’ve had the impression that people really shrink from you when they know you have Alzheimer’s. It’s not something you’re going to pass to them, but people are very uncomfortable.” As a childless widow, Ms. Banks was also concerned about imposing on the only family members she had, her brother and his wife, both living more than an hour away. To make matters more difficult, the lack of services available through her reputable and well-known healthcare organization dismayed her. She noted,

> They have treated some other problem that I have with my legs, and I will be going sometime in the next month or so to get my ears cleaned, things like that. But as far as Alzheimer’s, they have nothing to say,…they really don’t have any program on it or anything like that…There is really nothing.

Ms. Banks discovered that receiving a diagnosis of Alzheimer’s disease did not lead to specialized services to support her ability to live in her home. Medical providers such as her primary care physician and another neurologist she consulted told her to simply keep taking her medication. She observed, “The doctors tend to avoid telling you how bad it’s going to be until I die. They don’t want to give you bad news, right?” The visits with her primary care physicians were sporadic. Her requests to participate in clinical trials were ignored.

To find support, Ms. Banks resorted to the concierge of her elegant apartment complex. Through the concierge she hired Ms. Anna Lopez, a private home care aide serving other affluent tenants in the same building. Ms. Lopez purchased groceries, cooked, and cleaned the house. However, as her thinking difficulties progressed, Ms. Banks became less able to take major steps. Specifically, her original plan to offer her spare bedroom to a roommate, ideally a nursing student, in exchange for support became too difficult to execute.

Yet another element that made it difficult to live by herself with Alzheimer's disease was that she was residing in the United States. Had Ms. Banks lived in a country with a more entrenched social welfare system such as Denmark, perhaps her trajectory would have been different.

Addressing the Problem in Denmark

To better understand how country of residence influences the trajectories of Ms. Banks and other study participants, in September 2016 I flew to Denmark to interview healthcare providers as well as scholars of health policy at the University of Copenhagen for one week. Whereas the academic literature pointed to Denmark as a country with social policies focused on keeping older Danes in their homes as long as possible (11, 12), it was difficult to understand how the policies were implemented. The limited information available in English on specific public services for community-dwelling older adults inspired my visit (13).

Through my encounters I learned that each Dane is invited to receive a home evaluation to determine if they need specific and free home services when they turn 75 years old. These evaluations are offered every year after the 80th birthday. Eligibility depends not on specific diagnoses, but on their ability to perform functional activities essential to living at home, such as grooming, cooking, buying groceries, and walking. Should they qualify, they start receiving help with the activities they need help with from home care aides and nurses headquartered at the municipality level. If older Danes refuse services one year, they will be offered services the following years. These home care services are also available after the 65th birthday if someone starts living alone after the death of a spouse.

Additional resources become available as soon as a Danish resident receives a diagnosis of cognitive impairment. From her office in downtown Copenhagen, an experienced dementia coordinator of a municipality explained,

> The law says that if we have people with problems and they have cognitive impairment, we have to offer them help…We have to say we're here, how can we help you? And if they say no, we have to come again and say hello, would you like this? Or just be there. We have an obligation to continuously offer them help.

The diagnosis of cognitive impairment is the gateway for the services of a team of home care aides, assistants, and nurses, all trained in the care of persons with cognitive impairment. To reduce disorientation, the number of people on the team is kept at a minimum. The team assumes the responsibility to help clients with the tasks they find most difficult to perform e.g., creating grocery lists, buying food, preparing meals, showering, taking medicines, washing clothes. To perform physically demanding tasks, such as gaining strength, negotiating steps, or walking outside, older Danes have access to occupational therapists. To avoid the risk of fires, Danes with cognitive impairment often have their gas appliances exchanged for electric ovens with a timer. Dedicated smoke detectors attached to the nearest fire station are also installed in their homes. Government-subsidized “welfare technologies” are offered. A diagnosis of cognitive impairment often allows Danes to receive talking calendars, footwear or bracelets with GPS, special phones with large buttons and pictures of the callers, sometimes e-tablets to talk with nurses via wi-fi.

Similar to their counterparts in the United States, older Danes living alone often do not have someone to help them and they are usually reluctant to ask for help. The purpose of these services is to support Danes living alone with cognitive impairment to stay in their homes for as long as possible.

Back to the United States

In the apartment with the stunning views of the Pacific Ocean, I describe the discoveries of my Denmark trip to Ms. Banks. She is somewhat familiar with the Danish welfare system because she was born and raised in Europe, like me, and she is well read. When I finish, she says,

> Well, you went to a country where they always have had very good care for older people, unlike anybody elsewhere. It’s very unique and it’s partly because they’re small…Whereas the bigger the country, the less the services, right?

and shifts the conversation elsewhere.

I understand that an exact replica of the Danish system in the United States is unfeasible because of numerous structural differences in our healthcare payment and delivery system. Yet, I still believe that we have much to learn from other countries. The main lesson that I drew from my time with Danish healthcare providers is that it is feasible for Danes to continue living alone in the community because there is a robust political will to support this arrangement. This political will manifests in the automatic functional evaluation performed at age 75, extra services available upon the diagnosis of cognitive impairment, and in the firm commitment of healthcare providers to consistently provide help. As a result, older Danes are less afraid to asking for assistance for fear of being a burden, rather, they often understand that they are entitled to it.

Conversely, in the United States, the political will to support older adults living alone in the community is diffuse. The responsibility for creating the necessary support systems to live at home is spread across the cognitively impaired person themselves, caregivers (if any), and healthcare providers. Intensifying this difficulty, a diagnosis of cognitive impairment seldom leads to government-subsidized or affordable long-term specialized services to continue living at home. Low-paid public home care aides, an often critical resource for those who wish to remain at home, are only available to poor older adults who qualify for Medicaid. These diffused responsibilities often leave people like Ms. Banks not knowing where to turn to make a plan or obtain help. In her words, “ So, it’s getting worse. It’s getting worse. It is getting worse. I have a lot of trouble now, and I don’t know what to do, you know? I really don’t know what to do,” leaving me at a complete loss for words. At this point I can only imagine how Ms. Banks’ life would have changed if, as soon as she was diagnosed, she would had access to home care aides well trained in supporting people with cognitive impairment briefly checking on her on a daily basis, making sure she took her medications, connecting her to services, helping her find a roommate.

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