

# Washtenaw County Seniors & Caregivers: Findings from a Qualitative Data Study

In 2017, the Ann Arbor Area Community Foundation (AAACF) commissioned from Jewish Family Services (JFS) of Washtenaw County a qualitative study of the lives of vulnerable older adults in the County. The study would help support the Foundation's grantmaking and help JFS apportion and direct services. Historically, both organizations have committed significant resources to older adults and caregivers in the region.

The 2010 U.S. census found 53,000 adults age 60+ in Washtenaw County. By 2040, this number will more than double, with most being 75 or older. The number of seniors in poverty will also more than double, and the senior refugee population will increase 2-3% annually. For this study, investigators were equally interested in the lives of caregivers, many of whom were around the same age as those they cared for and faced the same housing, transportation, healthcare and independence issues.

"Caregivers shared the stage equally," says Abbie Lawrence-Jacobson, Ph.D., LMSW, the study's principal investigator. "The wellbeing of older adults hinges on having caregivers who can meet their needs. And the wellbeing of caregivers, often themselves older adults, hinges on the support they have in their caregiving role. The lives of caregivers and care recipients are so intertwined it was impossible *not* to give them equal billing."

Most all of us will assume, maintain, or, most likely, increase our caregiving duties for family or friends, even as we ourselves, between now and 2040, join the "vulnerable senior" population and come to depend of caregivers. Life *for everyone* in 2040 will be shaped to a large degree by how we respond *now* to the needs of the aging. Currently, Washtenaw County is not prepared to fully and justly support its growing senior population. This fact, combined with the Foundation's commitment to seniors and caregivers translated into a need to acquire more data about them.

*"Life for everyone in 2040 will be shaped to a large degree by how we respond now to the needs of the aging."*

"We have become much more data driven in the last few years," says Neel Hajra, CEO of the Community Foundation, reflecting an overall trend in philanthropy, which, like other professional fields, increasingly turns to data to support plans of action. If you found a program, focus on a population or a goal, or make a decision, you must produce data to justify it. We often think of this data as "hard" numbers produced by quantitative research. Numbers tell clear, gripping stories—for example, a senior population of 53,000 doubling in just twenty years—that can help move communities to action.

But this time, AAACF, JFS and the investigators sought something more.



**Ann Arbor Area  
Community Foundation**

“We had done *quantitative* studies,” says Lawrence-Jacobson, “that told us the basic needs of older adults. Now we were looking at *qualitative* research, to capture the *voices* of older adults. Ultimately the Foundation wanted to have an enriched way of understanding and supporting older adults and their caregivers.”

Qualitative research, Lawrence-Jacobson says, “gets at the hows and whys of human behavior. Qualitative and quantitative—narratives and numbers—flesh each other out. Things come alive, become real. And when you present results, having both types of data guarantees that learners with diverse learning styles will all be able to access our information. One type of data or the other will speak to them. This makes the findings more accessible.”

A qualitative study starts not by counting but by asking. It turns (often open-ended) questions over to interviewees who are living the lives the researcher seeks to capture. Qualitative research listens. The responses—rich in allusions, quotes, anecdotes, analogies, metaphors, hesitations, self-corrections and all manner of unique turns of phrase—add nuance and dimension to numbers and make us see them in unexpected, powerful, personal ways. Verbatim text becomes key to understanding—to *feeling*—experience. Qualitative data may then be presented directly, or researchers may sort, group and count words and phrases they have agreed are similar. Lawrence-Jacobson and her team heard many stories, indeed, but they could not be expressed in single, tidy paragraphs. And this was never the intention. The team did summarize their data in a somewhat conventional form, but they also went out of their way to present it less conventionally, inviting a theater artist to convert data into a time-bound communal experience that would move its audience by embodying text in telling varieties of speech, movement, lighting, music and so on.

The study asked four interrelated questions: Who are these seniors and their caregivers? Where and how do they live? How is their health, including their mental health? How do they get from place to place? And how are their relationships with those who play perhaps the second-biggest role in answering those questions: the caregivers. Who are those caregivers? Where and how do *they* live? How is their health, including their mental health? How do *they* get from place to place?

Using purposive sampling—focusing on the characteristics of a population and the study’s objective, as opposed to more random probability sampling—the team recruited 32 individuals over the age of 60 (10 caregivers, 22 care recipients) who fit one or more of the following criteria, taken from a previous quantitative study conducted by the University of Michigan’s Community Technical Assistance Collaborative:

- they lived in ZIP codes 48197 or 48198 (the latter has the lowest life expectancy in Washtenaw County; the former has the fourth lowest);
- they received rent assistance or Medicaid, or lacked sufficient money to pay bills;
- they lived alone; or
- they served as caregivers for someone over age 60 who met one or more of the criteria above.



Investigators conducted in-depth semi-structured interviews with each participant to understand their individual experiences and stories about caregiving, housing, transportation, health and health care, and other services to support independence. Each interview lasted one to two hours and was conducted in the respondent's home or in a public space convenient to them. Interviews were recorded, transcribed, and coded using both *a priori* codes from an interview guide referencing the domains of interest (housing, transportation, health/health care, and independence), as well as new codes that emerged from the respondents' narratives.

(The investigators note that the methodology had two limitations. By recruiting through agency contacts, we excluded isolated individuals not connected to helping organizations. And because recruitment and interviews were conducted in English, four individuals not fluent in English were not able to participate. We did interview three immigrants for whom English was not their first language.)

The caregivers and care recipients were a racially and geographically diverse group. The average age of caregivers was 61.7 years, and the average age of care recipients was 73.4 years. Caregivers had somewhat higher incomes than recipients (to be expected, given that many were still working full-time and were recruited for their caregiving status rather than for the financial vulnerability criterion). However, incomes of nearly three quarters of the respondents were at or below 250% of the Federal Poverty Level (\$31,225 for a household of one).

In addition to basic demographic questions, a sampling of this study's interview questions in all domains would include:

Tell me about your current living situation. ● How do you think your role as a caregiver affects your living arrangements? ● How do you think your role as a caregiver affects your physical and mental health? ● How long have you lived here? (with probes, i.e., more specific follow-up questions about cost and location) Do you live alone or with other people? ● Do you look after your spouse/partner? ● What do you like or what's helpful about your living situation? (with probes about affordability, safety, and proximity of friends and family) ● How often would you say you leave your home? ● How well does your usual means of transportation meets your needs?

How do you feel your health is, compared to others your age? ● How often do you go to the doctor? ● What is positive about visits to your doctor? ● What is negative? ● How hard do you find it to keep track of your medications?

How well do you feel you can cope with life's stresses? ● What do you find challenging about preparing and eating meals? ● How satisfied are you with the amount of time you spend with other people? ● How often do you feel lonely, or like you wish you had more contact with people? ● If you could change anything at all about your current life, what would it be?

From the answers to these questions, the investigators discovered the following about respondents' experiences in the basic areas the study set out to address.



**Unpaid caregivers** provided hands-on care for those with significant dementia or physical impairment. They oversaw medical care and accompanied loved ones to medical appointments or arranged transportation. They bought and/or prepared food and handled finances. They juggled competing demands, and when not physically with those they cared for, they still performed tasks and made decisions “in the background.” Some caregivers had been through bankruptcy or were receiving [Supplemental Security Income \(SSI\)](#) or [Social Security Disability Insurance \(SSDI\)](#) due to disabilities. Many who were retired maintained part-time jobs, often taking leaves of absence or reducing hours to have time for caregiving. Some financially insecure caregivers benefited from services provided to qualifying loved ones. Others struggled to pay for food and transportation. For these reasons and many others, both professional and unpaid caregivers are known to burn out quickly.

**Housing challenges** included: affordability, accessibility, safety and building maintenance. Some caregivers were reluctant to move loved ones into nursing homes; others expressed relief that they could rely on assisted living (paid for by PACE and Medicaid) to keep loved ones safe.

Caregivers and recipients relied on their own vehicles and on buses and on social service agencies for **transportation**. Many had given up cars due to maintenance costs. Riding with nonprofessionals (family and friends) might involve difficulties with walkers and wheelchairs. The convenience of public transportation was balanced by trade-offs around scheduling and cost.

Questions around **health and health care** generated the most passionate responses. All interviewees dealt with physical and mental health conditions, including pain, difficulty walking, and falls, and they adapted by limiting activities. Caregivers and recipients both spent significant time at doctors’ offices. They valued doctors who took time, listened and spoke honestly, and they wished for more personal guidance and one-on-one time with them.

**Health insurance** was a primary concern of nearly all respondents. Several carried medical debt and some ignored routine preventive care for lack of insurance. Caregivers knew the importance of maintaining their health in order to continue caring for loved ones. Respondents reported swapping prescription drugs for over-the-counter equivalents and choosing not to fill some prescriptions.

Caregivers spoke at length about **emotional wellbeing**. Mental health support was crucial. Many care recipients had once been caregivers and spoke about the toll that took. Stressors for both groups included family conflict, health issues, financial issues, death or other loss, trauma, loneliness, depression, abuse and homelessness.

Some respondents reported satisfaction with new and established **social connections**, and participation in organized activities, but health challenges or lack of time or money kept some from these activities. To cope with stress, respondents turned to therapy, humor, religion and spirituality, volunteering, hobbies, and the company of loved ones, including pets.



To maintain **independent living**, respondents relied on friends and family for rides, shopping, loans, companionship and help with housework. Some respondents with no available family or friends relied on agencies to provide services. Caregivers' work did not end when loved ones connected to agencies, as they still arranged and supplemented these services.

Responses underscored the need for **comprehensive, coordinated care** rather than piecemeal care from many organizations. Caregivers and recipients are best served by a central resource person helping with legal, financial, medical and emotional challenges. The best coordinated care providers give hands-on instrumental support, rather than just referrals.

Regarding **the treatment of older adults in society**, respondents felt that seniors are sometimes treated like children and are isolated by their age. Perhaps due to this sense of invisibility, respondents were particularly thankful for this opportunity to share their experiences with leaders in the community.

Lawrence-Jacobson reports not being greatly surprised at the above results. The broad issues were known to affect other populations of seniors and caregivers, and they were expected to surface here. The researchers were *most* gratified by the qualitative data—the stories, the language they had come to collect.

“Though the stories were not shocking or surprising, the ways people spoke about these situations was beautiful and eloquent,” Lawrence-Jacobson says. “Stories speak to a part of the brain that numbers can’t access. Stories build curiosity, empathy, and understanding. Numbers make big, clear statements about populations. Stories trigger empathy and generate passion for change. You see yourself or parts of your life or your loved one’s lives in qualitative data. We can then find themes across individual narratives. This gives us those numbers that say, ‘This situation is not unique. Last year it happened to X-percent of people, and it correlates with A, B and C.’ We universalize stories that people might otherwise write off as happenstance.”

Below is a sampling of striking comments from the interviews, with notes on how certain turns of phrase suggest complex feelings or unusual perspectives that a qualitative study captures best.

From the child of a care recipient: “I won’t want—God forbid—anyone putting their hands on her. I don’t want anyone getting too frustrated with her. That’s my greatest fear.” [“Putting their hands on her” suggests sexual abuse without stating it; this might not be counted officially as an expression of fear of sexual abuse.]

From a caregiver: “They say the first one that goes down is the caregiver, and I’m trying not to fall.” [The ominous, slangy “goes down” suggests that the “fall” might be fatal. Falling—probably seniors’ single greatest fear—becomes a metaphor for death *and* for failing another person.]

*From a caregiver:  
“They say the first one  
that goes down is the  
caregiver, and I’m  
trying not to fall.”*



From a care recipient: “The people that I know that are my age are gradually disappearing....Well, they’re not disappearing, but they’re going.” [The respondent balks at the unnerving but real idea of “disappearing” and poignantly substitutes “going.”]

From a care recipient: “You need a sense of humor to adapt to the new you, which is pathetic, but fun.” [Probably no numerical data could capture the touching frankness of the phrase “pathetic, but fun.”]

Following completion of the study, AAACF’s Vice President for Community Investment, Jillian Rosen, suggested that Prof. Jessica Alexander of Eastern Michigan University take data collected by Lawrence-Jacobson and her team and create from it a performance piece. Prof. Alexander specializes in the use of theatre for community performance and on community art and activism and academic service-learning. She had previously worked with AAACF on their In The Neighborhood initiative, which initiated a dialogue to help Washtenaw County communities better understand the local arts and culture landscape

If text and data can be “mined” by software, they can also be mined by artists. When an artist produces a performance from data, that artist is not just mining, they are refining and smelting and producing a unique product, *made from the original material*, to be presented to a community. Along the way, the artist uses theatrical techniques, many of them nonverbal, to convey points made in the text. (To the general public, two of the best-known American performance pieces taken from interview data are Moisés Kaufman’s [The Laramie Project](#) (2000) and Michael Bennett’s [A Chorus Line](#) (1975).)

“The study is rich in data, story and narrative,” Prof. Alexander says. “I was struck by the multitude of voices. It felt and sounded choral to me. Most ethnographic performance is presentational, like ancient Greek theatre, so a polyphonic or choral approach felt right to give voice to the system of care and to seniors.” Thus, Alexander structured the piece as a fugue, with pieces of text from the study introduced and then repeated and interwoven. The cast comprised four of Alexander’s current and former students, ages 24 to 55. The finished piece was presented at the AAACF’s [Vital Seniors](#) Community Celebration, which recognized local organizations that won a Community Foundation competition for innovation in long-term senior programs.

“Seeing *Vital* was a highlight of my professional life,” says Lawrence-Jacobson. “To hear words I helped choose and see them embodied onstage: I thought, *This must be how an author feels when their book becomes a movie!* The meaning we found in those stories is so helpful for the community to hear.” Says Alexander, “I believe deeply in the power of theater as a transformational tool, whether to illuminate, shift attitudes or prevent behavior.” Both she and the Foundation plan for *Vital* to have continued life.

In listening to and recording and disseminating seniors’ and caregivers’ voices, as in all of the work it does with these populations, the Ann Arbor Area Community Foundation seeks more than just solutions to aging issues. We seek new ways of thinking about the overall life, health, resources, and community in our County. Seniors benefit, of course, but in the process of studying their lives we expect to uncover ideas beneficial to all of us now, and as we age. In the near future, we expect aging will be understood in ways entirely different from how we think of it now. **We invite our Washtenaw County neighbors and partners**





**to join the conversation.** Says Neel Hajra, “We think we can play a major role in making sure that, for many decades to come, seniors are aging with dignity, and that they feel good about their lives.”

Because one purpose of this study was to move the community through language and story, we thought it would be appropriate to end with one community member—principal investigator Abbie Lawrence-Jacobson, Ph.D., LMSW—answering an open-ended question about her own personal experience of the study. We asked, “Was there a particular story or a particular moment in the data collection with which you made an especially strong personal connection?”

Her answer:

“There was a story shared by a caregiver that struck me as a perfect example of how I might feel, should I assume a caregiving role for my parents. This caregiver suffered from health challenges of her own, while simultaneously caring for her mother, who had dementia. One day she felt so ill and so scared that she put her mother to bed, then climbed in next to her with an overwhelming feeling of “I need my mommy.” She laid her head on her mother’s shoulder and explained how scared she was for her, while knowing that her mother could no longer understand or provide support. For me, that story got to the heart of what it’s like to be an adult child who still needs support and care, while taking care of a parent who used to provide that support. As adults, we need to feel we can both provide and receive care. This caregiver got me thinking about how I can balance the increasing role I foresee, caring for my parents as they age, with my awareness of how much I appreciate the support they still provide to me.”

