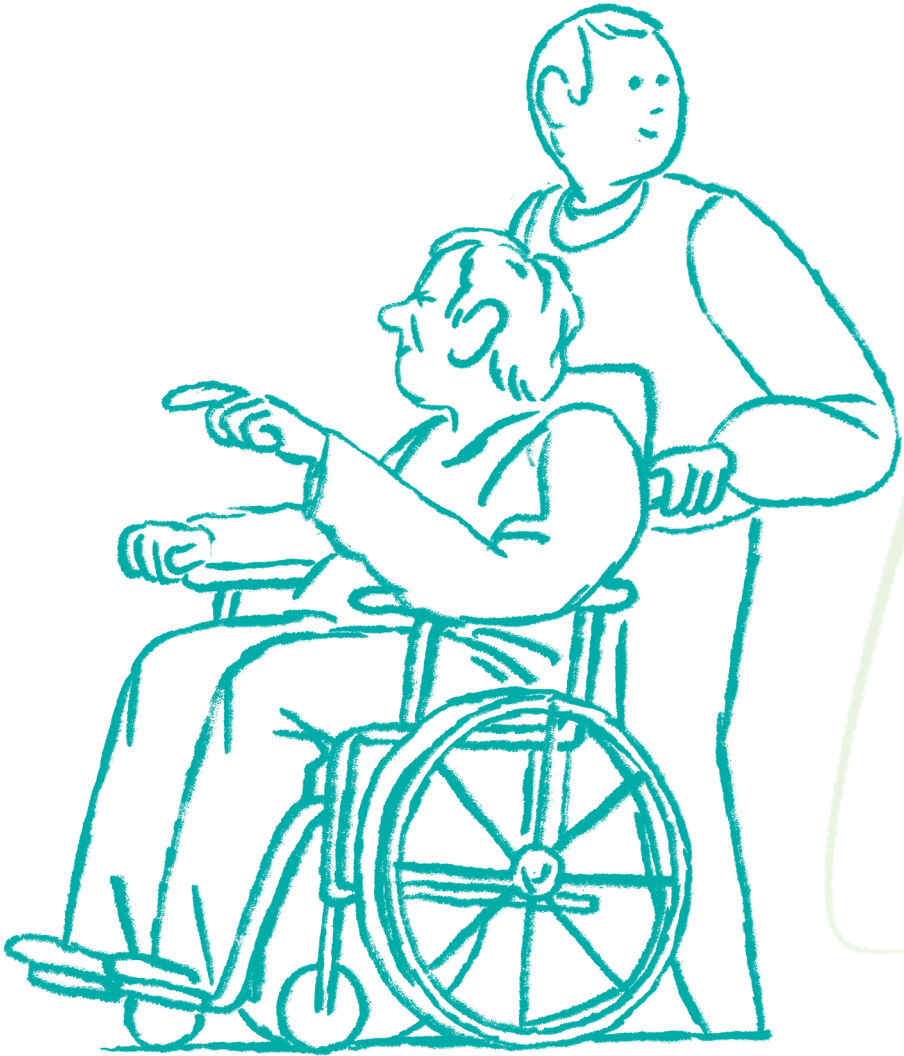


An Exploration of Family Caregiving

A publication
researched by
Practica Group

With support from
the Ralph C. Wilson,
Jr. Foundation





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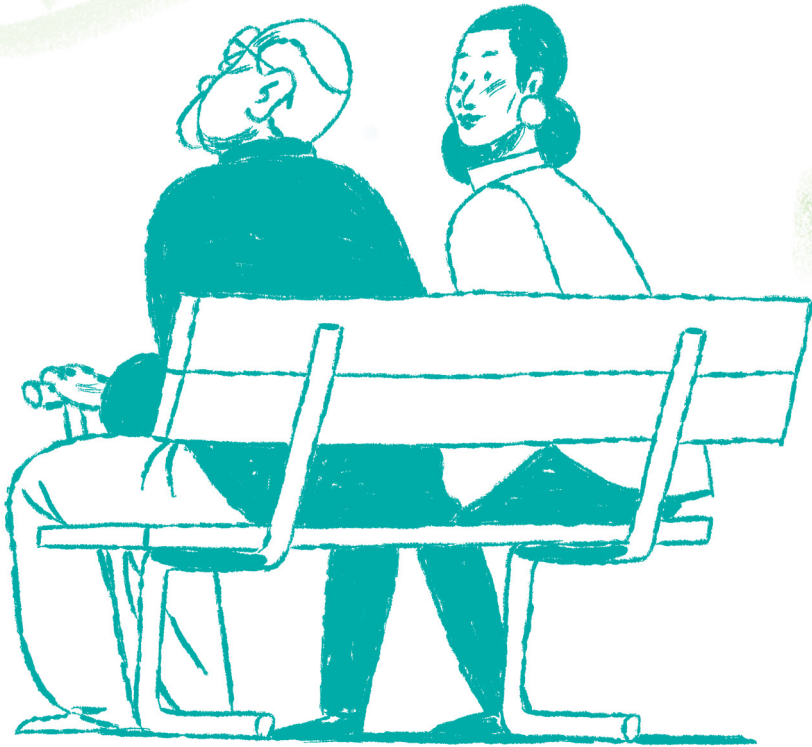
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With support from:



RALPH C. WILSON, JR.
FOUNDATION

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FOREWORD:

Recognizing the Critical Importance of Caregivers

An Exploration of Family Caregiving / Ralph C. Wilson, Jr. Foundation



Above: Ralph C. Wilson, Jr. put into motion the establishment of his namesake foundation. Driven by his love and loyalty for the places that shaped him, his foundation now exists to support and help improve those communities.

In the next 30 years, the number of people over 65 is projected to more than double, rising from 46 million to over 98 million. This population shift will affect every corner of our world, presenting both enormous challenges and unprecedented opportunities for families, communities, health care providers and businesses.

OUR FOUNDER, Ralph C. Wilson, Jr., witnessed this firsthand at the end of his life, recognizing the critical importance of caregivers in the health and wellbeing of our growing aging population. Moved by Mr. Wilson's observations, his hand-picked Life Trustees selected "Caregivers" as one of the four primary focus areas of his legacy foundation, striving to improve outcomes for both professional and family caregivers and those who support them.

To gain a better understanding of the "state of family caregiving," our foundation engaged Practica Group, a partnership of anthropologists and marketers, to conduct research and gain broad cultural insight into the everyday lives of this growing community.

"Ralph C. Wilson, Jr., witnessed this firsthand at the end of his life, recognizing the critical importance of caregivers in the health and wellbeing of our growing aging population."

By presenting Practica's findings, we strive to provide fresh perspectives on the life of caregivers, the challenges they face, their successes and joys. Ultimately, our goal is to work together with others to discover opportunities, initiatives and innovative solutions in caregiving that will make a lasting and positive impact.

The Research

Practica's team of three anthropologists set out to interview caregivers, agencies and community leaders in the areas we serve— Western New York and Southeast Michigan. Practica also offered caregivers the chance to record their day-to-day experiences in a video diary.

Research goals

- Identify key values and ideas associated with the caregiving experience
- Uncover the challenges and barriers of caregiving
- Understand the day-to-day realities of caring for loved ones



41

**half-day visits
with caregivers**



25

**interviews with
agency and
community leaders**



11

**caregiver video
diaries**

What we Discovered

This section provides a window into our caregivers' lived experience and offers "food for thought" with fresh perspectives for communities to consider when conceptualizing problems and identifying solutions, developing services and programs, instituting innovation or re-thinking policy.

Culturally, caregiving is seen through the lens of family - "it's family, it's just what you do." It is experienced as an act of giving back - an affair of the heart.



How our Culture Views Caregiving

1. Caregiving is a deeply moral commitment to family.

Culturally, caregiving is seen through the lens of family – “it’s family, it’s just what you do.” It is experienced as an act of giving back – an affair of the heart – and is assumed to emerge from American values of individualism and independence. Thus, asking for help outside the family, especially from government agencies, can be seen as a loss of dignity or a failure to sustain family self-reliance and autonomy.

—
“I look at it as my mom cared for me when I was younger, so now I can give her the reward of caring for her. I don’t look at it as a burden.”

Theresa, Caregiver

2. Our culture’s views on aging influence our views on caregiving.

In our society, the elderly are liable to become socially invisible. “Old” is a time of life when one’s personhood is at risk, a time of loss. Through this lens, caregiving is seen as looking after an ever-diminishing person in which the caregiver is the guide to safe passage (“nurse”) rather than “fellow traveller.” And yet caregivers often contest the assumption that their mom or dad, sister, spouse or grandmother had little left to give to their social circle or beyond.

“These are people who ran homes, they worked, they were contributors. My mother has a body of work over the past 70 years that’s impressive. And now to say to her, ‘sit in a chair and do nothing,’ it’s very hard for her, even in her diminished mental state.”

Lynn, Caregiver

3. Our ideas about caregiving are informed by a medical model that isn't enough.

Caregiving is often thought of as a dyadic, hierarchical relationship, much like the doctor-patient relationship. The focus is on the care recipient and not on the caregiver. There is an emphasis on health versus overall wellbeing, and on what is measurable (washing, toileting, dressing), not the immeasurable (happiness, vibrancy, enrichment). Because of this point of view, the realities of caregiving are often masked. The medical model doesn't prioritize difficult social situations that need to be navigated:

- A spouse having to infantilize a partner of several decades
- Role reversal struggles of children caring for parents
- Siblings coordinating and agreeing on caregiving decisions
- Challenges of geographic dispersion

Caring, when overly shaped by the medical model, can inadvertently destabilize social relationships and identities (e.g. parent-child, spouses and partners, relations among siblings or with extended family, friends and neighbors). These disruptions impact the health and wellbeing of the cared-for and caregivers alike. Caregivers are in urgent need of strategies for sustaining social relationships and fostering resiliency during these times of stress and microsocial change.

Food for Thought

Revive the concept of “aging” as a rich and meaningful stage of personhood.

Aging is not simply a saga of loss, diminishment and death. The goal of caretakers and those they care for is living well and richly: staying engaged and participating in a larger social world; exercising their talents and passions; finding fun, pleasure and humor; being productive; and creating ongoing meaning in their lives.

Shifting cultural perceptions of aging is a heavy lift, but programs and initiatives that increase visibility of the aging and integrate them into community and place will make subtle and incremental changes in perceptions and beliefs.

Consider how we care for children as a model for caring for older adults.

Comparing aging adults to growing children brings about radically different ideas about stages of aging that can be helpful. In child-rearing, a broad range of social resources are mobilized (parent groups, teachers and other specialists, schools, nutritional programs, enrichment programs, coaches, sports, mentors, etc.) while caring for an aging person is largely deemed a private family affair.

Why not apply the same principles of giving and community-based reciprocity that are in place for raising children to those at the opposite pole of life?

Think about the entire well-being of care recipients, not just their health.

Supporting social, intellectual and community ties is critical to the vitality of care recipients. It is at the heart of their goal of living richly and living well. This entails broadening the definition of “caring” to include all sorts of social and enrichment interactions.

Roofs, ramps, bathrooms, kitchens, gardens, porches are the practical infrastructure of the home as a portal to a good life for aging adults.



How our Caregivers Give Care

1. Caregiving isn't located in one individual.

Despite the notion of a “primary” caregiver, many people are involved in caregiving. From the great grandson who makes sure his great grandmother doesn't leave the stove on to siblings who pick up medications to neighbors who plow the driveway.

Caregiving also unfolds within longstanding family dynamics. In cases where caregivers and those they care for are living well (however that is self-determined) they typically have a supporting cast to make it happen. Mobilizing that supporting cast can be a terrific challenge. Families that are less likely to live well may have fewer resources (including familial), geographic separation or critical medical needs.

Finally, caregiving occurs in a real place – home. Home is a player too in supporting or hindering efforts

to live well. At best, home is a portal to other worlds of cultural and social life that keep caregivers and recipients engaged and alive.

“I have to pressure my work to try to get home quicker to help my grandma out. When I come home from work I have to help grandma get up the stairs. Most times, we can get her to the top, even if we have to carry her, my dad and I, but I hate doing it sometimes.”

Tamara, Caregiver

2. Outside resources are often resisted.

Caregivers have difficulty asking for help and accessing resources beyond the family and inner circle of friends. The commitment to self-sufficiency can prevent obtaining resources that can be critical to well-being. Caregiving resources like transportation and other government and agency-based services are considered “not family.” Instead they are often critiqued and filtered through complex familial relationships.

Services are sometimes considered signs of “being old,” resisted by recipients who push back against stereotypes. Government resources can be seen as stigmatizing (“just for poor people,” “not for me”), for “someone else” who doesn’t have the social, moral or financial capability to manage.

However, crisis frees resistance. Desperation or acute need is a culturally acceptable avenue to seeking help. Asking for medical or clinical aids is also seen as normalized: for instance, calling the number on the insurance card for what might be “covered.” Word of mouth also counters resistance, serving to localize rather than stigmatize.

“It’s wonderful with family and that’s the main thing. Instead of having a stranger come in. I still don’t need someone to dress me or put me to bed, not yet.”

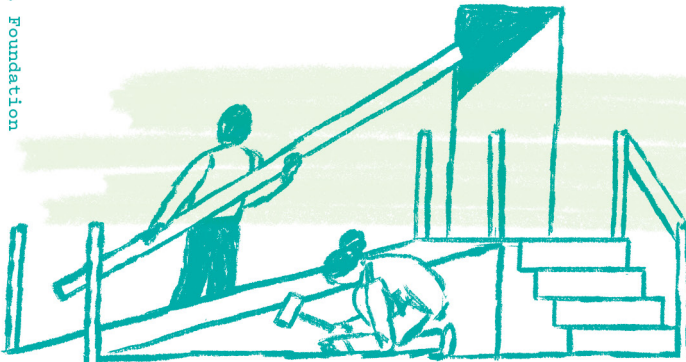
Tina, Caregiver

3. Language impacts how caregiving is valued and envisioned.

Caregivers are apt to talk about their efforts as a form of giving or helping, especially when the recipient is their parent. Their talk centers on returning what a parent or sibling or spouse has given in years past. This language of gift-giving captures the moral imperative of returning the gift, fueling reciprocity. It captures feelings and actions that make family “family.”

Is caregiving gift-giving or a job? Probably both. Caregivers accept the term “job” in certain contexts. It makes visible what is otherwise invisible. But the idea is limited – it suggests that caregiving is measurable; a set of tasks in time and stress level; something that can be made easier or more efficient. As a job, caregiving becomes amenable to bureaucratic assessment. But this view of caregiving is not wholly embraced by family caregivers. “Work” may be a better term – like the work of raising a child, something many participate in and something that is measured in multiple ways.

A caregiver described a wheelchair ramp as a “lifesaver,” allowing her mother to go on walks and connect with others.



“I try to do what I can do for my husband each day. To him, being married is us living together, living in the same house, me taking care of him. That loneliness for me is difficult, but I know what I do for him makes a difference. I know that when I look in his eyes and I see a look of, ‘I’m frightened, I need you there for me,’ I know that I make a difference in his life, and that’s important.”

Shelia, Caregiver

Food for Thought

Expand the scope of caregiving.

Instead of thinking of the primary caregiver as the sole target of services, establish the playing field of “care” to include friends, families, communities, experts, neighbors. Policy makers and service providers should also broaden their social lens to support an inclusive vision of family, neighborhood and community in the project of caregiving.

Home is a key to wellbeing.

Homes need upkeep and adaptive improvements for the cared for to live well. Roofs, ramps, bathrooms, kitchens, gardens, porches are the practical infrastructure of the home as a portal to a good life. A caregiver described a wheelchair ramp as a “lifesaver,” allowing her mother to go on walks and connect with others.

Word-of-mouth is a powerful method of finding resources.

Seeing “my circle of friends” or “people like me” using resources makes it more acceptable to seek out the same resources. Using neighborhood resource channels may also activate a local social network.

Cooking, helping mom to the shower, taking her for a drive, are all forms of caring. All are in the service of living well.



Reframe the language of caregiving.

Shift from the vocabulary of “tasks” and “jobs” to that of “helping” and “giving” when discussing the work of family caregiving. Cooking, helping mom to the shower, taking her for a drive, are all forms of caring. All are in the service of living well. Adopting family caregivers’ language of giving back and reciprocity acknowledges their mission.

The Impact of Giving Care on Caregivers

The goal of caregivers is to keep life vibrant. Caregivers lament that their parent or grandparent is starved for social stimulation and interaction. As social lives diminish, they often fill the gap in modest ways:

- Bird watching from the kitchen window
- Going to the hairdresser
- Going out to lunch
- Shopping for groceries
- Going for a drive or to the park

But, as a consequence, caregivers' own social lives narrow. Caregivers struggle to keep friendships active. They opt for doing solitary things like quilting and reading as a form of respite, often just being there with the person they are caring for, rather than going out.

“It’s difficult having a husband who can’t do anything anymore. It’s very hard to watch someone who was very active and smart not be able to screw a hose connection into a faucet. It’s difficult to hear him have socially inappropriate comments, but that part of his brain doesn’t work. And that’s probably why we tend to be socially isolated. We don’t have many friends who come anymore.”

Tricia, Caregiver

Food for Thought

Start early.

Caregivers who are most successful at keeping life from narrowing are able to rally their social networks and start adjusting early to challenges of diminishing health and mobility of those they care for before there is a crisis.

Support caregivers as they help their loved ones.

Caregivers want to provide safety and love; they want to sustain relationships based on friendship, growth and discovery. Yet renegotiating roles, managing family dynamics and geographic distances are ongoing challenges. Acknowledge the caregivers' therapeutic, logistical, managerial and coaching needs.

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Seeing "my circle of friends" or "people like me" using resources makes it more acceptable to seek out the same resources. Using neighborhood resource channels may also activate a local social network.



What Next?

Our hope is that these findings provide insight into the development of new programs, initiatives and solutions that can positively impact the lives of caregivers and care recipients. We believe aging can be an enriching, meaningful experience for all involved. Let's change the conversation.

1. Caregiving is a team sport.

Caregiving encompasses more than just the primary caregiver. It includes other family, friends, neighbors, and the wider community – involve all stakeholders in an inclusive vision that shifts the “caregiver’s burden.”

2. Alter the idea of “old.”

Aging doesn't have to be a story of loss. It can be an experience of discovery, humor, joy in relationships. It's important to bring the idea of living well and living richly into conversations with policymakers and providers, in messaging and positioning. Aging is for everyone.

3. Make efforts and actions visible.

How can we support reciprocating networks and social relationships so that caregiving is more broadly distributed and visible in communities? Support creative uses of local institutions; connect families across time and space; create bridges between medical professionals and larger teams.

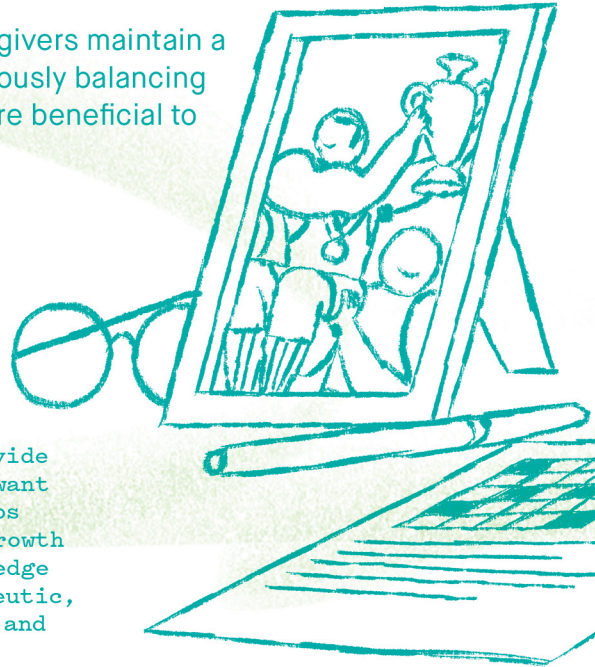
4. Change the language, change the dynamic.

Reframing caregiving as a kind of “cultural work” of giving and receiving, much like the work of raising children, multiplies possibilities for giving care and widens the social network of caring.

5. Caregivers need care too.

Programs that help caregivers maintain a broad, full life, while simultaneously balancing the challenges of caregiving are beneficial to everyone involved.

Caregivers want to provide safety and love; they want to sustain relationships based on friendship, growth and discovery. Acknowledge the caregivers’ therapeutic, logistical, managerial and coaching needs.



About the Ralph C. Wilson, Jr. Foundation

Ralph C. Wilson, Jr. believed effective change should make an impact from the start, yet carry long into the future. To do both, he earmarked a portion of his estate and the eventual sale of his beloved Buffalo Bills to fund his namesake foundation. The Ralph C. Wilson, Jr. Foundation began operations in 2015 to continue his legacy—one of generosity and innovation, healthy risk taking and collaboration, and an unshakeable community focus.

And today, his hand-picked Life Trustees have determined to focus the efforts of the foundation on Mr. Wilson's home and adopted home regions of Southeast Michigan and Western New York.

With a structure that dictates spend-down of our funds by 2035, we match the urgency that people in need feel every day and focus on collaborative investments that consider both immediate impact and long-term benefit.

Our time is short. But with collaboration, vision and a healthy dash of courage, transformation that shifts the very foundations of our communities is possible.

For more information about our organization or this report, please contact us at:

- (313) 885.1895 / info@rcwjrf.org

About Practica Group

Practica Group is a globally active partnership of anthropologists and marketers whose thought-provoking work spans consumer and B2B projects, delivering value through strategic insights.

Practica's staff of specialists and generalists come from varying backgrounds in technology, marketing, medical anthropology, sociolinguistics, visual anthropology, popular culture, cultural geography and industry. The group regularly partners with its global network of filmmakers, editors, designers, web developers, and other area specialists.

For more information, call/visit:

- (312) 560.3868 / practicagroup.com

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