

THE HAITIAN TIMES

BRIDGING THE GAP

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Caregiving for elder Haitians in America



Therese Michel and her daughter, Souerrette, on Therese's 84th birthday in October in Florida, where her daughter is her caregiver. Photo courtesy of Souerrette Michel.

OVERVIEW: Caregivers for elders have stress, financial difficulties and lack of time as they work two jobs, care for elders longer and with more significant illnesses.

Souerrette Michel remembers well the day in Spring 2017 when she returned early to her Miramar, Fla. home from visiting Haiti. As soon as she arrived, Michel had to rush her mother, 79-year-old Therese Michel, to the hospital. On the way there, Therese lost consciousness.

Hospital staff put Therese on a ventilator and intubated her to keep her trachea open for air, and doctors then diagnosed Therese with COPD.

From that day on, Michel began her stint as a family caregiver to Therese, who also lives with high blood pressure, diabetes, cataracts and glaucoma, among other maladies.

“The first time they said to send my mother to a nursing home, I said no,” said Michel, 50, who works full time at her litigation law practice. “When my mother has issues I will just call the ambulance, but I’m *not* putting my mother in a nursing home.”

Raised with the expectation to provide care for aging parents, many Haitians are finding the tradition more and more difficult to fulfill against the demands of life in America. For one, fewer family members are available across geographies to share in the day-to-day tasks. More people, particularly women, work remotely, are caring for children, or doing both at the same time.

As a result, some who care or will care for the estimated 10,000 aging Haitian elders in the U.S. have turned to American methods, including nursing homes — despite the feelings of guilt such a decision often elicits. However, when Haitian American families like Michel’s can, they choose to continue the tradition of caring for older relatives on their own. A choice filled with its own set of unanticipated roadblocks — financial and emotional — and rewards.

“I’m able to be here for my mom,” said Michel. “She’s been through a lot and I think the least I can do is just make her comfortable and keep her with me until whatever’s going to happen, happens.”

Caregiving patterns emerge — regardless of ethnicity

Michel is typical of caregivers in today's fast-paced society. A survey of The Haitian Times readership indicated a wide range of behaviors amongst those who serve as caregivers — consistent with behaviors among all U.S. [caregivers](#).

However broad the behaviors, Michel shares many specific characteristics with [one in five Americans](#) who are caregivers across the U.S. — high stress, a financial burden and a lack of time.

The Baby Boomer population, people between the ages of 59 and 77, are living longer and with more complicated diseases. Fewer potential caregivers are available as the birth rate dropped after this boom.

That problem isn't going away anytime soon. Racial and ethnic [minority populations increased](#) from 7.8 million in 2009 (20% of older Americans) to 12.9 million in 2019 (24% of older Americans) and are projected to increase to 27.7 million in 2040 (34% of older adults).

The 2020 [American Community Survey](#) (ACS) estimates the total Haitian American population to be over 1 million, with those over age 65 estimated at 10,000. Both figures, the [U.S. Census Bureau](#) has said, are likely undercounts.

Haitians' unique challenges

In many Haitian families, parents first migrated to the States in the 1970s during the [Mariel boatlift](#). Those who came after, often escaped Haiti's dictatorships or other turmoil. Many families report that their elders had no intention of staying long in the U.S. but envisioned returning to their homeland to live through their senior years.

Instead, they remained here.

The biggest issues now affecting older immigrants are social isolation and economic insecurity, according to [Changing the Care Conversation](#) Project. Although many immigrants are doctors, lawyers or highly-educated engineers, about half of older immigrants are low-income, first-generation Americans with a lack of English proficiency and limited education. They also have a poverty rate that is double the rate of other older adults.

In addition, there are health issues. Black adults in the U.S. are twice as likely as white adults to develop type 2 diabetes.

Dr. Brenda Owusu, Director of the Adult-Gerontology Primary Care Program at the University of Miami and her colleagues educate health workers and their Haitian American patients in ways to make changes in diet and lifestyle to help prevent chronic illness.

“There’s a lack of education in terms of risk factors for diabetes and how to deal with it in terms of the food because [of Haitian culture],” she said, recognizing that change is difficult.

Middle-aged children most often shoulder the burden of elders’ care. ACS estimates 400,000 Haitian Americans fall in the 35- to 64-year-old group.

Elders often become dependent on their adult children for resources, transportation and a place to stay. They look to adult family members not only for day-to-day needs but support to navigate the system and medical care.

Stress and burnout commonplace

Myriam Breton-Jones, whose parents emigrated from Haiti in 1963, was living with her two teenage children and husband in London when her mother was diagnosed with Alzheimer’s Disease in 2010. Her father, then a surgeon, was still on call.

Breton-Jones tried to become her mother's primary caregiver, flying back and forth, before her family moved back to the States.

"It's hard to see your parents age — trying to do what's best for them. But you're also trying to do what's best for your own family and for yourself," said Breton-Jones.

"My mother was a consummate housewife," Breton-Jones said. "She did everything for [my father]. And he didn't want his life to change."

Breton-Jones began to run a multitude of her father's errands, cook his favorite dishes — served at 5:00 p.m., the hour he preferred. Despite her desire to help, it always seemed inconvenient given the needs of her own family. She remembers her husband said that she was "running around like a headless chicken."

A consistent characteristic of caregivers is stress or burnout. Caregiving becomes a burden when additional help isn't available, or if a caregiver tries to do more than they have time, money or energy to manage. Burnout shows itself as a state of physical, mental or emotional exhaustion, according to [aginginplace.org](https://www.aginginplace.org).

More than 66% of unpaid caregivers for older adults reported at least one negative mental or behavioral health symptom, according to [a 2020 survey](#) by the American Psychological Association.

Caregiver profile:

- A few hours to 40+ hours
- A few to 10+ years — Amount of years care given
- One or many caregivers in a household
- Both men and women provide care
- Age range varies, from children to octogenarians
- Few are paid

- Also work a paying job

Close to 33% described those problems as anxiety, depression or substance abuse. A similar percent, 30.7, thought seriously about suicide. That figure compared with 3.6% for those *not* providing unpaid care for older adults. It was also higher than people in other high-risk groups including young people ages 18–24 (25.5%), Hispanics (18.6%) and Blacks (15.1%).

Caregivers take a hit with employers and benefits

“What we saw in [our 2017] survey was that relatively few workers even let anybody know that they’re a caregiver,” said Colleen Collison, president of [Transamerica Institute for Retirement Studies](#), a nonprofit research foundation. “Employers may not be aware of it because there’s an absence of an open dialogue.”

Caregiving financially impacts the caregiver short and long-term, particularly when people of color and women are more likely to work part-time and those workers are less likely to be offered any sort of workplace benefits.

Michel, at age 50, knows that she no longer has the energy she once had to put into her work. She’s come to terms with what she has and doesn’t have financially.

Breton-Jones was not in a situation where she needed to be paid for her daily work for her parents. She, however, suggests families draw up a contract for the family member who becomes the caregiver.

“If [the compensation] is not monetary, then it’s got to be *acknowledged*. It has got to be *positive feedback*. It has to be *understanding ‘my time’*. It has to be *boundaries*. It has to be *working together*.”

Collison advocates that workplaces offer paid time off or a financial assistance program specifically for caregivers. Just recognize the daily expenses that a caregiver incurs, like gas for a trip to the drugstore, is beneficial, she said. Public-private partnerships could address financial gaps for employers if that burden is too much for a small business, she offered.

The financial impact on caregivers is not only short-term.

“If [caregivers] are not employed, they’re not getting credit towards their Social Security, their *future* social security benefits,” she said.

There’s not enough time in any day

Michel is lucky. As an attorney, she’s able to work from her home that she shares with her mother. Self-employed, she can schedule her mother’s appointments around her appointments.

For others, time means finding resources and support. Breton-Jones happened upon a nearby elder daycare center.

***“[Caregivers] are just not prepared.
And we should be. This is nothing
new,”***

BRETON-JONES

Caregivers, responding to The Haitian Times survey, asked for information about reducing stress as a caregiver and tips on working and caregiving at the same time. They also requested topics that responded to the elders' needs — mental and physical activities for the elderly, better understanding of Medicare and end-of-life planning.

Despite such topics being available on the internet, caregivers often lack the time and energy to access, check and implement those resources.

The good and bad moments of caregiving

Despite the difficulties of caregiving, many voice the sentiment that there's nothing else they'd rather do for these elders than care for them during their last years. Caregivers remember times that were exceedingly difficult as well as those that were positive and delightful.

Soon after Breton-Jones' father died last year, she moved her mother, now 83, to a care facility, where she believes her to be safer with professionals than if her mother were living with Breton-Jones' family. The daughter sees her mother when she washes her laundry or cooks her a meal.

"I've had to learn, sometimes she recognizes me, sometimes she doesn't," said Breton-Jones. "I'm practical in the sense that my mother's physically here but not mentally. I also know that if she knew she was like this, she'd say, 'Let me go. This is not a life.'"

Michel says she has numerous friends whose parents died. Those friends say, "I could've done more." She, on the other hand, feels as if she's given all she can to her mother, and she's happy with that knowledge.

Michel remembers the time when her mother was in a coma for some days. The daughter worried that her mother might not recognize her when she returned to consciousness. But, as always, Therese was full of motherly surprises and didn't disappoint when she woke.

“You look pale,” said Therese to her daughter. “Have you been eating?”



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