

# Caregiver Burden and Mental Health: Millennial Caregivers

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## Article

### Abstract

Millennials are the next generation of caregivers in the United States, with unique qualities disparate from prior generations. The group is more racially and ethnically distinct, with gender differences varying by race and ethnicity. Research has shown that caregivers of those with mental illness have an increased incidence of depression and anxiety. Current research suggests that targeted interventions for caregivers that promote empowerment, attention to their health concerns, and addressing financial needs can assist in decreasing the risk for adverse health effects associated with caregiving. The National Alliance for Mental Illness (NAMI) program, Family to Family (FTF), is a nationwide free 12-week educational program designed to educate and support caregivers of persons with mental illness. Programs like FTF can assist Millennial caregivers by providing peer support, increasing knowledge about caregiving, and expanding understanding of mental illness. Implications for nursing practice and future research are discussed.

**Key Words:** caregiver burden, Millennials, mental illness, mental health, depression, anxiety, National Alliance for Mental Illness, Family to Family, peer support, empowerment

When a family member is diagnosed with a mental health illness, it is the family member or close relative who customarily assumes the responsibility of providing care ([Chang et al., 2016](#)). However, the person who takes on the role of the caregiver may not be fully equipped to render the necessary care for their loved one ([Jeyagurunathan et al., 2017](#)). Caregiver burden and mental illness can impact the health of the caregiver and the future global fiduciary cost of care for those with mental illness ([Trautmann, Rehm, & Wittchen, 2016](#)).

Caring for a family member with mental illness increases the caregiver's risk of experiencing future mental health issues. Sintayehu et al. ([2015](#)) report the psychological anguish of caregivers is two times greater than the general population, putting them at a higher risk for adverse health outcomes. Research has shown that caregivers of family members with mental illness have an increased incidence of depression, anxiety, and sleep disorders ([Ae-Ngibise et al., 2015](#); [Jeyagurunathan et al., 2017](#); [ODPHP, 2016](#); [Perlick et al., 2016](#); [Sintayehu et al., 2015](#)). Current research suggests that targeted interventions for caregivers that promote empowerment, attention to their health concerns, and addressing financial needs can assist in decreasing the risk for adverse health effects associated with caregiving ([Ae-Ngibise et al., 2015](#); [Chang et al., 2016](#); [Jeyagurunathan et al., 2017](#)).

In the United States, there are roughly 25% of individuals 18 years old or older who state they are currently providing care to an incapacitated individual or one with a chronic illness ([Anderson et al., 2013](#)). The National Alliance for Caregiving ([\[NAC\], 2016](#)) reports that there are roughly 8.4 million individuals who render care to adults diagnosed with mental or emotional health issues in the United States. Interestingly, within the aggregate population statistics of caregivers in the United States, 1 in 4 belong to the Millennial generation, with 35% ages 18-24, 31% ages 25-29, and 34% ages 30-34 ([Flinn, 2018](#)). One in three, or 33% of Millennials, care for someone with an emotional or mental health issue ([Flinn, 2018](#)).

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## Caregiver Burden

Family caregiving in the home provides the essential emotional and physical sustenance required to care for individual family members living with a chronic illness (Flinn, 2018). There are approximately 40 million American adults who assume the role of caregiver. Examples of caregiving activities for family members include assistance with activities of daily living (including medical and nursing responsibilities), household duties, and financial obligations so that the care recipient can remain in their residence and community (Flinn, 2018). Millennials are the next generation of caregivers in the United States, with unique qualities different from those of other generational cohorts.

Flinn (2018) reports millennial caregivers are noted to be more racially and ethnically distinct than the other generational cohorts, with more than half identifying as Hispanic/Latino, African American/Black, or Asian American/Pacific Islander. Caregiver gender differences vary by race and ethnicity. Hispanic caregivers are mostly men (57%), whereas women caregivers are found predominantly in other ethnicities. Some of the Millennial caregivers mainly identify as being lesbian/gay/bisexual/transgender (LGBT; 20.4%) over those who do not identify themselves in that group (16.6%). Millennials are more likely to be employed full-time (73%) while caregiving, which is opposite from the other generational caregivers. More than half of Millennials perform activities of daily living and medical/nursing procedures that are complex and like tasks performed by different generations of caregivers (Flinn, 2018).

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The stigma caregivers experience may not only be aimed at their family members but also at the caregiver, resulting in the isolation of the family unit (Ae-Ngibise et al., 2015; NAC, 2016). The financial strain of working full-time, lack of needed support, and caregiver education were additional reported issues (NAC, 2016). Therefore, to sustain care recipients' health, caregivers require education and support to decrease the incidence of adverse health and financial issues associated with caregiving (Ae-Ngibise et al., 2015; Chang et al., 2016; ODPHP, 2016).

### Effects on Client and Family

From a developmental perspective, individuals aged 18-30 represent what Arnett (2013) confers as the period of emerging adulthood, where the individual is neither adolescent nor adult and experiences changes in work, love, and worldview. The age range of emerging adults (18-30 years old) is the Millennial generation, and they are more apt to face undesirable penalties at their place of employment than the older generational cohorts (Flinn, 2018). Since Millennials reported working full-time while caregiving, Flinn (2018) states that Millennial caregivers can also experience work-related problems that result from caregiving. Several areas cited include leaving early from work, arriving late to work, and decreasing the total number of hours worked.

Gupta et al. (2015) indicated that working caregivers of family members with schizophrenia reported more absenteeism, presenteeism, general impairment when in the workplace, and indirect costs compared to non-caregivers. Similar findings were reported among caregivers of Alzheimer's patients. Laks et al. (2016) indicated caregivers in this group showed greater presenteeism-associated deficiencies and global workplace impairment. While the cited studies had participants outside the 18-25-year-old range, the findings have vital implications for the younger Millennials who are emerging adults. Emerging adulthood is a time for starting or advancing careers (Arnett, 2013). Performance warnings for work attendance or work performance resulting from the additional duties of being a caregiver can jeopardize the caregiver's long-term financial security for themselves and their own families, creating additional stress and burden (Chang et al., 2017; Flinn, 2018).

### Effects on the Healthcare System

The former National Institute of Mental Health director, Thomas Insel (2015), shed light on the current and future impact of mental health issues in America and the world. Insell (2015) reports a sobering fact from the World Economic Forum (2011), which asked health economists to approximate the projected global expenditures for mental health disorders to the year 2030. Using the 2010 data, the economists' results showed mental disorders as the most significant cost driver in 2010 at \$2.5 trillion in global cost and a protracted cost of \$6 trillion by 2030. The projected global cost of mental disorders outnumbers the combination of diabetes, cancer, and respiratory disease care costs (Trautmann et al., 2017).

Interestingly, according to Vigo, Thornicroft, and Atun (2016), present methods employed to estimate mental health burden have been undervalued by more than one-third. The authors cited the undervaluation resulting from conflation, crossover, combination, and exclusion of diagnostic categories and insufficient attention to the influence severe mental illness has on mortality from related sources. Refinement of the previous method for estimating mental health burden by the authors yielded 32.4% of years lived with disability (YLDs) and 13.0% of disability-adjusted life-years (DALYs). Earlier estimates showed YLDs at 21.2% and DALYs at 7.1% (Vigo et al., 2016).

Trautmann et al. (2017) expand on this topic by elucidating the impact mental health disorders will have on the economy's growth. Mental health disorders affect both direct costs through healthcare costs and indirect costs through productivity loss due to missed work and income loss due to disability. The growth of the economy is highly dependent upon capital and labor, and mental health illness impacts both areas. Healthcare costs can significantly decrease capital and mortality, and disability can dramatically reduce labor. Downturns in both capital and labor will negatively affect the gross domestic

product (GDP). With the projected global cost of mental illness surpassing several of the highest reported non-communicable disease care costs, in addition to the staggering increase in the recalculated mental health burden percentages, it would seem logical there would be an immediate global outcry to create policies and implement funding to speak to this issue. Unfortunately, there is not. The authors suggest several reasons for the continued global apathy in not addressing the problem. Causes include the relative nature of therapeutic interventions used in treating mental health disease, public stigma, and misconceptions of mental health illness (Trauttman et al., 2017). Therefore, to avert caregivers from becoming part of the statistics of those in the future developing mental health illnesses, it is imperative to include caregivers when assessing the client to help to decrease the future cost of care for mental health illness.

### **National Alliance for Mental Illness (NAMI) Family to Family Education Program**

The National Alliance for Mental Illness (NAMI) has been steadfast in helping to improve the lives of Americans with mental illness through their goals of education, advocacy, policy, and leadership. NAMI originated in 1979 as a grassroots effort of families with loved ones who had a mental illness. The organization comprises many local and state organizations, affiliates, and volunteers who offer support and education to those with mental illness and their families.

Corporate and foundation sponsors provide public awareness and financial support to assist the sustainability of NAMI and include Aetna, Anthem, Bristol-Meyers Squibb, Magellan Cares Foundation, and Kaiser Permanente and Lilly (NAMI, 2018). Stigma-free companies and brand partners include AOL, Kenneth Cole, Philosophy, Yahoo, Google, and Women's Health (NAMI, 2018). Influencer ambassadors are individuals from the sports, television, music, and movie industries who help educate, advocate, and fundraise for NAMI, including Utkarsh Ambekar, Mayim Bialik, and Brooke Johnson (NAMI, 2018). Finally, community partners are national organizations committed to NAMI in assisting them to raise awareness of mental health issues and raise funds for mental health efforts in communities across the United States. Examples include the National Institute of Mental Health (NIMH) and the Substance Abuse and Mental Health Services Administrations (SAMHSA) (NAMI, 2018).

NAMI Family to Family (FTF) is a nationwide free 12-week educational program designed to educate and support caregivers who are family, significant others, or friends of persons with severe mental illness. FTF is offered year-round. The program consists of trained volunteers who teach the curriculum using interactive exercises, discussions, and presentations.

Participants learn to problem-solve, handle crises, and utilize effective communication techniques in a group setting. Stress management and the importance of self-care are stressed. Exercises are implemented to promote confidence and stamina development by providing support with compassion. Instructors also share how mental illness influences the family. Resources include locating and using community supports and services. Individuals are also given evidence-based information on mental health conditions and their effects on the brain. Additionally, current evidence-based therapies, medications, and side effects are discussed. (NAMI, 2018).

### **Evidence Supporting Family-to-Family**

Lucksted et al. (2013) prospective, randomized control trial (RCT) examined to see if participants who completed the 12-week FTF program experienced less distress, increased family functioning, and increased coping and empowerment at baseline (end of program), 3-month and 9-month time points. Of the 158 participants, results indicated that the program's benefits lasted at least six months after completion without additional assistance from FTF. Lucksted et al. reported higher participant attendance in group classes correlated to the increased empowerment of participants. It decreased displeasure by participants with the care recipient and concluded that sustained benefits of attending the program resulted from peer group membership. Limitations noted were of the 158 participants, 17% were lost to follow-up at the 3-month time point; 26% of participants were lost at the 9-month time point; and the control group was not evaluated at the 6-month time point, so data from participants in the program could not be compared to the control group at that time point. Community health implications include broad accessibility of the free program and support and education facilitated by trained family members to family members (significant others or friends) who are caregivers. Member-to-member support can provide a renewable resource and sustainability of the program by recruiting current participants to become future-trained family members to teach in the program. The study's findings indicate the knowledge, skills, and attitudes learned from completing the course are helpful and can be translated over time.

A study conducted by Marcus et al. (2013) examined whether the effectiveness of the RCT outcomes from the FTF program was generalizable for participants who consented to be in the FTF program but did not consent to the RCT. The study reports that the effects noted by the RCT (Lucksted et al., 2013) were generalizable to participants declining to be participants in the RCT but who completed the FTF program. Findings support additional evidence of the program's effectiveness (Marcus et al., 2013).

Smith et al. (2014) examined race-related difficulties in caregiving encounters and looked at coping abilities and relations with mental health service systems. The 293 participants comprised 107 Caucasians and 107 African Americans seeking to join NAMI's FTF education program. There were no other races listed as participants in the study. The cross-sectional descriptive design yielded the following results: African American participants reported more significant ability to problem solve than Caucasians in advocacy and community involvement and denial in the form of religious coping. African Americans also had more negative experiences in their caregiving than Caucasians, reported greater difficulties navigating the mental health service systems, and expressed having less knowledge about mental illness. Limitations of the study included the following: sample participants were already members of NAMI and recruited from a Mid-Atlantic State in suburban and urban areas, reducing the generalizability of findings to other geographical locations and settings. Caucasian families recruited for the study lived in suburban areas, compared to African American families who resided in urban areas. Smith et al. suggested this might have influenced accessibility to mental health service systems. As members of NAMI, all participants were availed of community resources for treatment and health care provider services.

Finally, Toohey et al.'s (2016) RCT examined the impact of FTF on caregivers' assessment of their caregiving experience. The study was conducted in Baltimore, Maryland, and included five surrounding counties. It was based on the stress appraisal framework, central to the program's curriculum. The framework is a dynamic triad consisting of present stressors, the individual's appraisal of stressors, and the individual's coping resources in response to stressors. While caregivers may have a decreased capacity to lessen the objective incumbrances related to caregiving, Toohey et al. report that participation in FTF may change how the caregiver views the stressors, which can optimize their coping resources and decrease their distress level. The authors posited involvement in the program would raise positive assessments (positive experiences of caregiving) without reducing negative estimates (perceived stigma and losses related to caregiving). Their findings showed an increase in positive appraisals without change to negative ones compared to the control group. The study had limitations, which decreased generalizability. The pooled sample was recruited from one geographic area, with most participants being Caucasian, college-educated, and reporting above-average income levels.

While FTF has successfully empowered participants and provided education and support through psychoeducational and behavioral family therapies, there are additional limitations. First, Smith et al. (2013) was the only study where participants showed a modicum of diversity in the sample but did not include races other than Caucasian and African American. Millennial caregivers are incredibly diverse, ethnically and culturally. Therefore, additional studies must be designed with a methodology that speaks to their diversity.

Research has shown caregivers have an increased risk for depression, anxiety, and sleep disorders (Ae-Ngibise et al., 2015; Jeyagurunathan et al., 2017; ODPHP, 2016; Sintayehu et al., 2015), yet Perlick et al., (2016), contend that while FTF has shown to have a sustained positive effect for participants, neither their Behavioral Family Therapy nor their Family Psychoeducational programs have demonstrated a decrease in caregiver depression. Finally, none of the studies regarding FTF produced evidence to suggest the program impacted caregiver productivity at the workplace. With the projected global cost of mental health issues forecasted to be in the trillions and Millennials just entering the workforce, it would be interesting to see a prospective study emerge that examined if the program produced an effect in that domain.

### Resources for Family-To-Family

The FTF program is available in all 50 states. Several states offer a Spanish program called De Familia a Familia de NAMI (NAMI, 2018). NAMI provides multiple resources to members regarding treatment and finding healthcare providers in the community, increasing access to the mental health service system. Besides the caregiver program, the NAMI website offers additional resources. Examples include support for diverse communities (African American and Hispanic) in finding providers who are sensitive to the barriers faced among these cultures (increased stigma, decreased access to care, inadequate resources, and bias). NAMI also provides support and resources for LGBT youth and adults with mental illness. They offer hotlines and confidential text chats for suicide prevention, programs for LGBT youth/adolescents, and multiple online resources to find LGBT providers and counselors. NAMI also offers educational information and other websites for mental health resources for veterans, active-duty members, and their families (National Alliance for Mental Health, 2018).

Individuals must access NAMI's resources using a computer or smartphone device with Wi-Fi. The individual would also need to be proficient in reading, writing, and speaking English (the website is only in English). Additional impediments to accessing NAMI's resources are the availability and number of providers on the listserv that are near the individual's residence, the number of offered FTF programs near the individual's home, and the means of transportation (or the individual's lack of) to get to and participate in the FTF program. Lack of technology access was broached in a recent phone conversation with Pat Kakstis, PMHNP, RN, a mental health practitioner at a free health clinic for the uninsured. When the author asked what happens if individuals have no access to technology, Ms. Kakstis replied that in the past, she had given the phone number of FTF to patients who were caregivers to family members with mental illness after identifying their need and if technology access was an issue. She reported that NAMI's FTF is a widely known program among mental health care providers, and referral to the program is often done this way (P. Kakstis, personal communication, June 13, 2018).



## Caregivers and Barriers to change

One of the most significant barriers to change for caregivers is changing their self-care behavior. Caregivers believe they must do everything for the care recipient, thinking they can do it all, becoming selfless and "numbed out" over the daily issues faced in caregiving (Schempp, 2010). Also, acknowledging a change in the individual's role to "caregiver" from their previous role as daughter, son, or other family member is a barrier to recognizing when help is needed. How did the person come to assume the caregiver role? Was the person tossed into the position by default, or was it something that was discussed with family members ahead of time?

Other barriers include education, isolation, stigma, and financial issues. Millennials report getting most of their information from friends, family, and web sources (Flinn, 2018). While Millennials are consumers of some types of caregiving material, they are less likely to get information on caregiving and the care recipient's condition from a medical provider. Therefore, web sources must be evidence-based, clear and concise, and written in languages other than English to provide correct information and education (Flinn, 2018). Millennials also report desiring additional information beyond what they already know about caregiving or the care recipient's condition (Flinn, 2018). Their requisite for increased knowledge portends the need for more multicultural education sources as the number of Millennial caregivers increases (Flinn, 2018).

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Identifying the various support resources available for the caregiver is essential so caregivers can connect with others while caregiving. Knowing how and when to set limits, ask for help, and set time for oneself are equally crucial for promoting caregiver health. Stigma related to mental health (the care recipient) and the caregiver (family) can also be a barrier concerning isolation. Mental illness awareness has developed dramatically in recent times, yet the stigma related to mental illness ensues. Flinn (2018) contends that as cultural mores associated with psychological health continue to evolve, the future mores could impact how Millennials care for a family member with mental illness (Flinn, 2018). Interestingly, Flinn (2018) posits that if the current trend of Millennials being single continues, there could be a change from the typical family structure that can create further issues for Millennial caregivers. The difference could create a deficit of caregivers to provide care and support for individuals with mental illness in the future, as well as decrease the number of available people to rely on to provide care and support to the caregiver.

## Conclusion

Millennials are a racially and ethnically diverse population of caregivers who render care to individuals with emotional or mental health disorders. Millennial caregivers report working full-time (Flinn, 2018) while caregiving and risk the same health problems and financial issues as older generational caregivers. The data presented reflects the importance of assessing, providing support services, and educating caregivers who care for individuals with mental illness.

Recommendations include nurse practitioners prioritizing behavioral and mental health assessments for patients and caregivers, educating caregivers, and promoting public awareness campaigns to decrease stigma and create opportunities for parity in access to mental health services. Programs such as NAMI's FTF can assist Millennial caregivers by providing peer support, increasing their knowledge about issues under caregiving while expanding their understanding of the mental health illness of their loved one.

Future research studies focused on Millennials as the new generation of caregivers are warranted to examine if other health risks will emerge and to assess the impact of financial strain (career impact) while caregiving. Furthermore, creating prospective studies of the Millennial's use of programs for education and support, like FTF, to assess multicultural caregiver health over time and recipient of care outcomes (mental health state) will provide data to help to identify if the caregiver goals of Healthy People 2020 and beyond are met. The findings from future prospective studies can also help to determine if the educational program's outcomes produce a change in the magnitude and directionality related to the cost and burden of care for mental health disorders.

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