PURE insights
A publication of the Program for Undergraduate Research Experiences at Western Oregon University

Informal Caregiving Experiences: Challenges and Opportunities for an Age-Friendly University

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The growing Age-Friendly University (AFU) global network has been helping its members assess their institutions and identify action items for increasing age-friendliness. This research investigates one of the issues identified through previous assessment of an AFU as a weakness and area of opportunity, which is the lack of resources and information for campus community members who identify as informal or unpaid family caregivers. Data from *N* = 72 campus members (26% faculty, 15% staff, 52% students; 84% female, 16% male) were collected in early 2023 through a campus-wide online survey and analyzed by a team of researchers using quantitative analysis for responses to Likert-type items and thematic analysis for open-ended responses. Issues around physical demands, time demands, financial stress, and social and emotional health while caregiving were assessed. Results indicated that respondents are experiencing different types of stress and need additional support and resources as caregivers, particularly related to respite care, mental health services, financial support, and assistance with physical tasks such as housework and transportation. The findings from this research will be used to develop and share resources around caregiving broadly across the university campus, and to ensure that resources are culturally inclusive, particularly as nearly 25% of the enrollment of undergraduate full-time equivalent students is composed of students from a Hispanic/Latinx background. Findings will also be used to establish community partnerships to harness resources from outside the university, and ultimately to help support the campus community moving forward and to achieve a piece of the university's AFU vision.

Keywords: Informal caregiving; age-friendly university; caregiving resources; survey research

Since 2012, the Age-Friendly University (AFU) global network has been helping its members assess their institutions and identify action items for increasing age-friendliness. The designation of an AFU means that a university is "committed to promoting positive and healthy aging and enhancing the lives of older members of the global community through innovative educational programs, research agendas, curriculum development, online education, health and wellness activities, arts and culture programs and civic engagement opportunities" (AFU, 2023, para. 1). [Blinded for Review] University, a regional public university in [BFR], joined this network in 2019 upon receiving full support from administrators and faculty. University faculty from the Gerontology Department have since been assessing the university in terms of its strengths and areas for improvement for achieving its AFU vision. One of the findings discovered from the "Age-Friendly University Campus Report" (Silverstein et al., 2021) was that BFRU was lacking resources and information for campus community members who identify as informal or unpaid family caregivers. This finding became the central focus for the research described below, which involved surveying students, staff, and faculty on the prevalence and needs of informal caregivers across campus, with the goal of helping to achieve a piece of the AFU vision for BFRU.

INFORMAL CAREGIVING CONCERNS

Informal caregivers, also known as unpaid caregivers or family caregivers (families of kin or of choice) are considered the backbone of long-term care in the U.S. with an estimated 53 million having provided care to an adult or child with special needs at some time in the past 12 months. This includes an estimated 14.1 million caregivers of recipients ages 0-17, 6.1 million caregivers of recipients ages 18-49, and 41.8 million caregivers of recipients ages 50 and above. An increasing proportion of caregivers of adults are providing care to multiple people, with 24% caring for two or more recipients (in 2020, up from 18% in 2015) and are increasingly providing care for five years or longer (The National Alliance for Caregiving [NAC] and AARP, 2020, p. 4).

Several factors are contributing to increases in the numbers of informal caregivers. These include the aging of the large Baby Boomer population; limitations of formal support systems of care; efforts to facilitate aging in place with more home-and community-based services; and increases in those who self-identify themselves as caregivers (NAC and AARP, 2020). Previous research demonstrates that while many caregivers report that caregiving provides a sense of purpose or meaning (NAC and AARP, 2020; NORC, 2014), they also increasingly report being in fair or poor health, finding it difficult to take care of their own health, and that caregiving has made their own health worse (NAC and AARP, 2020). Especially during the COVID-19 pandemic, caregivers were disproportionately affected by financial stress, worry about their care recipient's health, lack of access to respite care, social isolation, and missing health care appointments (NAC, 2023; NORC, n.d.).

Currently, 17% of caregivers in the U.S. report being Hispanic or Latino (NAC and AARP, 2020, p. 5). Previous studies have shown that Hispanic/Latinx families rely on informal support networks more than formal support and that social support and caregiving extend broadly across social networks within these communities (Aranda & Miranda, 1997; Commonwealth Fund Commission, 1989; Cruz & Le, 2021). Hispanic/Latinx caregivers may be influenced by cultural values such as familism (i.e., the needs of the familyare greater than the individual) and may not realize they are or identify themselves as caregivers (Cruz & Le, 2021). Previous research indicates that Hispanic/Latinx caregivers experience higher task difficulties, less formal training, and discrimination from healthcare services (AARP, 2012; Cruz & Le, 2021). Over half of Hispanic/Latinx caregivers are the sole caregivers of their loved ones and report having difficulties with healthcare tasks such as medication management and wound care, while over one third report being isolated and experiencing emotional and physical strain due to caregiving (Cruz & Le, 2021). These issues were identified as of particular importance for this study, as BFRU is expected to achieve "Hispanic-Serving Institution" status in the next year, meaning that 25% of the enrollment of undergraduate full-time equivalent students is composed of students from a Hispanic/Latinx background (U.S. Department of Education, 2023).

The primary objectives for this study are to 1) describe the prevalence and needs of caregivers at BFRU, which joined the AFU network in 2019, and has an increasingly diverse student population; and 2) discuss inclusive opportunities for developing and sharing resources for informal caregivers which will help to improve one area of an AFU institution's age-friendliness.

METHODS

This study used a multi-method design that included analyzing both quantitative and qualitative data collected from a campus-wide survey of students, staff, and faculty at BFRU. Data were collected across two weeks in early 2023 using an online survey administered through Qualtrics. Campus members were notified of the survey with a campus-wide email sent from the university's Provost in order to catch the attention of the target population. They also learned about the survey from students who set up a table in the foyer of the university center on National Caregivers Day.

The survey was designed based on existing scales such as the caregiver burden scale and the caregiver reaction assessment. It included a set of questions asking respondents to describe their caregiving responsibilities, Likert-type items asking about their caregiving burdens and needs, and open-ended questions asking respondents to describe resources they have used and resources they would find helpful as caregivers. The survey was created using Qualtrics software and tested out multiple times before distributing. It could be completed in 10-15 minutes on a phone, tablet, or computer. A gift basket drawing was included as an incentive for participants to complete the survey.

Survey data were analyzed by a team of researchers using quantitative data analysis for responses to Likert-type items and thematic analysis for open-ended responses. For the quantitative data analysis, four categories were created to encompass the statements in the Likert scale: physical needs, mental needs, social needs, and financial needs. Individual scores were calculated for each participant within each of the four categories by calculating the mean of the scores given in the questions listed above. This calculated a 1-5 numerical score for the categories of each respondent. After calculating the mean scores, the numerical data were then transferred to ordinal data using a computational average. To compute the correlational values of each categorical variable against each other, the team used Spearman's Rho calculated in SPSS. For the qualitative data, the team used thematic analysis and followed the typical six step process: 1) familiarization; 2) coding (which entailed developing a coding frame and applied it systematically to the data (O'Connor & Joffe, 2020); 3) generating themes; 4) reviewing themes; 5) defining and naming themes; and 6) reporting (Braun & Clarke, 2006). The research team worked closely together throughout each step (e.g., reviewed the themes represented in the data, confirming themes and sub-themes, and discarding any that they would ultimately not consider themes). This ensured that throughout each step, a high level of agreement was reached among team members.

RESULTS

Demographics of respondents (N=62) included a majority identifying as female (84%), aged between 26 and 45 years (54.8%), White (85.5%), and students (51.6%), with 11.3% of respondents identifying as Hispanic/Latinx. Table 1 includes more details of sample characteristics. In total, 28 respondents answered "yes" to "Do you currently have an adult(s) over the age of 60 in your life who is dependent on you for certain needs, including care (such as physical, financial, live-in assistance)?" and 56 respondents answered "yes" to "Do you currently have a child/children or adult(s) (under the age of 60) in your life who is dependent on you for certain needs, including care (such as physical, financial, live-in assistance)?"

Of the stressors that respondents indicated having, "physical needs" had the highest agreement (i.e., exceeding what the caregiver believes they can do themselves) over any other stressor (M=1.957, with 64.3% of respondents agreeing or somewhat agreeing). Spearman's Rho data analysis revealed: physical needs significantly correlated with mental needs (r(70) = .514, p = .001), financial needs (r(70) = .361, p = .01), and social needs (r(70) = .477, p = .01); mental needs significantly correlated with financial needs (r(70) = .717, p = .01) and social needs (r(70) = .735, p = .01); and financial needs significantly correlated with social needs (r(70) = .475, p = .01).

Table 1. Sociodemographic characteristics of the participant sample (N=62)*

Characteristic	**%**
Age	
18-25	17.7
26-35	29.0
36-45	25.8
46-55	17.7
56-65	6.5
65+	3.2
Gender	
Male	16.1
Female	83.9
Race/Ethnicity (selected all that apply)	
White/Caucasian	85.5
Black/African American	0.0
Hispanic/Latino/Latina/Latinx	11.3
Asian/Asian-American	4.8
Native Hawaiian/Pacific Islander	1.6
IndigenousAmerican/American Indian/Alaskan Native	4.8
Other	6.4
University Affiliation	
Student	51.6
Faculty	25.8
Staff	14.5
Other/Student/Staff Combination	8.1
Marital Status	
Single, not married	24.2
Married	58.1
Living with partner	4.8
Separated	3.2
Divorced	8.1
Widowed	1.6

*10 of the 72 surveys were complete except for demographic information

Qualitative analysis revealed the following responsibilities as most discussed among caregivers: transportation (both arranging and providing transportation); activities of daily living (including transferring, grooming/dressing, incontinence/toileting, bathing/showering, feeding assistance); cooking/nutrition; supervision; and home maintenance.

There were some distinct differences in how caregivers of children described their responsibilities compared to how caregivers of older adults described their responsibilities. Notably, caregivers of children used the word "love" as part of their duties, which was not the case with caregivers of older adults. One individual stated, "As the sole parent of 3 children, I am responsible for [their] complete well-being, from feeding to housing to love to support with all aspects of their lives and emotional development" (F/Latina, 46-55, student, separated). They also were more likely to use "parenting duties" or "mom and dad duties," seemingly as shorthand to describe a common set of duties: "I am a parent, so some of my responsibilities include supervision, love, meeting basic needs" (F/Other, 26-35, graduate student, married); "Parenting, homeschooling, med management, emotional regulation assistance, etc." (F/Other, 36-45, student, single). Bathing/showering (or ensuring that care recipients did so) was also mentioned more frequently among this set of caregivers.

As for caregivers of older adults, responsibilities were more likely to include assistance with finances and technology (as one person shared, "internet, Wi-Fi and Bluetooth connection, captions on the TV, the smart-thermostat and smoke detectors, etc."), as well as overseeing care or advocating for care. One individual said, "My mother is disabled but has not been approved for disability through the state. She is one more fall away from being incapable of walking…I wish that she qualified for some program to help her live in an assisted living situation, but that doesn't seem to be the case, so we are making it work" (F/W, 36-45, student, married). Another shared that she was, "Overseeing her care at ALF [assisted living facility), being an advocate. Taking her to all medical appointments & interacting with physicians. Paying all her bills. Purchasing whatever supplies…support person when she is hospitalized" (F/W, 46-55, faculty, married).

Most respondents indicated that they did not know of any caregiving resources available at the university. Of those that they did know about, the most known (in order of frequency) included: Child Development Center; Food Pantry; clothing donation center; Student Health and Counseling; Center for Equity and Gender Justice; FMLA (Family and Medical Leave Act); the university's Basic Needs Coordinator; and the Gerontology program.

Respondents shared a wide variety of resources that they felt would be helpful to them. The most frequently mentioned included childcare, respite care, in-home care, and older adult care. Many of them emphasized care that is affordable, no-cost, or needing financial assistance with providing care. One individual said, "I would love to know if there was a program that would allow my disabled mother to live more independently, or a place where she could live (without income) where she could have assistance if needed" (F/W, 36-45, student, married). Another shared, "With two young children, no family nearby, and both parents in graduate school, we have few options for affordable childcare" (M/W, 46-55, student, married). Different types of supports mentioned included advocacy, support groups, mental health care, trainings, mentorship, and resource guides. For example, one respondent said "Someone to explain Medicare benefits and Social Security benefits and how to best use them. Also, how I should file taxes as a caregiver" (F/W, 26-35, faculty, married). Another shared, "A mentorship program for parent students. Someone who reaches out to me with resources, makes sure I am on track, and gives space for me to share my experience. Someone to advocate if I need accommodations due to caring for my family" (F/W, 26-35, student, married). Specific instrumental activities of daily living that were mentioned included assistance with housekeeping/cleaning and help with transportation.

DISCUSSION AND IMPLICATIONS

Results indicated that respondents are experiencing different types of stressors and need additional support and resources as caregivers, particularly related to care management, respite care, mental health services, financial support, and assistance with physical tasks such as housework and transportation. Importantly, Spearman's Rho revealed that different stressors compiled on top of each other, with stress/needs in one category correlating with stress/needs in all other categories.

There were interesting contrasts of reported responsibilities for individuals who cared for older adults compared to those who cared for children. These may reflect some of the cultural values related to familism, which involves a sense of collectivism and family attachment, often translated as obligation to provide care. Past research has indicated that African Americans and Hispanic/Latinx individuals are more likely to be guided by familism values in their caregiving role compared to Whites (Coon et al., 2004; Depp et al., 2005; Falzarano et al., 2022; McCallum et al., 2007). This could help illuminate why caregivers of children in this study reported their roles differently (i.e., duties understood as "what you do" as parents, out of love and obligation) from caregivers of older adults. This is an area that would benefit from further exploration.

There is also a need to analyze the results more regarding caregiving burden, needs, and use of resources. While the preliminary analyses indicated high levels of physical, mental/emotional, and financial stress, it would be helpful to better understand how these are connected to specific roles and responsibilities and to investigate how resources are being used among those indicating high levels of stress.

The response rate among Hispanic/Latinx members of the BFRU community was lower than anticipated. It would have beneficial to translate the survey into Spanish and ensure that it was culturally relevant. Existing caregiving resources need to be culturally inclusive, as BFRU has a diverse community including nearly 25% of the enrollment of undergraduate full-time students from a Hispanic/Latinx background. The findings from this research will be useful to develop and share additional caregiving resources in multiple languages across the university campus; these should include, at minimum, more guide/informational materials about resources that currently exist at the university and in the broader community such as respite care, support groups, and financial assistance. BFRU can work to establish more community partnerships to harness resources from outside the university and connect community members with them. Ultimately, this work will to help support the campus community moving forward and to achieve a piece of the university's AFU vision.

LIMITATIONS

A limitation of this study is that while 144 participants started taking the survey, only 72 of them completed it; of those, ten surveys were complete except for demographic information (see Table 1). This may have been due to the length or design of the survey; however, it is also common for caregivers to struggle with identifying themselves as such or see their tasks as "caregiving," so they may not have tried taking it or dropped out. Another limitation is that due to the lack of time and resources, the survey was not translated into Spanish language. Had this been done, it is possible that more participants who identify as Hispanic/Latinx would have completed the survey.

CONCLUSION

With the increasing numbers of informal caregivers in the U.S., communities need to be responsive by providing supports and resources to help with the various physical, mental, financial needs of caregivers. Universities can serve as examples for how this can be done, helping serve their goal to become more age-friendly. As populations become more diverse, it is critical to support those such as Hispanic/Latinx families who rely on informal support networks more than formal support and may have unique challenges. Supports and resources need to be available in multiple languages and culturally inclusive. Our results illuminate some of the specific responsibilities and needs of informal caregivers who are part of the university community, and how informal caregivers, even those part of the larger community, can be better supported.

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