2022 ARKANSAS CAREGIVER FEEDBACK

Preliminary Data Report

Abstract

The last time Arkansas conducted a state specific survey on caregivers and respite care was in 2017. Since that time, caregiving responsibilities have increased in the state while respite supports have remained stagnant. The purpose of this study was to provide Arkansas caregivers a platform to provide input and feedback into a caregiver's environment and their overall understanding of respite supports available to them, while collecting preliminary demographic and quantitative data to determine future activities and services to reduce caregiver stress and promote caregiver overall health.

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Overview

The Arkansas Lifespan Respite Care Program is slightly above grassroots level. While there is currently no state funding for this program, previous federal grant awards have allowed the Arkansas Department of Human Services ("DHS") to build a volunteer-based coalition comprised of respite providers and advocacy groups statewide. Additionally, that same federal funding provides voucher opportunities to caregivers, provides Arkansans with volunteer respite training, and conducts small-scale awareness/outreach events, including annual Lifespan Respite Awareness Days at Arkansas's State Capitol. A Lifespan Respite webpage maintained by DHS provides information to the public.

The program's vision is to enhance current grassroot, person-centered style activities directing service provisions, easing burdens in finding respite availability, and continuing to build collaborations and partnerships to strengthen our current respite status. Lifespan respite is also developing a sustainability framework to ensure long-term respite needs are met and supports for caregivers across Arkansas continue.

One of the most vital talking points, when it comes to understanding respite needs and service gaps in the state of Arkansas, is the demographic and census data on caregivers in the state. There are several reports and articles regarding caregiving and caregiver status on a national scale; however, Arkansas has never done a full independent state analysis. During 2017, the Arkansas Lifespan Respite Coalition did conduct a caregiver feedback survey. That survey contained five (5) basic questions to gauge whether the respondent was a caregiver and if the caregiver needed or had received a break/respite in the past. The survey was conducted online through SurveyMonkey, but no documentation can be found on survey methodology or how a target population was identified.

Feedback from the 2017 survey resulted in 574 respondents from 47 counties in Arkansas. Of those respondents, 76.56% (n= 428) indicated they were caregivers. Of those 574 total respondents, 67.60% (n=388) indicated they needed a break from caregiving. When respondents were asked if they had ever received a break, just 36.99% (n=209) indicated they had. When asked if they had ever received respite, just 23.34% (n=134) indicated they had. Furthermore, only 40.77% (n=234) knew what "respite" was. An enhanced feedback survey was created in 2018; however, no evidence or documentation has been found of its release. It is uncertain if data was ever collected beyond the 2017 basic survey. Additionally, a legislative study on the respite needs and service gaps in Arkansas was proposed during Arkansas State Legislative 92nd General Assembly Regular Session in 2019 but was never completed.

DHS's Division of Provider Services and Quality Assurance (DPSQA) was awarded a five (5) year federal grant through the Administration for Community Living (ACL) beginning July 1, 2021, through June 30, 2026, known as the Lifespan Respite Integrity and Sustainability Grant (#90LRLI0045). Within the award, DPSQA identified $40,000 in the first grant year (July 2021- June 2022) which could be used to conduct a statewide independent study on caregiver statistics and data analysis; however, there was difficulty in procuring an independent contractor to take on such a task when key data elements needed to be determined. At that time, the program decided to begin the data analysis with a preliminary data collection to 1) determine where to provide intense focus of marketing and informational outreach, 2) determine geographically where to hold small scale focus groups, workshops, and volunteer respite trainings, and 3) update infographics and other educational material. Scheduled grant activities will also include follow-up data collection and analysis in year 5 of the grant (July 2025-June 2026) on progress made through other grant activities.

The following report is based on preliminary data and statistics taken from a 2022 online survey produced by DPSQA.

Methodology

The survey pool was selected from recipients with open cases in 21 Medicaid categories administered by the DHS. To reach as many participants as possible, a report was run from the DHS ARIES Eligibility System with a list of all potential respondents. An initial report of 300,251 individuals were then sorted for duplications and email availability.

Based on the large quantity of email addresses available, DHS chose to use the survey services of SurveyMonkey to send the survey to potential respondents. This would provide quick access to data and eliminate the cost of postage, paper printing, and the need for hand tallying, which would increase the risk for human error. Survey questions were then developed to allow for responses of yes or no, multiple choice, or sliding scale so data could be exported easily into an Excel format.

The online survey was opened to the targeted population on February 24, 2022, and closed on March 11, 2022; a period of 16 calendar days. The population was notified of the online survey via email notification sent from DHS's mass notification system, Salesforce. The email was successfully delivered to 61,070 of the 64,943 available and unduplicated email addresses: a delivery rate of 94%. Upon closure of the targeted survey on March 11, 2022, the email had been opened by 23,463 individuals: 38.42% of those successfully delivered.

To qualify for the survey, respondents had to be 18 year or older and self-identify as someone who had provided unpaid care to someone. This unpaid care must involve helping the individual care for themselves, or caring for a child (minor, less than 18 years of age) due to a medical, behavioral, or other condition or disability (beyond required normal care.) Of the 23,463 successfully delivered emails, 553 identified as caregivers; this report examines their responses.

Study Limitations

It is important to consider the limitations in the data collected when navigating this report. The total respondents make up less than one percent (0.25%) of Arkansas's total population census as defined in 2021 (3,025,891) and less than one percent (0.33%) of Arkansans 18 years or older.

A study conducted in 2005 by the National Alliance for Caregiving indicated that at least 1.3 million youth caregivers between the ages of 8 and 18 are providing care for an ill or disabled parents or other individual in the United States.[1] The study conducted here did not consider any potential caregiver who may be under 18 years of age, in the State of Arkansas. Future data collection should allow respondents to enter exact numbers for ages to allow for analysis and comparison to national data sub-groups.

Additionally, the survey pool was comprised of individuals who have applied through DHS for some service or assistance in the past; therefore, it does not account for respondents that have never interacted with DHS.

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[1] National Alliance for Caregiving. Young Caregivers in the U.S.: Report of Findings September 2005, 2005. https://www.caregiving.org/wp-content/uploads/2020/05/youngcaregivers.pdf

Reading This Report

All demographic information provided by respondents is based on caregiving activities that had taken place within the last 12 months from the date of response.

The sample sizes (n) noted in each table or graphic represent the unweighted number of responses who answered the question. All reported results shown are weighted and rounded to the nearest whole number. Note that "don't know", "n/a" and "prefer not to answer" responses are not always represented in the charts and tables; therefore, some charts and tables will not total 100 percent. The results for multi-response questions may total more than 100 percent, as respondents were allowed to choose more than one category, if applicable.

Data derived from this survey was compared to three national data reports: a 2004 report from the National Alliance for Caregiving (NAC) and AARP titled *Caregiving in the United States*[2] and two follow-up reports titled *Caregiving in the United States 2015*[3] and *Caregiving in the United States 2020*.[4] Data from these three national reports will be referred to within the findings of this state report as "2004 National Data," "2015 National Data," and "2020 National Data" respectively.

Findings

Basics of Caregiving Situation

Of the 769 individuals who were screened in the online survey, the proportion of initial respondents who stated they are or have been a caregiver in the last 12 months, was 72% (n=553). One hundred twenty-five (125) of those identified caregivers failed to complete the remainder of the survey; therefore, data information will be provided based on those identified caregivers who completed the full survey (n=428).

Age, Gender, Race/Ethnicity of the Caregiver

Approximately 86% of caregiver respondents were female (n=368), while 12% identified as male (n=52), and less than 1% percent identified as non-binary (n=3). Caregivers ranging from 35 years of age to 54 years of age make up nearly half of the total respondents (48%, n=207). This data is comparable to 2020 National Data, which indicated that three (3) in five (5) caregivers are female (61%) and the average caregiver age is 49.4 years old in the United States.

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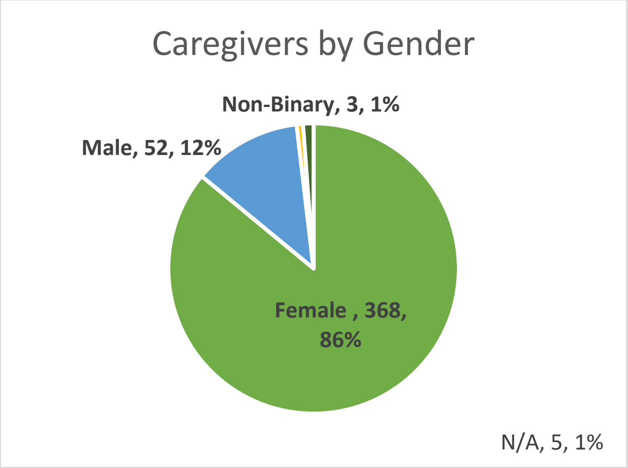
[2] AARP and National Alliance for Caregiving. *Caring in the United States.* Washington, DC: AARP. April 2004. https://assets.aarp.org/rgcenter/il/us_caregiving.pdf

[3] AARP and National Alliance for Caregiving. *Caregiving in the United States 2015.* Washington, DC: AARP. June 2015. https://www.aarp.org/content/dam/aarp/ppi/2015/caregiving-in-the-united-states-2015-executive-summary-revised.pdf

[4] AARP and National Alliance for Caregiving. *Caregiving in the United States 2020*. Washington, DC: AARP. May 2020. https://doi.org/10.26419/ppi.00103.001

Figure 1- Caregiver Gender



Care recipients were equally divided between male and female at 44 percent (n=188 equally), while less than one percent identify as non-binary (n=3).

More than three (3) out of every four (4) caregiver respondents identified as White/Caucasian (76%, n=327), 14% identified as Black/African American (n=58), and 2% identified as either American Indian/Alaska Native (n=9) or Hispanic/Latino (n=7). This data appears to also be comparable with 2020 National Data, except for Hispanic/Latino. Approximately 61 percent of respondents identify as White/Caucasian while 17% are Hispanic/Latino, 14% Black/African American, and 5% Asian American and Pacific Islander, according to 2020 National Data. Three percent of 2020 National Data indicate multi-racial ethnicity.

Figure 2- Caregiver Age/Ethnicity (State vs. National)

Age	**Arkansas**	**National (2020 Data)**
18 years to 34 years	18%	24%
35 years to 54 years	48%	23% *
55 years to 64 years	18%	35% *
64 years and older	15%	19% *
**National data age ranges vary from state data. National defines age ranges as defined: 18-34 years; 35-49 years ; 50-64 years; 65-74 years; 75+ years*		
Race/Ethnicity	**Arkansas**	**National (2020 Data)**
White/Caucasian	76%	61%
Black/African American	14%	14%
Hispanic/Latino	2%	17%
American Indian/Alaska Native	2%	-
Asian/Pacific Islander	1%	5%
Multi-ethnicity	3%	3%
**State data results are rounded and prefer to not answer responses are not shown; results may not add to 100 percent.*		

Caregiver Military Status

Of the 428 caregiver responses, roughly 4% indicated they had a military background (n=16), with one respondent indicating they are currently serving (0.23%, n=1).

Alzheimer's and Dementia

Thirteen Percent (13%) of caregivers indicated the care recipient has been diagnosed with Alzheimer's or other dementia related diseases (n=56). Fifty-one (51) respondents indicated Alzheimer's or dementia as a primary diagnosis while the remaining 5 respondents indicated it was an additional diagnosis for the care recipient. Three (3) out of every 10 caregivers caring for someone with Alzheimer's or another dementia related illness were 65 years or older (30%, n=17) and almost four (4) out of 10 caregivers were aged 35 years to 54 years (39%, n=22). Caregivers ranging from 18 years to 34 years made up 13% (n=7), while caregivers 55 years to 64 years old made up roughly 18 % (n=10).

Caregivers for Alzheimer's and dementia diagnoses care recipients identified as majority White/Caucasian (79%, n=44). Black/African American accounted for 14% (n=8), American Indian/Alaska Native for 2% (n=1), while the other 2% indicated ethic identity with two (2) or more options (n=1).

Additionally, nine (9) out of 10 caregivers in this group identified as female (91%, n=51) and 5% as male (n=3). One respondent identified as non-binary.

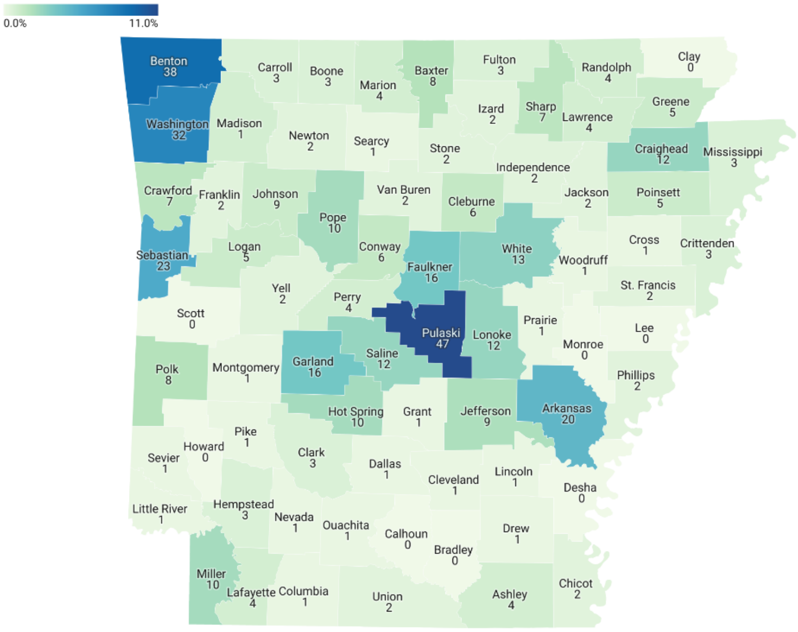
Geographic Demographics

Of the 75 counties within the State of Arkansas, 67 counties (89%) were represented in the survey participation. Percentages indicate the percent of survey respondents living in that county, and the number of individual responses for that county, out of the total survey respondents (n=428).

Figure 3- Where Caregiver Resides (by County)

Arkansas (4.67%, 20)	Ashley (0.93%, 4)	Baxter (1.87%, 8)	Benton (8.88%, 38)
Boone (0.70%, 3)	Carroll (0.70%, 3)	Chicot (0.47%, 2)	Clark (0.70%, 3)
Cleburne (1.40%, 6)	Cleveland (0.23%, 1)	Columbia (0.23%, 1)	Conway (1.40%, 6)
Craighead (2.80%, 12)	Crawford (1.64%, 7)	Crittenden (0.70%, 3)	Cross (0.23%, 1)
Dallas (0.23%, 1)	Drew (0.23%, 1)	Faulkner (3.74%, 16)	Franklin (0.47%, 2)
Fulton (0.70%, 3)	Garland (3.74%, 16)	Grant (0.23%, 1)	Greene (1.17%, 5)
Hempstead (0.70%, 3)	Hot Spring (2.34%, 10)	Independence (0.47%, 2)	Izard (0.47%, 2)
Jackson (0.47%, 2)	Jefferson (2.10%, 9)	Johnson (1.17%, 5)	Lafayette (0.93%, 4)
Lawrence (0.93%, 4)	Lincoln (0.23%, 1)	Little River (0.23%, 1)	Logan (1.17%, 5)
Lonoke (2.80%, 12)	Madison (0.93%, 1)	Marion (0.93%, 4)	Miller (2.34%, 10)
Mississippi (0.70%, 3)	Montgomery (0.23%, 1)	Nevada (0.23%, 1)	Newton (0.47%, 2)
Ouachita (0.23%, 1)	Perry (0.93%, 4)	Phillips (0.47%, 2)	Pike (0.23%, 1)
Poinsett (1.17%, 5)	Polk (1.87%, 8)	Pope (2.34%, 10)	Prairie (.23%, 1)
Pulaski (10.98%, 47)	Randolph (0.93%, 4)	Saline (2.80%, 12)	Searcy (0.23%, 1)
Sebastian (5.37%, 23)	Sevier (0.23%, 1)	Sharp (1.64%, 7)	St. Francis (0.47%, 2)
Stone (0.47%, 2)	Union (0.47%, 2)	Van Buren (0.47%, 2)	Washington (7.48%, 32)
White (3.04%, 13)	Woodruff (0.23%, 1)	Yell (0.47%, 2)	

Figure 4- Caregiver Residential Map (by County)



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In 2013, the University of Arkansas's Division of Agriculture identified three (3) rural regions within the state.[5] Those three regions included the Coastal Plains, the Delta, and the Highlands. Of the 428 responses received on the survey, nearly half (47%, n=191) reside in one of the three rural regions. The Coastal Plains counties account for 4% of the total respondents. The Delta counties account for 11% of the total respondents. The Highlands counties account for 30% of the total respondents. The remaining 55% of respondents did not live in an identified rural county or region.

Figure 5- Arkansas Rural Regions

The Coastal Plains (Little River, Hempstead, Nevada, Ouachita, Calhoun, Cleveland, Drew, Bradley, Ashley, Union, Columbia, and Lafayette)	19 responses
The Delta (Clay, Greene, Mississippi, Jackson, Poinsett, Cross, Woodruff, St. Francis, Prairie, Monroe, Lee, Arkansas, Phillips, Lincoln, Desha, and Chicot)	45 responses
The Highlands (Carroll, Boone, Marion, Baxter, Fulton, Randolph, Madison, Newton, Searcy, Stone, Izard, Sharp, Lawrence, Franklin, Johnson, Pope, Van Buren, Cleburne, Independence, White, Conway, Logan, Scott, Yell, Perry, Polk, Montgomery, Sevier, Howard, Pike, Hot Spring, Grant, Clark, and Dallas)	127 responses

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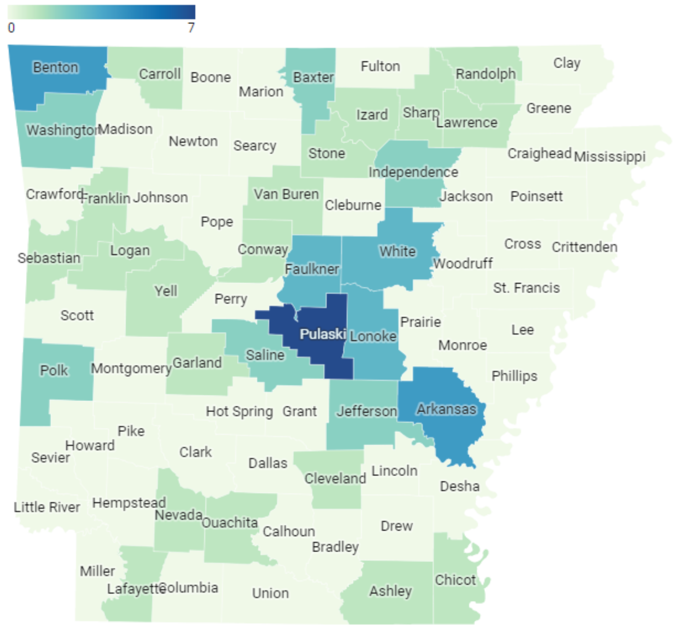
[5] University of Arkansas Division of Agriculture. *Rural Profile of Arkansas.* Arkansas: 2013. https://www.uaex.uada.edu/business-communities/economic-development/Rural%20Profile%20of%20Arkansas%202013%20Pub.pdf

Alzheimer's and Dementia

Respondents indicating an Alzheimer's or dementia diagnosis for their care recipient were identified in 32 counties with the most prevalent counties being Pulaski (13%, n=7), Arkansas (7%, n=4), and Benton (7%, n=4). Over half of caregivers identifying Alzheimer's or dementia reside in an identified rural county, as established in the geographic demographics. Thirty-one (31) caregivers within 23 rural counties indicated they are caring for someone with Alzheimer's or dementia.

Figure 6- Caregiver Rural Map (by County)



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Relationship of Caregiver to Care Recipient and Age

The average age range indicated for caregivers was 35 years to 44 years old (26%, n=112). Closely following was the age range of 45 years to 54 years (22%, n=95) and the smallest age range completing the survey was the 18 years to 24 years (3%, n=13). Age ranges for 25 years to 34 years, 55 years to 64 years, and 65 years and older came in slightly less than 20% each (15%, n=65; 18%, n=77; and 15%, n=66 respectively). For the purposes of this report, caregiver respondents will be grouped from 18 years to 34 years (n=78), 35 years to 54 years (n=207), 55 years to 64 years (n=77), and 65 and older (n=66).

An overwhelming majority of respondents indicated that the care recipient age range was 65 and older (35%, n=137). Approximately two (2) out of every 10 care recipients were aged five (5) years to 13 years (16%, n=61) while the age range of 55 years to 64 years averaged a little over one (1) out of 10 (12%, n=48). The remaining groups all indicated less than 10% of the responses in the following order: Less than 12 months (2%, n=6); 12 months to 4 years (5%, n=20); 14 years to 18 years (7%, n=29); 19 years to 24 years (5%, n=18); and 35 years to 44 years (9%, n=34). For this report, care recipients will be grouped Under 18 (30%, n=116), 19 years to 64 years (35%, n=135) and 65 years and older (35%, n=137).

Data elements indicate that older caregivers tend to be taking care of someone similar in age to themselves, while younger caregivers tend to care for the younger age range.

Figure 7- Caregiver Age in Relation to Recipient Age

Caregiver Age	**Care Recipient Age**			
	Less than 18 years (Minor)	18 years to 44 years (Adult)	45 Years to 64 Years	65 Years or Older
18 Years to 34 Years (n=78)	41% (n=32)	9% (n=7)	12% (n=9)	13% (n=10)
35 Years to 54 Years (n=207)	34% (n=71)	14% (n=28)	16% (n=33)	28% (n=57)
55 Years to 64 Years (n=77)	14% (n=11)	13% (n=10)	23% (n=18)	44% (n=34)
65 Years or Older (n=66)	3% (n=2)	12% (n=8)	8% (n=5)	55% (n=36)
Results are rounded and don't know/prefer not to answer responses are not shown; results may not add to 100 percent.				

The relationship between caregiver and care recipient leaned largely to a Parent/In-Law status (36%, n=141) with Child/In-Law following (26%, n=102). Rounding out the remaining top five relationships include Spouse/Partner (12%, n=48), Sibling (5%, n=21) and Non-Relative (4%, n=17). Non-relative includes friend, neighbor, and foster care. When comparing the care recipient's age to the caregiver relationship to that recipient, it was clear that some respondents misinterpreted the question of "What is your relationship with this person?". Based on the total data, it appears that some respondents answered this as to who they are in relation to the care recipient, while others answered as to who the care recipient is in relation to them (the caregiver). This is evident in the fact that 41 respondents indicated they were a child or child in-law to their care recipient identified as less than 18 years of age; therefore, further clarity will be required with this question in future data collection activities to ensure relational direction is accurate.

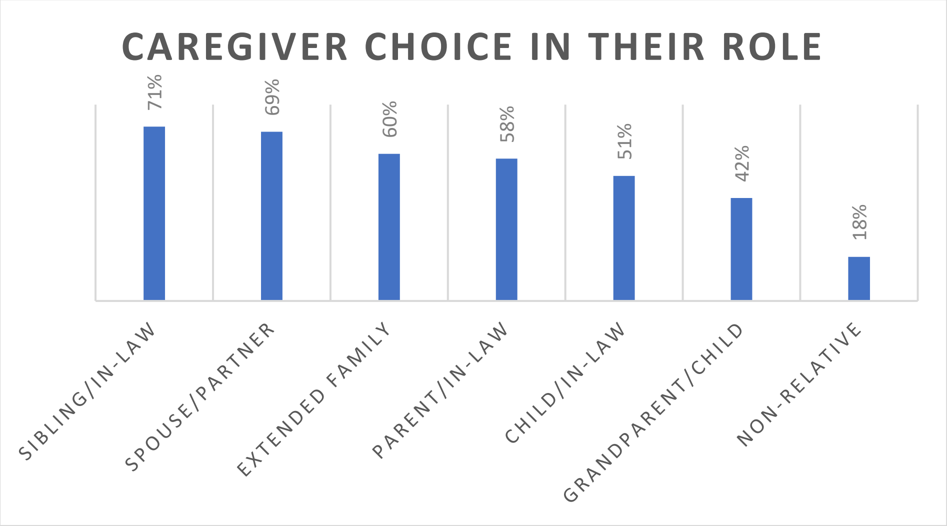
Figure 8- Caregiver Relationship in Relation to Care Recipient Age

Caregiver Relationship to the Care Recipient	**Care Recipient Age**			
	Less than 18 Years	18 Years to 44 Years	45 Years to 64 Years	65 Years or Older
Parent/In-Law (n=141)	38% (n=53)	14% (n=20)	12% (n=17)	36% (n=51)*
Child/In-Law (n=102)	40% (n=41)*	14% (n=14)	14% (n=14)	33% (n=34)
Spouse/Partner (n=48)	2% (n=1)*	17% (n=8)	56% (n=27)	25% (n=12)
Sibling/In-Law (n=21)	10% (n=2)	14% (n=3)	43% (n=9)	33% (n=7)
Non-Relative (n=17)	12% (n=2)	18% (n=3)	35% (n=6)	35% (n=6)

**Indicates data found to have potential misinterpretations*

When asked if the caregiver felt they had a choice in whether they took on their caregiver role, the percentage of caregivers directly related or married to the care recipient far exceeded the percentage of those non-related caregivers who felt they did not have a choice.

Figure 9- Taking on Caregiver Role within Relationship Status



Alzheimer's/Dementia

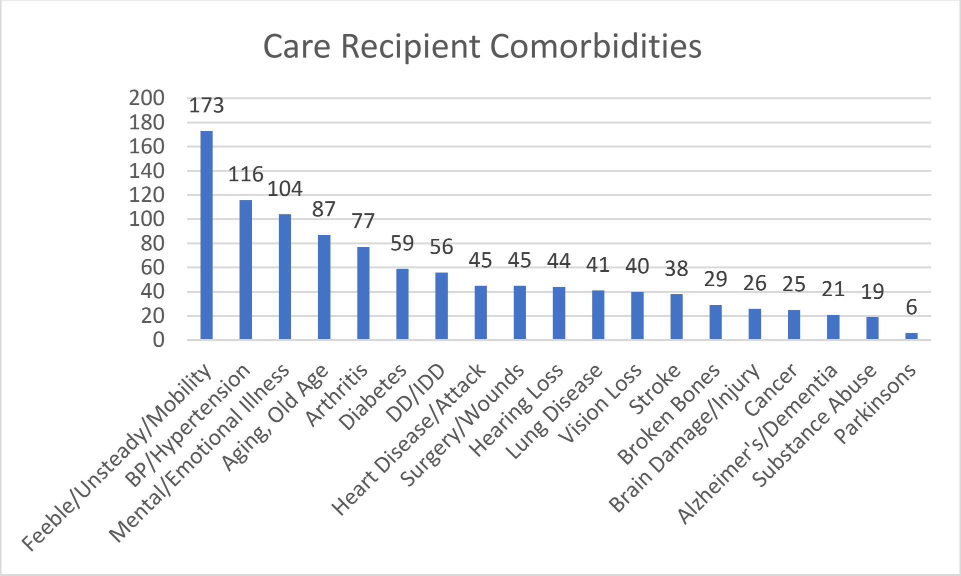
Nearly 40% of Alzheimer's/Dementia caregivers indicated their relationship to the care recipient as Parent/In-Law (n=22), while 25% indicated a relationship of Child/In-Law (n=14). 7% indicated a spousal or partner relationship (n=4), 5% indicated they were a sibling of the care recipient (n=3), and 9% indicated a non-relative status (n=5). Other relational identifications included grandparent and grandchild (7%, n=4).

Care Recipient Condition

The top five (5) identified care recipient primary diagnoses (n=371) reported included the following: Developmental/Intellectual Developmental Disability (DD/IDD) (20%, n=76), Alzheimer's or other dementias (14%, n=52), Cancer (10%, n=37), Mental/Emotional Illness or Depression (9%, n=35), and Brain Damage/Injury and other Neurological (6%, n=23). Other neurological diagnosis includes Lou Gehrig's Disease (ALS), seizure disorders, multiple sclerosis, and spinal muscular atrophy.

Caregivers were allowed to select multiple appropriate options when it came to comorbidities of the care recipient. Of those care recipients, 88% have comorbidities (n=328) with over half having mobility issues, including feeble/unsteady or frequent falls (53%, n=173). At least three out of every ten care recipients with comorbidities include a diagnosis of blood pressure issues or hypertension (35%, n=116) while almost one out of five also suffer from diabetes (18%, n=59). This data clearly shows that Arkansas caregivers not only have the stress of providing care for an induvial but are taking on that role to assist someone who may have increasingly complex medical or support needs.

Figure 10- Care Recipient Comorbidities

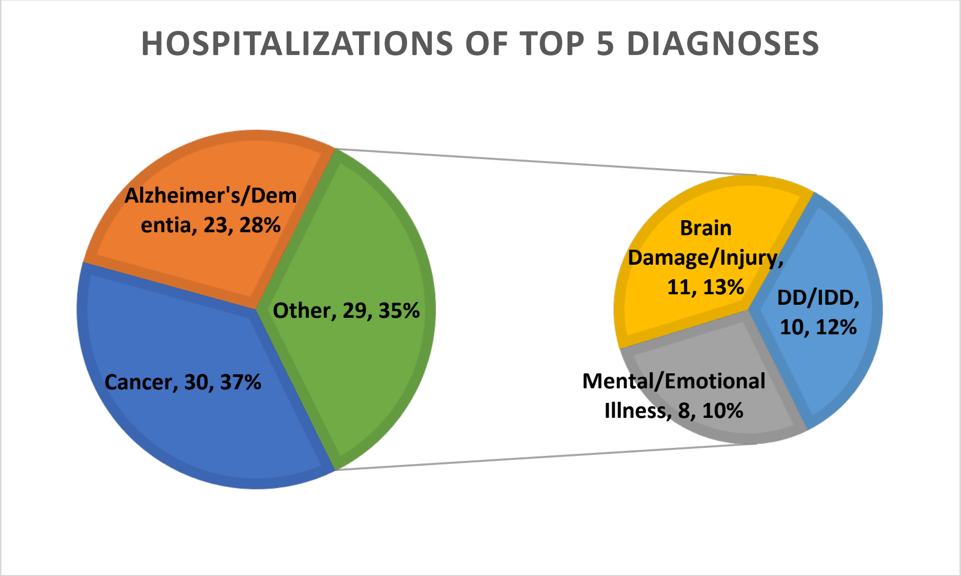


Forty-three percent of caregivers identified how long they have been providing care (n=371) and indicated they have been a caregiver for a period of 1-5 years (n=158). Twenty-six percent indicated they have been providing care for over ten years (n=98); 19% for a period of 5-10 years (n=71); and 12% for less than 1 year (n=44). 2020 National Data indicates the average duration of caregiving is 4.5 years, while the total number of years have increased since 2015 with 29% of caregivers now providing care for 5 years or longer. This number increased by 5% over 5 years (2015 indicating 24% of caregivers).

Of those in our state survey who have been providing care for ten or more years (n=98), two out of every 5 individuals were diagnosed with developmental/intellectual disabilities (DD/IDD) (n=40). Of those who have been providing care for less than 12 months (n=44), cancer was the top diagnosis (16%, n=7).

Thirty percent of caregivers indicated that their care recipient had been hospitalized overnight at least once within the last 12 months (n=165). Forty-seven percent (47%) of those care recipients (n=78) were hospitalized three (3) or more times within that year. Of the top 5 diagnoses with hospitalizations (n=82), 37% of those who were hospitalized with cancer (n=30) while 28% of those hospitalized had a diagnosis of Alzheimer’s or dementia (n=23). The remaining three top diagnosis- brain damage/injury, DD/IDD, and mental/emotional illness- made up another 35% of hospitalizations (n=29). 2020 National Data indicates that there has been a decline in hospitalizations of care recipients compared to their 2015 data. Within that five-year span, hospitalizations within a 12-month period dropped from 53% to 48%. The 2017 Arkansas caregiver feedback did not include this question; therefore, there is no state data currently to compare.

Figure 11- Care Recipient Hospitalizations



Care Recipient Military Status

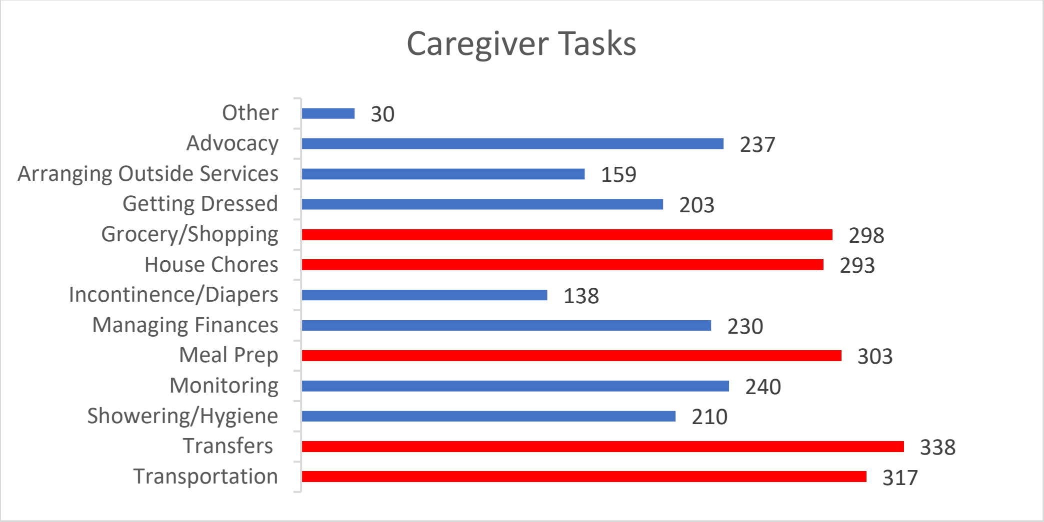
Of the 388 caregivers who responded, approximately 8% of care recipients they care for have a military background (n=32). None indicated that a care recipient was currently serving at this time.

Caregiving Activities and Level of Care

Of the caregivers who indicated a level of assistance within a normal week (n=428), 35% indicated they provide care off and on around the clock (n=150) while 26% indicated they provide care 24 hours a day, 7 days a week (n=113). Twenty-one percent (21%) of caregivers indicated they only receive small breaks during the day or just to sleep (n=91). Four percent (4%) provide care occasionally throughout the week (n=16), and another 4% as needed (n=16). The remaining half percent (0.5%) provide care on weekends only (n=2). Analysis of the data shows confusion between two of the data points in particular: providing care off and on around the clock and only receiving small breaks during the day or just to sleep. Future studies will need to clarify and streamline this data better to delineate more clearly.

When asked which tasks caregivers assist their care recipient with, caregivers were allowed to select multiple answers depending upon what was appropriate for their situation. Based on those that provided answers (n=425), the top five tasks include transfers (80%, n=338), transportation (75%, n=317), meal preparation (71%, n=303), grocery and other shopping (70%, n=298), and house chores (70%, n=293).

Figure 12- Caregiver Tasks

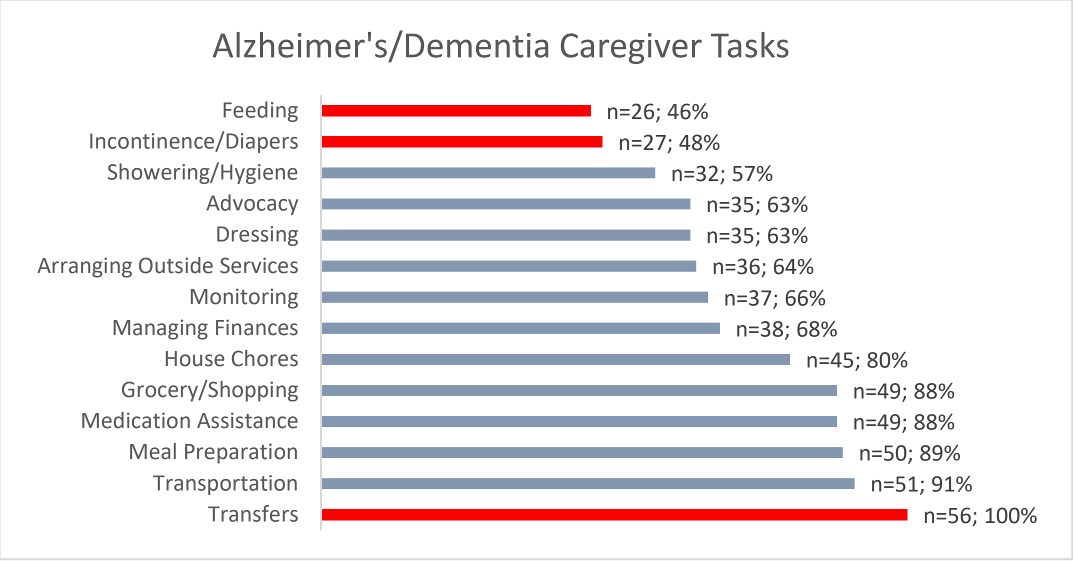


Other tasks include additional personal care tasks (i.e.: brushing, braiding hair), communication assistance, hospice care, and rehab therapy assistance.

Alzheimer's and Dementia

For those caregivers caring for those diagnosed with Alzheimer's or other dementia-related diseases (n=56), 71% indicated they provide care 24 hours a day, 7 days a week or 24/7 with an occasional small break or to sleep (n=40). Level of assistance with tasks were higher and more widespread for those providing care for Alzheimer's and dementia. Of the tasks available to select, only two (2) were below 50% selected: feeding and assistance with incontinence/diapers. Additionally, 100% of caregivers in this category indicated they assisted their care recipient with transferring, either to and from chairs, beds, or the toilet.

Figure 13- Caregiver Tasks for Alzheimer's and Dementia



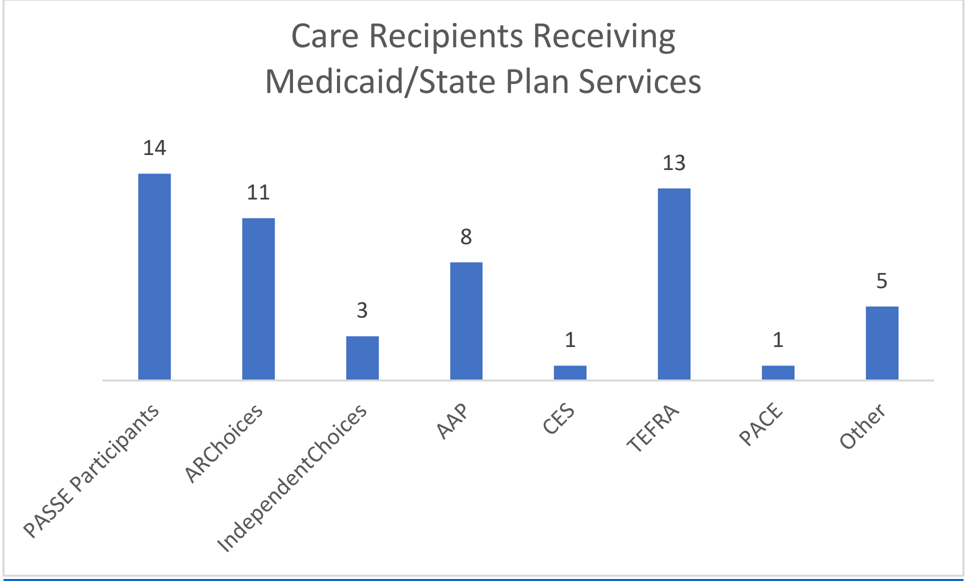
Presence of Other Help

Of the caregivers who have provided care within the last 12 months (n=425), only 32% indicated they had received some form of assistance or help from aides, housekeepers, or other people who were paid or unpaid to assist (n=136). Ninety-six percent (96%) of those that received assistance, received unpaid assistance, while 76% received paid assistance.

Fifty (50) caregivers indicated that their care recipient is or was on either Medicaid Waiver or State Plan services offered through DHS. Twenty-nine (29) caregivers indicated their care recipient was part of a waitlist while 40 caregivers indicated that their care recipient was denied services.

Twenty-eight percent (28%) of those receiving services were part of Arkansas's PASSE (Provider-Led Arkansas Shared Savings Entity) program, serving Medicaid clients with complex behavioral health, developmental or intellectual disabilities (n=14). Twenty-six percent (26%) indicated their care recipient received TEFRA (The Tax Equity and Fiscal Responsibility Act) aimed to help families with children younger than 19 years old who have a disability. Twenty-two percent (22%) of those receiving DHS services are in the ARChoices Medicaid Home and Community-based Program (n=11), while 6% are receiving services through Arkansas' self-direction personal care program, IndependentChoices (n=3). Sixteen percent (16%) received services through the Arkansas Autism Partnership (AAP) Medicaid waiver program and only one (1) individual is receiving services through Arkansas' Community and Employment Supports (CES) waiver and the Program of All-Inclusive Care for the Elderly, PACE (n=1). Others indicated they received financial assistance through SNAP, ARKids insurance, and general Medicaid.

Figure 14- Receipt of Medicaid/State Plan Services



Note: Some service recipients indicated multiple services (i.e.: waiver program and SNAP); therefore, totals equal more than 100%

Alzheimer's and Dementia

Nine percent (9%) of caregivers for Alzheimer's and dementia indicated that their care recipient was receiving Medicaid Waiver or State Plan services, the key services being ARChoices and

IndependentChoices (n=5). An additional 13% indicated they were on a waitlist (n=7) while another 11% indicated they were denied services (n=6).

Fifty-five percent (55%) of the 56 caregivers also indicated they had received either paid or unpaid assistance during the last 12 months.

Wellbeing of Caregiver

Caregivers were asked to evaluate their own overall health assessment in the categories of poor, fair, good, very good, and excellent.

Only 6 of all caregiver respondents indicated that their overall health assessment was excellent, leaving almost 99% of caregivers indicating that their health is less than excellent, while simultaneously caring for another individual. Of those 6 caregivers, 66% (n=4) were females and 50% were caring for recipients 65 years or older. Fifty percent (50%) (n=3) of caregivers have a grandparent/grandchild relationship to their care recipient while 33% (n=2) have a parental relationship and the remaining 17% (n=1) were a non-relative.

2020 National Data indicates 41% of caregivers report their overall health status as excellent or very good (down from 48% nationally in 2015); 21% report fair or poor health status (up from 17% in 2015).

Nationally, 51% of caregivers indicate that they feel their role as a caregiver gives them a sense of purpose[6]. Our state survey respondents also indicated that 52% of those providing care felt their role gives or gave them a sense of purpose or meaning in their life (n=222).

When asked if the caregiver felt alone or lonely because of their caregiver role, 37% indicated yes (n=158). This is higher than the 2020 National Data which indicated 21% of national respondents felt alone. Whereas nationally approximately 1 in 5 individuals indicated feelings of loneliness while caring for another individual, greater than 1 in 3 Arkansas caregivers indicated feelings of loneliness associated with caregiving.

Fifty-three percent (53%) of caregivers indicated they did not feel they had a choice in taking on their role as a caregiver (n=225), which is equal to the percentage of caregivers on a national scale (2020 National Data: 53%). When asked if they, as a caregiver, found it difficult to take care of their own health while caring for another, 43% indicated yes (n=185). For Arkansas caregivers this indicates almost double the 2020 National Data percentage, where nearly one in four indicated yes (23%). Arkansas caregivers are nearly twice as likely to find it difficult to care for their own health when faced with caring for the health of another. This raises concerning questions as to whether caregivers, particularly those 40 years and older, are neglecting their own age appropriate examinations due to their caregiving responsibilities (ex. mammogram, colonoscopy, prostate exam, eye exams, etc.)?

National research has found that multi-level stressors and responsibilities placed on a caregiver, including strains placed by caregivers that are still in the workforce, increase a caregiver's strain in all areas including physical, emotional, social, psychological, and leads to an overall caregiver burden higher

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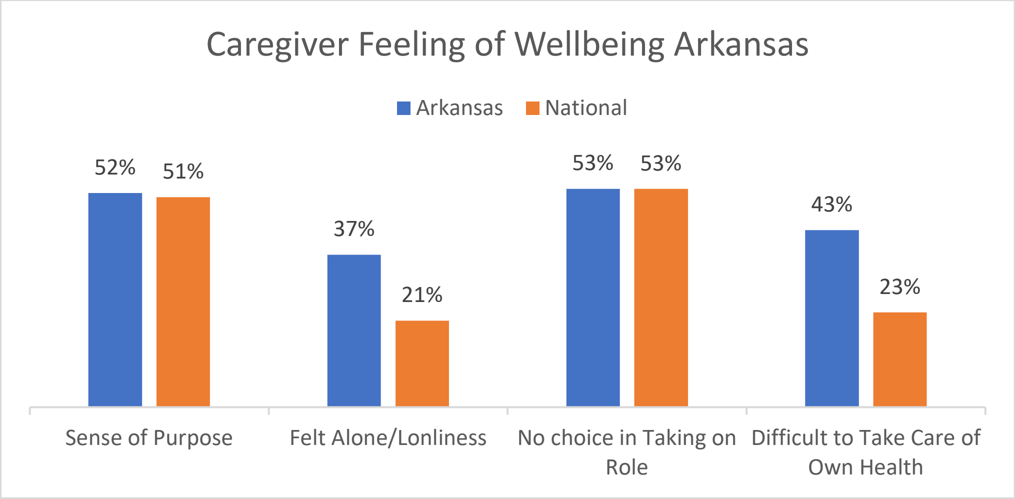
[6] AARP and National Alliance for Caregiving. *Caregiving in the United States- Executive Summary.* Washington, DC: May 2020. https://www.aarp.org/content/dam/aarp/ppi/2020/05/executive-summary-caregiving-in-the-united-states.doi.10.26419-2Fppi.00103.003.pdf

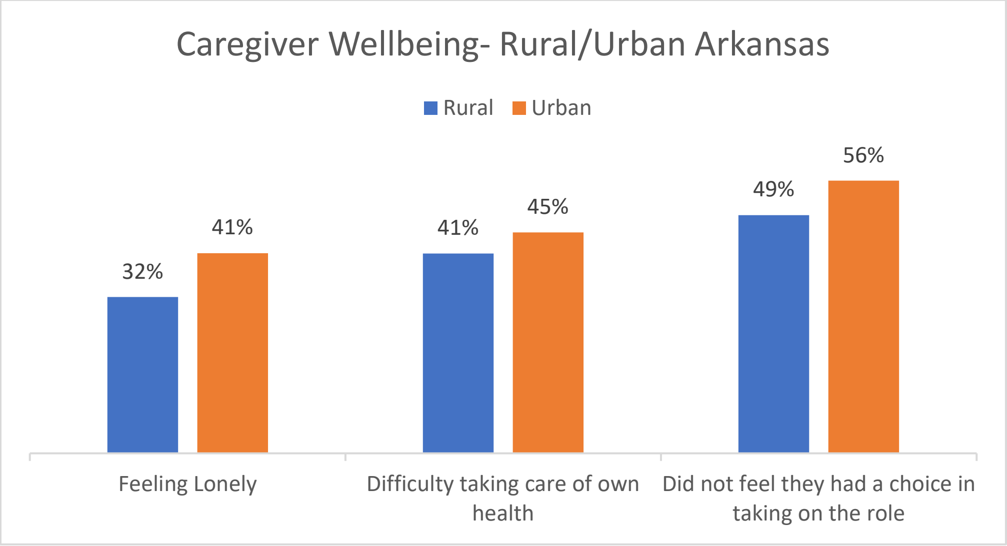
than non-caregivers. The high-strain lifestyle roles that caregivers take on increases the risk that the caregiver will experience declining mental and psychological health, such as depression and anxiety.[7]

Figure 15- Caregiver's Overall Wellbeing (State vs. National)



Additionally, when comparing rural caregivers with urban caregivers, urban caregivers identified slightly higher for caregiver well-being impacts than their rural counterparts. This may be due to the fact that caregivers identified 5% more urban than rural in geographic location.

Figure 16- Caregiver's Overall Wellbeing (Rural vs. Urban)



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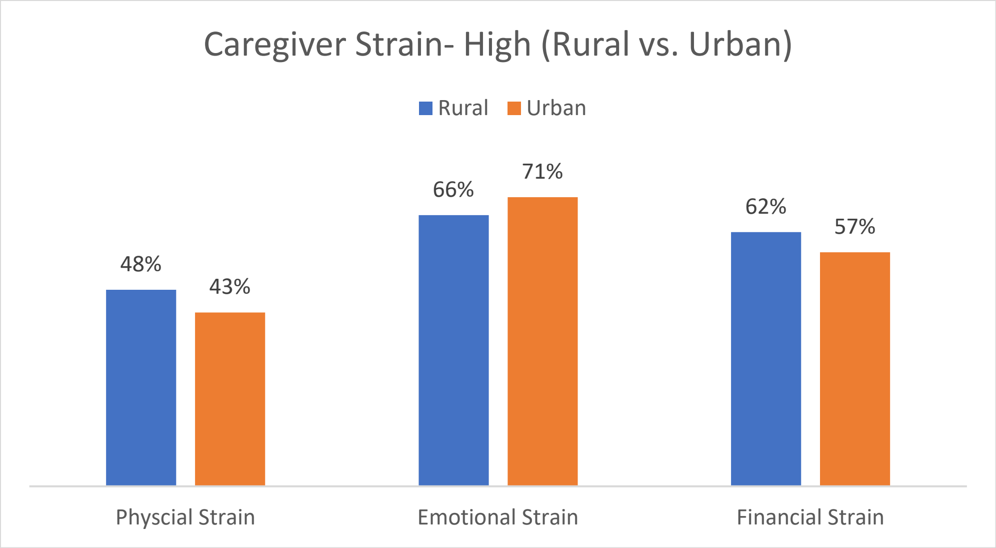
[7] Kayaalp, A., Page, K. J., & Rospenda, K. M. (2021). Caregiver Burden, Work-Family Conflict, Family-Work Conflict, and Mental Health of Caregivers: A Mediational Longitudinal Study. *Work and stress*, *35*(3), 217–240. https://doi.org/10.1080/02678373.2020.1832609

When comparing rural and urban caregivers as it relates to the strain: physically, emotionally, and financially, they feel as a caregiver that it does not appear geographical location plays a role in a higher or lower impact. Urban caregivers ranked higher than rural caregivers when it came to emotional strain by 4%; however, rural caregivers indicated more financial and physical strain than their urban counterparts by 5%.

Figure 17. Caregiver Strain (Rural vs. Urban)



Financial Impact

National data indicates “the lower the income and education a person has, the more likely he or she is a caregiver,” and that “47% of caregivers have an annual household income of less than $50,000, with a median income of $54,700.”[8]

Of the 425 caregiver respondents within our survey, 65% indicated a total annual household income (from all sources) of less than $30,000 (n=277). Twelve percent (12%) indicated an annual household income between $30,000 and $49,999 (n=51) while another 26% indicated between $50,000 and $99,999 (n=73). Less than 10% had an income over $100,000 (n=24). This far exceeds national data as 77% of caregivers who participated in our survey indicate an income less than $50,000.

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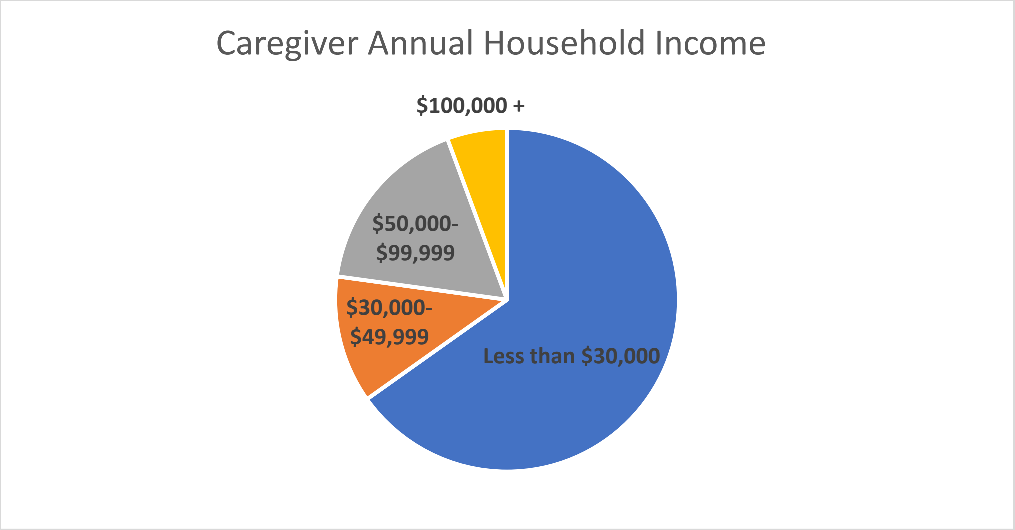
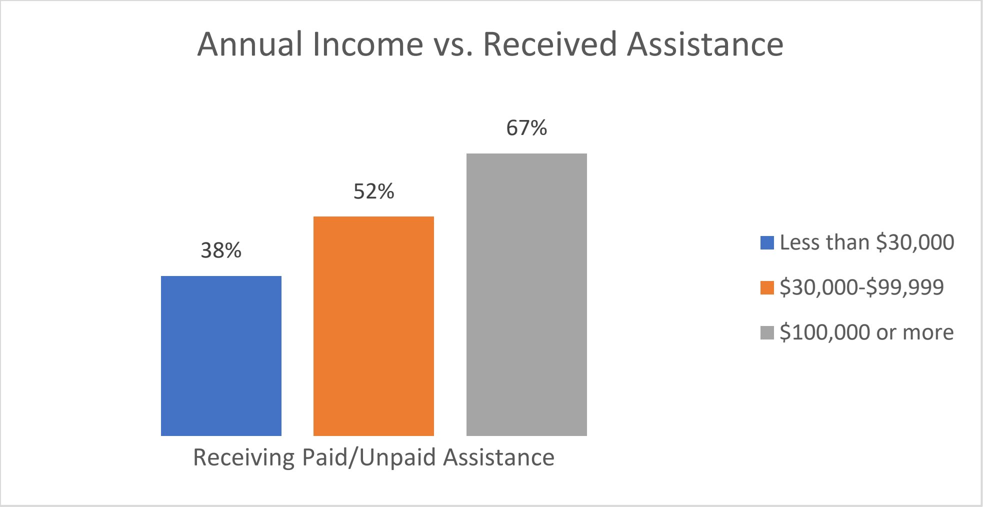
[8] Family Caregiver Alliance. Caregiver Statistics: Work and Caregiving. 2016: San Francisco, CA. https://www.caregiver.org/resource/caregiver-statistics-work-and-caregiving/

Figure 18- Caregiver Household Income



Additionally, 16 out of the 24 (67%) caregivers that indicated $100,000 or more in annual household income also indicated that they had received assistance, either paid or unpaid, during the last 12 months. This data indicates those with a higher household income are more likely to receive outside help, whether paid or unpaid. By contrast, only 105 out of the 277 (38%) of caregivers that indicated a household income of less than $30,000 had received either paid or unpaid assistance. Those with lower household income carry a higher burden not only financially but physically as well, as they receive much lower levels of caregiver assistance. This lower economic demographic of caregivers also tends to be sicker themselves due to compounding issues related to poverty.[9]

Figure 19- Caregiver's Annual Income vs. Received Assistance



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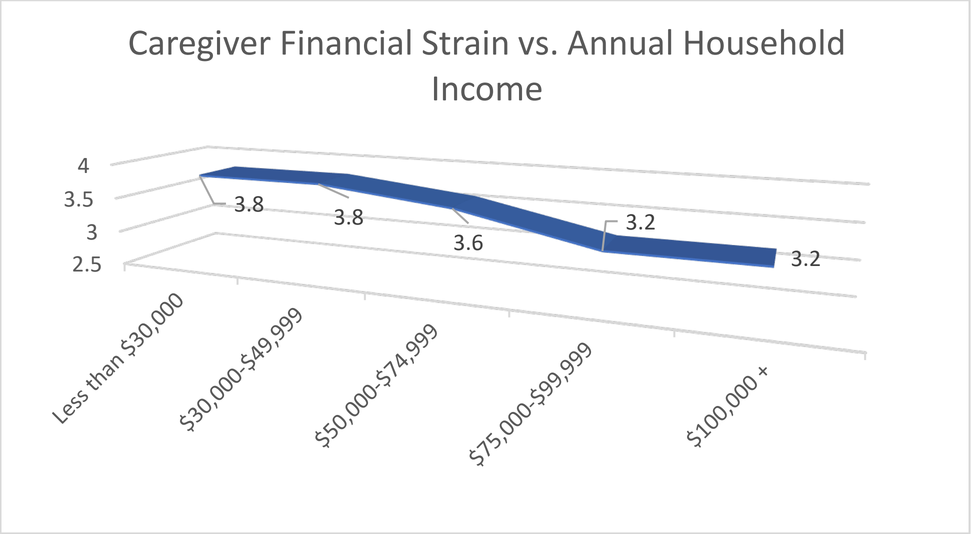
[9] BlueCross Blue Shield Association. The Health of America Report. *The Impact of Caregiving on Mental Health and Physical Health.* September 2020. https://www.bcbs.com/the-health-of-america/reports/the-impact-of-caregiving-on-mental-and-physical-health#impactshealth

When this state survey asked caregivers to rate financial strain from one to five (one being “no strain at all” to five being “very much a strain”), the overall financial strain among caregivers averaged 3.7. Financial strain did decrease slightly as annual household income increased.

Figure 20- Financial Strain vs. Household Income

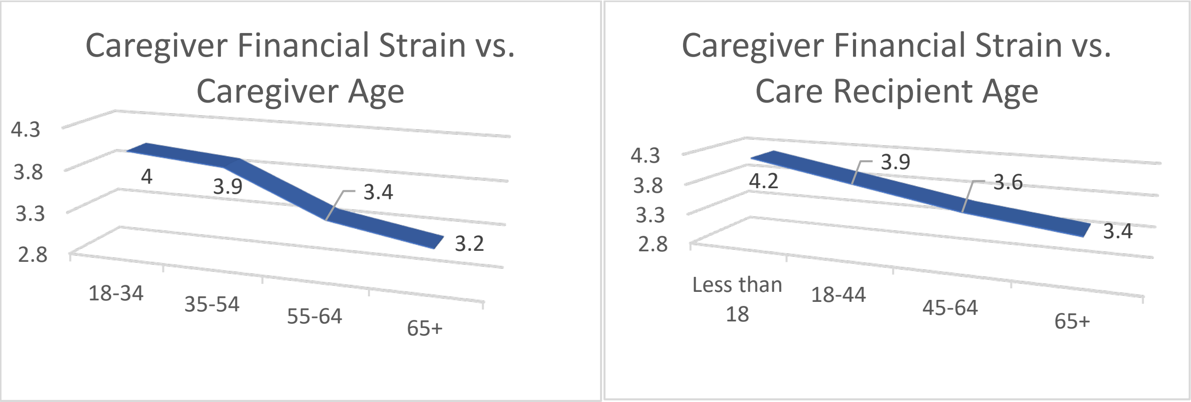


Male caregivers responded with a higher average financial stress rating than females (male=4.0; female= 3.7) while caregivers identifying as non-binary indicated the highest average financial stress rating of 4.3. Caregivers identifying with two or more ethnic categories averaged 4.6 out of 5.

Caregivers located in established rural counties and non-rural counties alike averaged a similar financial strain (rural= 3.7; non-rural= 3.8). Caregivers providing for care recipients diagnosed with Alzheimer’s or other dementias also averaged 3.7 out of 5.

Data does show that caregiver age and care recipient age both effect the level of financial stress to the caregiver. Younger caregivers reported higher financial stress than older caregivers; likewise, caregivers caring for younger recipients reported a higher financial stress than those caring for older adults.

Figure 21- Financial Strain vs. Caregiver Age and Care Recipient Age



Eighty-two percent (82%) of survey respondents indicated they have experienced some sort of financial impact as a caregiver (n=352). Caregivers were given the option to select multiple financial impacts that applied to them, 88% of caregivers indicated more than one impact (n=313).

Forty-eight percent (48%) of caregivers indicated that they have taken on more debt as a caregiver (n=171) and over half (53%) have had to borrow money from friends or family (n=189). Two of every 3 caregivers have either paid bills late or left them unpaid (n=233) and 1 out of every 6 have had late student loan payments (n=54).

Seventy-one percent (71%) of caregivers indicated they had stopped saving or stopped trying to save money (n=252). Over half of caregiver respondents have exhausted their personal short-term savings (n=183), while 1 out of 5 caregivers have used long-term savings like retirement monies to pay for things needed. Approximately one (1) in five (5) caregivers indicated they came out of retirement or took on a second job to meet financial needs (n=75) while 8% indicated they delayed retirement or decided not to retire (n=28).

One in every ten caregivers indicated they have filed for bankruptcy (n=34) and one in every four indicated they had to relocate to less expensive housing (n=87) in order to make ends meet. Nine percent (9%) of caregivers indicated they had been evicted or had their home foreclosed (n=32). Finally, approximately four out of nine caregivers stated they were unable to afford basic expenses like food (n=158).

When compared to 2020 national data collected by AARP for the caregiver's financial impact, financial impacts to Arkansas caregivers are doubled, if not three or four times higher, than the national numbers in almost all comparable categories except for long-term care savings. Comparable categories include taking on more debt, borrowing from friends/family, inability to afford basic needs, unpaid or late bill payments, use of short-term and long-term savings, and the cessation of saving money all together.[10]

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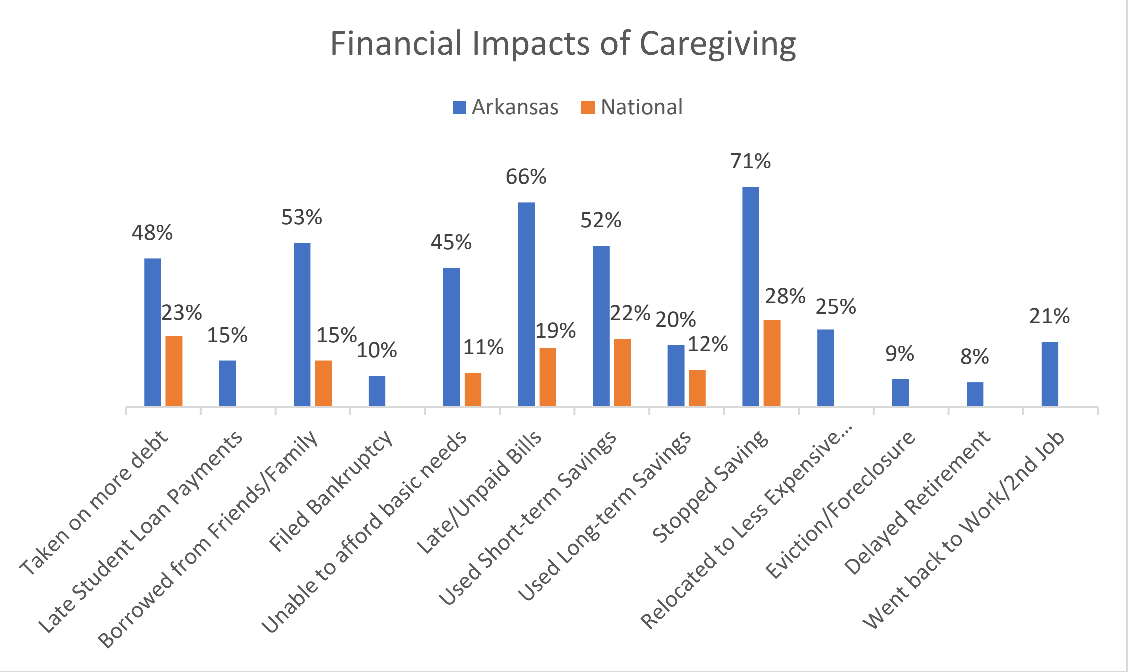
[10] AARP and National Alliance for Caregiving. *Caregiving in the United States- Executive Summary.* Washington, DC: May 2020. https://www.aarp.org/content/dam/aarp/ppi/2020/05/executive-summary-caregiving-in-the-united-states.doi.10.26419-2Fppi.00103.003.pdf

Figure 22- Financial Impacts of Caregiving (State vs. National)



Impact of Caregivers in the Workforce

National data from 2004 indicated that "59% of caregivers are employed either full or part time."[11] That number rose in 2020 to 61% of caregivers working outside the home or being employed in addition to providing care to another individual.[12] This is comparable to this state survey response in which 66% of caregivers indicated they had been employed while also providing care (n=281), while 37% of caregivers were currently employed at the time of the survey (n=160).

Employed caregivers often feel a strain of priorities and commitments between their job and their caregiving duties. One hundred thirty-four (134) of the 281 Arkansas caregivers who have been employed indicated that their supervisor was either unaware of their caregiver responsibilities or they were unsure if the supervisor was aware (48%).

Only 21% of these caregivers indicated they experienced no hardship or impact to their job (n=58); however, 79% indicated they had at least one work impact affecting them when it related to their caregiver status (n=223).

Sixty-three percent (63%) of employed caregivers experienced tardiness, had to leave work early or take time off work in relation to caregiver responsibilities (n=179). Twenty-seven percent (27%) indicated they had to stop working entirely or take early retirement (n=75). These numbers are comparable to national data in work impact; however, specific impacts range higher within Arkansas respondents than nationally.

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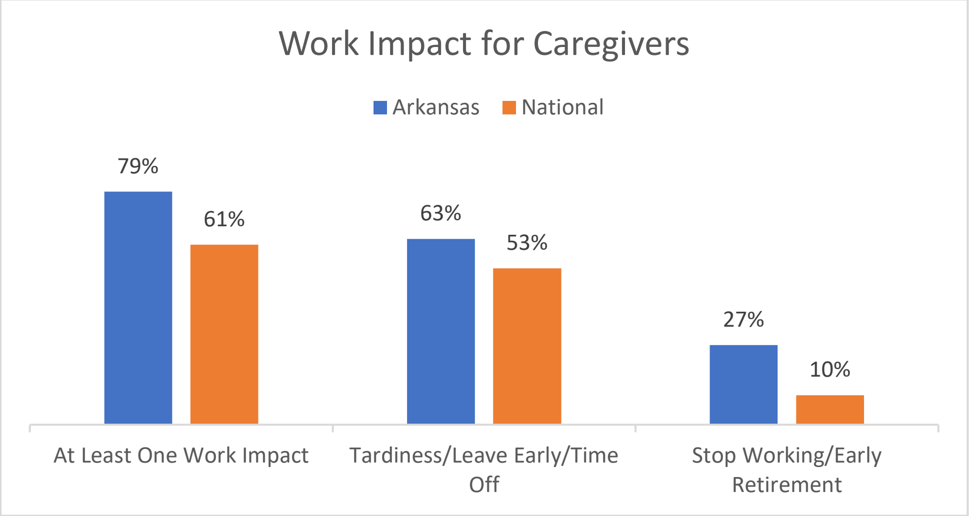
[11] AARP and National Alliance for Caregiving. *Caring in the United States.* Washington, DC: AARP. April 2004. https://assets.aarp.org/rgcenter/il/us_caregiving.pdf

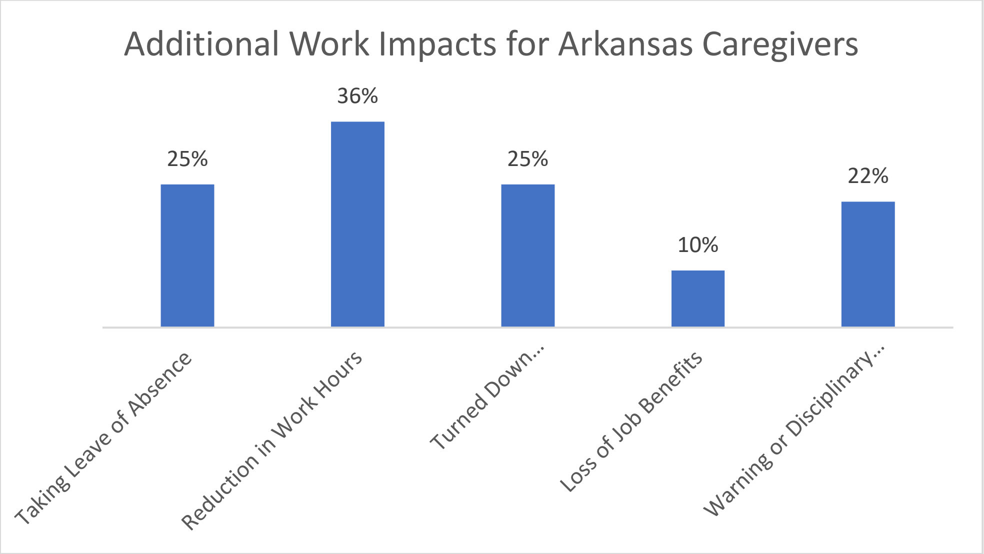
[12] AARP and National Alliance for Caregiving. *Caregiving in the United States 2020*. Washington, DC: AARP. May 2020. https://doi.org/10.26419/ppi.00103.001

Figure 23- Caregiver Impacts in the Workplace (State vs. National)



Additional work impacts that Arkansas caregivers identified in the state survey included reduced work hours (n=102), turning down a promotion or extra responsibility (n=69), loss of job benefits (n=28), and receiving a warning or disciplinary action about their performance or attendance at work (n=63).

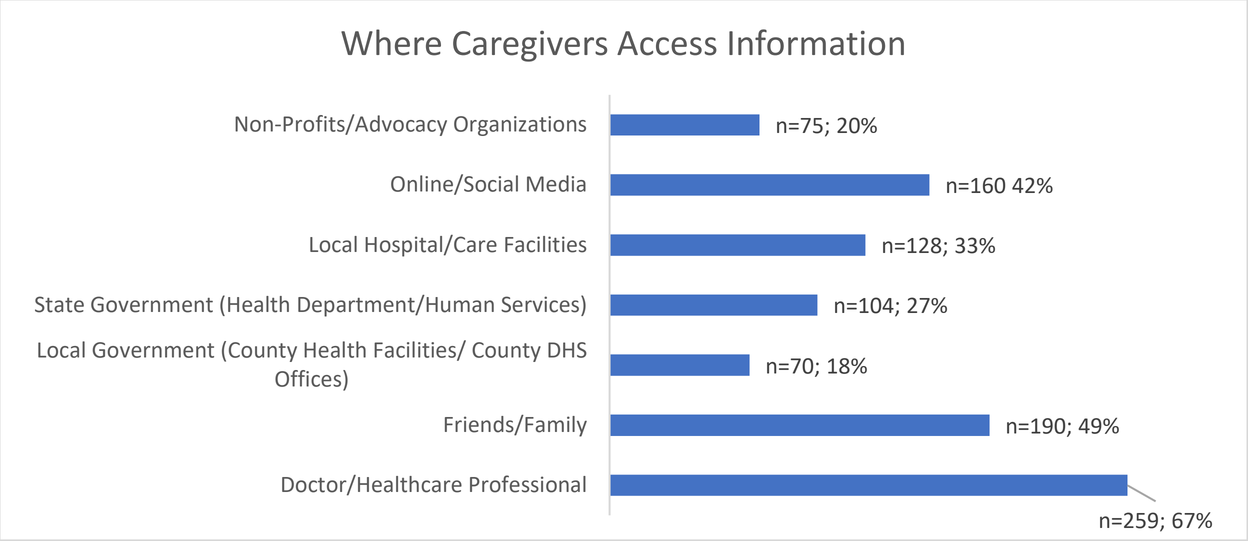
Figure 24- Additional Caregiver Work Impacts (State Only)



Where Caregivers Seek Information and Supports

During the survey, caregivers were asked to identify all places they use to learn more or gather more information to better help them as a caregiver. Caregivers were allowed to select multiple options as they related to them. Ninety percent (90%) of caregivers provided feedback to this question (n=385) with a predominant response indicating they look to their doctors or other health care professionals for information (67%, n=259). Half of the caregivers who responded also indicated they seek information and guidance from family and friends (49%, n=190), while approximately four out of ten caregivers look online or to social media (42%, n=160).

Figure 25- Accessing Information



Knowledge and Access to Respite

Thirty-eight percent (38%) of national caregivers believe that receiving respite care would be beneficial to them as a caregiver but less than half of them have ever used respite services.[13]

Less than 25% of caregiver respondents in Arkansas indicated they have heard of caregiver respite (n=103) and only 27% of those who have heard of respite know where to find or access it within Arkansas (n=28); less than 10% of the total number of caregivers surveyed.

More concerning is the fact that only approximately 7% of caregivers surveyed had experienced the benefit of respite, compared with the national percentage of 14%.[14] Twenty-nine (29) caregivers indicated they had used respite it the past 12 months and 55% of those caregivers indicated they had an easy to very easy time accessing it (n=16). The remaining 45% indicated that it was not an easy process (n=13).

Caregivers were allowed to choose from several activities typically used when respite time has been offered. Caregivers were allowed to select multiple activities they would consider doing or participating in if they were to receive a caregiver break with respite. Of the 428 caregivers, over 50% indicated they would take the time to just rest and relax in general. One of every four caregivers indicated they would like to participate in physical activity or exercise, and social/recreational activities, including church events. There were a similar number of caregivers who also selected activities including spending time with spouse, partner or other family and friends, and pursuing their own hobbies and interests.

It should be noted that approximately four of every ten caregivers (40%) stated they would use their break time to run needed errands or to complete household tasks. Twelve percent (12%) of caregivers selected other activities with write-in responses of taking a small vacation, taking classes, or completing

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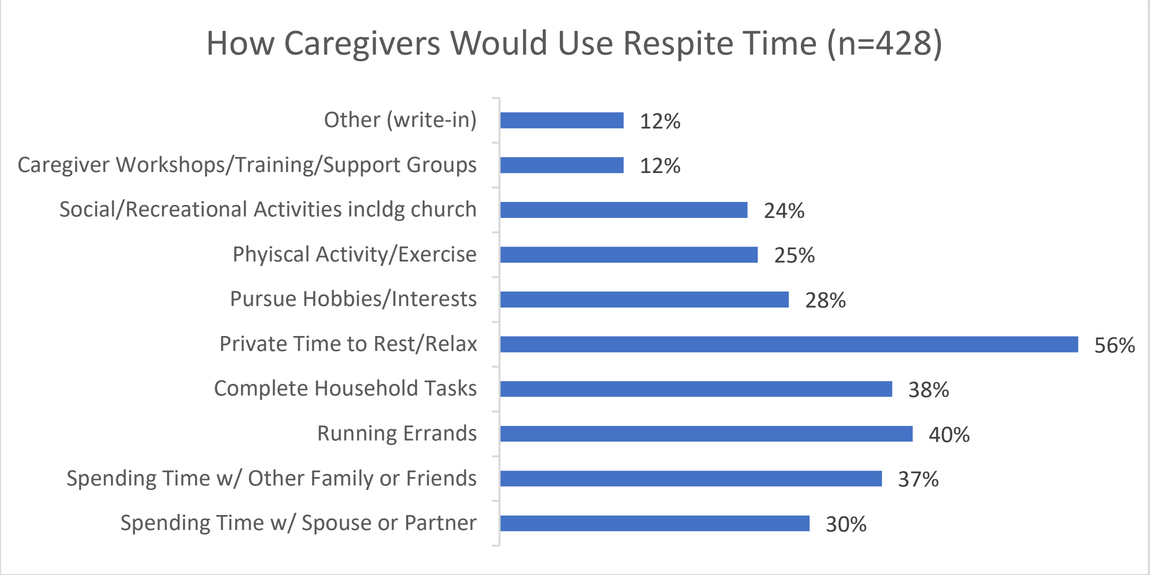
[13] AARP and National Alliance for Caregiving. *Caregiving in the United States 2020*. Washington, DC: AARP. May 2020. https://doi.org/10.26419/ppi.00103.001

[14] AARP and National Alliance for Caregiving. *Caregiving in the United States- Executive Summary.* Washington, DC: May 2020. https://www.aarp.org/content/dam/aarp/ppi/2020/05/executive-summary-caregiving-in-the-united-states.doi.10.26419-2Fppi.00103.003.pdf

school, applying for jobs, starting up their own business interests, taking care of their own health appointments, or just shopping/window shopping to decompress.

Figure 26- Respite



Limitations

Limitations of this study were apparent when comparisons and benchmarking were performed between national and state specific data. Parallels could not be directly drawn between some key data points. In the future, studies will strive to mirror national data collection methods, and state's specific data collection, from those states with similar population, demographic, and socioeconomic markers. Easier comparisons and contrasting of data will help Arkansas benchmark the work we are doing. When we can properly compare our work to National respite data, we will have a greater understanding of the areas where we lack, and the areas where we are excelling in respite provision. Additionally, continued data collection within the state will assist in determining any strides or setbacks we are making in our respite service goals.

Conclusions

In conclusion, more research is necessary to determine why caregiving outcomes in Arkansas are worse than national averages.

What makes Arkansas caregivers feel 50% more lonely than the national average caregiver? Is it due to our higher rural demographic? Other states comparable to Arkansas's rurality, like Texas, have state specific reports regarding informal caregiving. Future Arkansas studies should explore some of the same data analyzed in the Texas specific report for benchmarking purposes. Additionally, data collected in Arkansas needs to mirror national data collection for more in-depth national benchmarking.

Some of our worse outcomes were due to lower socioeconomic status as compared to national data. Arkansas has lower wages which leads to higher levels of poverty. While less than half of national respondents (47%) indicated annual household income of less than $50,000, more than 3 out of every 4 caregivers (77%) in the State of Arkansas has a household income of less than $50,000. The financial impact of caregiving in the State of Arkansas far outstrips the national burden. More than half of Arkansans (53%) qualify for the Supplemental Nutrition Assistance Program (SNAP).[15] Without proper support to this group, Arkansas faces a potential housing and public health crisis. The need for more infrastructure supports for this population is apparent. This group is at risk and financially vulnerable. Caregivers are living paycheck to paycheck. This puts the care recipient at risk. No longer having the ability to save money, as indicated by survey responses, and more than half of caregivers exhausting what savings they did have, creates potential for high rates of housing insecurity within this population.

Nearly 99% of respondents in the Arkansas study indicated their health is less than excellent. Are these caregivers getting necessary health care themselves? Are they neglecting preventative medical exams to care for the recipient? Do those with less than excellent health have medical insurance? How are those under the age of 65 getting health care if they are unable to work due to caregiving responsibilities? This may be why 66% are still working or why they have less than excellent health; they are uninsured.

In 2018, Blue Cross Blue Shield reported that 25% of commercially insured and Medicaid Fee-For-Service Arkansans are in need of caregiving.[16] In most cases employment is a prerequisite of health coverage. Sixty-six percent (66%) of Arkansas caregivers are employed while providing caregiving. Caregivers find it difficult to work and provide caregiving. Half of Arkansas caregivers indicated they have not or feel they cannot tell their employer about their caregiving responsibilities. Further research is needed regarding uninsured rates amongst caregivers. How many caregivers work because they would not have health insurance otherwise? If given an option to not work and have health care, would caregivers take it? Identifying the source of insurance for those that do have insurance coverage is also important as that will provide a better understanding as to why some individuals are choosing to continue to work.

Additional research is also needed to further understand employment impacts, and the effect on Arkansas's economy to lost working hours and wages due to caregiving responsibilities. Arkansas caregivers are nearly 3 times as likely to stop working or retire early, versus their national counterparts. Nearly 80% of working Arkansas caregivers indicated at least one work impact due to their caregiver responsibilities. More than one-third indicated they have a reduction in work hours due to caregiving, and 1 in every 4 caregivers seeking employment indicated they were turned down for a job due to their caregiving responsibilities. This may be the answer to why half of employed caregivers do not feel they can or have not told their employers about their caregiver status. Discrimination in the workplace against caregivers is concerning. Federal laws protect the rights of employees and allow up to 12 weeks of unpaid leave under the Family and Medical Leave Act (FMLA) to care for a sick family member. Certain criteria must be met in order to qualify. More research is needed to determine if employees are aware of the availability of FMLA leave.

More research is also needed regarding how caregivers would use their respite time, as seeking their own medical care was not an option to choose from.

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[15] Feeding America. *Food Insecurity among Overall *all ages) Population in Arkansas.* Interactive Map, 2020. https://map.feedingamerica.org/county/2020/overall/arkansas

[16] BlueCross Blue Shield Association. The Health of America Report. *The Impact of Caregiving on Mental Health and Physical Health.* September 2020. https://www.bcbs.com/the-health-of-america/reports/the-impact-of-caregiving-on-mental-and-physical-health#impactshealth

The lack of awareness of respite services is also of concern and should be addressed though increased advertisement and outreach to caregivers across Arkansas. More individuals would likely take advantage of a respite program if they knew more about it, and knew it was available to them.

Possible Future Solutions

Based on the research and data collected for this report, the following areas may be beneficial for possible future solutions:

- Continued research
- Expanded research
- Increased advertising and outreach for respite programs
- Easier access to respite services

Appendix A. Survey Questions

Q1. Have you ever provided unpaid care to a relative or a friend 18 years of age or older in order to help them take care of themselves OR a child (minor, less than 18) because of a medical, behavioral, or other condition or disability (more than required normal care)? This person must have lived in a private home or the same household as the caregiver?

Answered: 769 *Skipped: 0*

Answer Choice	*Responses*	
Yes	*553*	*71.91%*
No	*216*	*28.09%*

Q2. How old were you (the caregiver) on your last birthday?

Answered: 428 *Skipped: 341*

Answer Choice	*Responses*	
18 years to 24 years	*13*	*3.04%*
25 years to 34 years	*65*	*15.19%*
35 years to 44 years	*112*	*26.17%*
45 years to 54 years	*95*	*22.20%*
55 years to 64 years	*77*	*17.99%*
65 years and older	*66*	*15.42%*

Q3. Which ethnicity do you identify as?

Answered: 428 *Skipped: 341*

Answer Choice	*Responses*	
Spanish/Hispanic/Latino	*7*	*1.64%*
Black/African American	*58*	*13.55%*
White/Caucasian	*327*	*76.40%*
American Indian/Alaska Native	*9*	*2.10%*
Asian	*1*	*0.23%*
Marshallese	*0*	*0.00%*
Native Hawaiian/Pacific Islander	*0*	*0.00%*
2 or more	*14*	*3.27%*
Don't Know	*0*	*0.00%*
Prefer not to answer	*12*	*2.80%*

Q4. What gender do you identify as?

Answered: 428 *Skipped: 341*

Answer Choice	*Responses*	
Male	*52*	*12.15%*
Female	*368*	*85.98%*

Non-Binary	*3*	*0.70%*
Don’t Know	*0*	*0.00%*
Prefer not to answer	*5*	*1.17%*

Q5. Which county in Arkansas do you (the caregiver) reside in?

Answered: 428 *Skipped: 341*

Answer Choice	*Responses*	
Arkansas	*20*	*4.67%*
Ashley	*4*	*0.93%*
Baxter	*8*	*1.87%*
Benton	*38*	*8.88%*
Boone	*3*	*0.70%*
Bradley	*0*	*0.00%*
Calhoun	*0*	*0.00%*
Carroll	*3*	*0.70%*
Chicot	*2*	*0.47%*
Clark	*3*	*0.70%*
Clay	*0*	*0.00%*
Cleburne	*6*	*1.40%*
Cleveland	*1*	*0.23%*
Columbia	*1*	*0.23%*
Conway	*6*	*1.40%*
Craighead	*12*	*2.80%*
Crawford	*7*	*1.64%*
Crittenden	*3*	*0.70%*
Cross	*1*	*0.23%*
Dallas	*1*	*0.23%*
Desha	*0*	*0.00%*
Drew	*1*	*0.23%*
Faulkner	*16*	*3.74%*
Franklin	*2*	*0.47%*
Fulton	*3*	*0.70%*
Garland	*16*	*3.74%*
Grant	*1*	*0.23%*
Greene	*5*	*1.17%*
Hempstead	*3*	*0.70%*
Hot Spring	*10*	*2.34%*
Howard	*0*	*0.00%*
Independence	*2*	*0.47%*
Izard	*2*	*0.47%*
Jackson	*2*	*0.47%*
Jefferson	*9*	*2.10%*
Johnson	*5*	*1.17%*
Lafayette	*4*	*0.93%*

Lawrence	*4*	*0.93%*
Lee	*0*	*0.00%*
Lincoln	*1*	*0.23%*
Little River	*1*	*0.23%*
Logan	*5*	*1.17%*
Lonoke	*12*	*2.80%*
Madison	*1*	*0.23%*
Marion	*4*	*0.93%*
Miller	*10*	*2.34%*
Mississippi	*3*	*0.70%*
Monroe	*0*	*0.00%*
Montgomery	*1*	*0.23%*
Nevada	*1*	*0.23%*
Newton	*2*	*0.47%*
Ouachita	*1*	*0.23%*
Perry	*4*	*0.93%*
Phillips	*2*	*0.47%*
Pike	*1*	*0.23%*
Poinsett	*5*	*1.17%*
Polk	*8*	*1.87%*
Pope	*10*	*2.34%*
Prairie	*1*	*0.23%*
Pulaski	*47*	*10.98%*
Randolph	*4*	*0.93%*
Saline	*12*	*2.80%*
Scott	*0*	*0.00%*
Searcy	*1*	*0.23%*
Sebastian	*23*	*5.37%*
Sevier	*1*	*0.23%*
Sharp	*7*	*1.64%*
St. Francis	*2*	*0.47%*
Stone	*2*	*0.47%*
Union	*2*	*0.47%*
Van Buren	*2*	*0.47%*
Washington	*32*	*7.48%*
White	*13*	*3.04%*
Woodruff	*1*	*0.23%*
Yell	*2*	*0.47%*

Q6. Are you (the caregiver) or have you served in the US Armed Forces? This includes Army, Navy, Air Force, Marines, Coast Guard, Women's Armed Forces, National Guard or Reserves.

Answered: 428 *Skipped: 341*

Answer Choice	*Responses*	
Yes, currently serving	*1*	*0.23%*

Yes, have served but not currently	*15*	*3.50%*
No, I have not served	*407*	*95.09%*
Prefer not to answer	*5*	*1.17%*

Q7. Are you (the caregiver) or were you in the past, WHILE PROVIDING CARE, a student- either full time or part time?

Answered: 428 *Skipped: 341*

Answer Choice	*Responses*	
Yes, I am currently a student	*28*	*6.54%*
Yes, I used to be a student	*87*	*20.33%*
No	*312*	*72.90%*
Prefer not to answer	*1*	*0.23%*

Q8. Last year, what was your total annual household income from all sources, before taxes?

Answered: 428 *Skipped: 341*

Answer Choice	*Responses*	
Under $30,000	*280*	*65.42%*
Between $30,000 and $49,999	*51*	*11.92%*
Between $50,000 and $74,999	*50*	*11.68%*
Between $75,000 and $99,999	*23*	*5.37%*
Between $100,000 and $150,000	*18*	*4.21%*
Over $150,000	*6*	*1.40%*

Q9. Are you currently employed, or have you been employed during the time you were a caregiver?

Answered: 428 *Skipped: 341*

Answer Choice	*Responses*	
Yes, I am currently employed	*160*	*37.38%*
No, I am not currently employed but was during some point of my caregiver time	*121*	*28.27%*
No, I have not been employed during my caregiving time	*134*	*31.31%*
Prefer not to answer	*13*	*3.04%*

Q10. Approximately how many hours per week did/do you work?

Answered: 428 *Skipped: 341*

Answer Choice	*Responses*	
1-10	*78*	*18.22%*
11-20	*45*	*10.51%*
21-30	*48*	*11.21%*
31-40	*134*	*31.31%*

More than 40	123	28.74%

Q11. Does/Did your supervisor know that you were an unpaid caregiver?

Answered: 428 Skipped: 341

Answer Choice	Responses	
Yes	166	38.79%
No	142	33.18%
Unsure	82	19.16%
Prefer not to answer	38	8.88%

Q12. As a result of caregiving, have you/did you experience any of these at your place of employment?

Answered: 428 Skipped: 341

Answer Choice	Responses	
None of the above	151	35.28%
Tardiness, left early or took time off during the day to provide care	197	46.03%
Took a leave of absence	77	17.99%
Reduced work hours	109	25.47%
Turned down a promotion or additional responsibilities	81	18.93%
Lost job benefits	32	7.48%
Resigned from work entirely	85	19.86%
Retired early	35	8.18%
Received a warning or disciplinary action about your performance or attendance at work	71	16.59%

Q13. Have you/Did you ever feel/felt that your responsibilities as a caregiver led you to be penalized or discriminated against at your place of employment?

Answered: 428 Skipped: 341

Answer Choice	Responses	
Yes	106	24.77%
No	235	54.91%
Unsure/Prefer not to answer	87	20.33%

Q14. Please select any or all below that relates to you (the caregiver).

Answered: 428 Skipped: 341

Answer Choice	Responses	
None of the above	38	8.88%
My role as a caregiver gives/gave me a sense of purpose or meaning in my own life	222	51.87%

I find/found it difficult to take care of my own health while caring for another	*185*	*43.22%*
I feel/felt alone or lonely as a caregiver	*158*	*36.92%*
I do not/did not feel I have/had a choice in taking on the responsibility of providing care for this person	*225*	*52.57%*

Q15. How would you describe your own overall health (when you were caregiving)?

Answered: 428 *Skipped: 341*

Answer Choice	*Responses*	
Poor	*54*	*12.62%*
Fair	*183*	*42.76%*
Good	*135*	*31.54%*
Very Good	*50*	*11.68%*
Excellent	*6*	*1.40%*

Q16. On a scale of 1 to 5, how much physical strain would you say caregiving has/had on you?

Answered: 428 *Skipped: 341* *Weighted Average: 3.37*

Answer Choice	*Responses*	
1 Star- Not a strain at all	*35*	*8.18%*
2 Stars- (no label)	*56*	*13.08%*
3 Stars- (no label)	*144*	*33.64%*
4 Stars- (no label)	*103*	*24.07%*
5 Stars- Very much a strain	*90*	*21.03%*

Q17. On a scale of 1 to 5, how emotionally stressful would you say caregiver is/has been?

Answered: 428 *Skipped: 341* *Weighted Average: 4.00*

Answer Choice	*Responses*	
1 Star- Not stressful at all	*16*	*3.74%*
2 Stars- (no label)	*31*	*7.24%*
3 Stars- (no label)	*86*	*20.09%*
4 Stars- (no label)	*100*	*23.36%*
5 Stars- Very stressful	*195*	*45.56%*

Q18. On a scale of 1 to 5, how much of a financial strain would you say caregiving is/has been?

Answered: 428 *Skipped: 341* *Weighted Average: 3.72*

Answer Choice	*Responses*	
1 Star- Not at all a strain	*30*	*7.01%*
2 Stars - (no label)	*50*	*11.68%*
3 Stars- (no label)	*93*	*21.73%*

4 Stars- (no label)	92	21.50%
5 Stars- Very much a strain	163	38.03%

Q19. Below is a list of financial impacts that some caregivers have experienced. Select any and all that apply to you.

Answered: 428 Skipped: 341

Answer Choice	Responses	
None of the above	74	17.29%
Taken on more debt (credit cards, loans, line of credit)	171	39.95%
Missed/Was late paying for student loan	54	12.62%
Borrowed money from family or friends	189	44.16%
Filed for bankruptcy (medical or personal)	34	7.94%
Been unable to afford basic need expenses like food	158	36.92%
Left your bills unpaid or paid them late	233	54.44%
Used up your personal short-term savings	183	42.76%
Used long-term savings like retirement to pay for things	72	16.82%
Stopped saving or stopped trying to save money	252	58.88%
Moved to a less expensive home, apartment or other living arrangement	87	20.33%
Was evicted or had a home foreclosed	32	7.48%
Delayed your retirement or decided to never retire	28	6.54%
Had to start working again, working ore, or find second job	75	17.52%

Q20. How would you say being a caregiver plays/played a role in your overall health?

Answered: 428 Skipped: 341

Answer Choice	Responses	
Made/Makes it better	28	6.54%
Not affected	67	15.65%
Made/Makes it worse	180	42.06%
Unsure	140	32.71%
Prefer not to answer	13	3.04%

Q21. How old is/was the person you care/cared for?

Answered: 388 Skipped: 381

Answer Choice	Responses	
Less than 12 months	6	1.55%
12 months to 4 years	20	5.15%
5 years to 13 years	61	15.72%
14 years to 18 years	9	7.47%
19 years to 24 years	18	4.64%
25 years to 34 years	18	4.64%

35 years to 44 years	*17*	*4.38%*
45 years to 54 years	*34*	*8.76%*
55 years to 64 years	*48*	*12.37%*
65 years or older	*137*	*35.31%*

Q22. Is/Was the person you care/cared for, or do/did they identify as...

Answered: 388 *Skipped: 381*

Answer Choice	*Responses*	
Male	*188*	*48.45%*
Female	*188*	*48.45%*
Non-binary	*3*	*0.77%*
Prefer not to answer	*9*	*2.32%*

Q23. What is your relationship with this person?

Answered: 388 *Skipped: 381*

Answer Choice	*Responses*	
Husband	*21*	*5.41%*
Wife	*25*	*6.44%*
Mother/In Law	*109*	*28.09%*
Father/In Law	*32*	*8.25%*
Daughter/In Law	*59*	*15.21%*
Son/In Law	*43*	*11.08%*
Brother/In Law	*7*	*1.80%*
Sister/In Law	*14*	*3.61%*
Aunt	*6*	*1.55%*
Uncle	*1*	*0.26%*
Grandfather/ In Law	*1*	*0.26%*
Grandmother/ In Law	*14*	*3.61%*
Grandson	*2*	*0.52%*
Granddaughter	*9*	*2.32%*
Nephew	*1*	*0.26%*
Niece	*2*	*0.52%*
Companion/Partner	*2*	*0.52%*
Foster Child (NONRELATIVE)	*1*	*0.26%*
Friend (NONRELATIVE)	*12*	*3.09%*
Neighbor (NONRELATIVE)	*4*	*1.03%*
Prefer not to answer	*8*	*2.06%*
Other	*15*	*3.87%*

Q24. What is the primary diagnosis or illness the care recipient has/had, or which they need/needed your care?

Answered: 388 *Skipped: 381*

Answer Choice	*Responses*	
Alzheimer's/Dementia, confusion, forgetfulness	*51*	*13.14%*
Arthritis	*14*	*3.61%*
Blood Pressure/Hypertension	*8*	*2.06%*
Brain damage/injury	*16*	*4.12%*
Broken bones	*3*	*0.77%*
Cancer	*37*	*9.54%*
Developmental/Intellectual Disorder, Down Syndrome	*57*	*14.69%*
Diabetes	*9*	*2.32%*
Feeble, unsteady, frequent falls	*12*	*3.09%*
Hearing loss, deafness	*0*	*0.00%*
Heart disease, heart attack	*8*	*2.06%*
Lung disease, emphysema, COPD	*13*	*3.35%*
Mental illness, emotional illness, depression	*35*	*9.02%*
Mobility issues	*15*	*3.87%*
Old age, aging	*12*	*3.09%*
Parkinson's	*3*	*0.77%*
Stroke	*8*	*2.06%*
Substance abuse	*4*	*1.03%*
Surgery, wounds	*7*	*1.80%*
Vision loss, blindness	*3*	*0.77%*
Unsure	*5*	*1.29%*
Prefer not to answer	*12*	*3.09%*
Other	*56*	*14.43%*

Q25. Please select any additional/multiple diagnoses the care recipient has been diagnosed with.

Answered: 388 *Skipped: 381*

Answer Choice	*Responses*	
Alzheimer's/Dementia, Confusion, Forgetfulness	*47*	*12.11%*
Arthritis	*78*	*20.10%*
Blood Pressure/Hypertension	*117*	*30.15%*
Brain damage/injury	*26*	*6.70%*
Broken bones	*29*	*7.47%*
Cancer	*25*	*6.44%*
Developmental/Intellectual Disorder, Downs Syndrome	*57*	*14.69%*
Diabetes	*60*	*15.46%*
Feeble, unsteady, frequent falls	*110*	*28.35%*
Hearing loss, deafness	*44*	*11.34%*
Heart disease, heart attack	*45*	*11.60%*
Lung disease, emphysema, COPD	*41*	*40.57%*
Mental illness, emotional illness, depression	*106*	*27.32%*
Mobility issues	*142*	*36.60%*
Old age, aging	*87*	*22.42%*

Parkinson’s	*6*	*1.55%*
Stroke	*38*	*9.79%*
Substance abuse	*19*	*4.90%*
Surgery, wounds	*46*	*11.86%*
Vision loss, blindness	*40*	*10.31%*
Unsure	*19*	*4.90%*
Prefer not to answer	*16*	*4.12%*
Other	*80*	*20.62%*

Q26. Has the care recipient been diagnosed with Alzheimer’s or any other dementia?

Answered: 388 *Skipped: 381*

Answer Choice	*Responses*	
Yes	*56*	*14.43%*
No	*332*	*85.57%*

Q27. Has the care recipient served in the US Armed Forces? This includes Army, Navy, Air Force, Marines, Coast Guard, Women’s Armed Forces, National Guard or Reserves.

Answered: 388 *Skipped: 381*

Answer Choice	*Responses*	
Yes, currently service	*0*	*0.00%*
Yes, have served but not currently	*32*	*8.25%*
No, have not served	*350*	*90.21%*
Unsure/ Prefer not to answer	*6*	*1.55%*

Q28. How long have you been, or did you provide care to this person?

Answered: 388 *Skipped: 381*

Answer Choice	*Responses*	
Less than 1 year	*48*	*12.37%*
1 year to 5 years	*165*	*42.53%*
5 years to 10 years	*71*	*18.30%*
10+ Years	*104*	*26.80%*

Q29. Which of these best describes how much care or assistance you give/have given to this person because of their condition within a normal week?

Answered: 388 *Skipped: 381*

Answer Choice	*Responses*	
All the time; 24/7	*108*	*27.84%*
Almost all the time, only small breaks here and there	*64*	*16.49%*
Almost all the time, only break to sleep	*25*	*6.44%*

Off and on around the clock	140	36.08%
Other	51	13.14%

Q30. Which of these tasks do you/did you assist the person with?

Answered: 388 Skipped: 381

Answer Choice	Responses	
None of the above	3	0.77%
Getting in and out of beds/chairs	177	45.62%
Getting dressed	203	52.32%
Getting to/from bathroom or toilet	161	41.49%
Bathing/Showering	210	54.12%
Incontinence or Diapers	138	35.57%
Feeding or assistance feeding	130	33.51%
Medication Assistance (giving medications, eye drops, injections)	266	68.56%
Managing Finances (paying bills or filling out insurance forms)	230	59.28%
Grocery shopping or other shopping	298	76.80%
Housework (doing dishes, laundry, dusting)	293	75.52%
Preparing meals	303	78.09%
Transportation (driving or assisting in getting transportation services)	317	81.70%
Arranging outside services (nurses, home care aides, direct care support, meals on wheels)	159	40.98%
Advocating for the individual with healthcare providers, community services or government agencies	237	61.08%
Monitoring severity of their condition in order to adjust care when needed	240	61.86%
Other	30	7.73%

Q31. In the last 12 months (or the last year of previous caregiving duties), how many times has/had the care recipient been hospitalized overnight?

Answered: 388 Skipped: 381

Answer Choice	Responses	
None	206	53.09%
Once	51	13.14%
Twice	36	9.28%
3 or more times	78	20.10%
Unknown	17	4.38%

Q32. Has anyone else provided UNPAID help for the care recipient during your time as a caregiver?

Answered: 377 Skipped: 392

Answer Choice	Responses	
Yes	131	34.75%

No	*220*	*58.36%*
Unsure	*20*	*5.31%*
Prefer not to answer	*6*	*1.59%*

Q33. Has the care recipient received PAID help from any aides, housekeepers, or other people who were paid for their work/assistance during your time as a caregiver?

Answered: 377 *Skipped: 392*

Answer Choice	*Responses*	
Yes	*103*	*27.32%*
No	*253*	*67.11%*
Unsure	*21*	*5.57%*
Prefer not to answer	*0*	*0.00%*

Q34. Is/Was the care recipient on any Medicaid Waiver or Arkansas State Plan Waiver program offered by the Arkansas Department of Human Services?

Answered: 377 *Skipped: 392*

Answer Choice	*Responses*	
Yes	*74*	*19.63%*
No	*223*	*59.15%*
Unsure	*78*	*20.69%*
Prefer not to answer	*2*	*0.53%*

Q35. Is/Was the care recipient on any waitlist for services or programs offered by the Arkansas Department of Human Services?

Answered: 377 *Skipped: 392*

Answer Choice	*Responses*	
Yes	*50*	*13.26%*
No	*257*	*68.17%*
Unsure	*70*	*18.57%*
Prefer not to answer	*0*	*0.00%*

Q36. Is/Was the care recipient denied for any services or programs offered by the Arkansas Department of Human Services?

Answered: 377 *Skipped: 392*

Answer Choice	*Responses*	
Yes	*52*	*13.79%*
No	*236*	*62.60%*
Unsure	*89*	*23.61%*
Prefer not to answer	*0*	*0.00%*

Q37. Do you know which service program the care recipient has applied/had applied for or is currently receiving?

Answered: 377 *Skipped: 392*

Answer Choice	*Responses*	
None of the above	*215*	*57.03%*
ARChoices	*30*	*7.96%*
IndpendentChoices (self-directed personal care)	*11*	*2.92%*
Autism Waiver	*20*	*5.31%*
PASSE	*48*	*12.73%*
Community and Employment Supports (CES)	*6*	*1.59%*
TEFRA	*30*	*7.96%*
PACE	*4*	*1.06%*
LivingChoices	*5*	*1.33%*
Other	*51*	*13.53%*

Q38. Select below any and all places you use/used to learn more or gather information to better help you as a caregiver.

Answered: 377 *Skipped: 392*

Answer Choice	*Responses*	
None of the above	*43*	*11.41%*
Doctor or Health Care Professional	*259*	*68.70%*
Friends or Family	*190*	*50.40%*
Local Government Agencies (County Health Facilities/County Offices)	*70*	*18.57%*
State Government Agencies like the Arkansas Department of Human Services, Arkansas Department of Health	*104*	*27.59%*
Local Hospital or other care facility	*128*	*33.95%*
Online or social media	*160*	*42.44%*
Non-Profit or Advocacy Organization for aging, caregiving, or specific conditions	*75*	*19.89%*

Q39. Have you ever heard of caregiver respite before this survey?

Answered: 367 *Skipped: 402*

Answer Choice	*Responses*	
Yes	*103*	*28.07%*
No	*256*	*69.75%*
Unsure/Prefer not to answer	*8*	*2.18%*

Q40. Do you know where to find respite care in the state of Arkansas?

Answered: 367 *Skipped: 402*

Answer Choice	*Responses*	
Yes	*34*	*9.26%*
No/Unsure	*332*	*90.46%*
Prefer not to answer	*1*	*0.27%*

Q41. If you have received respite care within the last 12 months, how easy was it for you to find?

Answered: 367 *Skipped: 402*

Answer Choice	*Responses*	
I have not received respite care in the last 12 months	*338*	*92.10%*
Not easy at all	*13*	*3.54%*
Somewhat easy	*8*	*2.18%*
Easy	*3*	*0.82%*
Pretty easy	*3*	*0.82%*
Very easy	*3*	*0.54%*

Q42. If you received respite care, who provided that care for you?

Answered: 367 *Skipped: 402*

Answer Choice	*Responses*	
I have not received respite care	*318*	*86.85%*
A family member	*35*	*9.54%*
A friend	*7*	*1.91%*
A faith-based organization/church group or event	*4*	*1.09%*
Community group or event	*2*	*0.54%*
A service provider	*11*	*3.00%*
Other	*5*	*1.36%*

Q43. Did you pay out of pocket for the respite care?

Answered: 367 *Skipped: 402*

Answer Choice	*Responses*	
Yes	*19*	*5.18%*
No	*78*	*21.25%*
Unsure	*12*	*3.27%*
I did not receive respite care/Prefer not to answer	*258*	*70.30%*

Q44. If you were to receive some free time or a break from your caregiving duties, what do you think you would do with that time?

Answered: 367 *Skipped: 402*

Answer Choice	*Responses*	
Spend time with spouse/significant other	*127*	*34.60%*

Spend time with other family/friends	160	43.60%
Run errands	169	46.05%
Complete household tasks	163	44.41%
Private time to relax, rest	241	65.67%
Pursue hobbies/interests	121	32.97%
Participate in physical activities or exercise	108	29.43%
Attend or participate in caregiver workshops/training or support groups	52	14.17%
Participate in social/recreational activities, including church	101	27.52%
Other	52	14.17%

Q45. If the situation arises, would you be interested in participating in future research on caregivers?

Answered: 354 Skipped: 415

Answer Choice	Responses	
Yes	244	68.93%
No	110	31.07%

Q46. Your information and answers provided in this survey are confidential; however, if a reporter writing a story about the results of the overall survey wanted to interview caregivers who participated, would you be willing to provide your information? (This is completely optional)

Answered: 354 Skipped: 415

Answer Choice	Responses	
Yes	150	42.37%
No	204	57.63%