

Nebraska Lifespan Respite Network

Nebraska's Working Caregiver Survey

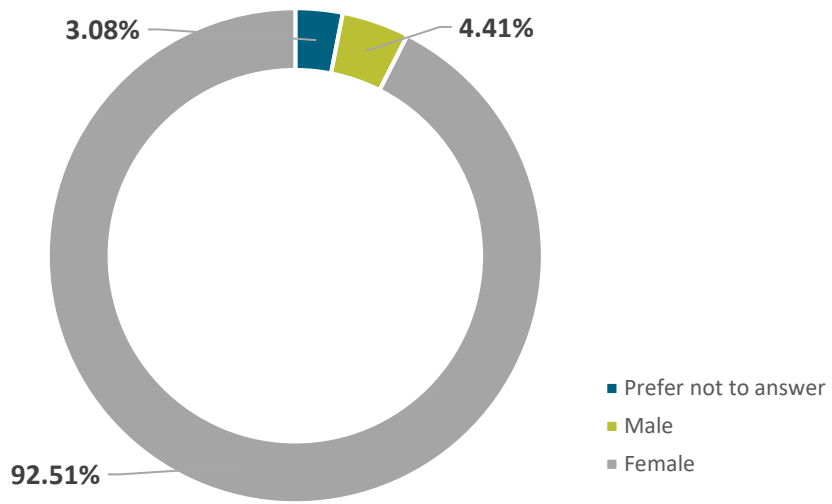
Employer Data Report
2021 Year End



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8-30-2021

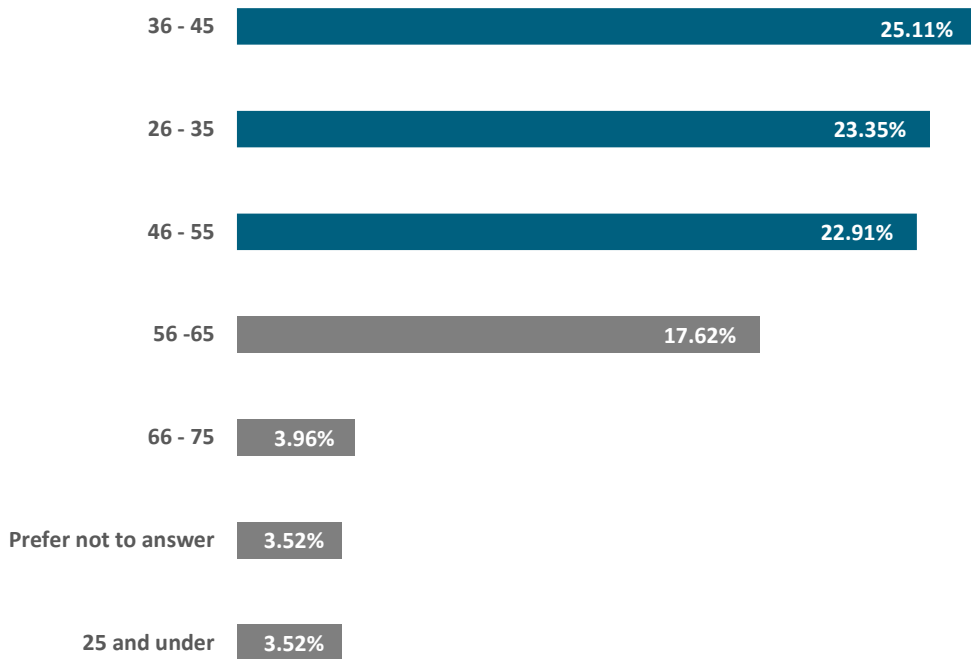
Who were the respondents?

The majority of respondents are female.



n = 227

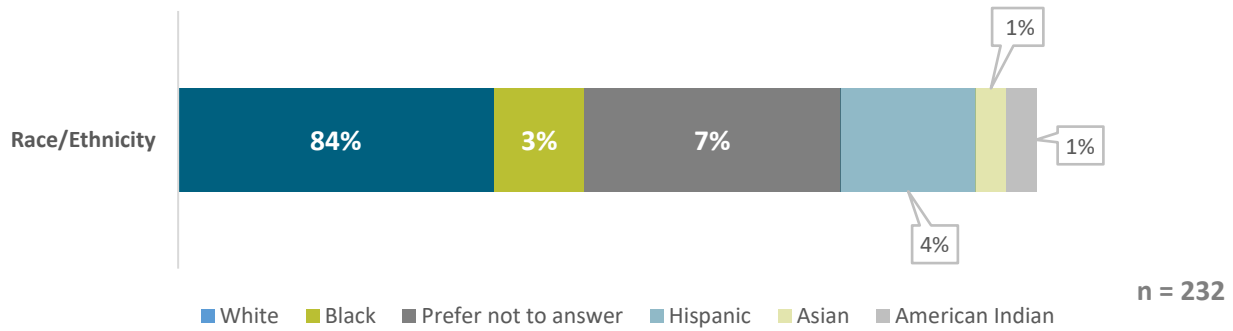
The majority of respondents are 36-45 years of age but there is a large range between 26 – 55 years.



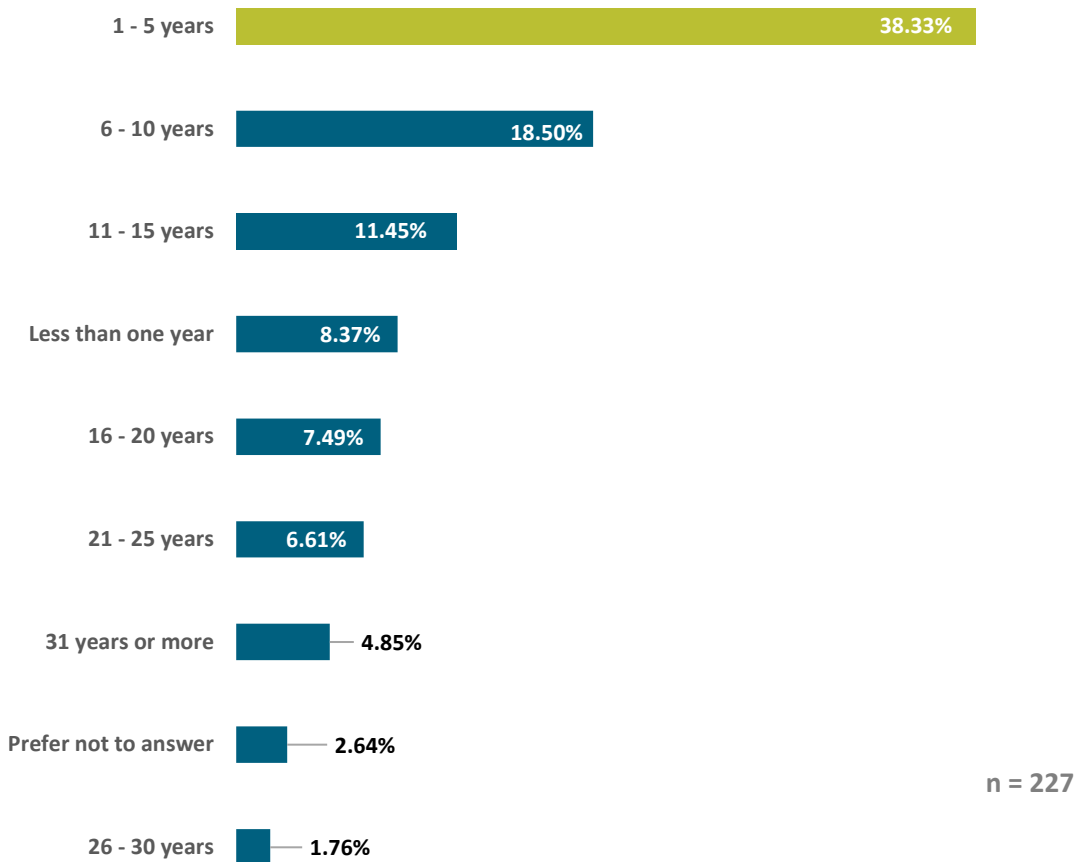
n = 227



The majority of respondents are white.



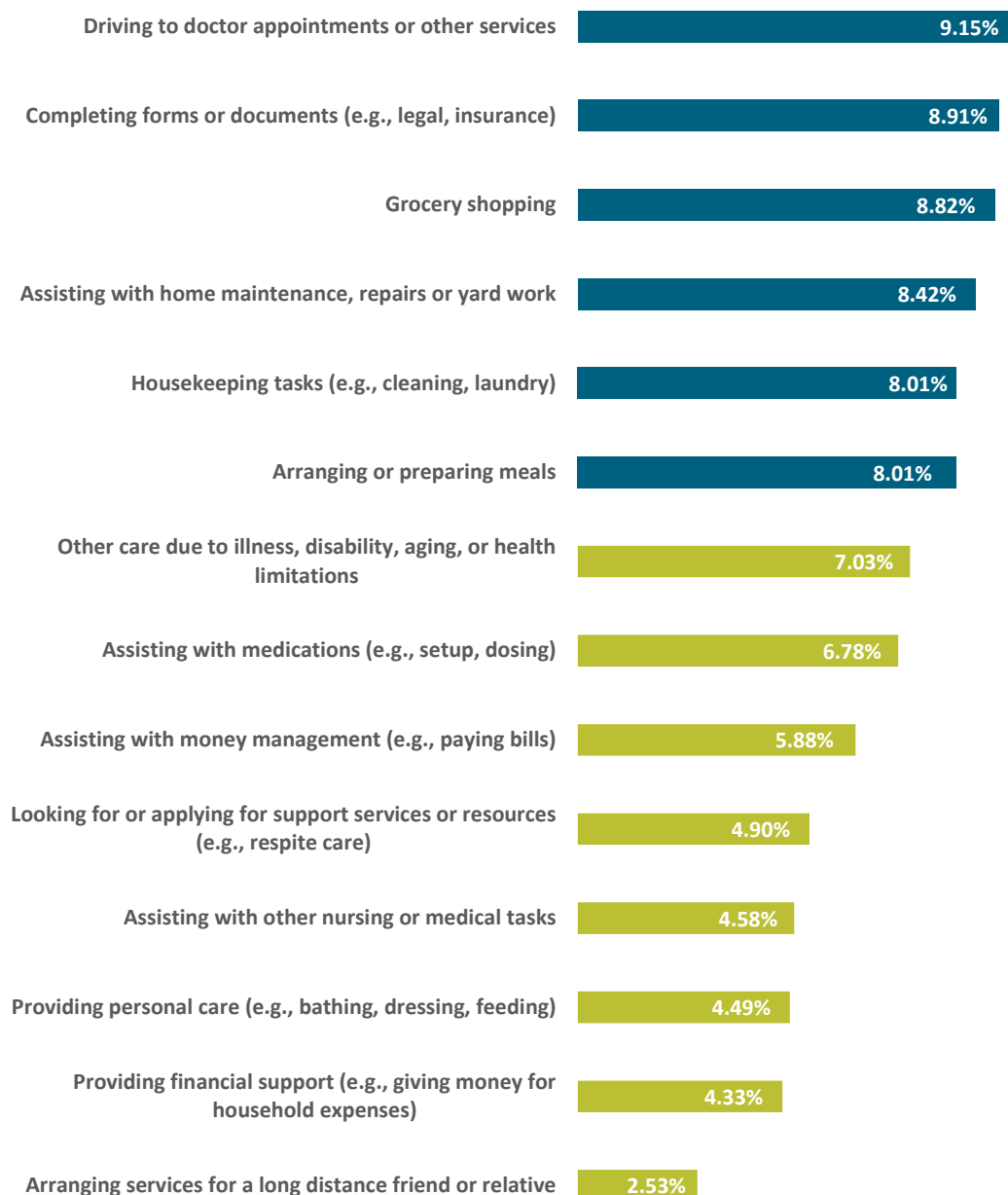
The majority of respondents have been employed by their organization 1 - 5 years.



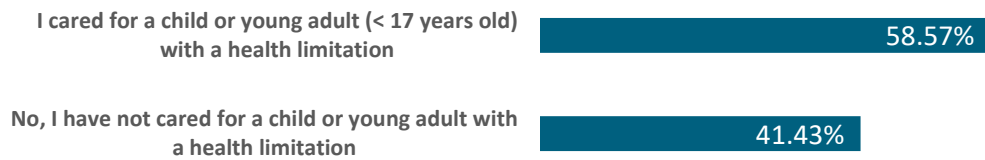
The majority of respondents reported helping an adult family member or friend in the past 6 months.



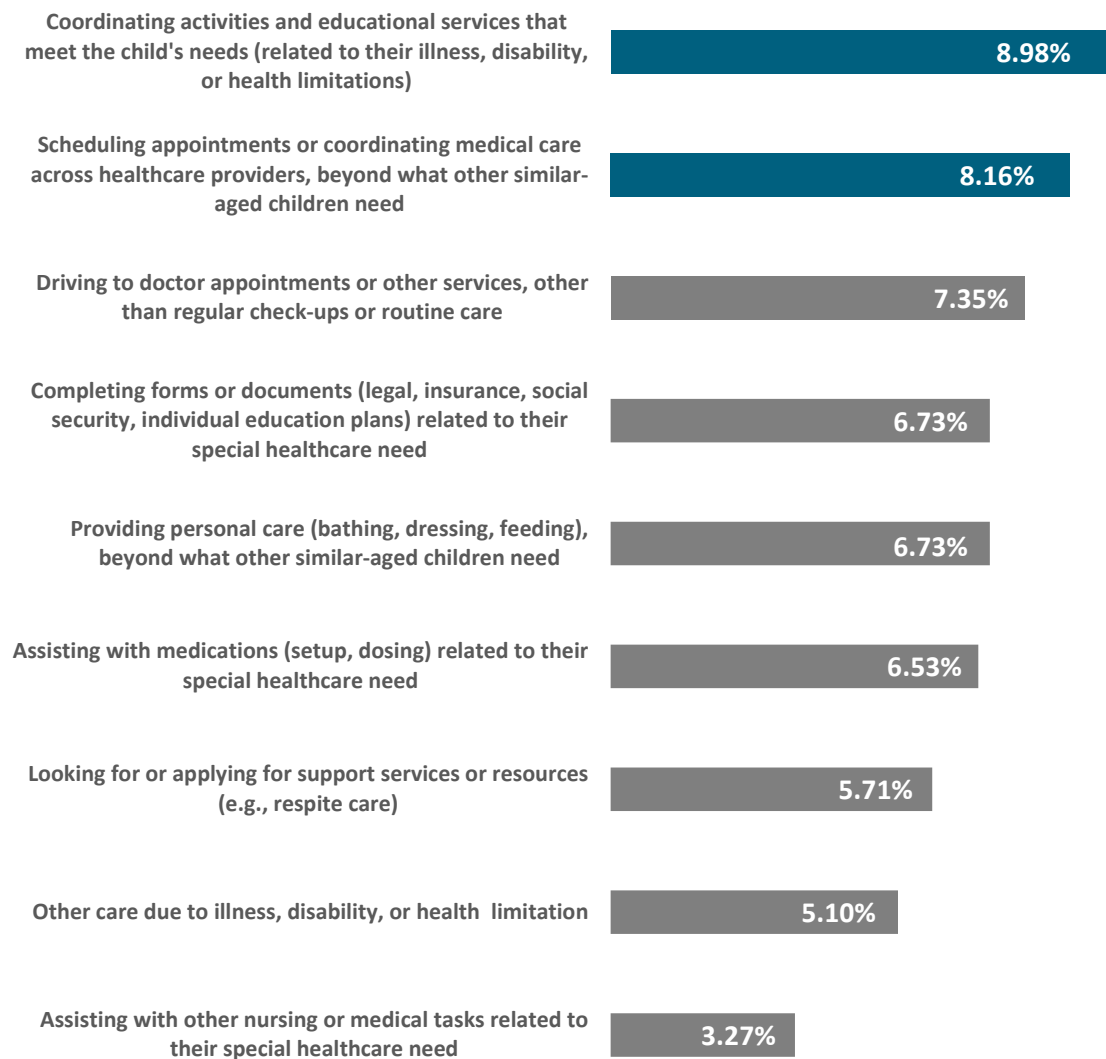
The most prevalent reported caregiving tasks is **driving to doctor appointment or other services**. Several tasks received similar percentages.



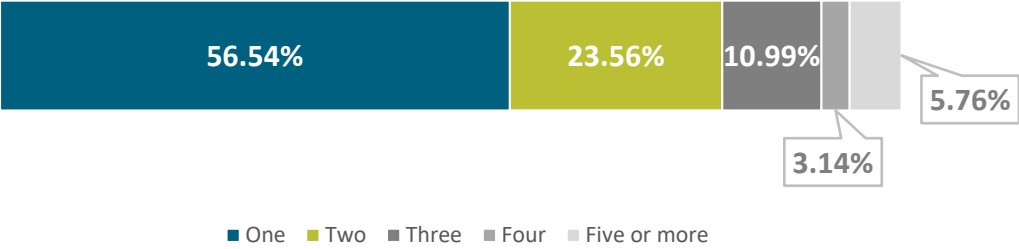
Over half of respondents reported caring for a child or young adult with a health limitation in the past 6 months.



The most prevalent reported task is coordinating activities and educational services that meet the child's needs. Scheduling appointments and medical care was also a frequently reported task.

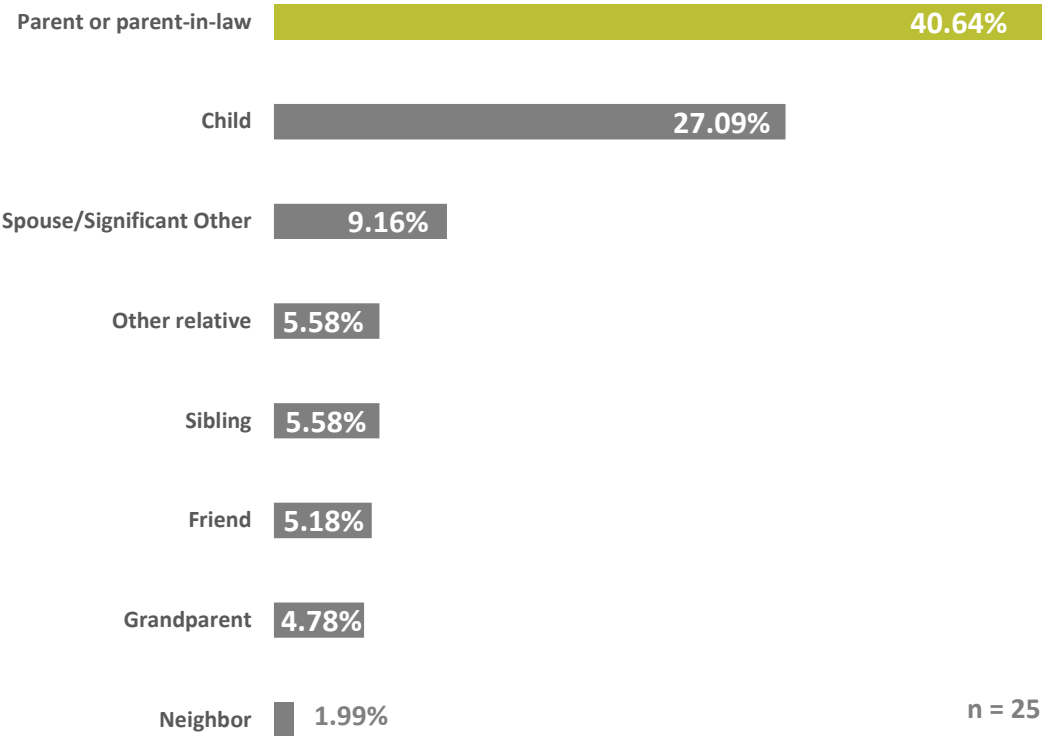


The majority of respondents reported caring for **one** individual. Some care for **two** and three individuals.



n = 191

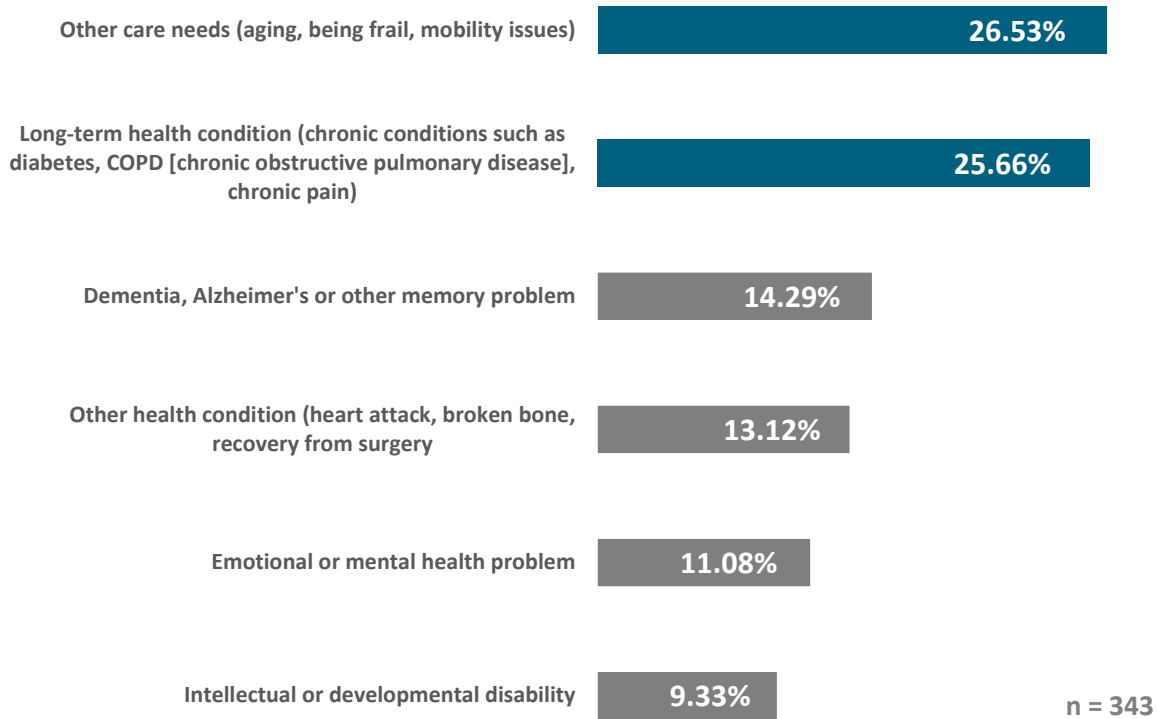
The majority of respondents reported caring for **a parent/parent in-law**.



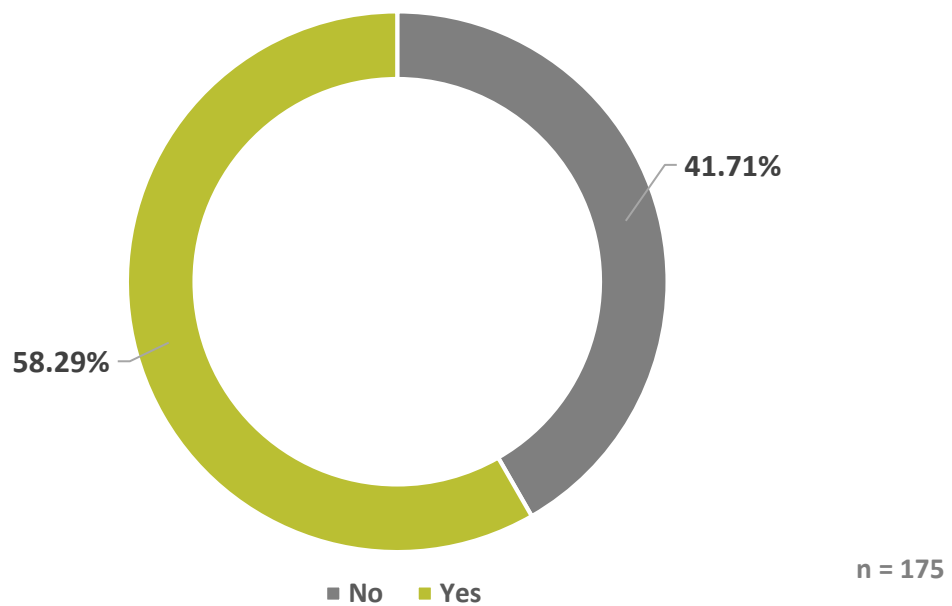
n = 251



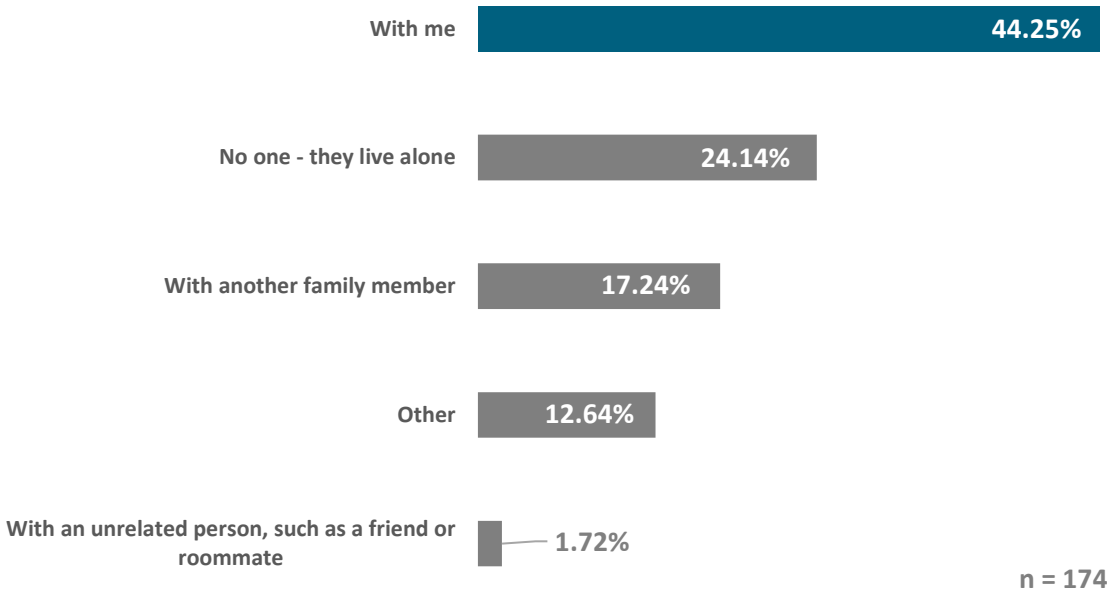
The most prevalent conditions requiring care are other care needs and long-term health condition.



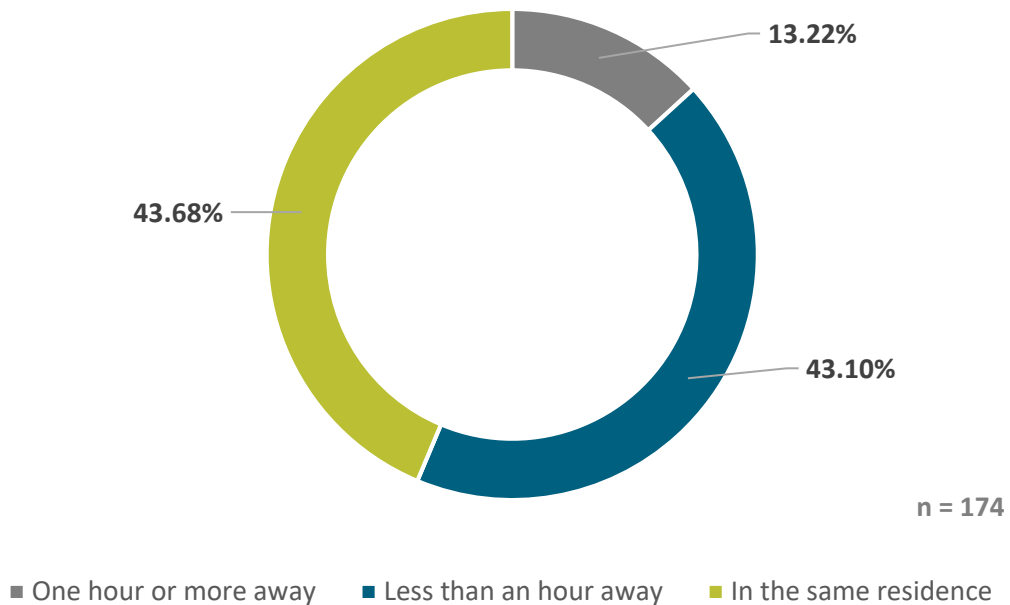
The majority of respondents are the primary caregiver for the individual they care for.



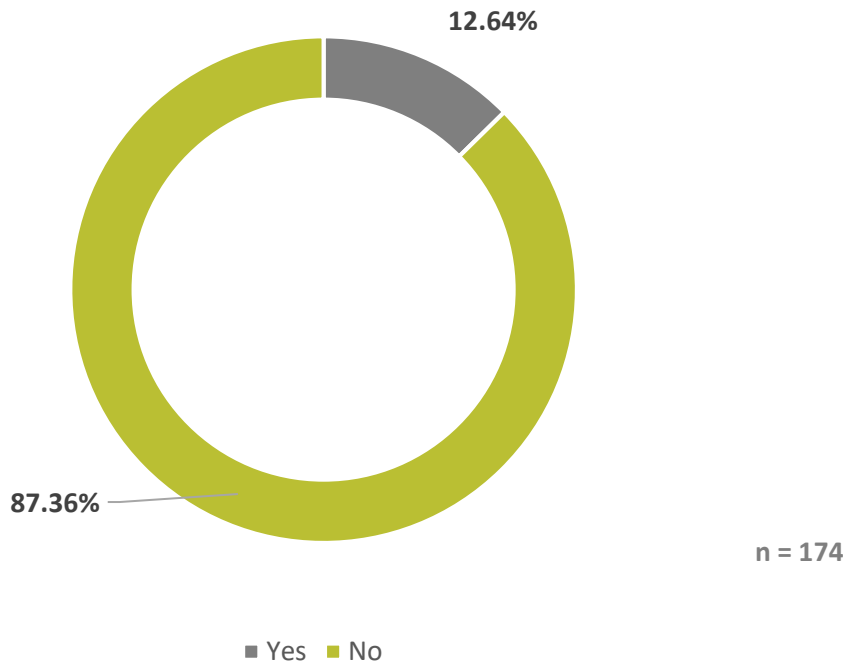
Most respondents report the individual they care for lives with them.



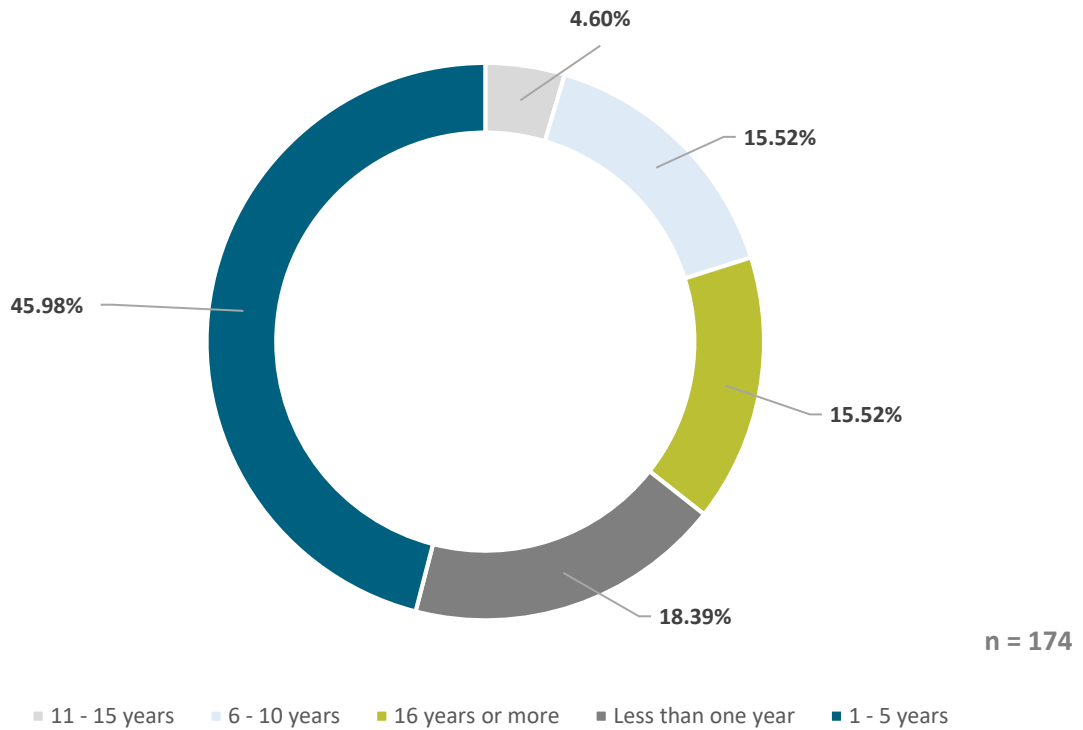
The majority of caregivers live with or less than an hour away from the individual they care for.



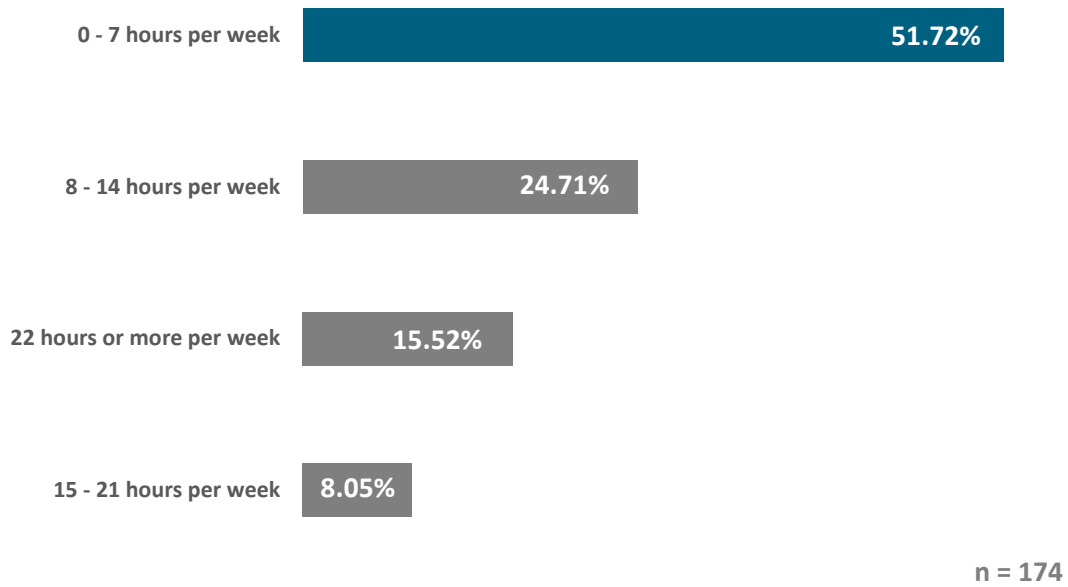
Few caregivers provide care for individuals living in an assisted living or residential care facility.



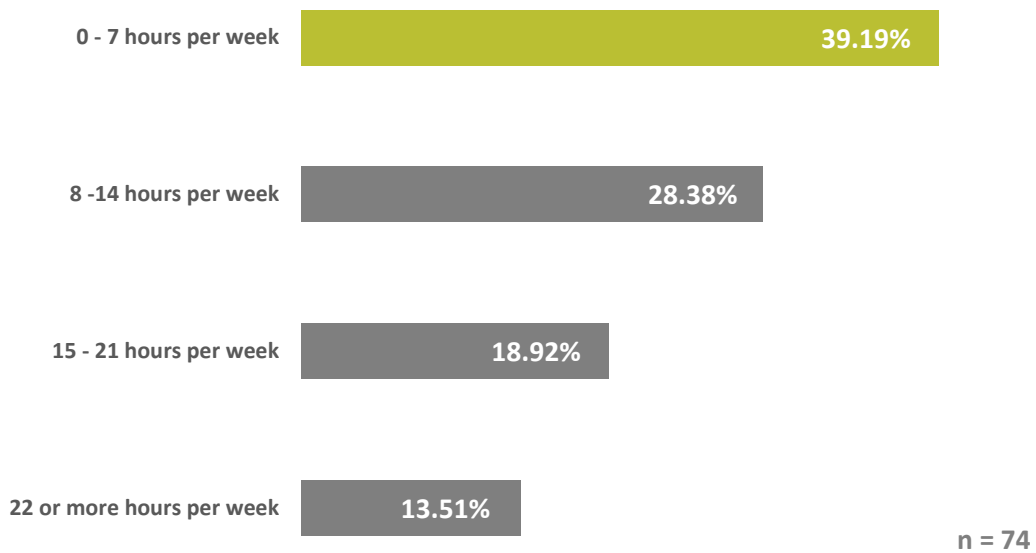
Most respondents report providing care for 1 - 5 years.



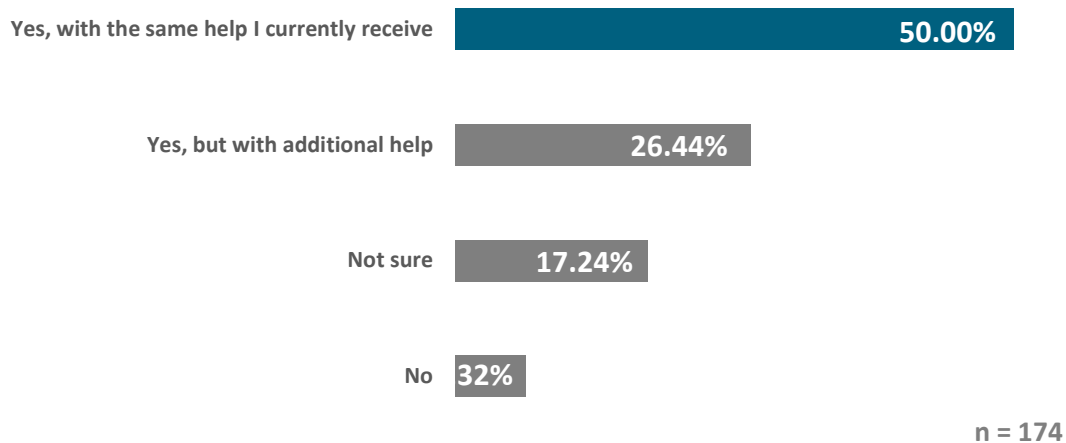
Over half of respondents provide care for 0 - 7 hours per week.



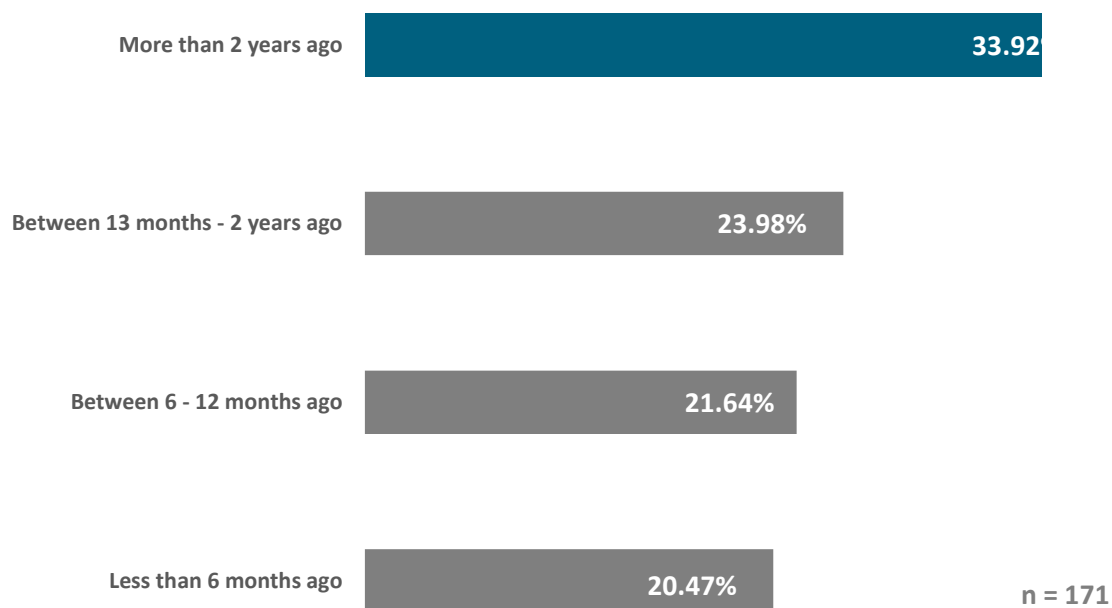
Caregivers who provide care for multiple individuals also provide 0 - 7 hours of care per week.



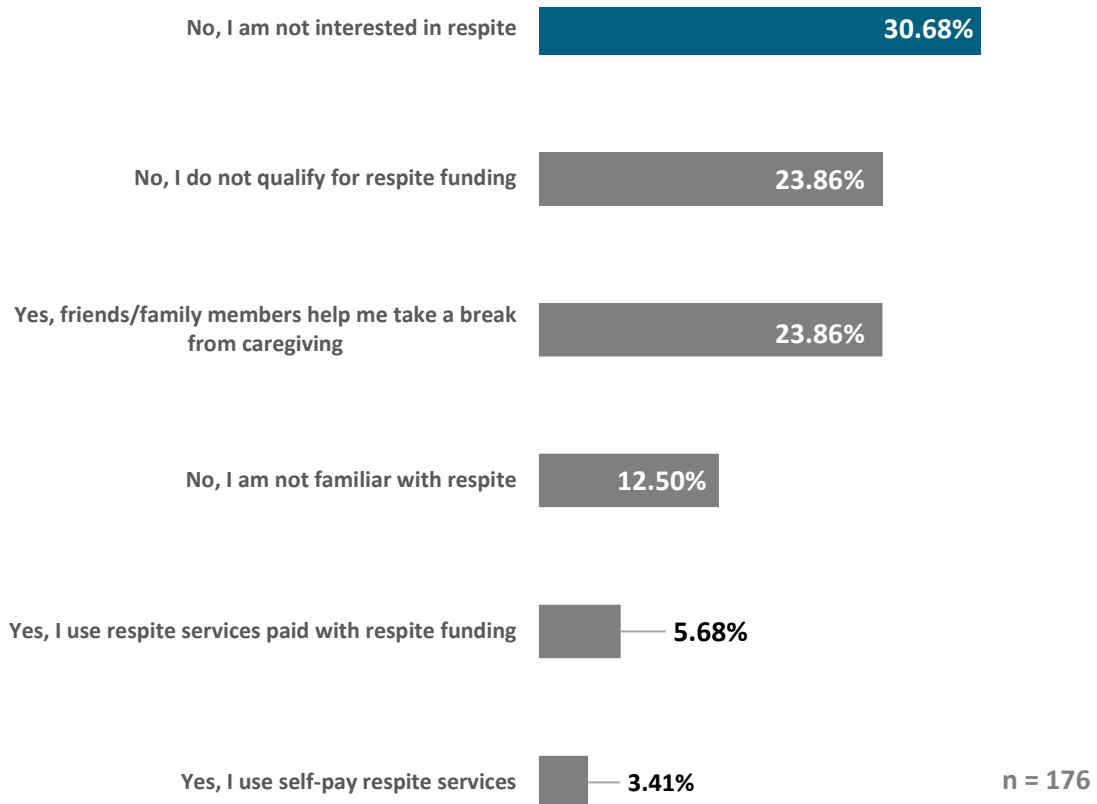
Half of these caregivers believe they will be able to continue providing care **with the same help they currently receive**. The other half need more help. Do they know about statewide Respite Resources that are available?



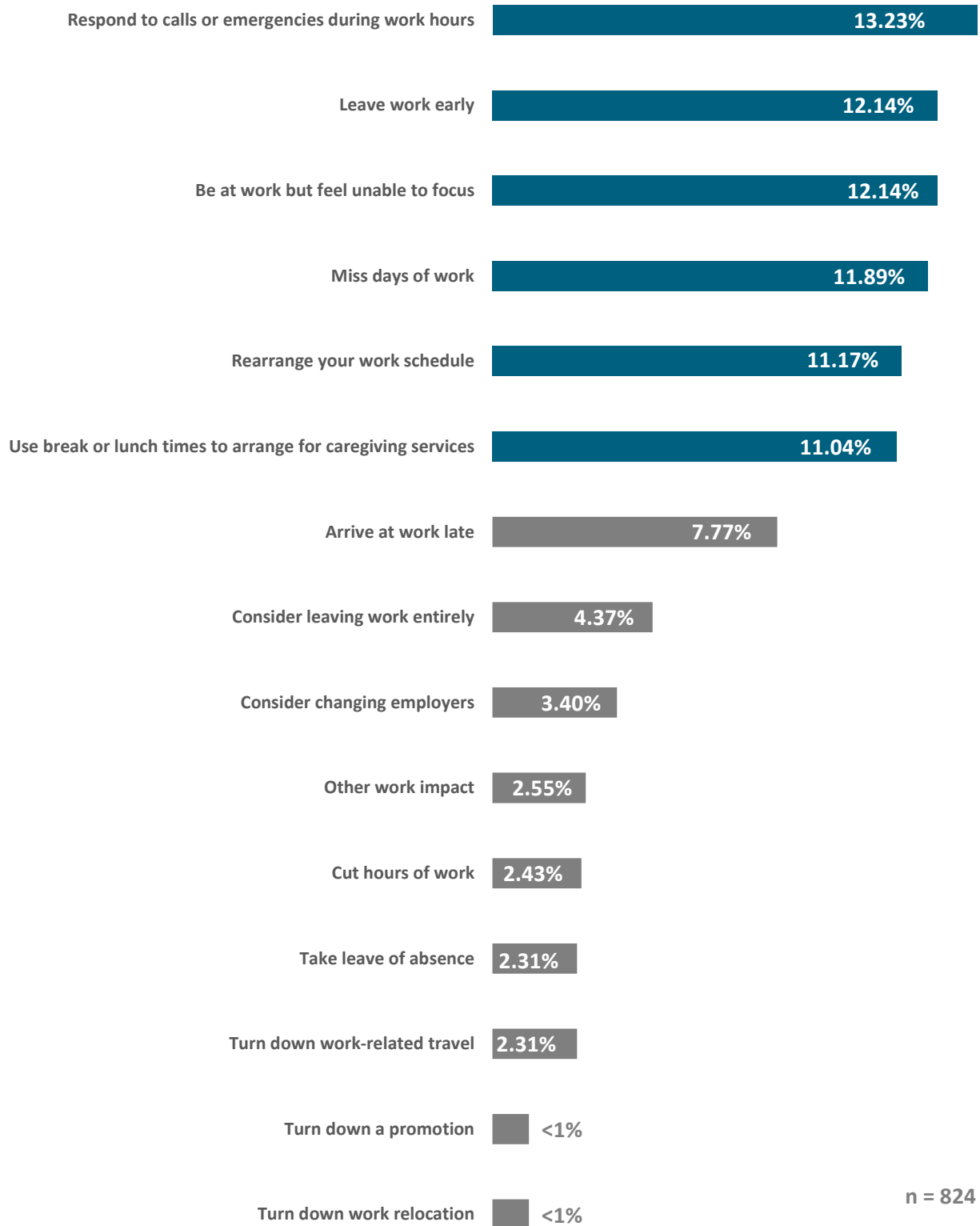
Over one-third of caregivers report it has been **more than two years** since they were able to take a vacation that allowed time away from their caregiving responsibilities.



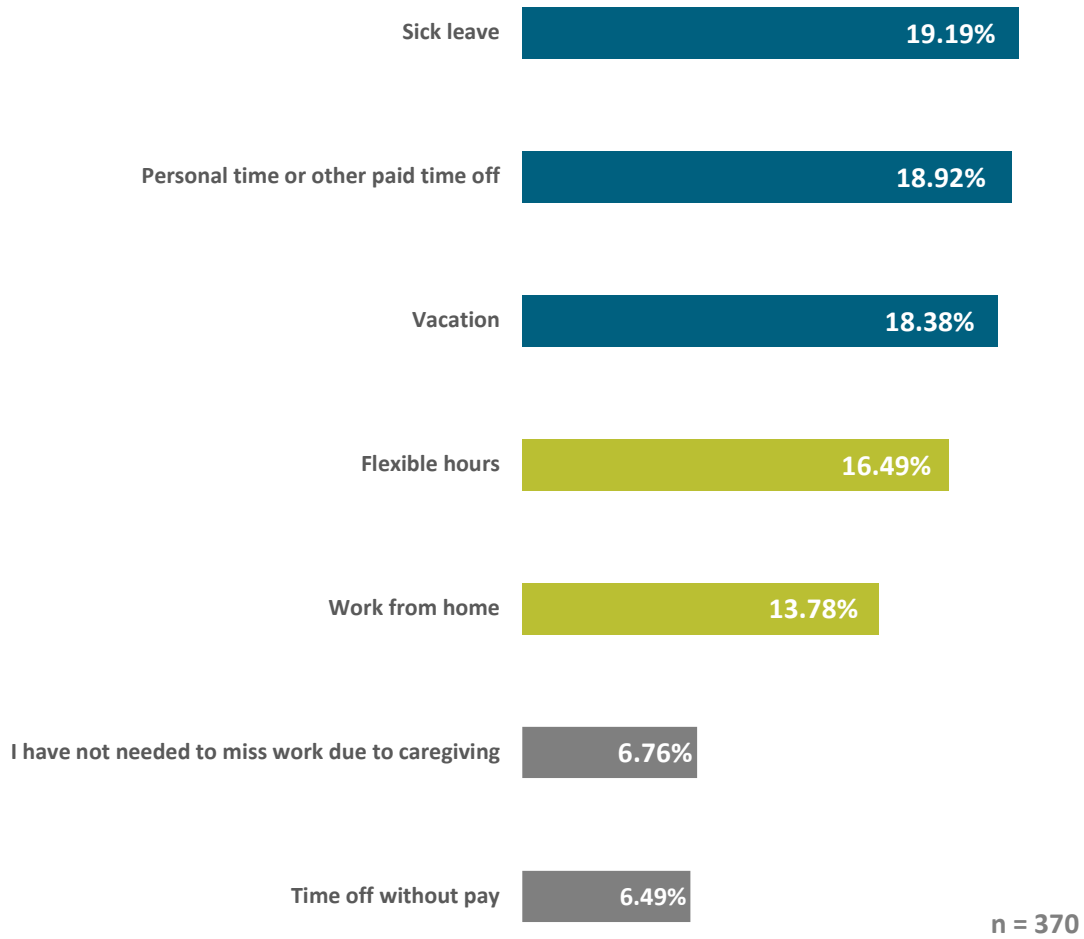
Most caregivers report they are not interested in respite. We wonder if they are aware of statewide respite resources that are available for free?



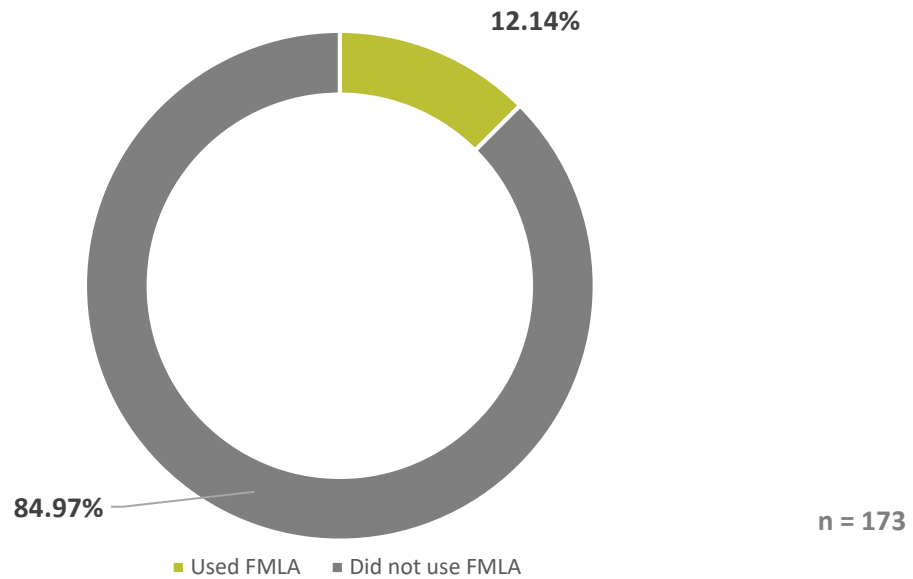
Caregivers report their caregiving responsibilities impact their responsibilities at work in a variety of ways.



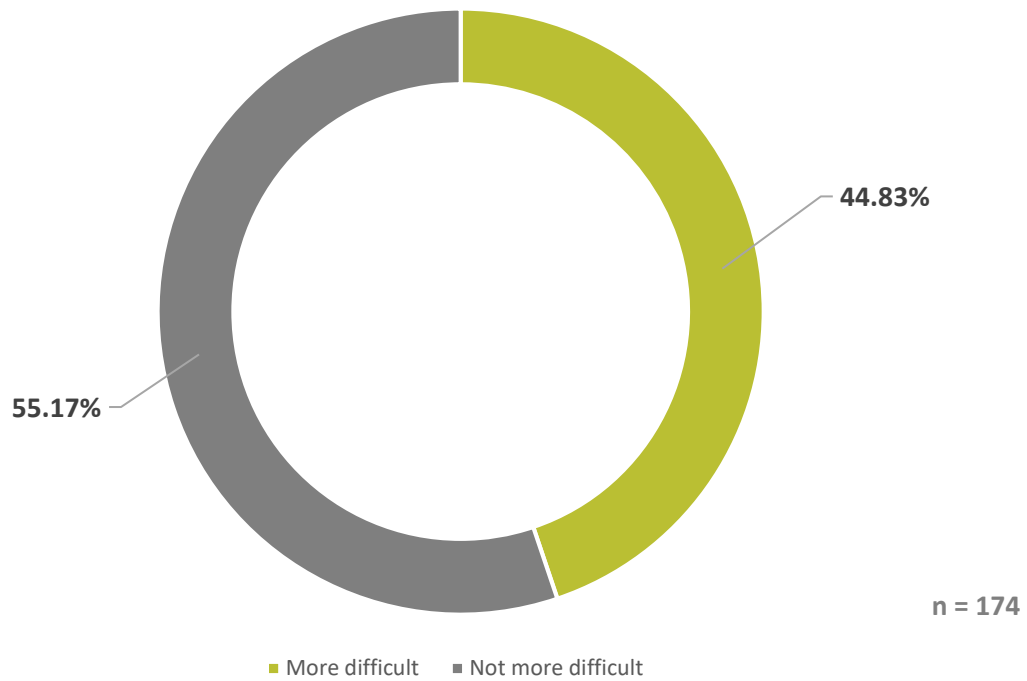
Many caregivers report using **sick leave, personal time or vacation** for time off from work to fulfill their caregiving responsibilities. **Flexible hours and working from home** help too.



Few caregivers report using Family Medical Leave Act (FMLA) for work time missed to fulfill their caregiving responsibilities.



Many caregivers report providing or arranging for care made their employment more difficult.



Respondents who reported providing and/or arranging care for the individual made their employment more difficult were asked to share specific examples related to this challenge. Four main themes emerged in their responses including (1) difficulty balancing caregiving and work responsibilities, (2) stress and emotions for caregivers, (3) employee leave usage (4) employer flexibility. The caregiver responses are grouped below according to these themes. Caregiver responses that did not align with the identified themes are listed as additional difficulties below.



Difficulty Balancing Caregiving and Work Responsibilities

- Pressure to leave work on time. Not participating in other organizational activities/committees due to caregiving.
- Child gets sick and I have to leave work immediately. Child exposed to COVID. Had to two 14 days of self-isolation with him.
- Managing and attending to therapy while arranging my work duties, has become more complicated, overwhelming, and exhausting.
- It is extremely difficult to balance work and home because of care-giving responsibilities.
- More challenging to pursue additional opportunities at work due to time needed for caregiving. Not a promotion, but just opportunities that would help with career advancement.
- I have only been able to work part-time due to my caregiving responsibilities.
- It takes considerable effort to juggle work and caregiver responsibilities. The time to coordinate caregiving around work hours can be exhausting. Both caregiving and work require 17+ hour days to do all that is required.
- The only issue I have had is I feel guilty for letting my caregiving role interfere with my job needs. My employer has been supportive. I sometimes feel guilty and stressed due to my caregiver role.
- The demand of caring for a loved one and any form of employment will always take some sort of toll on an individual. Denying such is, in my opinion, ignoring the true problem of inability to care for loved ones & not work.
- I would receive multiple frantic calls and text messages while in meetings which would disrupt my focus for the topic in discussion.
- I feel I am not giving 100% and do not want my team to suffer.
- No one was able or willing to cover my position at the time.
- It's nothing my employers have control over that make it harder to work
- During the 11 years that I cared for my mother, I did a variety of things to make it all work. At one point I worked part time. Another time, I switched jobs and moved geographically to be closer to her. In the last two years I had more flexibility with my current employer to use flex time to care for her. It is incredibly difficult even with this flexibility. My mother passed away three months ago from COVID.



- It is hard to focus when you have a person with a disability who needs constant supervision at home. I am lucky that he is able to attend a day program but the days he is home, I schedule my meetings around his special needs and my aging mother's needs
- I provided care for an adult child, an adult sibling, and a parent while trying to work.
- With taking care of the needs of children in my home, I often have to rearrange my schedule or take off work early and I get phone calls when my children are at school. My employer has been great in letting me also work from home. I find at times that it is difficult to focus on work (either at home working or in the office).
- Primarily, being the primary caregiver during COVID-19 has required me to work from home and has increased this individual's dependency due to the need for social distancing (e.g., running all errands on their behalf, etc.).
- I have a special needs child and it is harder to arrange activities for him, I have to work around more medical appointments, etc.
- I currently help two elderly neighbors. I was the primary caregiver for my father who lived with me from 2012 until his death at 94 in 2020.
- Having to leave for therapy or medical appointments means that I make up a lot of time off hours. While my supervisor is great about allowing this to happen it also means that I miss a lot of discussions that happen during appointments and I am overlooked for major projects and a higher role within the team.

Stress and emotions for Caregivers

- Splitting attention/energy between caregiving for family and giving care as my job. Stress is also increased due to demands increasing on both sides. Wait list for patients is increasing.
- I am getting older and sometimes I feel burned out when I didn't used to feel that way.
- It is a second job. The additional strain is something that can bring joy or guilt. No matter what I do, I feel like I am not giving 100% to work or my loved one. Leads to a lot of guilt.
- Multiple doctor appointments, lab work, testing-MRI, EEG. It is extremely difficult to find caregivers. Have not had a break in years.
- Since this will be shared with my employer, I am not comfortable giving an example. However, it is extremely difficult to balance work and home because of care-giving responsibilities.
- I stand on my head to take care of someone and get all my work done whether that involves spending all night in the ER and then walking in right on time at 8 am to work without missing a beat. But I'm held to a higher criteria than others because of it. Although I meet those higher standards, it is unsustainable and unfair.
- The person I referenced here died within the past 6 months. However, it is important to note what things people go through. We had limited help and I hope that this will give opportunity for other people to find more help. The biggest thing we struggled with is the person not wanting to work with hospice (belief that they would be giving up the fight with cancer). The distance of being 6 hours away was also a huge factor. Also, the patient's refusal of care and wanting to depend on her daughter, my wife, for everything.
- Pressure and feeling like I am not supported but a burden to my employer.



Employee Leave Usage

- I have to use my time off to care for this individual instead of using my PTO for myself.
- I have had to use floating holiday and vacation hours to assist my mother-in-law when she has had emergency medical issues. Since she lives more than an hour away, in a care facility, I have needed to take 4 half days off in the last year.
- My department is not family friendly. It is required to give a 30day notice for appointments. Unfortunately, sometimes, life does NOT happen on a 30day notice. I am forced to use FMLA and use my PTO, I would prefer to even have the option to take no pay. I have to care for my parents. Both are elderly and have MS and Parkinson's disease. They need to have someone attend doctor appointments with them. One would think, that working in a medical facility, there would be more understanding with their employees with situations like this.
- Taking several unexcused days off even with FLMA it makes it difficult for coworkers and feeling always behind at work
- It is frowned upon by co-workers to take sick leave for children. My supervisor is ok with it, but certain co-workers complain.

Employer Flexibility

- My children have developmental disabilities that put them at higher risk of COVID-19 difficulties. They are therefore in remote school at home, which means that I must be at home with them during the day. My supervisor has been very supportive and has allowed me to work from home with flexible hours. I have therefore been able to complete all of my work with no negative impact on my work product or work relationship with my supervisor.
- The last year has been incredibly difficult as my child has been virtual learning due to COVID and her medical conditions. I have rearranged work responsibilities and had to reduce my hours to keep her safe due to her increased risk. Flexibility and working remotely have been a huge blessing to being able to stay in the work force and not sacrifice my career, again. I have had to make that choice in the past. My husband and I have not had a break from caregiving in almost a year since we do not have support services at this time. We are exhausted but trying to do the best we can to get through this.
- It is not difficult because my employer is difficult to work with or because they won't work with me. It's just difficult because caregiving for my 98-year-old mother is a full-time job in and of itself and having to work full time is just hard.
- I appreciate that I have been able to adjust work schedule to accommodate unexpected care needs. Supervisor has been very gracious and supportive. I don't believe it has affected my quality of work. I think the worry and guilt that often accompanies this care is common among caregivers. My co-workers are also very supportive, which is no helpful.
- I am a new employee and my parents have been chronically ill for several years. My supervisor is understanding, and I do try to limit my care taking time. COVID has affected this and sort of helped because doctor appointments can be done via telehealth so I can be a part of the calls remotely. I cannot go with my mom though to her oncology chemo treatments or when she was recently in the



hospital only one visitor was allowed to see her---this was tough because that was my dad, and he has dementia, so I don't feel like I was given a clear understanding of the plan of care while she was in the hospital.

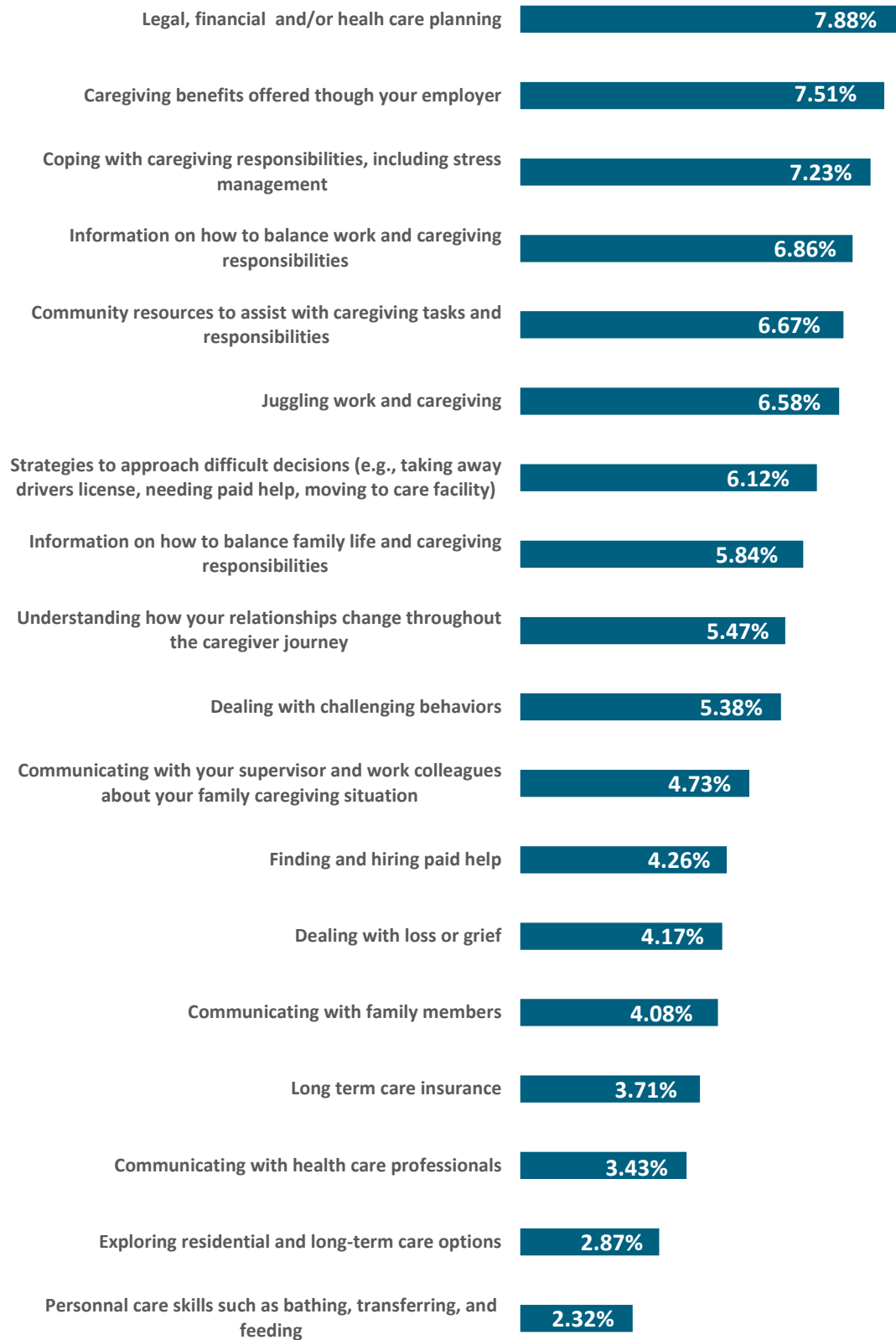
- I have left work in the middle of the day, taken off early, come in early to make up my time - I'm very fortunate to have a supportive work environment and great coworkers who cover for me when needed.

Other

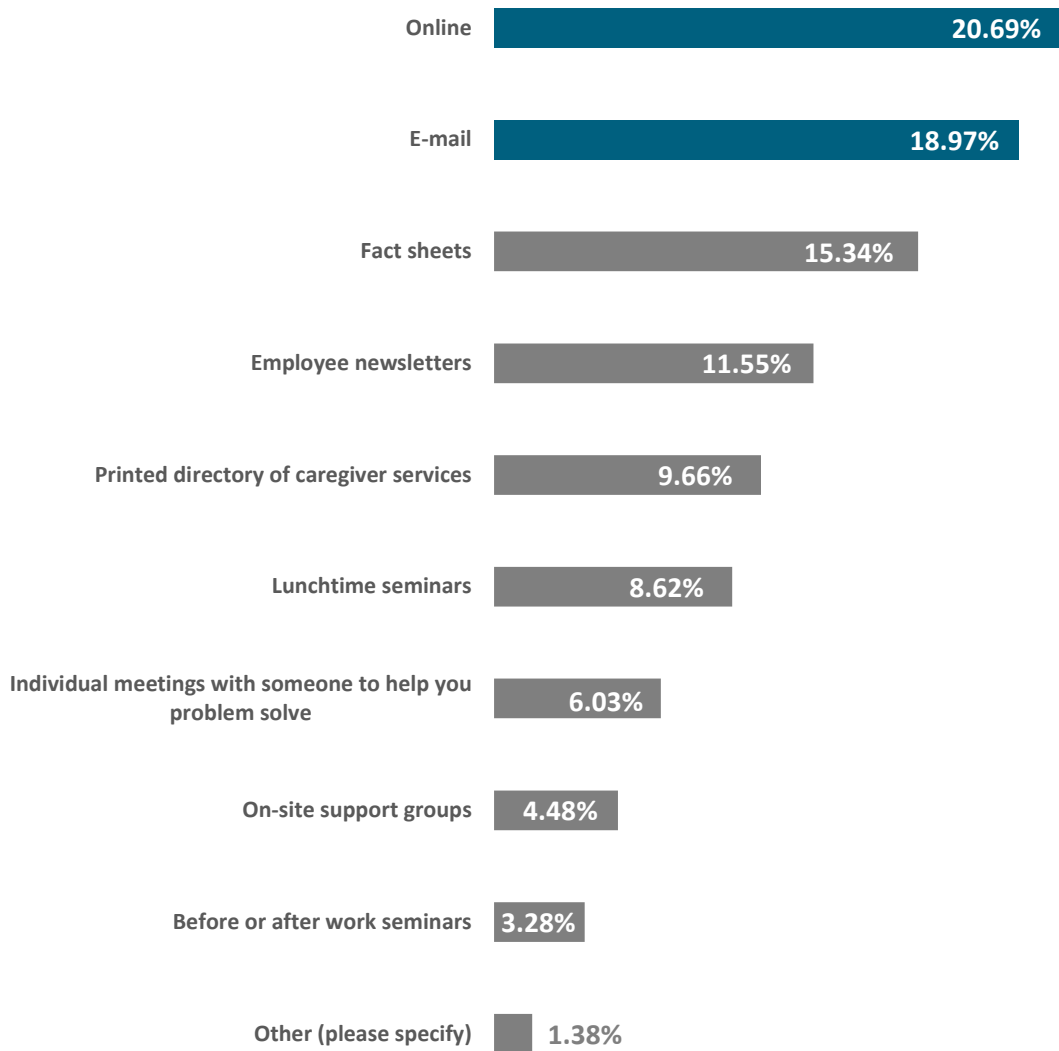
- As the health of my parents continue to deteriorate, I will need to make more significant changes to provide support for them.
- I do not get enough pay or hours to provide for all the resources that are needed.
- I wish this survey addressed my role as a caregiver within the last year, my answers would have been quite different before my father's death.



Respondents (both current caregivers and non-caregivers) are interested in learning more about a variety of caregiving topics.



Respondents report a preference for a variety of modalities for receiving caregiving information. Electronic communication **online and emails** were the preferred methods.



Other includes: Texts, all staff meetings, webinars and evening events.

