Exploring the Psychological Effects of Caregiving for Individuals with Dementia: The Role of Ethnicity and Culture

AP Research

Word Count: 4740

Introduction

In 2019, The World Health Organization reported that 55 million people around the world were living with dementia. This number is expected to nearly triple, to 139 million people by 2050 (World Health Organization, 2023) **(Image 1)**. Dementia is a condition that affects a person's cognition including their: memory, problem solving, communication, and ability to carry out everyday tasks. As dementia progresses it severely affects an individual's independence. When this happens, family members or close friends must often step in to provide care, helping with medical management, daily activities, and financial needs (Adams, 2006). However, the caregiving role can be extremely stressful, especially as caregivers deal with the emotional and physical challenges of supporting a loved one with dementia, while simultaneously facing the burden of their own lives. Many caregivers experience high levels of psychological stress, including anxiety, depression, and feelings of guilt or frustration. According to the Family Caregiver Alliance, 30-40% of dementia caregivers report experiencing significant emotional distress (Caregiver Health - Family Caregiver Alliance, 2021). The emotional toll of caregiving suggests the need for more research into how caregivers cope with stress and the kinds of support they need. However, while negative effects predominate, caregivers often report positive effects as well. A study done by Carole A. Cohen at the University of Toronto surveyed two hundred and twelve caregivers and found 73% noted a positive aspect of the caregiving experience. Respondents recorded that the journey helped them discover healthy coping skills and to become closer to the person they were caring for (Cohen et al., 2002).

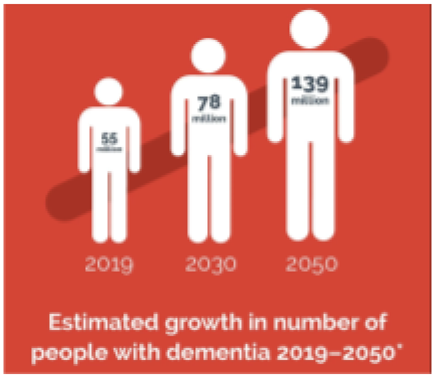


Image 1: A graphic showing the dramatic increase in dementia cases that is expected to happen by 2050. (*Dementia and Palliative Education Network (DPEN)*, 2025)

The broad variability of the individual caregiving experience begs the question whether the experience is affected by the caregivers' background and expectations. Do cultural beliefs and ethnic influences shape how caregiving is approached and how the role affects the mental health of caregivers? What if culture and ethnicity changed a person's caregiving experience and had an effect on the positive and negative psychological effects?

University of Michigan professor Mary Janevic created a study looking at caregiving practices and how they differ between Western, African, and Asian cultures. She found that in Western cultures, caregiving is often individualized, with a primary family member or friend taking responsibility. This often led to higher levels of stress and depression. One positive aspect is that caregivers in Western societies have greater access to formal caregiving and support. Such as nursing homes and at-home care assistance. These resources alleviate the pressure that the caregivers would often feel. On the other hand, in African and Asian cultures caregiving was often collective. A network of family and friends sharing responsibility. While this approach provides emotional and practical support, there is also a lack of formal caregiving facilities. African and Asian caregivers often reported feeling guilt, as if they were not doing enough for their family members. Mental health stigma in these communities also prevented caregivers from seeking help perpetuating the psychological toll (Janevic & Connell, 2001). Additionally, there has been a noticeable increase in the number of people taking on caregiving responsibilities due to rising life expectancy. The need for families to care for elderly or chronically ill relatives has grown as people live longer. In the U.S., 52 million people are currently informal caregivers and about 25% are caregivers for dementia (Deeken et al., 2022). Previous research into the demands placed on caregivers uncovered the different types of burden they experience, both tangible (physical demands) and emotional (stress and worry) (Papastavrou et al., 2007). Other studies, such as one by Richard Schulz, a professor at the University of Pittsburgh, studied the mental and physical health of caregivers. Schulz found that caring for someone with dementia often leads to higher levels of stress compared to caring for individuals with other health conditions. Dementia caregivers faced similar struggles: increasing amount of care needed, the patient's cognitive decline, and additional stressors like financial problems or family conflicts. All of these increased the caregivers' negative emotional effects (Schulz et al., 2021). Not only does the condition play a role, but also the cultural and ethnic influences. Dr. Jennifer Pharr, of the University of Nevada, did research focused on how cultural values impact caregiving, particularly in minority communities in the U.S. Pharr found that in African American, Asian American, and Hispanic American communities, caregiving is often seen as a family duty. This can lead to chronic stress because caregivers may feel reluctant to seek help from outside sources. In these communities caregiving is often a cultural expectation and caregivers may feel obligated to care for elderly relatives due to a strong sense of filial duty. In contrast, European American communities may not feel the same level of cultural pressure or expectation (Pharr, 2021). While Pharr's work shows how culture can shape caregiving, it doesn't really dive into ethnicity on its own. Culture is more about shared traditions and ways of life, while ethnicity is tied to someone's background and identity. Leaving ethnicity out means some important parts of a person's experience might get missed. Ethnicity tends to get lumped in with culture, which means our understanding of ethnic identity is lacking. But ethnicity can still influence people's experience caregiving and the kind of support they need. Peggye Dilworth-Anderson, PhD, a Professor at the Department of Human Development and Family Studies, University of North Carolina, looked specifically at Race, Ethnicity, and Culture in Caregiving. She highlighted how, although these ideas are often grouped together, there was a bigger gap in research when looking at the ethnic effects of caregiving. However, her study found that culture, race and ethnicity all have an effect on the caregiving experience (*The Cultural Influence of Values, Norms, Meanings, and. . . : Alzheimer Disease & Associated Disorders*, n.d.). Together, these studies highlight the complex nature of caregiving, where emotional and psychological factors intersect. Much of the current research focuses on one or very few aspects of culture or ethnicity; they don't look across a wide range of ethnic or cultural factors, especially how the positive and negative psychological effects may differ across groups. Given the growing number of dementia diagnoses and the increasing strain on informal caregivers, it is crucial to understand how different cultural and ethnic factors influence caregivers' mental health effects. A broader understanding of ethnic and cultural factors could provide more comprehensive and focused insights into the caregiving experience.

This research aims to fill this gap by exploring how cultural and ethnic values shape the psychological toll on dementia caregivers. By looking at caregiving through this perspective, this project seeks to understand the unique challenges caregivers from different backgrounds may face. The question, 'how do the psychological effects of caregiving for individuals with dementia vary across ethnicity and culture?' Can highlight how cultural norms and ethnic values influence the mental health of caregivers and suggest ways to improve support for diverse caregiving populations.

Methodology

My research looked at the psychological effects of caregiving and how these effects are shaped by cultural norms and ethnic values. I designed a survey-based method that aligns with my research goals and ensures a comprehensive approach. Surveys are widely used in caregiving research because they allow researchers to gather large amounts of data from a diverse sample.

Making them an effective tool for understanding the complex, multifaceted experiences of caregivers. I originally based my methodology on a study by Marieke Zwaanswijk, a senior researcher at the Netherlands Institute for Health Services Research. She used what is called comparative survey research. She examined informal caregivers for individuals with dementia, but solely focused on their problems, needs, and support. I ran into this study at the beginning of my methodology search, and discovered the idea of a survey. As I continued to do research, I found more studies that support the use of surveys, specifically in caregiving research (Zwaanswijk et al., 2013). For example, in a study by Erin Giovannetti surveys were used to gather demographic data on caregivers and explore the psychological effects of caregiving across different cultural backgrounds (Giovannetti & Wolff). Building on these methods my own survey consisted of three different sections focused on demographic information, cultural and ethnic difference, and the psychological effects (Appendix A). My survey looked for quantitative data as well as qualitative data. Each section of my survey included both multiple choice questions and free response questions. The mix allowed me to examine how the caregiving experience differs across ethnic and culture groups and the psychological effects that occur.

The first section focused on the caregiver's background, gathering demographic information such as age, gender, relationship to the patient, and caregiving history. It included six multiple choice and two free response questions. This section was used to identify trends or discrepancies in caregiving roles based on different contexts.

The second section focused on cultural and ethnic influences by asking questions related to ethnicity, family caregiving norms, and cultural expectations surrounding caregiving. This included three multiple choice and five free response questions. For example, I asked multiple choice questions such as, "What type of caregiving is most commonly practiced or accepted in your cultural or ethnic community?" and free response questions like "Does your cultural or ethnic background influence how you approach caregiving?" This provided valuable insight into how cultural and ethnic values influence the caregiving experience and shape caregivers' perspectives.

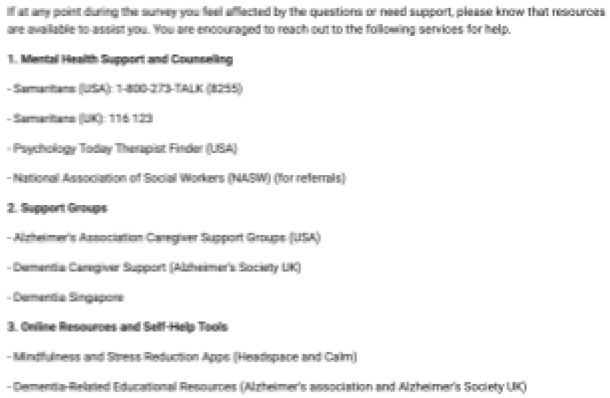
The third section addressed the psychological impacts of caregiving by asking one multiple choice question related to the negative and positive effects of caregiving including the presence of symptoms like depression, anxiety, and stress as well as personal growth, resilience, and a sense of purpose. The final question in this section was a free response question asking caregivers to describe their experience. Respondents had freedom to write as much or as little as they wanted, and express anything significant in their personal experience.

I hoped my survey would reach a wide audience across various geographic and demographic groups to encompass a variety of caregiving effects as well as how their culture or ethnicity affects them. I initially distributed a flyer to nursing homes and formal caregiving facilities around my area **(Image 2)**. I also reached out to online caregiving support groups, social media sites, and asked my classmates and teachers for support.


Have you provided care for someone suffering from dementia? Share your experience & help research.

Image 2: Flyer that was posted throughout various nursing homes.

To ensure ethical practices, I followed all necessary research protocols including obtaining informed consent from all participants ensuring confidentiality, and being mindful of any potential biases (Appendix A). I also made sure the survey and interview questions were worded in a culturally sensitive manner, ensuring caregivers from different backgrounds were comfortable participating and sharing their experiences. At the end of my survey I included a list of helpful resources in case participants raised past emotions



If at any point during the survey you feel affected by the questions or need support, please know that resources are available to assist you. You are encouraged to reach out to the following services for help.

1. Mental Health Support and Counseling

- Samaritans (USA): 1-800-273-TALK (8255)

- Samaritans (UK): 116 123

- Psychology Today Therapist Finder (USA)

- National Association of Social Workers (NASW) (for referrals)

2. Support Groups

- Alzheimer's Association Caregiver Support Groups (USA)

- Dementia Caregiver Support (Alzheimer's Society UK)

- Dementia Singapore

3. Online Resources and Self-Help Tools

- Mindfulness and Stress Reduction Apps (Headspace and Calm)

- Dementia-Related Educational Resources (Alzheimer's association and Alzheimer's Society UK)

Image 3: What participants saw at the end of the survey if they were in need of any help

of trauma **(Image 3)**. Finally the last step I took to ensure ethical protocols was to get approval from an Institutional Review Board (IRB). The IRB approved my research with revisions, where I modified my survey to be more gender inclusive, as well as correcting the grammar and syntax to be more culturally sensitive. After this I was officially approved to begin research following a short presentation to my teacher to ensure everything was correct.

Data analysis

I used both statistical methods and thematic analysis to examine the responses. The qualitative and quantitative data was analyzed with google sheets which allowed me to use tools to categorize the characteristics of individuals based on their ethnicity, cultural background, and psychological experiences.

The multiple choice questions were placed into graphs or charts that best fit the data. To analyze the free response data I looked for keywords that indicated a yes, no, or maybe response to the question. This mixed-methods approach of multiple choice and free responses allowed me to draw both broad conclusions from the quantitative data and deeper, more personal insights from the qualitative data.

Results

As previously mentioned, the survey was split into three sections: demographic information, cultural and ethnic differences, and psychological effects. Though I may not have received as much data as I originally hoped for, I still received 15 thorough responses. Even with the limited responses, there were still interesting takeaways that deserve to be highlighted. Each of the sections features the most important data gathered pertaining to the caregiver experience and the cultural and ethnic differences.

Demographic information

The first demographic question asked about the caregivers gender. The majority of responses came from women with only one male respondent **(Fig. 1)**. The next important data point was age, with ages spanning from 23 to 80, the average age being 51 **(Fig. 2)**.

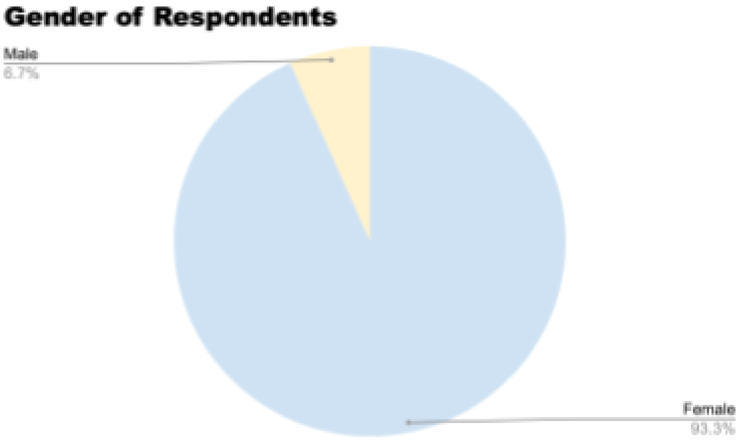


Figure 1: Percentage of gender of survey respondents

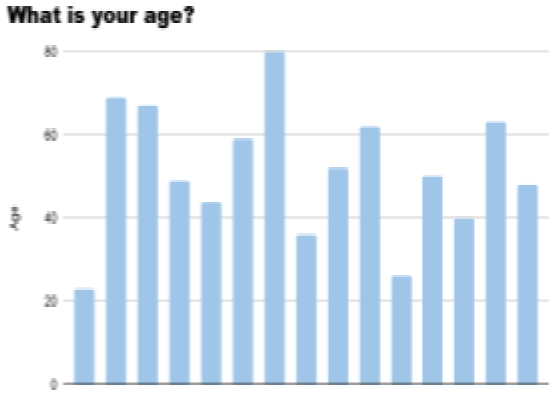


Figure 2: Representation of each individual age from survey respondents.

The last two demographic questions asked about culture and ethnicity. In culture, one respondent picked Italian, two chose Hispanic, and 12 picked Western **(Fig. 3)**. In the ethnic breakdown, one picked Slavic (Central Europe), two picked Hispanic / Latino, seven chose Anglo Saxon (English / British), while five picked White (Caucasian) **(Fig. 4)**.

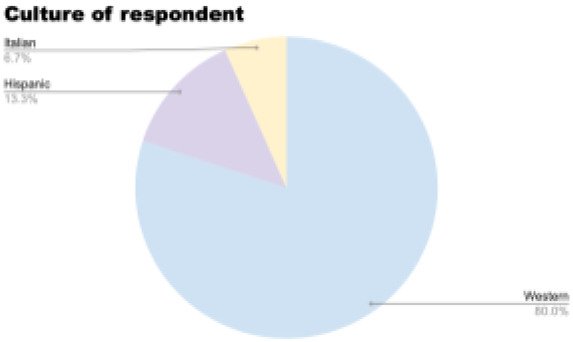


Figure 3: Percentage of culture of respondents.

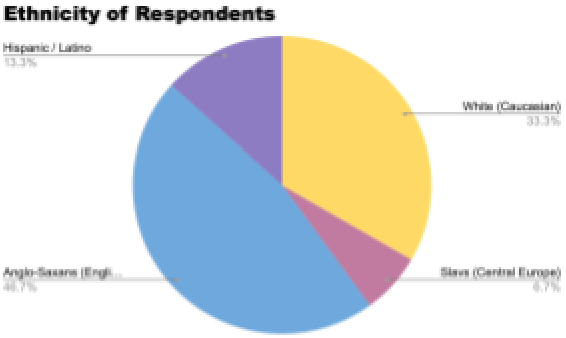


Figure 4: Percentage of ethnicity if respondents.

Culture and Ethnicity

Moving on to the cultural and ethnic differences section, the survey asked what type of caregiving is most commonly practiced, where 40% of respondents chose familial care, 46.7% picked institutional care, and 13.3% claiming a mix of both at home care and familial care **(Fig. 5)**. I then asked what is the typical view of dementia in your culture and ethnicity. 40.9% claimed it was seen as a natural part of aging, while 40.9% claimed it was a medical condition that needed professional care. Finally, 13.6% claimed it was misunderstood or stigmatized, with 4.5% responding it is seen as something that can be cured or treated with alternative remedies **(Fig. 6)**. Moving on to the free responses of this section, when asked if their culture or ethnic background

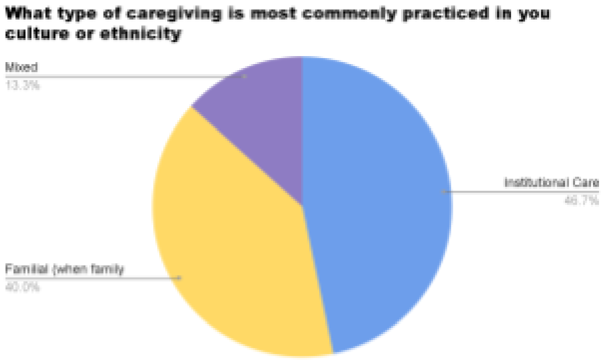


Figure 5: Percentage of the most common type of caregiving practices.

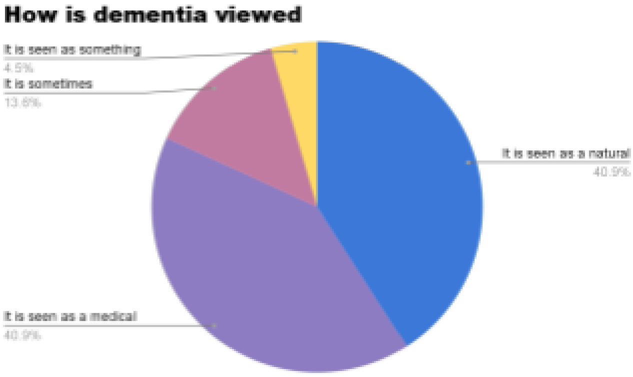


Figure 6: Percentage of how dementia is viewed in various culture and ethnicities.

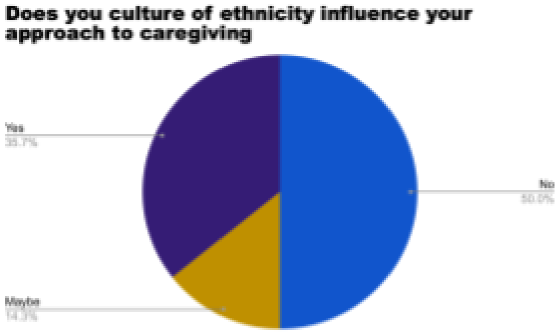


Figure 7: Percentage of whether or not culture and ethnicity affected respondents approach to caregiving

influenced their caregiving. 50% claimed their culture and ethnicity did not have an effect, while 35.7% said it did. Finally the other 14.3% responded maybe, with unsure tones on whether or not it is predominantly culture or ethnic influenced or family influenced **(Fig. 7)**. The final question asked, whether or not there were support services near them, the responses varied. 75% said yes, 12.5% said maybe, and the other 12.5% said no **(Fig. 8)**.

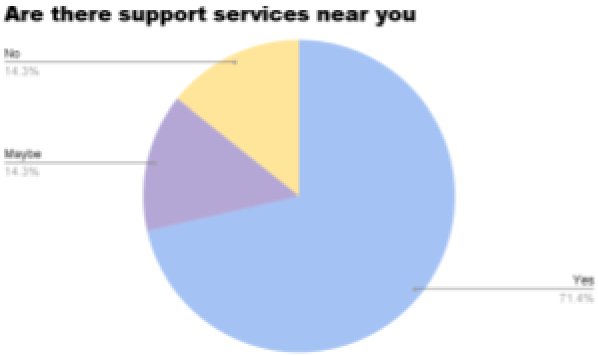


Figure 8. Percentage of support services near respondents.

Psychological Effects

In the psychological effects section, I presented respondents with 14 total options, seven negative and seven positive. In total 32 positive options were picked and 40 negative options were selected. This breakdown highlights that negative psychological effects were reported more frequently than positive ones. Negatively, stress (22.5%) and emotional stress (20%) were the most common. With burden (15%) and burnout (15%) being next. Finally, depression (7.5%), guilt (10%), and social isolation (10%), were the least picked **(Fig. 9)**. In the positive breakdown, empathy (21.9%), strength in family bonds (18.8%), and resilience (18.8%) were the most common. Following that, a sense of purpose (15.6%) and emotional reward (12.5%). Finally, personal growth (6.3%) and healthy coping (6.3%) were picked least **(Fig. 10)**. This breakdown underscores the emotional and mental toll caregiving can have, especially across diverse cultural contexts.

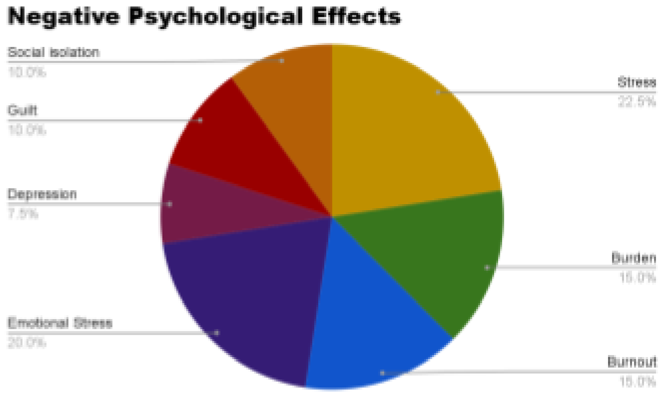


Figure 9: Percentage breakdown of the negative psychological effects.

Figure 10: Percentage breakdown of the positive psychological effects.

Discussion

My research question asked how the psychological effects of caregiving for individuals with dementia vary by culture and ethnicity. My hypothesis suggested there would be many differences in the psychological experience due to ethnic influence and cultural background, however personal factors like a caregiver's individual choice and family history would also have a meaningful impact. Unfortunately, without a larger data set of responses from different cultures and ethnicities it is hard to draw definite conclusions. Nonetheless there are still some commonalities across the same cultures and ethnicities, as well as interesting differences.

Starting with the demographic information, the majority of respondents were female. This is important as gender plays a huge role in caregiving and studies have shown that the majority of caregivers in most cultures are usually female. A study done by Nidhi Sharma, at the Department of Psychiatry, in the Institute of Medical Education and Research in India did a study looking at the gender of mental health caregivers across the world. She found that women are more commonly caregivers for both the elderly as well as the mentally ill. She also stated women more commonly face the negative consequences of caregiving especially after prolonged periods (Sharma et al., 2016). This is relevant because one of my main goals for this research was to improve the psychological help caregivers can receive. But this also brings attention to the severe lack of data when it comes to male caregivers. With only one male respondent in my research, I am unable to draw any meaningful conclusions about male caregiver experiences, highlighting a significant gap in the data.

The age responses provided an interesting range of data points spanning a 51 year range from 23 to 80. Age can also offer insight into how different life stages might affect caregiving. Where older individuals might be more susceptible to stigma than young individuals, as they have grown up in times where the disease dementia was seen as shameful rather than as a disease. But younger individuals might not have as much of a connection to the person they are caring for, because of how long they have been suffering or their relationship to the person.

Finally, the last set of questions focused on ethnicity and culture. The charts show the majority of respondents identified with Western culture and were of Caucasian and English ethnicity. This is most likely reflective of the area I conducted my research, which has a predominantly white population. This also greatly affected my results as I was not able to get a wide range of cultures and ethnicities to see if there was a difference. However, I did receive two respondents from Mexican culture and Latino ethnicity, who both indicated a strong push from family to care for an individual. This was vastly different from the data I received from a white culture and ethnicities who claimed there wasn't as much of a push.

This can be related to the free response question asking if respondents felt an influence from their culture and ethnicity in their approach to caregiving. One participant said she feels no ethnic or cultural obligation, only the love for her significant other pushes her to be a caregiver:

saying, “I'm still IN love with my husband, and at this point I feel my care is best for us/him.” While a participant from a different cultural and ethnic background said, “Being Hispanic means we feel the responsibility first. We want to help and not bring in others because of how important family values are. Also the expectation that we help our elders.” Finally one participant noted a sense of responsibility arising from their Irish Catholic religious background. This showcases how caregiving can be deeply influenced by cultural values, traditions, and even religious beliefs, factors that can significantly affect the emotional experience and sense of duty in the caregiving role.

In the culture and ethnicity section, I asked what type of caregiving is most commonly practiced or accepted in your community. The split was almost completely even, with seven caregivers choosing familial care, while six saying institutional care is most commonly practiced. The remaining two others said they do a mix of at-home formal caregiving and familial care. I found this really interesting because it shows how different communities approach care in very different ways. For some, taking care of family at home is just what’s expected, while for others, institutional care might be more normal or accessible. The fact that some people do a mix also shows that care often has a gray area. People have to figure out what works best depending on their situation. This kind of variety underscores how important it is to have flexible support systems that can meet people where they are.

The next question I asked was how dementia caregiving is viewed. This is significant to my survey as it highlights how different types of cultural background and ethnic influences can affect the person who is sick. The majority of respondents picked that it was either a natural part of aging or a medical condition that is out of their control. Two individuals, one from a Western culture and Caucasian ethnicity and another from an Italian culture and Caucasian ethnicity, stated that it is often stigmatized. Janevic also discussed this topic in depth in her research, stating that dementia is still a misunderstood disease. Like many other illnesses, because there has been no viable solution or cure, many cultures still view it as a ‘disgraceful’ illness (Janevic & Connell, 2001). One other respondent, from a Mexican culture and Hispanic/Latino ethnicity, claimed that dementia in her culture is actually viewed as something that can be treated with home remedies or solutions. Cathleen Connell, a PhD and Director at the Education and Information Transfer Core at the Michigan Alzheimer's Disease Research Center, found something similar. When studying Black versus Mexican cultures and their caregiving approach, more respondents from Mexican culture noted the use of family remedies when caring for someone with dementia (Connell & Gibson, 1997). I cannot draw this same conclusion, as only one respondent happened to answer that way, however, this question still highlights the importance of background and how it is influential to the care that is given.

Responses regarding formal support services were also interesting. While most caregivers noted formal caregiving services were available, four pointed out how expensive they are, saying “Yes, but they are all expensive. If you have money there are resources.” Others claimed that while there were resources available a lot of them don't fit the needs of the person they are caring for, “I'm sure there are, but at the stage (2/3), we are at, when you need the help/care it's unpredictable.” Finally, two participants noted while formal caregiving services were available, they found useful other semi-formal resources such as online caregiver training, in-home assistance, or counseling. This is an important question to the survey because previous studies have shown the need for strong support. Janine Wiles, a professor of human geography at the University of St Andrews, did a study looking at the mental health of caregivers when they had access to support services versus when they didn’t. She found that without these services caregivers were often confused and unsure of how to properly care for someone. She also pointed out that because of how overwhelming caregiving can be, many caregivers don’t have the time or energy to even look for available help (Wiles, 2003). Considering how important things like counseling and formal caregiving facilities are, this is a big deal, and it directly connects to one of the bigger goals of my research. The availability of these services really show how essential support is for caregivers, not just for the people they’re caring for, but for their own mental health too.

Finally, the psychological effects section of the survey posed two questions. The first was a multiple choice question about what type of psychological effects participants experienced. I gave them the option of seven positive and seven negative effects. Overall, 72 were selected by the 15 participants: 40 negative and 32 were positive. I expected this, as more commonly when thinking back on the emotional toll of caregiving, participants often remember the bad and not the good. In Zwaanswijk’s research, she focused solely on caregivers' problems, needs, and support and found that 98% of the surveyed caregivers had problems related to the caregiving experience, and with that 100% noted negative feelings throughout the experience. My results along with Zwaanswijk’s show the emotional weight of the caregiving experience. Specifically the negative ones, which highlight the need for better strategies to support caregivers throughout their journey.

The second question was a free response question. Respondents were able to talk about anything they wished about the caregiving experience, the good and the bad. They could share as much or as little as they like. Here are the most interesting responses:

One caregiver, the child of the dementia sufferer, from Western culture and English / British descent said “It is a rollercoaster of emotions. Like dementia - there are good days and bad days!”

Another, who cared for their grandmother said “You lose the person with dementia before they actually die. You have to have a lot of support and outlets (social, emotional, financial etc) to survive it.” She was also of Western culture and caucasian descent.

Several noted the struggle to have a personal life in the midst of caring for someone, while some also claimed they had a severe lack of knowledge not only about the disease but the steps they should take. An individual of Western culture and Slavic ethnicity said “I did not have a lot of support and after my mom passed I learned even more. Especially from her Doctor who did not tell me my mom had dementia until she died.” The sad experience of many caregivers is to watch the person they love drift away.

Finally an individual from Mexican culture and Latino / Hispanic ethnicity wrote, “Caring for my dad opened my eyes in ways I never expected.”

These quotes are so important and there are so many more I wish I could include. Overall, these comments reveal the complexity of caregiving where individuals have to balance the loss of a loved one along with their own daily challenges. They also emphasize the critical need for strong social, emotional, and financial support when navigating this journey.

Limitations

Unfortunately I struggled a lot with the lack of data which affected my ability to support or reject my hypothesis. The biggest struggle came from recruitment. I started off the data collection by reaching out to various nursing homes in my area to try and put up my flyer in hopes that caregivers who might be visiting would be able to take my survey. I called, emailed, and went in and was sadly only able to have two nursing homes display my flyer. After this I decided to go online in hopes that I might be able to reach a broader audience. I reached out to two online dementia support services, Alzheimer's Association and Dementia Support, neither of them were able to help me post. After this I posted my survey with a short synopsis online to Facebook and NextDoor, and again got a lot of support but not a lot of responses. Finally I turned to my classmates and teachers for help and got a lot of support through them. The process was draining and often hard to continue as I was worried I was going to get no data. But at the end of the day, the data I received was still responsive to my question, and helped in my journey to aid caregivers.

Implications

The biggest implication I found is that caregiving really isn't one-size-fits-all. There is a broad range of experiences, and the kind of support caregivers need changes based on their environment, their family situation, and their access to resources. What I saw across the board is that caregiving takes a huge emotional toll, especially when there's not enough support. That's why it's so important that any kind of mental health support we try to build for caregivers actually takes those differences into account. Another thing that came up is how different communities and individuals have their own needs and norms. So, when it comes to creating real solutions or policies that help, they can't be rigid. Flexibility and personal choice have to be at the center of it.

Conclusion

In the end, what really stood out is that caregiving is incredibly personal. No matter someone's ethnicity, culture, how they identify, or who they're caring for, every story is different. My original hypothesis stated that culture and ethnicity would shape the caregiving experience.

While that is true. I found that the emotional journey looked different even within the same cultural backgrounds. What stayed consistent across the board was the grief and the weight of loss that every caregiver carried. That's why we can't just group people by background. What caregivers actually need right now is support that's accessible and real. Caregivers need to know they're not alone. They are valued and their stories are heard. They need easier access to clear, straightforward information about the disease they're navigating and how to take care of themselves in the process. Keeping caregivers in mind is key to creating the best solutions. Supporting people is actually listening to what they need and crafting approaches that are best for them.

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Appendix A: IRB paperwork and Supplemental Materials

Consent Form.

https://docs.google.com/forms/d/1Ls8vBcvan5xd1hZ1RODxTRZGVMeXKj4KN-ECKzyY7FI/edit

IRB Human Participants Video Training Questions.

https://docs.google.com/document/d/1TyaQ8qqROH_zTC_edK8XBsZDfqXNcGFPN6vswWHgMW0/edit?tab=t.0

IRB Proposal Form.

https://docs.google.com/document/d/1yQTQ4dLKcZYv_aoVLCCpIMHE_r69Oudtt07DqBUZ-P0/edit?tab=t.0

Survey.

https://docs.google.com/forms/d/1tX8TYyUmdGI4TCa7ySnBvSidGCF2h5EK-R8HWaOSHEs/edit