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## How Providing Care For Individuals With Dementia Affects How A Caregiver Changes Their Lifestyle: A Focus on the Positives

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HOW PROVIDING CARE FOR INDIVIDUALS WITH DEMENTIA AFFECTS HOW A  
CAREGIVER CHANGES THEIR LIFESTYLE: A FOCUS ON THE POSITIVES

By

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## Abstract

**Background/significance** Caregivers of individuals with dementia (e.g. Alzheimer's Disease) may change their day-to-day life, especially self-care, to meet the needs of the person with dementia, which can be detrimental to their health. Caregivers for individuals with dementia experience both primarily negative and primarily positive effects on physical and mental health through exposure to the effects of dementia. Caregivers often report substandard self-care practices and unpleasant impacts on mental health. Others report notable beneficial influences within different aspects of their life. The positive effects have not been widely researched in literature.

**Purpose** The objective of this research study is to understand how caregivers of individuals with dementia change their day-to-day life due to the impact of caregiving in aspects including physical and mental health, in an effort to determine ways to enhance caregiver's coping methods and promote positive outcomes for both personal and professional caregivers.

**Methods** The general population included in this study are caregivers of individuals with dementia. To be included in the study, one must be (or previously have been) either a personal or professional caregiver of an individual with dementia, of any sex, over 18 years of age. Those who were excluded from this study included caregivers of non-dementia patients and caregivers under the age of 18.

To understand the impact of caring for an individual with dementia, a qualitative research study was conducted to answer the research question "How does providing care for an individual with dementia affect how a caregiver changes their lifestyle?" The study was implemented as

follows: a sample of 16 caregivers participated in a qualitative interview process to provide insight into their personal opinions on how caregiving for an individual with dementia (personally, professionally, or voluntarily) affects or has affected their well-being. An interview process developed for the study was followed, which included demographic data and questions about the caregiver's life and activities. Each interview lasted an average of between 15 and 30 minutes. The interviews were transcribed and cross-analyzed to search for the common themes of physical activity, eating habits and diet, spirituality, mental health, lifestyle, and outlook on life. Advice to enhance a positive experience for future caregivers, as well as additional resources that the participants think are necessary to improve the positive effects of caregiver, were also analyzed.

**Results** Although there was a prevalently negative impact on caregivers' eating habits and mental health, each other category proved to be either neutral or positive. The category with the most positive outcome was outlook on life. Qualitative interviews disclosed the excessive levels of stress experienced by every caregiver of an individual with dementia, but in turn, each participant communicated the strategies they found to be effective to cope with the negative effects of caring for someone with dementia.

**Conclusion Implications** Those who care for individuals with dementia, whether on a personal or professional basis, must make sure to take care of their personal physical and mental health as well as that of their patients, to avoid the detrimental effects that caregiving for an individual with dementia ultimately have on a caregiver. The results of this research study can be used for a greater understanding of the impact of caregiving for individuals with dementia. Current and future caregivers can use the results of this study to recognize which aspects of their life that they

may need to focus more on while caregiving in order to stay healthy, and take the advice offered by the participants to promote an overall positive experience. Further research on how to improve the number of positive outcomes in each aspect of self-care for caregivers can be conducted based on the results of this study.

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### **Thesis Summary**

The purpose of this study was to determine which aspects of a caregiver's life are more positively affected when caring for an individual or individuals with dementia and determine ways to combat the areas that were negatively impacted with healthy coping mechanisms. Qualitative interview questions were formatted to understand the impact of being a caregiver for an individual or individuals with dementia on six main aspects of a caregiver's lifestyle (physical activity, eating habits and overall diet, spirituality, mental health, lifestyle, and outlook on life). 16 participants were interviewed and each interview recording was then transcribed and analyzed to determine themes surrounding the six categories. The results revealed that the caregiving experience had the most positive effect on one's outlook on life, along with mostly positive impacts on spirituality and a caregiver's lifestyle as a whole. The categories of physical activity, eating habits and overall diet, and mental health had either neutral or mainly negative results but were accompanied by advice from caregivers on how to improve a positive experience for current and future caregivers.

## **Background**

*Dementia* is a general term for a variety of diseases and conditions involving memory loss and other cognitive abilities that interfere with daily life. (What is Alzheimer's, 2019). Dementia is an overall term encompassing multiple diseases in which there is deterioration in memory, thinking, behavior, and the ability to perform everyday activities to a normal extent (What is Dementia, 2021). It is challenging to understand the emotional impact of dementia on the patients due to their slowly declining ability to communicate effectively, however, it is possible to study the impact that this disease has on their caregivers. Studies have been conducted in the past to determine the aspects of a caregiver's life influenced by the extremely demanding disease. Most studies had results that proved an overall negative impact that caregiving has on a caregiver's physical and mental health. However, other studies focused on the positive impacts on other aspects of a caregiver's life (like spirituality and outlook on life).

Caregivers should attend to their physical and mental health properly to avoid the detrimental effects that caregiving for individuals with dementia can ultimately have on a caregiver. Caregivers of individuals with dementia, especially Alzheimer's disease, experience a caregiver burden (Liu et. al, 2017), which correlates to the experience of poor mental health compared to non-caregivers. The results of this research study can be used for a greater understanding of the impact of caregiving for individuals with dementia on caregivers (Ma et. al, 2018). The information gathered in this study will be used to determine ways that will enhance a caregiver's coping



methods when caring for individuals with dementia. This information will hopefully be used to create a baseline for efforts that caregivers of individuals with dementia should promote for themselves and their colleagues to maintain their health while caring for others. Further research on how to improve the number of positive outcomes in each aspect of self-care for caregivers can be conducted based on the results of this study.

### **Introduction/Purpose**

A qualitative research study was conducted to answer the research question “How does providing care for an individual with dementia affect a caregiver’s lifestyle?” The objective of this research study is to understand changes caregivers face in day-to-day life when caring for individuals with dementia in the realms of physical and mental health. The long-term goal is to determine ways to enhance a caregiver's coping methods.

Caregivers of individuals with dementia (e.g. Alzheimer’s Disease) may change their day-to-day life, especially self-care, to meet the needs of the person with dementia, which can be detrimental to their health. I hypothesize that caregivers for individuals with dementia experience both primarily negative and primarily positive effects on their physical and mental health due to substandard self-care practices in areas of their life including, but not limited to: physical activity, eating habits and diet, spirituality, mental health, lifestyle and overall outlook on life.

### **Methodology**

**Population** The general population includes caregivers of individuals with dementia. To be included in the study, one must be (or previously have been) either a personal or professional caregiver of an individual with dementia, of any sex, over 18 years of age. Those who were excluded

from this study are caregivers of non-dementia patients and caregivers under the age of 18. The demographic results can be found in Table 1.0 (See Maps and Tables).

**Design** To understand the impact of caring for an individual with dementia on caregivers, a qualitative research study was conducted to answer the research question “How does providing care for an individual with dementia affect a caregiver’s lifestyle?” The study was administered as follows: caregivers were recruited via social media (Instagram and Facebook) and through snowball sampling and asked to participate in a 15 to 30 minute (average) interview through Microsoft Teams, a secure and safe social networking site. Participants were asked consent before being recorded, and each audio-recording was transcribed and analyzed using a thematic analysis approach. The participants were asked 18 questions, 8 of which were demographic, and 10 of which were in-depth questions pertaining to the impact that caregiving had on certain aspects of their lives. The questions were developed from the diagram seen in Map 1.0 (see Maps and Tables), through which the researcher sought to include the main categories of well-being that may be impacted by being a caregiver. The demographic questions were as follows:

1. What is your sex? (e.g. Male, Female, Other, Prefer not to say)
2. What is your ethnicity? (e.g. American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or Pacific Islander, White, Other, Prefer not to say)

The descriptions for each ethnicity are as follows (and were presented to the interviewee upon request):

American Indian or Alaska Native: A person having origins in any of the original peoples of North and South America (including Central America), and who maintains tribal affiliation or community attachment.

Asian: A person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam.

Black or African American: A person having origins in any of the black racial groups of Africa. Terms such as "Haitian" or "Negro" can be used in addition to "Black or African American".

Native Hawaiian or Other Pacific Islander: A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands.

White: A person having origins in any of the original peoples of Europe, the Middle East, or North Africa.

Other/Prefer not to say

3. Do you consider yourself to be Hispanic or Latino?

The description for Hispanic or Latino is as follows (and can be presented to the interviewee upon request):

Hispanic or Latino: A person of Mexican, Puerto Rican, Cuban, South or Central American, or other Spanish culture or origin, regardless of race.

4. How old are you? Age ranges will be applied after the interview process (18-19, 20-29, 30-39, 40-49, 50+, prefer not to say)

5. How old were you when you began caring for a patient with dementia?

Age ranges will be applied after the interview process (18-19, 20-29, 30-39, 40-49, 50+, prefer not to say)

6. What is/was your relationship to the individual with dementia whom you care/cared for? (e.g. Professional, personal (family member), personal (friend), voluntary, other)

7. If you work, what kind of job do you have? (This question is only for those who are non-professional caregivers)

8. What is your marital status (e.g. Married, Single, Widowed, Committed, Separated, Divorced, Other, Prefer not to say...)

The in-depth questions were as follows:

1. Tell me your story about being a caregiver for an individual with dementia.

2. What is your usual physical activity like?

Probe: How has it been impacted by your caregiving

3. What are your usual eating patterns and overall diet?

Probe: How has it been impacted by your caregiving?

4. Tell me about your spirituality?

Probe 1: What have you noticed that is different or the same regarding your spirituality since caregiving.

Probe 2: Can you tell me more about your positive experience?

5. Tell me about your mental well-being.

Probe: How has it been impacted by your caregiving?

6. What experiences in caregiving have impacted your lifestyle?

7. How has caregiving impacted your outlook on life?

If positive, tell me more about that?

If all negative, can you think back about anything positive?

8. Is there anything I haven't asked about that I should have asked or you would like to tell me?

9. If positive, what advice would you give someone to enhance a positive experience?

10. Are there any resources that you think caregivers should have that are not available or non-existent?

**Instruments or Surveys** All 16 interviews were done over Microsoft teams and recorded for later transcription. The interviews remained anonymous. Each interviewee was asked the same 18 questions regarding the research question and answered in about a 15-30 minute full interview.

After the data was collected, the qualitative data was put in a table (see Table 2.0 in Maps and Tables) to determine the overall effects, and an application of thematic analysis based on

Braun and Clarke's "Six Phases of Thematic Analysis" was used to perform a line-by-line examination of common themes among the interviews.

## Results

There were many common themes among the 16 qualitative interviews, all pertaining to the changes a caregiver has to make when caring for an individual or individuals with dementia. Each caregiver was asked to give advice to enhance a positive experience for current or future caregivers of individuals with dementia based on their personal experiences. In an effort to improve each of the six main categories analyzed throughout this study, each grouping is listed below with the evidence and advice pertaining to that subject and resources suggested by caregivers.

**Physical Activity** Out of the 16 participants in the study, 1 (6.25%) determined that caregiving had a positive impact on their physical activity, 9 (56.25%) were neutral, 5 (31.25%) were negative, and 1 (6.25%) mentioned *both* a positive and negative impact.

Most caregivers that experienced negative effects on their physical activity due to the constant responsibility of caregiving spoke of complete exhaustion. Professional caregivers spoke of the physical strain they experience(d) on a day-to-day basis at work while moving patients on long shifts. Many of the personal caregivers mentioned that their physical health declined without them noticing as a result of putting their needs aside to care for their loved ones. One personal caregiver discussed the impact of mental stress on physical deterioration and said "I really didn't internalize that the stress of what happened to me was manifesting itself in my

aches and pains,” (Caregiver 5) revealing the importance of both mental and physical health while being a full or part-time caregiver.

To combat the negative impact that caregiving can have on a caregiver’s physical activity and overall physical health, some advice from participants include:

- “Mental health check-ins and making sure the caregiver is okay not only in physical aspects but in mental aspects as well” (Caregiver 6).
- “But I will try to exercise and get my walk in ... as much as possible ... At this point, I really try to make that a priority and realize that for myself care is essential, that I cannot ignore mine in the process of caring for them” (Caregiver 2).

**Eating Habits and Diet** The impact of caring for an individual with dementia had a predominantly negative impact on eating habits and diet of caregivers, with 11 (68.75%) of caregivers expressing negative impacts and 5 (31.25%) expressing neutral effects that neither harmed nor helped the status of their eating habits at the time of caregiving.

Almost every participant in this study claimed that caregiving harmed their eating habits and diet, regardless of whether they were in a personal or professional setting.

Professional caregivers said:

- “During the work shift, it definitely varied because your patients come first” (Caregiver 6).
- “I never ate when I was there [at work] because I didn't want to eat things that they couldn't have” (Caregiver 7).

- “If I am able to get a break when I'm at work, which doesn't always happen ... it's just something super quick to eat and then back on the floor. It's usually not all that healthy. It's usually something either from the vending machine or from the little bistro that we have downstairs, but not great” (Caregiver 8).

Personal caregivers said:

- “Now everybody cooks for themselves. We don't have very many family meals anymore” (Caregiver 1).
- “I started eating ... frozen meals because I was just too tired to be cooking twice a night” (Caregiver 1).
- “I tend to have worse eating habits, a little bit less disciplined eating habits, and I eat at times I never would have eaten before for sure” (Caregiver 3).
- “I would just eat whatever kind of can or whatever frozen dinner” (Caregiver 13).
- “I gained too much weight, we all gained too much weight” (Caregiver 14).
- “[I ate] Mostly sandwiches, anything I could put together” (Caregiver 16).

A common theme among these responses is *convenience*. Caregivers often resort to frozen meals or unhealthy snacks because of the convenience factor in their busy schedules, rather than having to take the time to prepare a healthy meal. To hinder the negative impact of caregiving, many participants praised planning, “I would try to plan ahead and do meal prep,” (Caregiver 2).

**Spirituality** Most of the participants acknowledged that caregiving had a positive influence on their spirituality. 11 (68.75%) caregivers expressed a positive impact, 3 (18.75) remained neutral



on the subject, and 2 (12.50%) revealed that caregiving had a negative impact on their spirituality.

Many caregivers turned to faith to give them strength and patience as they navigated the daily struggles that dementia presented them with.

Personal caregivers often mentioned that spirituality acted as a common ground for them and the individual whom they care(d) for, as well as an outlet for frustration and a basis for hope:

- “We just talk about it more, and ... believe that. Just believe that she'll be fine, she'll be good, and He'll take care of her. So ... just more talking” (Caregiver 3).
- “It has gone to another level for me because it takes a lot of patience, and it takes lots of prayer because it's hard” (Caregiver 4).
- “And sometimes people don't understand that, so that's the time I really have to turn to my faith and say you know I need some strength for this” (Caregiver 4).
- “So, I really had to depend on faith and prayer. I just think spirituality just to help me get through it” (Caregiver 4).
- “Spirituality is me and my mom's commonplace ... That's where we can find things that we can talk about, or we can sing together, or we find those moments where we have the same song or we may look at a preaching clip on TV or something like that” (Caregiver 4).
- “It was a reinforcement, that God uses people where they are, and sometimes in situations that you wouldn't even think of” (Caregiver 5).

- “Oh, yeah, definitely, definitely. It gave me a lot of strength and really, I know that even though I prayed about it, nothing could help - nothing could help Alzheimer's. But I prayed to God, give me patience and understanding. And that helped. Yeah, of course, I had - in church now you have a lot of support and you have had a lot of support through those years from the church” (Caregiver 14).
- “I don't know what I would have done if I didn't have [spirituality]” (Caregiver 15)

Professional caregivers benefitted from sharing faith with their patients; not necessarily the same faith, but simply having faith strengthened the patient-caregiver relationship. Others found that their purpose as a caregiver was reinforced through spirituality.

- “I think my caregiving experience actually increased my level of spirituality, just seeing certain patients that have the same religion as me and how they would go about it. Even with dementia, their religion was still a big part, that's something that most patients remember, and you even see patients praying. So, you really learn to appreciate more of the things in life and expand my gratitude” (Caregiver 6).
- “It definitely made me feel more connected to my purpose and knowing that everyone has their own thing that they do” (Caregiver 7).

Overall, spirituality became a foundation for caregivers to build from as they faced the challenges of caregiving. Based on these results, it would be safe to advise caregivers to find a faith base to give them support. One caregiver spoke of spirituality in his advice to future caregivers:

- “You have to stay alert and never lose patience, that's the biggest thing. Never lose patience. You have to be patient all the time, and **for patience, you have to pray a lot.** So,

prayer, patience, and alertness. Those are the three things. **Prayer, alertness, and patience**” (Caregiver 11).

**Mental Health** The participants revealed that caregiving had a substantially negative impact on their mental health. 11 (68.75%) caregivers said that caregiving had an overall negative impact on their mental health, 3 (18.75%) said there was not much of a change and remained neutral, and 2 (12.50%) experienced both negative and positive effects on their mental health.

Similar to eating habits and diet, 11 caregivers attributed negative impacts on their mental health to caregiving. “That's the hardest, I think,” Caregiver 1 answered. Many personal caregivers mentioned feelings of guilt and anger while determining the best course of care for their loved ones.

- “ You're angry that you're the one doing it, then you feel guilty because you offered to do it” (Caregiver 1).
- “I was angry that I had to take care of a mother that didn't take care of me. Very angry, furious” (Caregiver 15).

Both personal and professional caregivers accentuated the stress, exhaustion, and frustration that they felt while caring for individuals with dementia. To cope with these negative mental effects, some caregivers offered advice:

- “Try to do some mindfulness meditation every night before bed to try to clear some of that [stress]” (Caregiver 2).

- “I think that that has helped at least having someone else that you can talk to, I think is very important” (Caregiver 2).
- “Just celebrating them instead of mourning was a big thing” (Caregiver 7).
- “You just need somebody to talk to who won't look at it ... in a judgmental way” (Caregiver 4).
- “Take everything that is said to you in a negative way with a grain of salt” (Caregiver 7).
- “Definitely any kind of mental health counseling that you can get during your time caregiving is important, just to have someone even to hold you accountable for caring for yourself, it's really easy to get wrapped up in what other people need whether it's a dementia patient, an older person or a family member, but it's really easy to get hyper-fixed on what they need and forgetting completely about what you need to do” (Caregiver 7).
- “And have someone that is holding you accountable for making sure that you are living your life in a healthy way as well” (Caregiver 7).
- “I guess I would just encourage them to be realistic about what they can do, and then whatever they can do, do” (Caregiver 9).

**Lifestyle** The impact of caregiving on a caregiver's lifestyle was fairly neutral, leaning positive. 6 (37.50%) caregivers expressed that their lifestyle has improved in a positive way, and 6 (37.50%) remained neutral, expressing neither a positive nor negative impact. 3 (18.75%) caregivers said that their lifestyle took a negative turn because of caregiving, and 1 (6.25%) experienced both negative and positive changes.

In terms of overall lifestyle changes, caregivers reflected on how their lifestyle as a whole changed during and after their experiences. During caregiving, participants all expressed that their focus was not on themselves, but on the individual whom they were taking care of.

- “It takes away from some of your routine when you're checking on someone more regularly and on a regular basis” (Caregiver 11)
- “ But then from the time she got up until the time she would go to bed, everything was being with her and on her schedule and following a certain routine and so you have no freedom” (Caregiver 13).
- “You get up and you do exact same things every day for months and months and months. Until one day you don't” (Caregiver 13).
- “You had to give up all your lifestyle ... So as long as you're the caregiver, you have no time. **They're your lifestyle**, you have to do whatever it takes to take care of them” (Caregiver 14).

As a consequence of going through the experiences of caregiving, many participants said that they live a more appreciative, empathetic, compassionate life.

- “I think I'm a little more empathetic than I used to be” (Caregiver 1).
- “ I have a lot more patience and especially working with dementia patients because that just added a whole other layer of empathy for me” (Caregiver 7).
- “I feel like my lifestyle just has more compassion in it and I'm also way more appreciative of my body functions and the way my brain functions that I have that are not impacted by dementia” (Caregiver 7).

- “Be a little sympathetic, a little more empathetic” (Caregiver 8).
- “[Caregiving] certainly made me more empathetic as far as for the elderly people” (Caregiver 12).

The general theme of the caregivers’ response to this question was an increase in empathy and a longing to appreciate and improve upon one’s own life before it is too late. Many caregivers also expressed the desire to reach out to those who are not familiar with how to deal with caregiving, and relay their experiences to them in an effort to improve their experience.

**Outlook on Life** The most positive results were within the category of outlook on life. 14 (87.50%) caregivers said that their outlook on life became more positive during and after caregiving, while 2 (12.50%) caregivers said that their outlook on life did not change and they remained neutral.

There has been an overwhelmingly positive impact on outlook on life for the participants of this study during and after caregiving for an individual with dementia. Many caregivers expressed their apprehension about growing old and developing dementia, which stimulated a more urgent and positive outlook on their current life and the life ahead of them. Some responses included:

- “I am much more conscious about what I’m going to do, as far as when I die, and how I’m gonna leave my children ... Trying to put my things in order now as opposed to the way my parents did things” (Caregiver 1).
- “I tend to be a little kinder and a little more patient than I used to be. ... And then after a while, I realized these people are just lonely and old. And you know, they need somebody

to talk to. So I think it was more, you know when you think of somebody who's had a full life and then they are left with not even knowing how to take a shower, go to the bathroom” (Caregiver 1).

- “I think it's made me try to enjoy each day. That we don't necessarily know what lies around that corner” (Caregiver 2).
- “The other thing is planning ahead, so being aware of, okay, this could happen. So if it could, what can I put in place to help my children to be able to make those decisions? So I think it has really prompted us to not put that burden on our children and to have those discussions with them early on. And to make sure that they are on the same page that we are” (Caregiver 2).
- “I've developed a lot more respect [and] love, overall” (Caregiver 3).
- “It just really taught me that life is just short. You really have to appreciate the small things and the little things. And I get nervous like don't let that happen to me, I fear the day that I will not remember. So, you know, it helps me to put into perspective to enjoy this time with your daughters and your grand babies and don't rush so much that you miss all these small memories, because you just never know what state of life that you're in” (Caregiver 4).
- “Meeting every person with compassion and curiosity and not passing any kind of judgment without knowing all the information” (Caregiver 7).
- “I guess it makes you realize that you're living a good life now ... It makes you realize that you cannot waste your time with anything that is not worth your time. I guess you could say that” (Caregiver 8).

- “It’s given me a completely different perspective on death. And I think it’s something that you can’t learn from a book” (Caregiver 10).
- “It makes you more spiritual but makes you appreciate people more, it makes you more empathetic with other people's issues, and it just makes you more aware of the life going on around you. And it sounds very cliché but it makes you appreciate more of your own life, and what you have and what you should do with your life, they're always like you don't want to waste a day and well that's true right again it sounds pretty simplistic but it's true” (Caregiver 12).
- “You learn to look at things from a different perspective” (Caregiver 13).
- (When asked if caregiving had a positive impact on outlook on life) “That's like saying, you know, there's a broken arm to help you feel better. It's just something you go through. You got to do it” (Caregiver 14).
- “It makes me want to live my life” (Caregiver 15).
- “I want to help somebody, I want to help others” (Caregiver 16).

### **Discussion**

There are innumerable studies on the negative impact of caring for individuals with dementia on the caregiver. This study aimed to look at the positive impacts and to look at the negative effects as something to improve upon. It is imperative that caregivers of individuals with dementia be mindful of their own needs and health, yet many caregivers often inadequately attend to their personal needs due to the burden of caregiving. This is especially critical for caregivers of patients with dementia, who face distinctive health challenges due to the progressive



nature of the disease (Wong et al 2018). The purpose of this research study was to gain an understanding of how caregivers of individuals with dementia change their day-to-day life due to the impact of caregiving in aspects including physical and mental health, in hopes of revealing ways for future improvement of coping strategies for caregivers, as “the use and development of coping strategies may have ameliorated the depressive symptoms, anxiety, and burden of caregivers” (Monterio et al 2018).

The dynamic of personal versus professional caregivers is very important to recognize, yet both populations can experience the adverse effects of caring for someone with dementia. The most vulnerable populations include women, spouses, and those in lower socio-economic groups (Sörensen et al 2011). This study includes many women and many spouses who care or cared for an individual with dementia. The socioeconomic groups of the participants are unknown, but there is a low representation of minorities in this study which suggests a major avenue for future exploration.

As with the results section, each of the six categories of well-being in this study are listed below with the major implications that can be used in the future for continuing research and execution of modern, healthy coping mechanisms for current and future caregivers.

**Physical Activity** Prioritizing the caregiver’s health is often viewed as a selfish act, as they have taken on the job of caring for someone else. This mindset must be overcome and the importance of a caregiver’s health should be heightened because if the caregiver becomes sick they will, in turn, provide substandard care for the individual whom they are caring for. In short, there will be *two* victims rather than just one.

Caregivers of individuals with dementia must be in tune with their physical health, especially in terms of how declining mental health can manifest into physical complications. To improve physical health, caregivers suggest prioritizing daily activity (ex. a walk) and doing both mental and physical check-ins often to recognize problem areas and areas that are doing well.

**Eating Habits and Diet** Caregivers of individuals with dementia often value the convenience factor of frozen meals, fast foods, and unhealthy snacks while caregiving due to their busy schedules, rather than valuing the health benefits that healthy meals provide for themselves and the individual whom they care for. To counter the convenience of unhealthy foods, participants recommend planning ahead by doing meal prep.

**Spirituality** Most caregivers connect(ed) with the individual whom they care(d) for through a common spirituality, or a common understanding of a greater good. Few caregivers felt that their faith wavered due to unanswered prayers or factors outside of caregiving, although it is significant to note. Advice from participants includes finding a faith base to give them support during the challenges of caregiving and praying for patience while one gives care.

**Mental Health** Mental health must be taken very seriously when it comes to the caregiver. Caregivers should seek mental help to relieve stress and release anger and frustration in a healthy way, or it could manifest in physical and mental deterioration that can lead to other health issues. A study conducted in 2021 by Contador demonstrated that the negative impact of stress could be moderated by maintaining feelings of control, particularly self-efficacy and contingency. This could be achieved through journaling, meditation, therapy, or any healthy coping mechanism that each individual caregiver deems fit for their mental health.

**Lifestyle** Caring for an individual with dementia can take over the caregiver's lifestyle completely as they give their time and energy to caring for someone else, rather than themselves. Losing a sense of one's own lifestyle can lead to many physical and mental health issues, along with a loss of routine and pattern for the caregiver. Participants advise current and future caregivers to reach out to those who have been caregivers in the past or are current caregivers. Speaking to others who have gone through similar situations can help the caregiver to gain a sense of control in their caregiving, as well as their personal life.

**Outlook on Life** As previously mentioned, caregiving had the most positive impact on the caregiver's outlook on life during and succeeding caregiving. Apprehension about growing old and being diagnosed with dementia themselves causes many caregivers to evaluate their life choices and gain a sense of urgency along with a positive outlook on their current life and the life ahead of them. Many caregivers also become thankful for their own health and recognize the importance of taking care of themselves as well as those around them.

**COVID-19** Although many of the participants were caregivers prior to the current pandemic, there were others who not only experienced the austerity of caregiving but were faced with the task of being a caregiver during a pandemic (and some are currently still doing so). A few participants expressed that their lack of personal time and social interactions not only came from caregiving, but also because of the restrictions from the pandemic. Multiple personal caregivers recognized that the pandemic provided additional time to care for their loved one with dementia due to having to commit less time to work. Professional caregivers encountered the effects of the pandemic first-hand in their places of work where they were faced with the challenge of attempt-

ing to explain COVID precautions to patients with dementia who did not understand the severity of the situation. One caregiver acknowledged that the caregiver-mentality instilled in her work transposed directly to her actions during the pandemic, saying:

- “ I definitely think I live my life differently because of caregiving, especially during this pandemic, you see a lot of people going out and not really following protocol and COVID guidelines, but as a caregiver, you have a different mentality that you want to stop the spread of COVID-19 and you want to keep everyone safe and healthy and you don’t want to spread this virus. So, I think that I definitely have been more concerned and not just thinking about myself during this pandemic with the mindset of a caregiver” (Caregiver 6).

**Limitations** The small sample size (n=16) and racial homogeneity limits generalizability to a broader population. The self-developed questionnaire did not cover every aspect of a caregiver’s life impacted by caring for individuals with dementia. This study was only generalizable to caregivers who recognize themselves as caregivers. Among the participants, 100% recognized themselves as caregivers, however, thousands of people around the world do not label themselves as caregivers, refusing to take on the job title due to personal preference. Often, these caregivers are the ones who experience the most negative effects from their roles, because they are not in the position to receive help. There must be more research studies done to help caregivers like these and improve their caregiving strategies and coping mechanisms.

## **Conclusion**

This study found that caring for individuals with dementia has both negative and positive impacts on caregivers. The results of this qualitative research study found that elements of physical health, eating habits, and mental health are most negatively impacted by caregiving, while areas that were mostly positively impacted included spirituality, lifestyle, and outlook on life. This qualitative study confirms the results of earlier reviews and broadens the spectrum of studies that cover this topic while focusing on the positive effects and ways to ease the burden of the negative effects. In expectation of experiencing negative effects of caregiving, current and future caregivers should turn to the advice of past caregivers who know what it is like to go through this experience.

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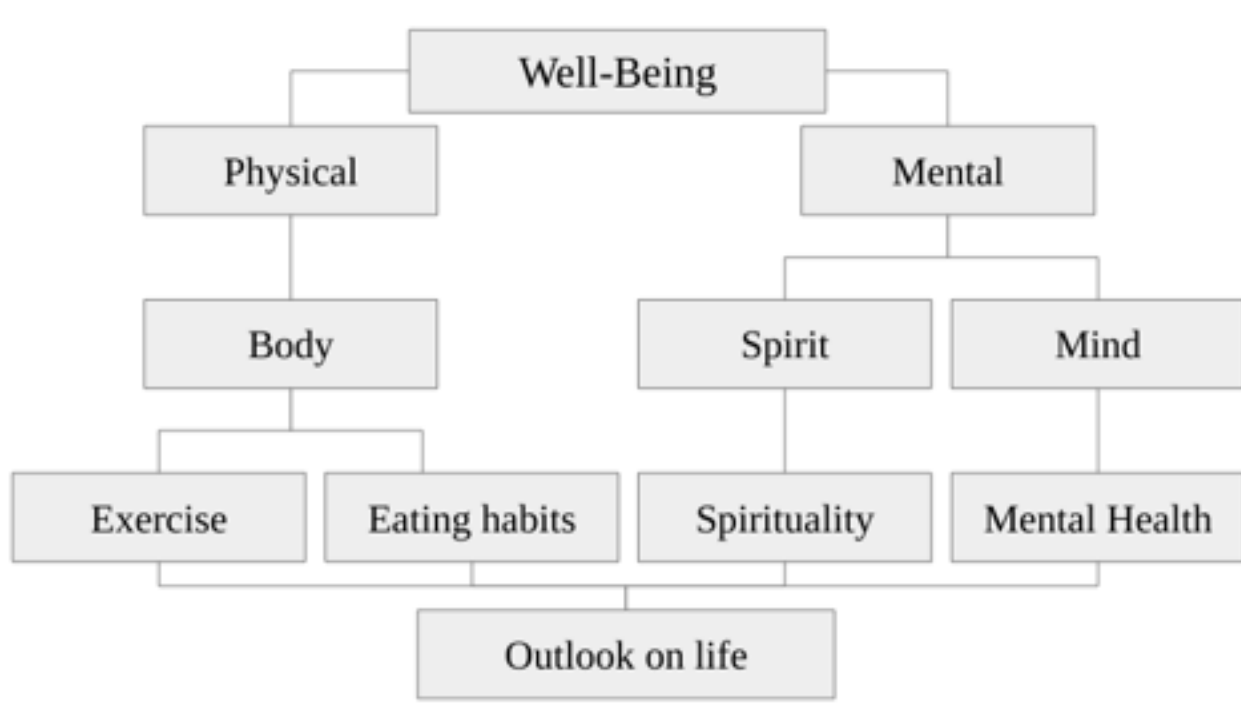
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## Maps and Tables

**Map 1.0** Basis for Well-Being



**Table 1.0** Demographic Results

Variable	Number of Participants	N (%)
<b>Sex</b>		
Female	10	62.50%
Male	6	37.50%
Other	0	0



Prefer not to say	0	0
<b>Ethnicity</b>		
American Indian or Alaska Native	0	0
Asian	0	0
Black or African American	1	6.25%
Native Hawaiian or Pacific Islander	0	0
Caucasian	15	93.75%
Hispanic	0	0
Other	0	0
<b>Hispanic or Latino</b>		
No	16	100%
Yes	0	0
<b>Age</b>		
18-19	1	6.25%
20-29	2	12.50%
30-39	1	6.25%
40-49	2	12.50%
50+	10	62.50%
<b>Age participant began caring for individual with dementia</b>		
Under 18	2	12.50%
18-19	0	0
20-29	3	18.75%
30-39	1	6.25%
40-49	2	12.50%
50+	8	50%
<b>Relationship to individual with dementia</b>		
Professional	2	12.50%

Personal (Family)	11	68.75%
Personal (Friend)	0	0
Volunteer	1	6.25%
Combination of 2 or more	2	12.50%
Other	0	0
<b>Current employment</b>		
Medical professional	3	18.75%
Teacher	2	12.50%
Corporate	1	6.25%
Unemployed	1	6.25%
Retired	2	12.50%
Other	7	43.75%
<b>Marital Status</b>		
Married	7	43.75%
Single	4	25.00%
Widowed	4	25.00%
Committed	0	0
Separated	0	0
Divorced	1	6.25%
Other	0	0
Prefer not to say	0	0

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**Table 2.0:** Overall Impact on 6 Main Categories

	Overall Impact					
	Physical activity	Eating habits & diet	Spirituality	Mental health	Outlook on life	Lifestyle
1	neutral	negative	neutral	negative	positive	positive
2	both	neutral	negative	negative	positive	positive
3	negative	negative	neutral	negative	positive	negative
4	negative	negative	positive	negative	positive	neutral
5	negative	neutral	positive	neutral	neutral	neutral
6	neutral	negative	positive	both	positive	positive
7	neutral	negative	positive	both	positive	positive
8	neutral	negative	neutral	negative	positive	positive
9	negative	negative	positive	negative	positive	negative
10	positive	neutral	positive	neutral	positive	neutral
11	neutral	neutral	positive	neutral	positive	neutral
12	neutral	negative	positive	negative	positive	positive
13	neutral	negative	positive	negative	positive	neutral
14	neutral	neutral	positive	negative	neutral	negative
15	negative	negative	positive	negative	positive	both
16	neutral	negative	negative	negative	positive	neutral
	Totals (n = 16)					
	Positive = 1	Positive = 0	<b>Positive = 11</b>	Positive = 0	<b>Positive = 14</b>	<b>Positive = 6</b>
	<b>Neutral = 9</b>	Neutral = 5	Neutral = 3	Neutral = 3	Neutral = 2	<b>Neutral = 6</b>
	Negative = 5	<b>Negative = 11</b>	Negative = 2	<b>Negative = 11</b>	Negative = 0	Negative = 3
	Both = 1	Both = 0	Both = 0	Both = 2	Both = 0	Both = 1







