Exploring the Caregiver Caring for the Aged: 
Experience through Social Media Forum

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Abstract

Purpose: In 2030, the United States will face a caregiver deficit. Currently, family members are taking on the role of unpaid caregiver as a key component to the American Healthcare system. Many family members take on this role out of love and familial obligation. As families assume this daunting task, they also take on a level of intense caregiver burden that causes stress on the caregiver in multiple aspects of their life. The purpose of this research is to explore and describe how caregivers use social media forums to address the financial, physical, mental, and relationship stresses of caregiving. By examining social media forums, this research describes the issues of the current caregiving environment. As the need for more caregivers’ increases with the retirement and health decline of the Baby Boomer generation, the public policy implications increase as well. The American Healthcare System, public policy, and senior care public programs are behooved to reform as caregiver burdens and resources become limited.

Methodology: The literature identified the categories of caregiver burden: relationship burden, financial burden, and health concerns. These three categories were used to explore social media forum Aging.com Caregiver Forum. The forum is used by caregivers where they connect, seek advice, and relate about their caregiving experiences. The framework developed from the literature divides caregiver questions and responses into the three categories included in this research. The subcategories included under the relationship burden, financial burden, and health concerns are displayed in the results data, where the question, answers, and number of likes and comments were analyzed.

Findings: Caregivers used Aging.com Caregiver Forum to ask each questions and gather recommendations. Many caregivers utilized this social media outlet as a support group. The topics and subcategories were divided to show where caregivers are experiencing the most burdens. Financial and Relationship burdens were clearly identified in this research. This explains the challenges caregivers face with the family dynamics, as well as the financial constraints and stress in the caregiving experience. As the Baby Boomer Generation increases in age and declines in health, public policy and programs will need to adapt to this growing scarcity of unpaid informal family caregivers.
# Table of Contents

Table of Tables                                                                 5
Table of Figures                                                               6
About Author                                                                  7

## Chapter I  Introduction                                                    8
Research Purpose                                                               8
Caregiver Scenario                                                            8
Social Media: Online Forum                                                    12
Purpose Statement                                                             13
Chapter Overview                                                              14

## Chapter II  Literature Review and Conceptual Framework                     15
Chapter Purpose                                                               15
Caregiver Definition                                                          15
Caregiver Burdens: Conceptual Framework                                       16
Relationship Burdens                                                          17
  *Relationship Stress Between Spouses*                                       17
  *Relationship Stresses between Adult Child and Aging Parent*                18
  *Relationship Stress between Family*                                        18
  *Relationship between Caregiver and Employer*                               19
Financial Burdens                                                             20
  *Financial Implications for Female Caregivers*                              21
  *Medicare and Medicaid*                                                     22
Health Concerns                                                               24
  *Physical Health Burden*                                                    24
  *Mental Health Burden*                                                      24
  *Social Integration*                                                        25
Summary of Conceptual Framework                                               26
Chapter Summary                                                               28

## Chapter III  Methodology                                                   29
Chapter Purpose                                                               29
Operationalization Table of the Conceptual Framework                          30
Grounded Theory                                                               33
Strengths and Weaknesses                                                      35
Sampling                                                                      36
Human Subjects Protection                                                     37
Chapter Overview                                                              38
Chapter IV  Results and Analysis

Chapter Purpose 39
Results and Analysis 39
Relationship Burdens 41
  New to Caregiving 41
  Family and Relationships 43
  Living with Family 45
Financial Burdens 47
  Paying for Care 47
  Financial Matters 50
  Navigation through Complex Health and Legal Network
    Power of Attorney and Guardianship 52
    Medicare and Medicaid 55
    Elder Law 58
Health Concerns 61
  Caregiver Burnout 61
  Physical Wellbeing 61
  Emotional Wellbeing 66
  Tough Issues 68
  Depression 70
Categories not included in Framework
  Work Life Balance 71
  Home Safety 73
  Tax Tips 75
  Insurance Matters 76
Chapter Summary 78

Chapter V  Conclusions

Chapter Purpose 79
Conclusion 79
Bibliography 86
Appendix A 89
Appendix B 90
Table of Tables

Table 2.1 Conceptual Framework  27

Table 3.1 Operationalization of the Conceptual Framework  31
Table of Figures

Figure 3.1 Forum Website 33
About the Author

Jessica Ancira has been a part of healthcare sector since she graduated from St. Mary’s University. Her first entry level job was as an internal marketing director for a Skilled Nursing Facility in East Austin. There she learned the intricacies of the senior healthcare system, including Medicare and Medicaid. She has since worked her way through various positions with other geriatric care companies, where she had to admit seniors into the nursing home and be an advocate for new patients and their families. Over the last ten years, Jessica has formed bonds with many families and caregivers and understands the burdens and stresses that caregiver’s experience. After pursuing her MPA, she understood the connection between public policy and caregivers; and where legislation is failing them as a critical component to our healthcare system. When choosing her Applied Research Project, she wanted to select a topic that is meaningful and prevalent in today’s healthcare agenda.
Exploring the Caregiver Caring for the Aged: 
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Introduction 

Chapter I 

Research Purpose 

As the practice of caregiving is becoming a more prevalent, so is the need to improve upon the institution and the support to those who provide the care. The costs and burdens of caregiving that are left to the caregiver cover multiple aspects of their lives. Caregivers must consider managing the care recipients’ finances while maintain their household income, they must manage the care logistics and medical necessities for the care recipient while maintaining their own health, and finally caregivers must do what is the best interest of the care recipient while maintaining relationships and dealing with the emotional conflict that is a result of making tough choices. The caregiver scenario of Joann depicts the story of a typical American caregiver that experiences the burdens of caregiving. The scenario shows how caregivers are filling in the vacancies left by public programs and the American Healthcare System. Ultimately, this research is to serve as a voice for caregivers that give tirelessly to their care recipient and acknowledge the value they contribute to the United States senior population and healthcare system. 

Caregiver Scenario: 

Joann has cared for her family her entire life. When she was a child, she was instructed daily to watch over her younger brothers for her parents. Joann had to make sure the house was clean, her siblings were fed, and that nobody was injured. Joann who was just a child, she was
given so much responsibility that it made her anxious. She could not go play with her friends without her younger brother by her side. A few years later, Joann wanted to go to her first high school dance. Gleefully, Joann asked her mother if she could go to the dance with her friends. Her mother said no because they needed her to watch her brothers while she and Joann’s father went out on a date. Joann was devastated and pleaded with her mother for permission to go spend time with her friends. As Joann aired her grievances about the constant responsibility of caring for her younger siblings, her mother stopped her mid-sentence and said “Joann, we are a family, you are our only daughter, and this is just what we do!” Joann did not go to the dance. She continued caring for her siblings until they were old enough to care for themselves, and Joann moved out, got married, and started a young family of her own.

Joann’s role as a mother was not so different to when she was a child. She made sure the house was clean, her children cared for, and dinner was always on the table by 6 o’clock. Joann was a stay at home mom for more than a decade. Then she went to work small jobs to contribute to the family income, but never pursued a career with benefits. She had her family and her home and that was enough for her to feel complete. One day her youngest child finally moved out to go to college, and it finally hit Joann that she was an empty nester and that her identity of caring for someone else was gone too.

Joann started to make new friends and find new ways to spend her time. Getting used to her new life, she gets a phone call from the hospital. Joann’s mother fell and broke her hip. At the hospital, the doctor went over the list of diagnoses that show a decline in her physical and mental health. The doctor finally suggested that Joann’s mother needed fulltime care and that she cannot live by herself any longer. The social worker went over care options, but Joann’s mother was adamant about not going to a nursing home. Joann’s siblings finally showed up to
the hospital. Neither of them wanted to put her in a nursing home but neither of them wanted to have their mother live with them. Both brothers stated they did not have space, or that they were consumed with caring for their children. That moment, Joann said that mother could move in with her given that she had the space as her children moved out. Joann once again was caring for someone like she always had.

Fast forward 4 years later, Joann is still caring for her mother. Her mother is living on a fixed income. Her mother’s health is still declining. She is no longer ambulatory, she needs physical therapy, and she is incontinence issues. On top of the physical health decline, Joann’s mother has dementia and acts out. She yells at Joann and says mean things. In addition to dealing with her mother, Joann’s husband also passed away 2 years ago and she is experiencing her own health problems. Joann is beginning to collect her widow’s benefits, which is not much money. Joann is exhausted. She has reached out to her siblings for help with their mother, but they often say they do not have time to visit or cancel when they do say they are going to help.

Joann is angry, tired, and full of resentment. She had no idea that taking in her mother would be this bad when she agreed to the arrangement 4 years ago. She is constantly arguing with her mother. Joann’s entire life consists of caring for her mother. The new friends she made are non-existent now. Joann’s children will come over to help, but this assistance was not regular. Her siblings are nowhere to be found other than on holidays. Joann is at her wits end, she has no idea where to find help and she has found herself to be unhappy and unhealthy.

One day Joann decided to look up on the internet for equipment for her mother’s physical therapy. She saw a link for an online group for caregivers. As soon as Joann accessed the website, she saw all the content and felt a rush of relief. The forum provided accessibility to
caregivers all over the country that felt the exact same way as she did. She accessed the categories and was able to articulate her feelings to someone who could relate to her and validate what she was feeling. Joann was able to get advice on how to manage the constant arguing with her mother, find home health and respite care so that Joann could take care of herself, and how she could find ways to pay for a nursing home through Medicaid given that both she and her mother live on a fixed income. Joann realized that what she was experiencing was a normal occurrence.

Joann was amazed how she was able to connect to other caregivers like herself. The ability to relate to another person who did not judge her negative feelings towards caring for her mother was a relief. Joann was able to get on the caregiver forum as her schedule permitted and connect immediately with another caregiver. She could ask a question regarding her caregiver experience and could get feedback from her peers. This networking and collaboration of caregiver expertise was held on the forum for future utilization. Joann and others like her use this social media forum tool for guidance and connection, which is often lacking during the caregiver experience.

Unpaid caregivers are a critical link in the healthcare chain that is often an unacknowledged and unpaid provider supporting out long-term health care system. As our population continues to age, the availability of family caregivers will become increasingly scarce (Dingell 2015, 315). In 2010, the United States had more than seven caregivers for each person age eighty or older. Projections indicate this ratio could decline to four caregivers per every one elderly individual by 2030, and three to one in 2050. The current system of care is unsustainable as the number of available caregivers declines rapidly (Dingell 2015, 315). Individuals, like Joann, bear the burdens and experience isolation. They are a hidden and understudied group who
contribute to our eldercare system adjacent to public policy programs that address the healthcare needs of the elderly. Caregivers who often provide care 24-7 have difficulty leaving the house to socialize and provide self-care. Social media forums have emerged as a tool for caregivers to find kindred spirits, ask questions, express frustration, and give advice from their own experiences.

Social Media: Online Forums

The online forum communication is through questions and reciprocating comments, and liking of those comments from members all over the world. Social Media (SNS) comprise any website that enables users to create or share a public or semi-public profile with the specific purpose of engaging in social networking with other users who may be previously known or unknown to them (Al-Bahrani et. al, p.1). In this case, caregivers are creating an online space to engage one another. The forum platforms is not as sophisticated as Facebook, but allows for questions and statements to be in larger amounts of words and are specific to the topic the user is wanting to address.

Online caregiver support groups are available through any search engine exploration. With the increase of caregivers, the need for information and resources will expand as well. Currently, over 30 million adults currently provide an average of 24.4 hours per week of unpaid/informal caregiving services to an older adult in the United States. By 2030 the older adult population is projected to rise by 101%, however, the number of family members available to provider informal care is only expected to rise 25%. As such, increasing the demands and stressors on informal caregivers (Al-Bahrani et. al, p.1). Caregiving stress occurs when the care demands found within the caregiver role exceed the available resources to cope with demands.
As demand and stressors increase the amount of caregiver burnout will accumulate as well, creating a resource gap for a generation that is caring for their parent or loved one while maintaining their own affairs.

The use of social media and online forums can be used to alleviate the experience of caregiving. Benefits of these health-related social media functions include increased interactions with others, shared information, social and emotional support, accessibility to health-related information, and capacity to influence health-related policies (Nikzad-Terhune et al p.275). Examining the content of the Agingcare.com Forum questions provides insight to the challenges caregivers are currently facing.

**Purpose Statement**

The purpose of this research is to explore and describe how caregivers use social media forums to address the financial, physical, mental, and relationship stresses of caregiving. By examining social media forums, this research describes the issues of the current caregiving environment. As the need for more caregivers’ increases with the retirement and health decline of the Baby Boomer generation, the public policy implications increase as well. The American Healthcare System, Family Medical Leave Act (FMLA), and senior care public programs are behooved to reform as caregiver burdens and resources become limited.  

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1 Family care has been viewed as a personal and private family responsibility—and largely a women’s issue—it has generally been ignored and overlooked in public policy, although it would cost an estimated $470 billion to replace that care (Reinhard et al., 2015).

2 Experts believe that our nation’s lack of a comprehensive, coordinated, and affordable LTSS system—linked with the healthcare system—intensifies family caregivers’ daily struggles. A dominant feature of both our healthcare and LTSS systems is its fragmentation. (Feinberg and Levine 2015, 13)
Chapter Overview

Chapter II is a review of the literature explaining the burdens of caregiving. This chapter explores the definition of a caregiver and the caregiver burdens that are addressed in the Agingcare.com Forum. The chapter concludes with the conceptual framework with the three categories identified in the literature. The three burden categories established in the literature, are used to group the caregiver questions and comments from the Agingcare.com Caregiver Forum.
Exploring the Caregiver Caring for the Aged: 
Experience through Social Media Forum 

Chapter II 
Literature Review

Chapter Purpose 
This chapter examines the scholarly literature on caregiver demographics, definitions, burdens, and the previous efforts made by government at the local, state, and national level to alleviate caregiver stress. Social media is used by organizations as an outlet to promote services and education of caregiver experiences in a public forum. A framework is developed to describe and assess the dimensions of the burden expressed by caregivers. A framework is informed by past studies and is subsequently used to examine social media postings from contemporary caregivers.

Caregiver Definition 
Throughout the literature the variations of concept of caregiving highlighted the specific sub-categories of caregiving. Caregiver and the practice of caregiving varies in definition because of the broad array of exercises encompassed in caregiving. Caregiving is the act of providing unpaid assistance and support to family members or acquaintances who have physical, psychological, or developmental needs (Dentra 2007). Caring for others generally takes on three forms: instrumental, emotional, and informational caring. A caregiver is described as a friend or relative who provides unpaid assistance to a person with a chronic or disabling condition (Collins and Swartz 2011, 1312). The unpaid status is considered informal caregiving. Formal caregiving constitutes services and assistance provided through a paid caregiver, such as home health or private duty nurse. Formal caregiving is more expensive than informal caregiving, making it
difficult for senior citizens on a limited income to afford. Family support takes on this role of caregiving hastily and with a lack of thoughtful planning that often result in a caregiving burden.

An estimated 39.8 million adults in the United States have provided unpaid care to an adult age 50 or older in the past year (AARP 2015, 6). Many caregivers enter the role with positive expectations, not fully grasping the amount of time and resources will be appropriated throughout the entirety of the caregiving experience. The caregiver creep is defined as when a care recipient needs minimal assistance that steadily requires more support overtime. As expectations and demand increases, the burden and impact on the caregiver’s relationships, physical and health, and overall financial outcome leading to caregiver burden.

**Caregiver Burdens: Conceptual Framework**

Caregiving burden is explained as both observable and perceived. Observable burden is related to the costs and tasks of providing care to the recipient. Perceived burden is the extent to which the caregiver is troubled or disturbed and the feelings they experience while providing care (Lai 201, 2010). Mental health and relationship burden are categorized as perceived burden in the literature. Physical and financial burden is classified as observable burden.

The burdens to caregivers have been identified through the literature review. The categories to be examined are listed in the framework (Figure 1.1). The conceptual framework consisting of relationship burdens, financial burdens, and health concerns is used to analyze the posts submitted by caregivers to Agingcare.com Caregiver Forum. The forum categories are

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3 The estimated prevalence of caring for an adult is 16.6%. (AARP 2015)
4 The majority of caregivers are female (60%), but 40 percent are male. Eight in 10 are taking care of one person (82%). They are 49 years of age, on average. A large majority of caregivers provide care for a relative (85%), with 49 percent caring for a parent or parent-in-law. One in 10 provides care for a spouse. Higher-hour caregivers are almost four times as likely to be caring for a spouse/partner. Nearly 1 in 10 caregivers is 75 years of age or older (7%). (AARP 2015)
assigned to corresponding caregiver burdens listed in the framework and the content is examined to explore the depth and complexity of the caregiver experience.

**Relationship Burdens:**

The caregiving experience can strain relationships. Caregiver stresses often negatively impact relationships between the caregiver and the care recipient, the caregiver and their spouse, that caregiver and their siblings, the caregiver and their nuclear family, the caregiver and their social network, and the caregiver and their employer. The tension in relationships can contribute to negative outcomes for the caregiver’s quality of life. This tension is described as role conflict, which is related to caregivers having simultaneously balance the roles of spouse, parent, breadwinner, employee, and a care provider for elderly relatives (Lai 2010, 201).

**Relationship Stress Between Spouses**

Stresses and tensions of caregiving manifest differently between spousal caregivers and adult children caregivers. Spouses often experience less burden than others, in particular spouses with more satisfying relationships (Chappell et al 2014, 464). Research has suggested that spouses view caregiving as a normal part of their marriage vows. However, other relatives view caregiving as extra work and experience the burden of role reversal (Bastawrous, 435). According to a 2010 study, Earle and Heymann reported that spouses over the age of 65 found that despite the burdens reported by caregivers, those who provided physical assistance, such as feeding, bathing, and toileting, experienced more positive emotions and better well-being than adults who were obliged. The lesser burden experienced by the spouse is attributed to their view of their marital role, whereas the difference with adult children caregivers view it as a significant change in their lives (Chappell et al 2014, 466).
**Relationship Stresses between Adult Child and Aging Parent**

Role changes in the relationship between adult children and their parents are emotionally strenuous. Many changes occur suddenly, impacting the lives that adult children have with their own nuclear family and employment. The current generation of adult children caregivers is called the “sandwich generation” because they are caregivers for both their parents and their children. Of the 49 million Americans living in multigenerational family household, 47% live in a household made up of two adult generations of the same family (Cohn and Taylor, 2010). Support from family can result in less anxiety and a more positive environment for the primary caregiver (Chappell et al 2014, 469). Support systems and resources are a substantial element of a positive caregiving experience. Many caregivers do not seek resources out prior to immediate or emergency situations that mandate caregiving services. Much of the previous research supports the argument of adult children have multiple demands of home, interests, work, and caregiving roles to their burden (Chappell et al 2014, 469), all that contribute to health and financial risks.

**Relationship Stress between Family**

Role conflict is also seen when caregivers have less time for their children and family, possibly leading to potential psychological stress for the caregiver (Lai 2010,201). Many caregiving roles are assigned to family members out of cultural and societal norms. Filial obligation is the practice that children should ensure their parents are well cared for in old age. Filial piety is manifested through providing parents with the necessary materials for the satisfaction of their physical needs and comforts, including attending to them when they are ill,

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5 This research supports past arguments that adult children are more likely to have multiple demands of home, interests, work, and caregiving roles which all contribute to their burden (Chappell et al 2014, 469).
paying attention to the parent’s wishes and obeying their preferences (Lai 2010, 205). Cultural norms on role expectations can reveal tensions and rivalries between siblings when they need each other the most (Timmerman 2015, 36), and escalate tension to the relationship as well as the emotional and mental health of the caregiver.

Caregiving assignments are usually allocated out of convenience or “kin availability” (Cohn and Taylor, 2010). Clear expectations are not initially set, and many caregivers take on this responsibility in conjunction with the other commitments to work, family and friends, and themselves. Resentment can fester as responsibilities increase and bandwidth is overcome with burdens, leaving the caregiver and care recipients in a difficult position.

**Relationship between Caregiver and Employer**

Caregiving negatively affect caregivers’ employment. Caregivers may have to quit their job that includes health insurance benefits, causing them to lose healthcare. Reducing work hours or quitting their job also negatively affects individuals’ personal retirement savings. In reducing their own personal retirement, their lack of retirement income reduces their ability to provide for their own senior care and increasing the likelihood they will need to rely on unpaid caregiving.

In order to change the current pattern of caregiving, a global effort is essential to provide assistance for family caregivers to ensure their longevity in the workforce and establishing their own financial security. Employers are beginning to respond by remaining flexible in work attendance and performance expectations (Gibson-Hunt and Reinhard 2015, 77).

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6 Choice in Taking on Caregiver Role When asked if they had a choice in taking on the responsibility to provide care for their loved one, half of caregivers felt they had no choice in taking on this role (49%). Higher-hour caregivers—those providing 21 hours of care or more each week—are more likely to feel they had no choice in taking on their caregiving role. (Caregiving in the U.S. 2015 AARP)

7 The typical family caregiver spends about twenty hours per week providing unpaid care to a family member for nearly five years, totaling a massive amount of unreimbursed time and energy. (Dingell 2015, 315)
caregivers adjust their work schedules, take leaves of absence, or reduce work hours because of care responsibilities. Changes in the demographic complexion of employment have had the repercussions on the proportion of individuals who are undertaking both work and eldercare responsibilities (Kim et al 2011, 348). As the caregiver population grows, support for caregiving employees is expanding to meet the demand. As often compared to child-care, elder care providers receive more interruptions during the work day. Work place support can be considered a benefit when choosing an employer. The types of support vary and are slowly making an impact on society.

Financial Burdens

The contributions and sacrifices family caregivers make are endless and have real impacts on their economic well-being. In 2009, the average out of pocket expenses for caregivers was $5,531, representing 10 percent of the caregiver’s income. Caregivers may have to purchase equipment to assist with mobility, medical bills, and home improvements for the health and safety of the care recipients (Lai 2010, 201). Additional costs include loss of salary, benefits, loss of promotional and training opportunities, and reduction in retirement savings and Social Security benefits that has an overwhelming effect on caregivers. Family caregivers age fifty and older who leave the workforce to care for a loved one will lose an average of $304,000 in wages and benefits over their lifetime (Dingell 2015, 315). The financial implications for female caregivers are substantially higher.

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8 Women suffer greater economic losses—on average, men will lose $283,716 in benefits and wages while women will lose an average of $324,044.30. (Dingell 2015, 315)
Financial Implications for Female Caregivers

The financial burdens of caregiving are particularly harsh for women. Female caregivers who provide care for their parents are 2.5 times more likely than non-caregivers to live below poverty (Collins and Swartz 2011, 71). Female caregivers that are either spouses or adult children are more likely to live in poverty due to their caregiving service. Wives may be considered more at risk for living in a poverty because assets that were accumulated over her lifetime and often fully utilized during the care of her husband, therefore having depleting resources for herself (Timmerman 2015, 37).

As for female adult child caregivers, there are implications for their financial wellbeing as well. Over the last two decades, social scientists have studied the relationship between women providing informal care and women’s employment. Taking on family responsibilities is associated with intermittent work history and employment loss, followed by earning losses, and eventually poor economic health outcomes (Donato and Wakabayashi 2006, 259). The 1987 National Survey of Families and Households, McLanahan and Monson, found that caregiving lowered married women’s chances of being employed and their hours worked for pay, but it did not affect male caregiver’s employment. Once a woman initiated caregiving, she was more likely to reduce her hours worked for pay and to leave the labor force. When the caregiving services were terminated, women tend not increase their hours worked. This finding suggests that women have difficulty recovering employment losses in midlife. Employment losses occurred substantially among women ages 46 and older, women with fewer skills, lower education, and married women. As addressed in the next section on mental health, there is a relationship between financial stress, anxiety and depression. Women who have a difficult time returning to
the work force may experience isolation, increased stress, and a decrease in fulfillment and quality of life.

**Medicare and Medicaid**

Since the Great Depression and its aftermath, the United States has developed a complex network of programs to work as a social safety net, designed to assist individuals with specific needs such as low-income levels and disabilities (Dingell 2015, 311). Both Medicare and Medicaid are critical elements of our social safety net (Dingell 2015, 311) and healthcare system. Medicare is a health insurance program for people age 65 or older, people under age 65 with certain disabilities and people of all ages with End-Stage Renal Disease (permanent kidney failure requiring dialysis or a kidney transplant) (Centers for Medicare and Medicaid, 2017). Medicare serves a primary payer source for many seniors, however it does not pay all healthcare costs at 100%. Caregivers must navigate the Medicare system to prevent out of pocket expenses that would ultimately be the caregiver’s responsibility to pay. This navigation includes finding physicians and providers that accept Medicare and accepting that Medicare only pays 80% of covered services. To ensure the remaining 20% is covered, many seniors and caregivers must purchase a Medicare supplement plan or meet income eligibility for Medicaid.

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9 Part A Hospital Insurance - Most people don't pay a premium for Part A because they or a spouse already paid for it through their payroll taxes while working. Medicare Part A (Hospital Insurance) helps cover inpatient care in hospitals, including critical access hospitals, and skilled nursing facilities (not custodial or long-term care). It also helps cover hospice care and some home health care. Beneficiaries must meet certain conditions to get these benefits.

Part B Medical Insurance - Most people pay a monthly premium for Part B. Medicare Part B (Medical Insurance) helps cover doctors' services and outpatient care. It also covers some other medical services that Part A doesn't cover, such as some of the services of physical and occupational therapists, and some home health care. Part B helps pay for these covered services and supplies when they are medically necessary.

Prescription Drug Coverage - Most people will pay a monthly premium for this coverage. Starting January 1, 2006, new Medicare prescription drug coverage will be available to everyone with Medicare. Everyone with Medicare can get this coverage that may help lower prescription drug costs and help protect against higher costs in the future. Medicare Prescription Drug Coverage is insurance. Private companies provide the coverage. Beneficiaries
Medicaid is a jointly funded, Federal-State health insurance program for low-income and needy people. It covers children, the aged, blind, and/or disabled and other people who are eligible to receive federally assisted income maintenance payments (Social Security Administration, 2017). Seniors who meet income eligibility can receive Medicaid and use it to supplement their Medicare primary payer source. Medicaid has become an essential part of senior care payer sources. Due to outliving retirement funds, many seniors rely on Medicaid (and Medicare) to receive health care and maintain a quality of life. Medicare does not pay for long term care, therefore many seniors that must live in a nursing home (long-term care facility) or participate in home-based programs utilize Medicaid benefits. Currently, 10.9 million individuals receive long-term care in a community or home setting and 1.8 million people receive such care in an institution (Dingell 2015, 311). Medicaid is not an easy payer source system to navigate. There are many income restrictions, asset requirements, and medical necessity benchmarks that must be correctly accounted. Mistakes can be costly to the recipient and the caregiver. Caregivers can seek resources, education, and expertise regarding both Medicare and Medicaid eligibility to prevent expensive penalties.

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choose the drug plan and pay a monthly premium. Like other insurance, if a beneficiary decides not to enroll in a drug plan when they are first eligible, they may pay a penalty if they choose to join later. (CMS 2017)

10 Long-term care encompasses many different health-related services linked to helping people engage in daily living activities over an extended period of time. Examples include providing assistance with eating, bathing, dressing, reading, or hearing. Long-term care is not a medical service and is not designed to treat a specific disease or ailment. The goal of these services is to improve the quality of life for beneficiaries by helping them with activities of daily living that they are no longer able to perform on their own so they can live as normal of a life as possible (Dingell 2015, 311)
Health Concerns

Physical Health Burden

When individuals become caregivers, they immediately increase their risk for mental and physical health problems. A decline in health has been found among caregivers. Seventeen to thirty-five percent of family caregivers report that their own health is “fair to poor” (Dingell 2015, 315). They are more susceptible to developing a chronic disease such as heart disease or high blood pressure (Hong and Harrington 2010, 155). Caregivers have higher rates of insomnia and depression and are less likely to engage in preventative health measures (Collins and Swartz 2011, 1310). This statistic is problematic because during preventative screenings, medical professionals can identify illness and disease at earlier stages and mitigate possible damaging and fatal outcomes. Research confirms that caregivers have 23 percent higher levels of stress hormones, and 15 percent lower antibody responses on average (Earle and Heymann 2011, 70). Stress not only affects the physical health of a caregiver but the mental health as well.

Mental Health Burden

There is fulfillment and joy in caring for a loved one. However, research has demonstrated that informal caregivers are found to experience more emotional stress than non-caregivers. Forty-seven percent of family caregivers are more likely to feel high emotional stress (Dingell 2015, 315). Emotional stress is contributed by burden, depression, guilt, worry, anxiety, loneliness, emotional strain, physical function, and social functioning. (Bastawrous 2013, 436). Depression and anxiety can be associated with the burdens described in this research. By providing caregiver services multiple hours a day, a caregiver loses their identity prior to this drastic change in their life. Many caregivers are coping with the mental and physical health
decline of their loved one. They experience a change in roles where they may feel that they are acting as the parent. When caregiver assignment is designated, there is not much preparation and planning that the caregiver can utilize prior to their experience. Caregivers can feel an overwhelming feeling as their day to day life routine has changed, and stressors associated with caregiving situations are often persistent, uncontrollable, and unpredictable, with one-third of all caregivers describing a high burden of care (Collins and Swartz 2011, 1310). Caregivers try to do the best for their care recipient, however at some point they will reach an over-extension where another entity of their life will suffer.

Social Integration

The association between mental health diagnoses, such as depression and anxiety, in conjunction with isolation are due to an increase in caregiving hours. One of the greatest risks for caregivers is becoming ill themselves (Collins and Swartz 2011, 1315). Caregivers have higher rates of insomnia and depression, are at risk of serious illness, and are less likely to engage in preventive health measures. The availability of having persons with whom to talk or to socialize, and the receipt of feelings of positive regard and self-esteem from others—appear to have a mediating effect upon our respondents' feelings of life satisfaction. An increase in isolation comes with a decrease in social support (Kaufman et al 2010, 257). Social integration of family, friends, and networks, is associated with better caregiver mental health and physical health (Rokowsk, et al 2012, 2229). Resources and support groups (online support groups) when

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11 Caregivers reporting the highest burden are more likely to be less educated, to live with the care recipient, and to perceive they had no choice in assuming the caregiver role. A majority of caregivers report having less time for family and friends; having increased emotional stress; and neglecting self-care, such as healthy sleep, exercise, and dietary habits. (Collins and Swartz 2011, 1310)
utilized appropriately can be an outlet for caregivers where they can learn from others and find
relief to the mental health stresses they have accumulated.

**Summary of Conceptual Framework**

Table 2.1 summarizes the conceptual framework (caregiver burden categories—physical
and mental health concerns, and relationships) and links it to the literature. The framework is
used to organize the exploration of Agingincare.com Caregiver Forum.
**Table 2.1 Conceptual Framework**

**Title:** Exploring the Caregiver Caring for the Aged: Experience Through Social Media Forum

**Purpose:** The purpose of this research is to explore how caregivers experience financial, health (physical and mental), and relationship burdens of caregiving.

<table>
<thead>
<tr>
<th>Category</th>
<th>AgingCare.com Caregiver Forum Topics</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><a href="https://www.agingcare.com/caregiver-forum">https://www.agingcare.com/caregiver-forum</a></td>
</tr>
</tbody>
</table>

1. **Relationship Burdens**

1.1 Caregiver and Family | Lai (2010); Timmerman (2015) |
1.2 Caregiver and Spouse | Earle and Heymann (2011); Bastawrous (2013); Chappell et al (2014) |
1.3 Caregiver and Parent | Chappell et al (2014); Cohn and Taylor (2010) |
1.4 Caregiver and Employer | Gibson-Hunt and Reinhard (2015); Kim et al (2011) |

2. **Financial Burdens**

2.1 Financial Burden to Spouse | Lai (2010); Dingell (2015); Timmerman (2015) |
2.2 Financial Burden to Child | Donato and Wakabayashi (2006); Dingell (2015) |
2.3 Navigating Complex Health/Legal Network | Dingell (2015); Centers for Medicare and Medicaid (2017); Social Security Administration (2017) |

3. **Health Concerns**

3.1 Health changes to the caregiver | Collins and Swartz (2011); Earle and Heymann (2011); Dingell (2015); Hong and Harrington (2016) |
3.2 Caregiving and Feelings of Overwhelment | Collins and Swartz (2011); Bastawrous (2013); Dingell (2015) |
Chapter Summary

This chapter examines the scholarly literature referring to the institution caregiving and caregiver burdens. This chapter has identified the three caregiver burdens: financial, physical and mental health concerns, and relationships. These three categories will be used to explore and identify burdens presented in the online forum. The next chapter discusses the methodology used to explore caregiver burdens in the Agingcare.com Caregiver Forum.
Chapter III
Methodology

Chapter Purpose:

The purpose of this chapter is to describe the methodology used to explore how caregivers of the elderly experience financial, health (physical and mental), and relationship burdens of caregiving. Caregivers have much in common and yet are isolated from one another. Internet discussion groups or forums offer them a chance to seek support from individuals with similar experiences. It also gives them a chance to express their feelings and describe their experiences. This paper draws AgingCare.com Caregiver Forum as a source data to explore caregiver experiences.

The operationalization table (see table 3.1) takes the issue framework drawn from the literature and illustrated in the conceptual framework table and connects it to topics identified in the forum. Each topic associated with the three components is categorized into either financial, health (physical and mental), and relationship burdens of caregiving. The topic categories are analyzed to observe caregiver burdens from the participants of the AgingCare.com Caregiver Forum. This chapter will discuss the description of the data collection method of grounded theory, the operationalization table, the data collection standards, and the protection of human subjects.
**Operationalization Table**

The operationalization table (3.1) is read from left to right. The first column is the where the burden category is listed: 1) relationship burdens 2) financial burdens 3) health concerns. Within each category, there are sub-categories. For example, relationship burdens include the type of relationships the caregiver holds (family, spouse, care recipient, employer) that are effected by the caregiving experience. In the right column, AgingCare.com Caregiver Forum Topics that pertain to the caregiver experience are detailed. The forum topics used in this research have comments and topics that pertain to the corresponding category. For example, the forum topics “New to Caregiving”, has questions/comments/discussions that describe the burdens to the caregiver and their family’s relationship. Another example is how “Paying for Care” places a financial burden on the caregiver. The forum topics are itemized to show where the burden types are discovered (Shields and Rangaranan, 2013; Shields and Tajalli, 2016; Shields & Whetsell, 2017).

<table>
<thead>
<tr>
<th>Burden Category</th>
<th>AgingCare.com Caregiver Forum Topics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relationship</td>
<td>New to Caregiving, Paying for Care</td>
</tr>
<tr>
<td>Financial</td>
<td></td>
</tr>
<tr>
<td>Health</td>
<td></td>
</tr>
</tbody>
</table>
Table 3.1 – Operationalization of the Conceptual Framework

**Title:** Exploring the Caregiver Caring for the Aged: Experience Through Social Media Forum

**Purpose:** The purpose of this research is to explore how caregivers experience financial, health (physical and mental), and relationship burdens of caregiving.

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</tr>
<tr>
<td><strong>1. Relationship Burdens</strong></td>
<td></td>
</tr>
</tbody>
</table>
| 1.1 Caregiver and Family | - New to Caregiving^a  
- Family and Relationships^f  
- Living with Family |
| 1.2 Caregiver and Spouse | - Family and Relationships^g  
- Work and Life Balance^i |
| 1.3 Caregiver and Parent | - New to Caregiving^b  
- Family and Relationships^h |
| 1.4 Caregiver and Employer | - New to Caregiving^c  
- Work and Life Balance^i |
| **2. Financial Burdens** | |
| 2.1 Financial Burden to Spouse | - Paying for Care^j  
- Home Safety^l |
| 2.2 Financial Burden to Child | - Paying for Care^k  
- Home Safety^m |
| 2.3 Navigating Complex Health/Legal Network | - Financial Matters  
- Medicare and Medicaid  
- Tax Tips for Caregivers  
- Elder Law |
<table>
<thead>
<tr>
<th>3. Health Concerns</th>
<th>- Power of Attorney (POA) and Guardianship</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Caregiver Burnout</td>
<td>- Insurance Matters</td>
</tr>
</tbody>
</table>

### 3.1 Health changes to the caregiver
- Caregiver Burnout<sup>d</sup>
- Physical Wellbeing

### 3.2 Caregiving and Feelings of Overwhelmment
- Caregiver Burnout<sup>c</sup>
- Emotional Wellbeing
- Tough Issues

### 3.3 Caregiving and Isolation
- Depression

<sup>a</sup>New to Caregiving - concerns regarding the caregiver and family burdens

<sup>b</sup>New to Caregiving - concerns regarding the caregiver and the parent burdens

<sup>c</sup>New to Caregiving - concerns regarding the caregiver and their employer burdens

<sup>d</sup>Caregiver Burnout - concerns regarding health changes to the caregiver

<sup>e</sup>Caregiver Burnout - concerns regarding feelings of overwhelmment by the caregiver

<sup>f</sup>Family and Relationships - concerns regarding relationships between the caregiver and family

<sup>g</sup>Family and Relationships - concerns regarding relationships between the caregiver and spouse

<sup>h</sup>Family and Relationships - concerns regarding the caregiver and parent

<sup>i</sup>Work and Life Balance - concerns regarding the caregiver and employer

<sup>j</sup>Paying for Care - concerns regarding the financial burden to the spouse

<sup>k</sup>Paying for Care - concerns regarding the financial burden to the child

<sup>l</sup>Home Safety - concerns regarding the financial burden to the spouse

<sup>m</sup>Home Safety - concerns regarding the financial burden to the child
The research design for this applied research project is both a deductive method of theorizing and inductive grounded theory. When research is guided by deductive reasoning, the researcher first moves toward the development of a logical explanation or theory and next gather evidence to test the theory (Shields and Rangarajan 2013, p. 27). Inductive reasoning moves in the other direction. It begins with a systematic observation of the world and then a logical explanation or theory is developed (Shields and Rangarajan 2013, p. 27). The deductive method was utilized to establish a framework for this research project and establish categories. Once the categories were identified the forum topics were chosen for each individual category, grounded theory was then used to analyze forum responses and refine the sense of the caregiver experience. This method is necessary for the comprehensive analysis of caregiver burdens detailed within the Aging Care Caregiver Forum. Grounded theory, originated from sociologists...
Barne Glasser and Anslem Struass, is “an inductive approach to the study of social life that attempts to generate a theory from constant comparing of unfolding observations. This differs greatly from hypothesis testing, in which a theory is used to generate hypotheses to be tested through observations” (Babbie 2014, 315). The main objective of the grounded theory is to generate an organic production theory of data. (Akbar et al 2016, 201) “Grounded theory is commonly used in human interaction or social research as a method to assign symbolism to people, objects, or the human phenomenon. Grounded theory involves constant comparative data collection and analysis. Data are typically derived from observations, incidents, and/or interviews; these are theoretical insights of the researcher, who is an active participant in the study. The researcher continuously codes the data to create a series of theoretical elements (e.g., sub-categories or categories). Key patterns, concepts, or subcategories emerge from the data to support the theory as a whole and establishes a core category. A core category is the overall central meaning that is related to the sub-categories” (Mennella 2016, 3).

Open coding is utilized to in order to organize key patterns and concepts in the subcategories. Open coding captures themes within the data (Mennella 2016, 4); there are 3 types of open codes:

- Level I codes are vivid terms.
- Level II codes are intermediate codes: broader individual core categories derived from similarities found
- Level III codes are theoretical constructs: the most abstract codes, which add meaning or purpose to the research by using action words.

Observation of the caregiver forum will operate similar to an interview. The AgingCare.com Caregiver Forum (Table 1.1) has a search bar at the top of the website page where any caregiver
in any location can ask a question. On the left hand side of the page, there is a side bar with a list of specific topics that a caregiver can access at any time. Each topic link categorizes the level one code, which is the initial search for the caregiver question. Within each link, topic threads are listed that are similar to conversations amongst caregivers. Conversation threads are evaluated by the amount of responses and the solid content derived in the comment interaction. By observing forum topic threads for commonalities, themes of the current caregiver experience can be accurately captured.

The categories were chosen by the specific burdens listed in the framework. For example, Financial Burdens would encompass the forum topics such as Paying for Care and Financial Matters because they have both stated that specific forum will engage in discussions regarding finances and issues regarding finances in the caregiving process. This research explores the burdens and experience as expressed in the forum categories. By observing the overall conversation and participation in each forum, this research detects issues that are complex and combined with other burdens in the caregiver’s life.

**Strengths and Weaknesses**

The strengths of utilizing ground theory and interview style tactics, is the observation of candid caregiver interaction and discussion. The ground theory method allows for the researcher to have an understanding of the caregiver burdens explained through the forum responses, and obtain multiple viewpoints. AgingCare.com Caregiver Forum connects people from across the United States that are facing the same challenges. Caregivers may encounter limitations to attend a support group, but in the online forum they can address their issues with caregiving to a larger audience. The national online forum allows for a diverse group of participants which is an asset for research purposes.
Weaknesses are also present in grounded theory and interview forum setting. There is no interaction between the researcher and the participants. The online social interactions are limited to an internet setting. This could be problematic because of the inability to connect the actual emotion that the participant is undergoing. The use of open coding identifies commonalities through vivid wording. There is a possibility for different wording to not be identified and therefore not contributed to the significance of a caregiver issue. Even though the national online forum allows for a greater sample size, the actual number of participants may not be an exact representation of caregiver burdens.

Sampling

Data collection from AgingCare.com Caregiver Forum are compiled of caregivers nationwide discussing their questions, concerns, and caregiver experience on an open public forum. Comments that are made by forum users explain the highs and lows of caregiving. Whether someone is looking for an answer to a caregiving question or they are venting about a problematic experience, caregivers are utilizing a conversational forum setting that allows for free conversation that is similar to an interview. An interview is a “data collection encounter in which one person (an interviewer) asks questions of another (a respondent)” (Babbi, 2014, p. 281). The difference in this forum analysis is the caregiver participants ask one another questions. Other caregivers provide a response directly to the question. Multiple caregivers can reply to the same questions, so the conversation can include multiple perspectives of the caregiving experience. This research only observes the responses to explore the burdens of caregiving.
Data was collected between October 1, 2017 through October 28, 2017. The caregiver topics in the forum was examined to determine common themes in the observation period. The unit of analysis is the initial comment or question. The responses to the initial question scaled the significance of the issue to caregiving. Responses include a reply to the initial comment and the number of “likes” that are given to the initial comment and comment replies. The top 5 comments with the most content in each forum topic will be cited in the results component of this research project.

**Human Subjects Protection**

This applied research project did not require submission to the Texas State Institutional Review Board. The AgingCare.com Caregiver Forum is an online public forum that openly displays caregiver comments and questions as they pertain to caregiving. No participant uses their own name on the online forum, however they create a screen name to be identified. In this research, neither their name nor screen name are not identified. Observations of the comment content are used solely to explore the caregiving experience. There is no contact between the caregiver participant and myself as the researcher. This research project intention is to uncover the challenges of caregiving, which is an overlooked, undervalued, public health resource.
Chapter Overview

This chapter provided an outline of the research and methodology used throughout this research project. A hybrid forum analysis utilized deductive method theory to create the framework and grounded theory to analyze the data from the forum categories. Chapter four presents the results of the hybrid forum analysis to assess the burdens of caregiving through their own words.
Chapter Purpose

The purpose of this chapter is to assess how caregivers experience financial, health (physical and mental), and relationship burdens of caregiving. This is done using a hybrid forum analysis that utilized deductive method theory to create the framework and grounded theory to analyze the data from the forum categories. This chapter summarizes the results of the data collected from the AgingCare.com Caregiver Forum. Evidence was collected and examined though a selection of forum questions in each category established in the framework. The overall results indicate that caregivers nationwide are experience burdens in multiple sectors of the caregiver experience that combines to a stressful and challenging wide-ranging experience.

Results and Analysis

The first step of this research was to establish which categories were to be analyzed in this research project. Many of the forum topics on the AgingCare.com Caregiver Forum were obvious in nature given the title of the forum, i.e. Caregiver Burnout, Family and Relationships, Financial Matters. Categories were chosen through the caregiver burdens identified in the literature review and the framework. Once the categories were established with the pairing forum, the analysis of the individual forum content could be collected and examined. Comments inputted into the selected caregiver forums were reviewed. Categories that were identified in the research but did not pertain to the framework designed from the literature review are included at the end of the results compilation. Even though these additional categories were not able to be
categorized within the framework, the information generated in the data collection did show high participation and valuable information to describe the current caregiving experience.

Overall, 17 forums were used for this research project. From the dates of October 1, 2017 through October 29, 2017, the forum was accessed weekly for new comments and questions entered by caregivers nationwide. Each of the top three comments, that generated high amounts of participation, were used in this research study. The participation rate was identified through the number of responding comments and “likes” to the responding comments. To understand the caregiver experience, the top comments identified in the AgingCare.com Caregiver Forum were also identified in the data collection. If there was no “top comment” listed, I as the researcher identified a relevant comment to be analyzed.

In order to analyze closely, each category was divided with all the questions entered into each individual forum. Appendix A depicts the number of questions entered from 10/1/2017-10/29/2017. The highest number of questions were in categories Caregiver Burnout, Medicare and Medicaid, Family and Relationships/Elder Law/ Power of Attorney and Guardianship. The total number of 318 questions were entered the AgingCare.com Caregiver Forum from 10/1/2017-10/29/2017. This large sample size of 318 was reduced as the top three comments of each category were used for the content analysis, resulting in 63 questions used for this research study.
Relationship Burdens

New to Caregiving

The forum category New to Caregiving is a combination of problems and issues that caregivers are reaching out for advice and guidance.\(^\text{12}\)

1. **How do you react to a 93 year old verbally abusing his 92 year old wife?**
   - This question generated 22 likes and 10 comments.
   - Observations of the comments received back were advice on how to monitor the care recipients, suggestions of how to recognize cognitive decline, and possible history of abuse prior to the physical and mental health decline.

   This question shows the complications of cognitive declines of the care recipient and the preexisting family and relationship dynamics. The caregiver is seeking advice on how to handle a situation that is causing stress on the caregiver and the other care recipient, contributing to the emotional burden of caregiving.

2. **I am about to become a caregiver to both parents; how do I begin?**
   - This question generated 432 likes and 77 comments.
   - Observations of the comments received back were to not be a caregiver at such a young age and those diagnoses described are very manageable for 60 year old parents. Much of the advice explained the difficulties and challenges brought on by caregiving for loved ones. The respondents explained that

\(^{12}\) The New to Caregiving common words and phrases included: Cope, Where do I begin? Verbally abusive, Resources, Struggle. Experienced caregivers relate to the origins of these common words and provide insight and recommendations to the new caregiver. Appendix B
becoming a caregiver at this time while everyone is able-bodied and sound of mine was unnecessary.

This question displayed the unfamiliarity of the caregiving experience from the person asking the question. Both parents are in their mid-sixties with manageable medical conditions that do not necessarily require caregiving services at this time. The responses from the other caregivers were overwhelming advising the questioner to not embark on this caregiver journey until it was necessary. They spoke of their own experiences, which most were negative, that have affected many areas of their lives emotionally, physically, and their relationships.

3. Is anybody else dealing with a parent who refuses to help themselves or improve their situation and expects you to do it all for them?

- This question generated 42 likes and 22 comments.
- This question was asked on the forum 2 years ago. The reason it is included in this research, because the substance of the question resonates with caregivers today as caregivers continue to respond. The responses include advice on how to set boundaries and expectations with the care recipients. Also, the responses include their personal experience with this type of situation. Given the number of responses, this experience is common in the caregiver world.

This question is a timeless inquiry as it is 2 years old and continuing to generate responses. The responses include how the relationship dynamics are tested between the caregiver and care recipient. The demand and burden is expressed in the question and the responses display this is a common occurrence in the caregiver experience.
Family and Relationships

Family and Relationships are tested on a daily basis for caregivers. Family dynamics that were established from childhood are still relevant in later years and are amplified during the caregiving experience. An ideal caregiving situation would have civil and harmonious relationship characteristics to work towards a common goal of a pleasant experience for the care recipient. As this Family and Relationships forum depicts the relationship problems that arise during this stressful time for all family members, caregivers reach out to each other for tactics to make this difficult component of the caregiver experience much easier to navigate.13

1. How do we handle a disagreement about in-laws? In-laws that are very critical of the potential caregiver and wife are asking them to buy a bigger house to all live together. Husband did not say no, but that they would think about it

- This question generated 167 likes and 45 question responses.
- Many respondents stated that the husband needed to work on setting boundaries given the current relationship and family dynamic that exists now. Respondents also stated that their marriage would drastically change for the worse should the in-laws move in.

In comparison to other forum categories, this question had a much higher participation rate. Most of the responses echoed the same warning that this situation will only get worse for the questioner should she and her husband allow for his parents to move in. This question

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13 The common words found in this forum include: Siblings, Don’t trust, Asking for money, Emotional blackmail, Guilt, Disagreement, Withhold information from Sibling, Anxious. One can assume that if there is a positive relationship amongst family members they would not be reaching out for coping mechanisms. Appendix B
qualifies as a relationship burden given the stress the question itself is putting on the between both the caregivers’ marriage and the caregivers and the care recipients.

2. How do you deal with parents who expect care because “you’re my daughter”?

- This question generated 112 likes and 32 question responses.
- The responses to this question were a combination of both voicing filial commonalities and advising. Many recognize the parent and child dynamics of society and how societal norms cultivate caregiving roles. The main theme throughout this thread in the forum is that there is pressure amongst daughters and daughter in laws to provide care and an open home.

This question resonated with many participants in this forum. Many respondents explained their own experiences and how they were given their caregiver role, and many of times it was assumed. The question itself is stated as an expectation and the role of the daughter, not the son. There are many components in societal norms that produce this expectation among daughters to fill this caregiver role, for the research purposes this question is classified under family and relationship burdens.

3. How can you deal with money hungry family members? Family will not assist with the care recipient because they are not given any money from the caregiver, or she will not give them access.

- This question generated 4 likes and 4 question responses.
- Respondents were able to relate to this question and shared their experience.

There was a top answer in the forum that provided guidance that could useful for the questioner. Top answer: As legal guardian you can petition the court to
receive payment for your services – you will need to submit those related to guardianship expenses and backup documentation as to living expenses and you needing to be her full time caregiver.

The question had limited advisable answers. Those who responded to the question with a similar experience were able to express their familiarity and concerns with “money hungry family members.” The question exposes the tension among family members, siblings of the care recipient that is a familiar outcome of caregiving.

**Living with Family**

Many circumstances require caregivers to live with their care recipient. If the care recipient does not meet medical necessity for long term care, or does not have the income to live in independent or assisted living, then living with family is the only option. With co-habitation comes more complication and stresses on relationships. Many caregivers are feeling overwhelmed with the amount of work, regret and misery.\(^\text{14}\)

1. **I feel guilty asking this question, but has anyone regretted their decision to let a family member move in? I think I made a mistake.**
   
   - This question generated 460 likes and 152 question responses.
   
   - This question was initially asked 7 years ago, and still being responded to as it is a hot topic amongst caregivers. Some responses over the years sympathized with the frustration feeling but did not necessarily fully regret their decisions. Other respondents expressed their regret with their decision to let their family member

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\(^{14}\) The common words and phrases identified are: Miserable, Regret, Mistake, Marriage to change, Too much work, Supporting, Cope, Controlling parent, Can't live w/mom anymore. Appendix B
move in. One response that stood out was “I should qualify my answer and say that IF I KNEW THEN WHAT I KNOW NOW – My mother in law would never been invited to be here.”

This question displayed the emotional burden of regret and guilt of the real tensions of caregiving. The responses also displayed more honesty of their caregiver situation that has stressful similarities. As this thread is 7 years old, proving that this element of caregiving is a real problem for caregivers.

2. My husband is considering having our family move in with his mother, who has dementia. Any advice?

- This question generated 367 likes and 50 question responses.
- Most responses state to not proceed with allowing her mother in law to move it, not even on a temporary basis. Many respondents explained the troublesome complications with moving someone with dementia. Other respondents explained there are resources for dementia patients and how to seek out those resources.

This question displays the inexperience of caring for someone with dementia. The overall consensus of the respondents was that this was a terrible idea and should be avoided. The experienced respondents were aware of the emotional and relationship burdens that would be imposed on this new caregiver.

3. My 84-year-old father-in-law moved in with us and I'm having a really hard time adjusting to having to deal with another person in the house. Any advice?

- This question generated 14 likes and 12 comments.
Most of the responses have sympathy for the questioner and have made suggestions to get the father in law out of the house and ways to establish privacy.

This question displays the life changes that are felt through being a caregiver. Moving a care recipient into their house is an adjustment for all parties. Creating privacy and boundaries will need to be implemented to maintain positive relationships.

**Financial Burdens**

**Paying for Care**

Like financial matters, paying for care is a similar category in the AgingCare.com Forum. The identifiable difference is the question of how caregivers can be compensated for the full time care they provide.\(^{15}\)

1. **How can I get paid to care for my elderly mom?**

   - This question generated 1000+ likes and 134 question responses.
   - This is a common question that people asked over the last 7 years. In addition to this question, there were 6 additional similar questions regarding compensation for caregiving.
   - Top answer identified in the forum with 873 likes: One and 1/2 years ago, I was working full-time at a job that paid fairly well for the area where I live. My mother had complications from an operation and I went on FMLA. I was starting to work a few hours here and there, but was not fully back from FMLA when they ended my position. I have been on unemployment since then. I have looked for work, but there

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\(^{15}\) Key words and phrases include “Too much to qualify for Medicaid, Paid to be caregiver, No money for senior care, financial assistance, monetary support, VA benefits.” Appendix B
is nothing that really fits my new reality. I would have to work from home and greatly reduced hours, which would have to be flexible. In addition, it is becoming increasingly clear that I am needed at home. My mother has problems walking and has fallen several times. She is on oxygen 24/7. Her oxygen level drops into the 80s with just minimal exertion. She needs help with her baths and meal preparation, etc. My father, though not formally diagnosed, seems to have early stage Alzheimer’s. In addition, they have frequent doctor visits to which I have to take them. I feel that my parents need me to be home with them at this time. Their care really is a full-time job. Does Social Security not help in these situations? If I could draw now, I would be perfectly willing to accept reduced payments in the future once I am no longer needed to care for my parents.

This question is the most reoccurring inquiry on the Agingcare.com. There were 6 additional similar questions asking for compensation for caregiving. The top answer explained how caregiving is a full time job, and that the care recipients need around the clock care. This demand for care is not conducive with full time employment. The caregiver utilized their Family and Medical Leave Act (FMLA) benefits and their employment was eliminated. The caregiver had to apply for unemployment benefits and has not had success with obtaining with new employment. This answer explains the challenges caregivers face while being a full time caregiver and the problem with losing their employment and income.

2. **If you make too much money to qualify for Medicaid, but not enough to pay for care, does this mean only the wealthy or the very poor can get care?**
   - This question generated 4 likes and 1 Expert Answer from Elder Law Attorney John Roberts.
• The recommendation given to the questioner was to contact the office of an elder law attorney in your state. The elder law attorney can explain how the Medicaid program can help your parents. If the problem is ""over - under"" (meaning an income amount that is ""over"" the monthly amount that Medicaid would pay for care in a nursing home, but under the amount that is needed to pay the nursing home's ""private pay"" rate), the Elder Law Attorney can help your parents plan a monthly spend down program that will bring them into compliance with Medicaid regulations in your state. If the problem is that your father can't afford memory care and an assisted living facility that can also accommodate your mother, consider whether home care can fill the gap. Again, the Elder Law Attorney should be familiar with home care programs that provide hours of care to supplement services provided by you or family members. Guessing about your circumstances here can't provide specific solutions. An Elder Law Attorney can bring you understanding all of your options, if you take the time to explain your circumstances."

This question displays the concern with Medicaid eligibility. When care recipients saved their retirement, many outlive their savings and qualify for Medicaid with ease. Others who have too much income and assets have to go through a process to spend down their money to qualify for Medicaid. The process is important to follow correctly to avoid expensive penalties. Using an elder law attorney can alleviate penalties.
Financial Matters

The forum Financial Matters is a broad forum topic that encompasses many issues that are considered a financial burden.16

1. My mom received a collections notice stating she owes a nursing facility around $2k when it was covered by Medicare at the time. Is this a scam?

- This question has the most participation as it generated 31 likes and 13 question responses.
- Most responses were pertaining to the experiences of the caregivers. One answer provided guidance on how to deal with this fraudulent issue. Many respondents stated to contact Center for Medicare and Medicaid for assistance and to see the validity of the charge.

This question shows the time and possible stresses that are in a caregiver experience. Many responses displayed how this issue can be more common, and how to resolve the issue. This also shows the caregiver may not have taken into account the 20% copay that Medicare does not pay for nursing home care, creating a financial burden for the caregiver.

2. My mom has the mortgage on her home but deeded the entire property to me in 2004. Will the state take her home?

- This question generated 8 likes and 8 question responses.
- Many respondents suggested a working with an attorney. The top answer provided the most helpful information “Yes, since there is a mortgage that equate to giving you

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16 The common words and phrases in the Financial Matters are similar to those in the Elder Law and Power of attorney forums. The common words and phrases are Money, Money runs out, Will, paid for services, Control of parent’s finances, burial contract, mortgage, Qualify for Medicaid, nursing home payment. Appendix B
a gift each and every month equal to the mortgage payment. You could purchase it from her for fair market value then she could afford the care she needs. Different rules may apply is you provided medically necessary care for two years prior to her entering a nursing home. Yes, only nursing home not assisted living.”

This question shows the complexity of the Medicaid eligibility qualifications and maintaining that qualification. Given the intricacy of this process and penalties involved, legal counsel is advised as many respondents suggested.

3. **Is a will needed?**

   - This question generated 1 like and 6 question responses.
   - This minimal question left many respondents asking for more information. The top answer provided helpful and thoughtful reasons as to why we all need to have wills. The top answer stated “If your family member does not have any assets or money, then they may not need one. Many states have procedures for small estates under a certain threshold dollar amount that don’t require probate court. Each state is different. You might try posting your question on Avvo.com where attorneys answer simple questions like this one, sort of like a message board. It’s a rather general question you can ask without divulging too much personal information”

   This question does not express burden felt by the caregiver, but as someone doing their due diligence. The respondent explains who and why someone would benefit from having a will. If caregiver is dealing with a large estate, then more stresses and burdens can arise from not having a will in place.
**Power of Attorney/Guardianship**

Power of Attorney and Guardianship is similar to the elder law category. In essence, elder law attorneys assist caregivers with obtain power of attorneys and guardianship. These are both complex and elongated processes. The forum generated 29 questions from the sample period of October 1, 2017 to October 29, 2017. The majority of these questions were in regards to the process and validity of power of attorneys.\(^\text{17}\)

1. **Is a financial power of attorney in one state valid in all states?**
   - This question generated 10 likes and 10 question responses.
   - The top answer recommended “consult with a local attorney that is in the state where she will sign it. There could be differences in how many witnesses are required or some other details. While you're there, I would explore her Healthcare POA too, and an Advance Medical Directive.” Other responses suggest getting legal advice to the state they are moving to, others stated they had no issues.

   This question was a rudimentary and prompted others to respond because obtaining power of attorney can be a difficult process. The suggestion to obtain Medical Directives and Healthcare POA displays how useful these legal documents are to caregivers.

2. **POA Cancelled by Bank. I have durable POA over my father's financial affairs. He has dementia/Alzheimer's and my parents have always kept their checking accounts separate. My mother pays all the household expenses out of her social**

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\(^{17}\) The key words identified in the question analysis: Financial POA, Durable POA, Contest guardianship, POA revoked, Override POA, Guardianship if still married, Sued for mishandling POA, Social Services. Appendix B
security check, and he basically gambles or spends his check on whatever he feels like. I went to the bank and exercised the POA by transferring money from his account to her account so she would be able to pay bills. When he found out about it, he went to the bank (Bank of America) and told them he was revoking my POA and they allowed him to do so, even though he has dementia (I showed the bank the diagnosis from the doctor). Can banks cancel a POA like this? It seems like that should not be legal for them to do so, since the reason for a POA is so that someone can manage the affairs of another once they are no longer able to do so.

- This question generated 4 likes and 4 question responses.
- Clarification by questioner “Thanks everyone. Yes, I worded that wrong...my father went into the bank and told the bank that he wanted my POA cancelled....I just didn't think the bank could do it but I was wrong. And as for competency, he has been seen by 3 psychiatrists and they all say he is still considered competent. So, there is really no point in pursuing guardianship. I think it is time to get an attorney involved.

This question shows the complications that arise with relationships and revocation of POA assignments. Financial institutions are exposed to risk given competency issues. The caregiver is foreseeing problems when the care recipient becomes incompetent and no legal documentation proving he is the POA or guardian.

3. Can I get guardianship over my Alzheimer’s mother if she is still married? My step-Father is literally a road block with every health care decision I want to make for my Mother. My step-Father can hardly walk because of back issues, he
refuses to use a walker, he falls all the time and he has rubber bones. He refuses to talk about a care facility. He cannot remember to give my Mother her medication because he drinks at night. My step-Father cannot take care of my Mother and my Mother cannot take care of him. I have Medical and Durable POA over the both of them. I would like my Mother to go to a memory care facility where she would get regular meals and care. I work full-time and cannot take care of her. I have a care-giver coming into their house every Tuesday night to fix dinner. (That's all my step-Dad would allow). My Mother is so tiny, she's not getting good nutrition and she's not drinking enough liquids. HELP! All 6 of my sisters live out of state and refuse to come help.

- This question generated 4 likes and 4 question responses.

- The top answer responded “You have DPOA and that should be fine to accomplish what is best for your mother and step father. Why get the courts involved and potentially contested by your siblings? Guardianship takes aways the rights of the individual in a major way. Does your mother and step father deserve that? You sound like you have their best interests at heart. Talk to your mother's MD about your concerns. I would advise to not go for guardianship because is it not necessary at this point and just adds more stress when the courts are involved. Find a good elder law attorney to make sure you are acting appropriately as DPOA and keep track of everything you do and spend. Keep your siblings informed even though they are not involved. Be transparent. You never know who may accuse you of something nefarious so have a clean paper trail. Families change when caregiving and dementia impact them and you may
see sides of your siblings you never knew existed. Good luck.” Other responses stated it is a lengthy expensive process, and prepare for relationship issues with the step father.

Here is another example of relationship tensions when it comes to POA and guardianship. The daughter feels she can help her mother more than her step-father. This may appear to be crossing a boundary, but the questioner understands the complexity of the healthcare system and necessity for decisive decision making process.

**Navigating Complex Health System/Legal Network:**

**Medicare and Medicaid**

The second category with the highest amount of participation is the Medicare and Medicaid Forum. The forum generated 40 questions from the sample period of October 1, 2017 to October 29, 2017. The major concern recognized in the questions was the qualifications for Medicaid and how it effects there caregiver. In addition the Medicaid eligibility, there were questions that asked for opinions on Medicare Supplement Plans and Medicare Advantage Plans.18

1. **If my father qualifies for Medicaid, will I be impacted?**

   - This question generated 54 likes and 17 question responses.
   - The responses advised the initial questioner to talk to a financial attorney as well as questioning if the caregivers name is on the assets. This question received the attention of an “Expert Answer” from Gabriel Heiser who stated “I wrote an article for AgingCare.com about filial responsibility laws and their impact on Medicaid.

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18 The key words identified in the question analysis were “Medicare for free, Medicaid/Medicare cover cannabis oil, figure out Medicaid, Medicaid denied, qualify for Medicaid, Medicaid Rules, make too much for Medicaid, Medicaid process, Eligibility, Medicare Advantage.” Appendix B
This question shows the impact of financial burden that is experienced by the caregiver. A primary concern for caregivers is the transfer of financial responsibility to themselves and the amount of risk they incur. This question had the highest amount of participation in the forum because many people had experience with the Medicaid qualifications system and understand the tedious task of obtaining Medicaid benefits. Given the complexity of this issue and how each case is different according the finances of the care recipients, many overwhelmingly advised to seek legal assistance to ensure accuracy.

2. **My father is 90 years old and we want to change him from HMO to Medicare and a supplement. Can he qualify for a supplement plan?**

   - This question generated 27 likes and 16 question responses.
   - Many of those responses explained the difference between traditional Medicare and Medicare Advantage plans. Many responses were lengthy describing the confusion of this issue. The top answer identified in the forum, explained how Medicare Advantage Plans work and the difficulty to switching to traditional Medicare.

   This question generated the second highest amount of participation. The differences between payer sources can be confusing. The question itself shows how the questioner is unaware of the challenges obtaining a Medicare Supplement Plan for a 90 year old, given that Supplement Insurance policies are subject to pre-existing conditions. The responses show how many people...
learned the hard way when trying to assist their care recipient. This also shows the complexity of the Medicare system and the new products used by private insurance companies.

3. **What are our options if family can no longer pay for a nursing home?**

   - This question generated 8 likes and 5 comments.
   - Many of the responses explained that the caregiver should not be responsible or obligated to pay for a long term care nursing facility. Many suggested to be mindful of the Medicaid eligibility and to seek an elder law attorney.

Many caregivers do not understand the complexity of payer sources for long term care. The question insinuates that the caregiver was paying out of pocket for the care recipients nursing home care. Like the responding comments, caregivers are not obligated to pay privately from their own income. Medicaid is a payer system that allows for those with limited incomes to qualify for long term care Medicaid. Eligibility requirements can create stress for the caregiver especially if assets are involved. In addition to financial stresses, this process can inflict confusion and stress on family relationships if there is inheritance and property to be forfeited.
Elder Law

Elder law attorneys have been suggested throughout the forum. Elder law professionals are recommended for guidance regarding power of attorneys (POA), Medicaid eligibility, and guardianship.¹⁹

1. I do not want any kind of POA for my mom, nor does my brother. What happens if she becomes incompetent?

   - This question generated 8 likes and 6 question responses.
   - Many of the respondents suggested the need for someone having Power of Attorney. They also explained that as Power of Attorney, they are not responsible for debts but to get the care recipients funds to the necessary receivers. Also, by not having Power of Attorney responsibility will still fall on the next of kin.

   The question displays the reluctance of caregiving responsibilities, in particular financial duties and a responsibility, where having a Power of Attorney is useful and many times required. The responses suggest that have a Power of Attorney assigned while the care recipient is competent is a good decision. Many respondents reiterate that financial responsibility is limited and the pros outnumber the cons for obtaining an official Power of Attorney assignment.

2. My sister has backed out of being executor of mom’s will, so it passes to me. Any ideas? Mom did state in the will for her condo to be sold and divided equally

¹⁹ The key words in this forum are Spending down, nursing home admission without permission, will executor, forged POA, invoke POA, Caregiver rights, eviction, Trust, refund check, No POA, nursing home legal rights. The questions in the Elder Law forum were various topics regarding Medicaid eligibility, Veteran’s Affairs assistance, executor decisions, and power of attorney issues. Appendix B
between me and two other siblings, not including the sister who backed out as she is wealthy. This is tricky for me as I want to stay in the condo where I have lived for 8 yrs. And am way too tired to be dealing with packing up and moving at this point. My sister says that with me being executor it puts me in better place strategically to stay here. I need strategies on how to do this......with the least conflict possible. Any ideas?

- This question generated 11 likes and 7 question responses.
- Respondents made suggestions based on personal experiences. A top answer received the most likes stated to buy out the other siblings, payoff existing mortgage, and if buying out siblings is not an option then the questioner can stay in the condo for a set period of time while you settle the estate.

This question shows the complexity of issues that arise to caregivers and family members. This one question encompasses both financial and family relationship stressors. The respondents to this question had their own personal stories of both positive and negative outcomes. They provided careful advice on how to tread through a delicate matter.

3. When my aunt died the refund check was paid in her name. The bank won’t accept the check. Any advice?

- This question generated 13 likes, 23 question responses, and one Expert Answer from Gabriel Heisers.
- The responses from the forum participants included their own personal experiences and suggested the questioner obtain legal advice. The expert answer from Gabriel Heisers stated the following: “I represented the heirs of a person who died before receiving a large settlement check. Again, it was made out to the deceased. We had to
open a probate case just to get the check cashed. As mentioned by others, here, under state law there may be creditors that need to be paid before the estate can be distributed among the heirs (if no will) or beneficiaries (if there IS a will). Most states have a quick and inexpensive version of probate that you can use, hopefully.”

This question is another example of the complexity of issues that a caregiver must navigate. Many financial issues coincide in the legal realm as well. Push back from a financial institution is a common occurrence that many of the respondents could relate to and is probably why this question had the most participation.
Health Concerns

Caregiver Burnout

From October 1, 2017 through October 28, 2017, the top three questions were explored during this research in the Caregiver Burden Forum. The top three questions were determined through the substance of the question, number of likes, and number of responses.20

1. Is being miserable worth it when you’re taking care of a parent? I’ve been taking care of my 81yr old father for years now. After a massive heart attack, accompanied with Diabetes and prostate Cancer he doesn’t care to live or eat in a way that’s conducive to life. He is so ungrateful. He’s always lived a life of selfishness. He was an abusive husband. He has 100 kids which he’s abandoned all. I’m the only one who will care for him. Growing up he always put me down and wasn’t around much. It’s like caring for a child who’s always defiant. I can’t even expect him to drink water in a day without monitoring him. He lives with my family, my daughter and my husband. Currently, I’m pregnant and feel completely overwhelmed and miserable. I can’t put my pregnancy or family first. He has no real retirement money so any assisted living facility will be just above poor. I’m trying to care for someone who makes it so difficult when he refuses to do the required minimum. He’d be happy if he could smoke weed, eat greasy food and not be told what to do. But if I put him in a facility I feel he will

20 The key words in the Caregiver Burnout are various negative words expressing the overall feeling the caregiving experience. Stress, give up caregiving, destroy everything, guilty, demand, family dynamics, spouse of a caregiver, trapped, angry, burned out at 6 weeks, compassion fatigue, anxiety, prisoner, anger, bearing all the weight, personal life balance, miserable, isolated, mistreatment by care recipient are all words captured during the analysis of the Caregiver Burden forum. Appendix B
be dead in a year. I feel completely burdened and I don’t know what the “right” thing to do.

• This question generated a large response of 202 likes and 39 comments.
• Many responses were in of sympathy and relation to this caregiver’s situation.

A large portion of the comments advised placing the care recipient elsewhere and provided options such as group homes and senior apartments that accommodate limited incomes. The top answer that accumulated the most likes stated that she needed to choose what is most important between her father and her family.

The nature of the question expressed many factors of burdens explored in this research project. There is a strain on relationships between the caregiver and the care recipient and between the caregiver and her family. The financial burden of limited income of the care recipient, meaning she would need to provide housing and food costs. Her emotional health is taking a toll as she is miserable as she feels guilt and resentment from the family dynamics created early on in their relationship.

2. How do you not let caregiving completely destroy everything? My day starts with my father’s suite smelling awful. Old man smell. Every day we clean it, I light candles, but by the end of the day, it just smells old and sick. I go to my own bed wanting to scald off my skin so I can’t smell it. This weekend, I was gearing up for today – the ONE day where I could do work – complicated work, that involved multiple locations and video shoots. I told everyone – I MUST GO TO WORK ON MONDAY. MUST. DO. MY. WORK. This morning, the aide comes and she’s new, so once again, I have to explain the big dog, the 62eurig
coffee maker, and location of silverware, on and on and on. Then dad starts to complain that he is in terrific pain – he has JUST gotten out of rehab last Thursday – way too soon in my opinion, with a fractures (no surgery needed) hip. He wants to go to the hospital – unusual for the pain. Thus, while I’m trying to get ready for work, I have an ambulance coming, the aide is upset because her patient isn’t around for our four hours, and dad is barking at everyone. In the midst of all of this, EMTs are looking for his current list of meds and asking me questions, while I attempt to put on mascara.

- This question generated 49 likes and 17 question responses.
- A response that related to with “I feel your stress. It seems that we’re caught in a waiting game. We want our lives back, but feel guilty about wanting it.” Many respondents understood the stress and inconvenience of caregivers that need to work as well as be a full time caregiver. They do recognize there is a breaking point, and offered was to mitigate these challenges and problematic feelings.

This question showed the adjacent problems that come with the caregiving territory. The underlying factor is the time management issue that many caregivers face as well as the necessity to work while being a full time caregiver. Both of these problems are not one the initial radar when one becomes a caregiver, however by the responses received to this question moments as described in the question are a familiar to other caregivers.

3. **How do you deal with the guilt your parent gives you for not doing more?** My husband and I both work full time and have our own health issues. My 2 older sisters are no help whatsoever with my dad. He’s always been a difficult person that seems to be worse as he has aged. I’ve always been upfront and honest
about what we can and can’t do. I’m tired of the guilt and manipulation, when I have told him we do the best we can and it’s not our fault he has no one else to help him. What do you guys do to handle it?

- This question generated 33 likes and 15 question responses.
- Many respondents suggested letting him know the burden the caregivers are feeling. Also, another popular suggestion was to give him other living options if he was unhappy living with the current caregiver. The option of getting him involved at senior centers and church activities may give him autonomy.

This question depicts the family and relationships stress that caregivers can experience with their siblings. The caregiver is experiencing exhaustion, overwhelmment, and guilt that can lead to problems with her emotional health. The caregiver has to work full time, meaning this caregiving experience can cause stress with the employer and job responsibilities. Finally, she stated both her and her husband have their own medical issues, therefore they must not neglect themselves during this caregiving experience.

**Physical Wellbeing**

All but one question in this forum were about the physical wellbeing of the care recipient. There was an older question that is still generating responses titled “Can caregiving kill you?”

- This question generated 308 likes and 79 question responses.
- The top answer that received the highest number of likes stated: Yes, I truly believe that Caregiving can kill you. I know the stress of just dealing with my parents has affected my health, I developed breast cancer when there were no other markers pointing at me. I am
now in remission I hope as I haven't hadn't seen my Oncologist in over a year... and am now battling panic attacks.

- Other helpful answers:

  a. I believe stress can kill you, and this is the most stress I've ever experienced -- worse than divorce, moving, loss of my other parent, being broke, job issues. The general unpredictability is what really stresses me. Never knowing who to expect when I call or visit my mother. Always on edge around her, because anything can set her off into a verbal attack, or crazy thinking. --I firmly believe the stress of caregiving can kill you. When I was trying to work full time and arrange in home care for my Mom who has dementia I thought for sure I was going to have the big one (heart attack). It was an incredibly stressful time and I was used to working in a high stress environment. I finally gave Mom and my brother the option - I either stay home and take care of Mom fulltime and be financially compensated for it or she has to go into a nursing home so I could go back to work full time. The choice was for me to stay home and care for Mom. I will say the stress is much less now.

- I often wonder though if we caregivers can't die of a "broken heart". All the things we've given up to do this job; all our dreams, our homes, our careers, our lives. It's all so incredibly sad. How much loss and sadness can one human being take?"

This was the only question that addressed the health of the caregiver. Many of the caregivers agree the accumulation of all the burdens addressed in this research cause health declines to themselves.
Emotional Wellbeing

The forum topic Emotional Wellbeing had limited number of questions regarding the wellbeing of the caregiver. Many questions consisted of emotional wellbeing of the care recipient.21

1. **Mom drudging up the past is taking its toll on me. Am I wrong for feeling like this?**
   - This question generated 11 likes and 6 question responses.
   - Most responses recommend the caregiver set boundaries and state that victim and martyrdom mentality is not acceptable. Also, others suggested giving the care recipient the option to move out given her capacity level.

   This question shows how the relationship burden is morphing into an emotional burden for the caregiver. The caregivers that responded to this question expressed the need to set boundaries as an example to alleviate the emotional burden the questioner is experiencing.

2. **Feeling so sad watching mom's dementia grow worse. What can I do?**
   - This question generated 20 likes and 7 question responses.
   - The responses expressed sympathy and explained their own grief and coping mechanisms. They also validated these feelings by replying with their own experiences.

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21 The top comments included: Caregiving is over, what to do now?, drudging up the past, taking a toll, feeling sad. The following three questions were related to the emotional wellbeing of the caregiver. Appendix B
This question did not address burdens with relationships in conjunction with emotional burdens, but to emotional toll that a caregiver feels watching the health decline of their parent. Even with the best of circumstances, this transition can cause grief for the caregiver.

3. Caregiving is over...what do I do now? For the past seven years I've been caring for my parents almost 24/7 (with taking little breaks to go to school part time). My mother passed in 2016 and my father passed just a few weeks ago. I thought my father's passing might be easier as I was closer to my mother (although I was close to my father, too, at least in the past few years) but, in fact, it's been harder. There just seems to be a vast emptiness in me now that both my parents are gone. At first there was a certain sense of relief and freedom, but then I started asking myself, what am I now? What am I here for? I've self-identified as a caregiver so much for so long that I started wondering if the world even needs me now. I am doing well in school, and I contributed chapters to a recently published academic book, but I still can't figure out what the next part of life is going to be. On top of it, I suffer from Generalized Anxiety Disorder (GAD) and clinical depression, so that hasn't helped. And I'm being more social and planning to join a bereavement group. But I still feel lost.

- This question generated 8 likes and 7 question responses.
- Responses included condolences, and grieving strategies. The top answer stated “You have my deepest sympathy, C------. Be gentle with and kind to yourself. Get good sleep. Eat well. Get outside and enjoy some sunshine and fresh air. Honor your parents by honoring yourself. You were a good son. And that's enough right now as you sit with your sadness and learn to live a new life.”
Grief is categorized under an emotional burden. This particular question is identifying the multiple factors the caregiver is experiencing. Caregivers on this forum have called this process their caregiver journey. There are highs and lows and eventually this journey comes to an end. Grief of losing parents, the relationship and family dynamics change, and the caregiver’s identity changes all contributing to the emotional toll on the caregiver.

**Tough Issues**

The Tough Issues forum is an inclusive forum that is dedicated to topics that the caregiver deems to be difficult to address.22

1. Anyone start drinking while caring for a loved one? My father was an abusive alcoholic until I was 11...smacking my mom around for years and scaring/keeping me a nervous wreck...after he quit drinking I learned to love him and helped my mom care for him the last 2 years of his life....now my mom has dementia among many other ailments..brain stem stroke mini strokes heart attack afib multiple falls fracturing back tailbone and breaking an arm..diabetes..long story short I have always hated alcohol and never wanted anything to do with it...after caring for my mom (she's been in rest home for last 3 months) I finally had test done as like most caregivers I had neglected..I already had hbp gerd arthritis bulging discs knee replacements bone spurs in spine neck and shoulders and am bipolar for 27 years with panic disorder..needless to say I came to hate the person my mom had become and realized I could no longer handle it after thinking how can I get out of this situation or get her out of it..sad I know...but I started drinking and taking xanax as

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22 Top words and phrases identified in this category include abuse of caregiver, permanent disability from being a caregiver, alcohol dependence of care recipient, grandma constantly calling the fire department Appendix B
a coping tool...and I am an emotional eater gained 55 lbs in the first year my dad passed..it doesn't help that I have a near nonfunctioning thyroid...like lizzywho61 I am also a medical train wreck...I don't want to end up being an alcoholic like my dad and popping tramadol for pain and xanax for nerves...how’s everyone else cope??

- This question generated 21 likes and 11 question responses.
- Many of the responses advise to immediately stop this combination of alcohol and psychotropic medications as it displays self-destructive behavior. Many suggested to start exercising, utilizing resources such as respite care, and to reevaluate the caregiver role.

This question is an example of a coping mechanism used to mitigate emotional burdens. The caregiver suggests that they have been emotionally eating that could in turn have an effect on their physical health as well. The caregiver is reaching out for healthy coping mechanisms and the forum responded with helpful recommendations.

2. This is mom's second day in memory care, and I feel guilty. Will it get better? Thanks to all of you who gave advice about moving my mom to memory care and how to break the news. Long story short, with a mix of aid from her doctor, a long talk from me, a short visit a week in advance, a boost from a family friend and multiple white lies, I moved her in 2 days ago. The good news is she’s out of bed, dressed and clean, and eating. The bad news is she’s obviously disoriented and scared. I also wonder if she’ll regress as others seem less cognitively with it. It’s not as though I expected she would thank me for suddenly uprooting her from her home of 57 years. But she looks so
fragile that I find myself wondering if there wasn’t some other way or alternative (even if my rational mind says there wasn’t). Will it get better?

• This question generated 2 likes and 4 question responses.
• Many could relate to the guilt she was feeling. The responses provided encouragement that she did the right thing.

This common feeling of guilt is felt by many caregivers throughout the forum. The question in particular addressed the emotional burden felt by the caregiver after they made a difficult but necessary decision.

**Depression**

The depression forum was similar to the emotional wellbeing forum due to have limited responses regarding the depression of the caregiver. All but one question were related to the depression of the care recipient. “How can I tell if I am feeling depression?” is the only question about depression from the caregiver’s point of view and has been on the forum for 2 years.

1. **How can I tell if I am feeling depression?**

• This question received 10 likes and 24 question responses.
• Many of the respondents’ agreed with the possibility of having undiagnosed depression. Contributing factors of stress, caregiver burnout from multiple facets in the caregiver experience and isolation can accumulate to a depressive status for the caregiver.
• The top answer identified in the forum stated, “Here's my take on that: Sadness and grief are appropriate reactions to gradually losing a spouse to dementia. There is nothing ""wrong"" with you that has to be ""fixed."" But if the perfectly natural
feelings are getting in the way of normal functioning and the above-normal functioning needed for caregiving, then it makes sense to consult a mental health professional. In addition to seeing a therapist, I have two other suggestions: 1) find and join a support group for caregivers of persons with dementia. 2) (if you are a reader) have a look at the book by Pauline Boss called ""Loving Someone Who Has Dementia. This on-line support group can be very helpful, too. Even if you just read posts and seldom post yourself, it can help you feel less isolated. It is a connection to others who share some of your experiences."

The topic of depression is delicate matter. Mental illness and emotional wellbeing are sensitive subjects for society. Recognizing emotional deficits and new behavior developments takes self-awareness and work to alleviate those developments to create a healthy environment. The last note in the top answer is to use resources and this online support group forum for connection to others with similar experiences. Depression amongst caregiver is not uncommon. Given the amount of stress and tension on other life components the feelings of overwhelmment are expected with the territory.

Categories Not Classified in the Framework

Work Life Balance

1. How do you learn to take time for yourself without feeling guilty or worried?

- This question generated 54 likes and 15 question responses.

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23 As stated in financial matters and returning to fulltime work, Retire, Manage Full time Job, Focus on work, Take time for self, Updating resume. Appendix B
Many of the respondents provided advice and indicated they related to the questioner. Recommendations included taking time for them and make sure they are caring for themselves. Every respondent related to the feelings of guilt.

The question conveys the need for time management and feelings of guilt. The increased number of responses indicates that this issue of taking time for one’s self is a popular issue. Also, the feelings of guilt point to an emotional burden that is felt by the caregiver.

2. Returning to full time work? I am the 24/7 caregiver for my mother but want to inquire to those who after their job of care giving is done; or if they decide to work part time; what have you done to explain to prospective employers what you did as a caregiver, and how receptive are the employers to this job experience? Has this experience prevented you from getting interviews? Are the employers still looking at your previous job experience prior to your taking on your caregiver experience? (Knowing that the job we have as caregivers is the hardest job most of us will ever have) What have you experienced?

- This question generated 47 likes and 9 question responses.
- Many responded with their experiences and difficulties re-entering the work place. The top answer was from retired human resources professional stating “My main advice is to be confident and matter-of-fact in your presentation about your choices. The prospective employer is going to want to know about your ability to fit into the job they have and the skills that are needed for that job. What have you done to keep your skills current? How does your skills/experience fit what they
need? Be able to articulate that to them because they're not going to take the time to figure it out. You have to do the work for them.”

Re-entering the workplace is difficult. The challenges of returning to work and obtaining employment are evident by the amount of responses to this question. By decreasing employment hours and quitting their job, caregivers are creating a financial burden for themselves by not generating income or contributing to their own retirement.

3. How do you manage working a full-time job and being a caregiver?

- This question generated 50 likes and 42 question responses.
- Many say their job suffered as a caregiver. They also provided advice on how to deal with the day to day logistics of caregiving. Recommendations included working with social workers to establish plans and resources for the care recipient and to not rule out long term care services when the care recipient’s health declines further.

This question is another example of the challenges of both working and caregiving full time. Multi-tasking intensive responsibilities can contribute to the financial and emotion burdens of the caregiver, and burden the relationship between the caregiver and their employer.

Home Safety

The category of Home Safety is a smaller category in the Agingcare.com with limited participation.24

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24 The common words and phrases include install, gun safety, smoking, smoke/natural gas alarms, and affordable resource to fix A/C. Appendix B
1. In need of air conditioning for my elderly father's home. What are some affordable resources?
   • This question received 5 likes and 4 question responses.
   • The responses included suggestions to seek out resources from local agencies.

Most seniors have limited incomes so local senior care agencies can assist with paying for services. If the care recipient does not qualify for specialty programs, then the cost would transfer to the caregiver creating a financial burden.

2. My father is 96, lives alone, and refuses to let me install a smoke detector in his house. What can I do?
   • This question received 97 likes and 27 question responses.
   • The responses included techniques to reason with the care recipient and how to distract. The caregiver later replied "We installed a smoke detector! He was furious, but has completely forgotten about it today... I like the suggestion that homeowners’ insurance rates might be a perk! Thanks everyone! So glad I found this site!"

This question displays how caregivers use this forum as a resource to find techniques to work with the relationship tensions the caregiver is facing.

3. My 83 year old mom keeps two loaded hand guns in the house "for protection". How do I deal with this? (2012)
   • This question generated 160 likes, 69 question responses, and 1 expert answer.
Carol Bursak provided the expert answer: This is scary! Do you think you can get rid of the ammunition? While there are some people who can still aim and shoot at 83, a paranoid personality could be a tragedy waiting to happen. If nothing else, you may have to involve law enforcement. I don't know the laws in your state, but they maybe will have suggestions for you. Good luck.

Other responses included personal opinions citing personal safety and potentially harming others or themselves.

This question was initially asked on the forum 5 years ago. The gun control issue is prevalent throughout the responses. This is an emotional burden to worry of everyone safety given the factors of cognitive decline. As this is a constitutional issue, there can be tension with confiscating firearms.

**Tax Tips for Caregivers**

Taxes for caregivers can be more complicated given the increase of dependents and resources provided to those dependents.25

1. **What is considered "chronically ill" and how to separate the "medical" part of the assisted living monthly cost from other expenses for taxes? Can anyone help?**

   • This question generated 3 likes and 7 question responses.

   • The top answer provided the resource GuestShopAdmin, an accounting professional and can offer good insight. “I think what you're also thinking is that the cap gains will raise her taxable income, and ensuring you take all qualified

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25 The common words and phrases in this forum include deduction, report money, expenses, add parent Appendix B
medical deductions may help offset that. I've been thinking the same thing myself in terms of private care. One thing to check is whether or not your mother's investments yield qualified dividends, which are taxable at different rates than nonqualified dividends. GSA can probably explain this better. I'm able to offset the cap gains by the qualified dividends, so income otherwise taxable from IRA distributions and cap gains are in fact not taxable.”

This question shows how assets used for care can complicate navigation through the current tax system for caregivers. Providing resources for caregivers in all socioeconomic backgrounds is an attribution of this forum.

2. How do I report $69k taken as caregiving services for 13 years after mom was placed in a care facility? My sister paid herself after my mother was placed in a care facility for severe dementia. I am the trustee and not sure if I can file a W2 on those monies since she (sister) claims it was income.

- This question generated 29 likes and 19 question responses.
- The majority of the responses recommended that given this complex question and expert would be able to provide the correct guidance.

**Insurance Matters**

In addition to Medicare and Medicaid, there are other insurance concerns that a caregiver can encounter. 

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26 The key words and phrases in this Life insurance policy, beneficiary, open enrollment, Medicare supplement, Long term care. Appendix B
1. Is there any reason to continue with the Medicare supplemental program for a parent in a facility? My dad is on Medicaid and about to enter a facility (ALZ). It is about $250/month.

   - This question generated 0 likes and 1 question back.
   - The only response back stated “If receiving Medicaid to pay for his nursing home payments then he should be getting Medicaid insurance. Check with the home and see what they have covering him. If getting a Medicaid supplemental and prescription you can cancel.

   This question only received one response; however it is an accurate advice. The caregiver is trying to save money while ensuring the care recipient receives the proper care.

2. "Do you need to sign up every year for Medicare and co-insurance? We are newly in charge of caring for all my in-laws financial and healthcare matters. We discovered after a hospitalization and rehab stay that Mom and Dad were behind in their bills and frankly confused by it all. Dad has always taken care of everything and now can't remember if they need to sign up every year for Medicare and co-insurance or whether it just rolls over the same each year unless changes need to be made. Any help/guidance for me and my hubby to make sure something doesn't lapse is most appreciated!"

   - This question received 2 likes and 4 question responses.
   - Many responses recommended to call the Agency on Aging.
   - The top answer stated “Once they've signed up, they don't need to register again. Typically premiums are deducted directly from SS, at least that's my experience. If by co-insurance you mean gap insurance, the only plan of which I can speak is
the BCBSM Medigap Plan C. Premiums are billed and paid monthly. If they're not, coverage can lapse.”

The question shows the financial and medical responsibility placed on the caregivers. The Medicaid and Medicare system have multiple options with very different rules. Staying current with policies can prevent a future financial difficulties.

Chapter Summary:

This chapter discussed the results of category analysis identified in the literature. Chapter V concludes the research explored the burdens and tensions experienced by caregivers. The chapter provides the overview of concerns regarding financial, health (physical and mental), and relationship burdens of caregiving. The questions and responses are directly from caregivers and caregiving experts that participate in the Agingcare.com forum. By exploring the selected questions, caregivers are voicing problems with their experience that allude to the shortcomings of the caregiving system in the United States and provide recommendations for improvement.
Chapter Purpose

The purpose of this chapter is to explore the commonalities in the responses in each category as they pertain to the experience of financial, health (physical and mental), and relationship burdens of caregiving. By establishing the commonalities in caregiver burdens and recognizing common themes, then recommendations for future research and public policy can be made. The purpose of this applied research project was to explore the how caregivers experience financial, health (physical and mental), and relationship burdens of caregiving as explained through a social media forum setting.

Conclusion

Responses from the Agingcare.com Caregiver Forum participants show a picture similar to caregiver experience in the literature. Responses in the sub-category forums displayed an overwhelmingly bleak sentiment, which caregivers attribute to their experience. In most postings caregivers strongly identified with the experiences of fellow caregivers. The sense of community was a positive aspect of the forum. Here members provided advice and normalized their feelings. The Forum was a safe place for participants to access and share their caregiver experience.

Caregivers focused on three of the major issues forums identified in the literature: relationships, monetary issues, and the navigation of the complex healthcare system. The “relationships forum” exposed the complications that arise from the stress of caregiving. There are dynamic complications between spouses that possibly existed before the caregiving role was
assigned. The most common relationship complications expressed were between adult child caregivers and the care recipient, as well as between siblings and the caregiver. The consensus of the forum is that family problems are revealed through this difficult and stressful end of life experience.

Monetary issues and categories identified within the “Navigation of the complex healthcare system” were widely used in the forum. This finding was expected due to the financial risk and responsibility the caregiver makes when they adopt the role of caregiver. The broad category of monetary issues includes senior care payer sources, managing retirement accounts, insurance coverage, and public programs such as Medicare, Medicaid, and Social Security. Caregivers are often responsible for the care recipient’s finances, making sure their healthcare needs are met and paid for accurately. Difficulties arise with finances, particularly when income restriction, payer limitations, insurance regulations and network restrictions, and penalties for mistakes occur. Members of the forum noted the importance of the Power of Attorney. When care recipients did not draft a Power of Attorney or guardianship, the uncertainty enhanced an already stressful situation because it became more difficult for the caregiver to make decisions and handle finances. Most caregivers cannot pay out of pocket therefore finances create increased amounts of stress as displayed in the Agingcare.com Caregiver forum.

**Medicare**

Much of the healthcare system works in conjunction with Medicare and Medicaid public programs. Aside from traditional health insurance, Medicare and Medicaid are considered a top payer source of healthcare service providers. Seniors use Medicare and Medicare Advantage Plans (MAPD) as primary payer sources, as well as Medicaid and Medicare Supplement Plans as
a secondary payer source for healthcare services. All insurance programs vary in benefits, coverage and eligibility that cause confusion for caregivers during the decision making process. The implementation of these programs are almost by default left in the hands of unpaid caregivers who are ill equipped to understand the system, much less make the best decision. The stress of this untenable situation was palpable among the forum participants.

Forum participants expressed many general questions and comments regarding confusion about Medicare and Medicare Advantage Plans. The most common question was in regard to switching from Medicare Advantage to tradition Medicare with Medicare Supplement Plan. There are distinct differences between the two payer sources, including guidelines and guaranteed acceptance for Medicare Supplement Plans. Traditional Medicare is a straight forward public insurance plan that seniors have paid into over their lifetime. Medicare Advantage Plans is an alternative public delivery system where a private insurance company manages the members Medicare benefits. MAPD plans are very enticing with the additional value added services that traditional Medicare does not include. For individuals that are very healthy, do not find themselves needing a broad provider network with multiple specialists and limited hospitalizations, MAPD plans can meet their healthcare service needs. The problem that was stated on the Ageing.com Caregiver Forum was in regard to a 90-year-old man to be switched to a Medicare Supplement Plan because it would meet his medical needs while he is in long term care. This is a problem because Medicare Supplement Plans can still deny members for pre-existing conditions. The forum identifies the lack of knowledge most caregivers have regarding the Medicare program and the distinction between options. Unfortunately, the way the system is designed, unpaid, family caregivers are expected to make sense of the program and then make important decisions with little knowledge of the implications of their choice.
Medicaid

Medicaid is another public program that is utilized by lower income populations to receive healthcare. Seniors are among those populations that rely on the Medicaid program for their healthcare needs. Like Medicare, Medicaid is a complex government run program that has steep requirements of medical necessity and income requirements. Medicaid is often subject to funding cuts from state and federal government; however it has not decreased the need from seniors, disabled children, and lower income populations.

The Medicaid forum participation was the highest of the explored forums. Most participants were on the forum to discuss Medicaid eligibility requirements regarding income and processes to meet eligibility. Most questions were asking what to do if they make too much money for Medicaid, options for families where the care recipient does not qualify and the family does not have the resources to pay long term care out of pocket, and the willing to divorce to meet eligibility. This forum displayed the gap of Medicaid resources for people who are not considered rich or extremely poor, placing caregivers in a position to make drastic and distressing decisions to ensure long term care options for their care recipient. Another observation in the forum was the unfamiliarity of the Medicaid program, the resources available, and the financial and stress relief it can provide for those who qualify.

Forum participants also reiterated that they were in no position to pay for their care recipient’s long-term healthcare. Caregivers will often manage their care recipient’s finances. Care recipients can often start their retirement with a larger fund. However, if they outlive their savings they are subject to a limited income of their social security. If they require more intensive care that exceeds the caregiver’s capabilities, then they may have to admit into a long-term care facility. The problem for most long-term patients is that they spent all of their
retirement prior to their admission. Most caregivers are not equipped to pay out of pocket costs for nursing home services; therefore they must apply for Medicaid. The application process includes the scrutiny of finances, insurance policies, and anything that could be considered income. Often caregivers, who are assigned the role during an emergency situation, find it difficult to track all the required documents making this process a stressful experience. This example is not unusual. In the long run, Medicaid is not a perfect system however it serves vulnerable populations and ensures they receive adequate healthcare.

**Recommendations**

Throughout this applied research project, the presence of caregiver burdens is strongly evident in the typical caregiver experience. There are many public programs that serve the care recipient, but nothing allevies caregivers currently. The main issue of this applied research project is to bring attention to the valuable resource of unpaid informal caregivers as they reduce costs by billions of dollars to the American Healthcare System. As caregiver availability decreases significantly in the next 30 years, the Federal Government must mitigate the decline and establish incentives for unpaid caregivers to ensure their own financial security.

**Recommendation #1**

Amending current public programs to include adequate and fair compensation to caregivers through both Medicare and Medicaid could be a simpler approach. Medicare Part B pays for diagnostic care, therapies, and equipment. Part B could include programs for caregiver compensation. For example, caregivers would bill Medicare Part B for hours and services. In order to prevent fraudulent claims, there would need to be an assessment of the care recipients needs and abilities similar to a therapy evaluation. A primary care physician would need to
confirm this necessity to prevent fraudulent claims as well as observing any increased burden on the caregiver.

**Recommendation #2**

Another recommendation would be to extend caregiver compensation through Medicaid services. This caregiver compensation plan would operate similar to the disabled children long term services and support (LTSS) program. The assessment and oversight of a physician would operate similar to the previous recommendation but funding would not be from the Medicare program.

**Recommendation #3**

If expanding Medicare and Medicaid to extend to caregiver compensation for caregiving services is not an option, then utilizing formal caregiving will be a secondary option. Formal caregiving could be paid through Medicare Part B, Medicaid, Medicare Supplement Insurance plans, or private pay. This homebased care should be considered because the cost to institutionalize seniors is an expensive service. If caregiver compensation cannot be implemented, then states must be open to lifting nursing home Medicaid requirements to accommodate seniors that need more care with limited funding. Currently, nursing home/long term care Medicaid is often identified to funding cuts, leaving many nursing homes with more acute cases and with less money to provide care. This is a problematic trend for upcoming deficit of caregivers because without unpaid caregivers and limited long term care options, senior will not have many options for the care they need.
**Recommendation #4**

The final recommendation is to the American society and healthcare system. Caregivers provide a vital service to seniors and to the healthcare system. They are the link in the healthcare chain that saves on costs of care. However, the recognition of the service they provide is non-existent. There are few caregiver programs that are implemented through public policy initiatives. As elected officials run on the institution of family and family values, there is no action taken place that addresses the families that sacrifice and fill in the void of the American healthcare system. Previously stated recommendations can assist with caregiver compensation, but the American federal budget must prioritize and allocate funds to implement either expansion.
Bibliography


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## Appendix A

### Number of Questions Entered 10/1/2017-10/29/2017

<table>
<thead>
<tr>
<th>Category/Topics</th>
<th>Number of Questions Entered 10/1/2017-10/29/2017</th>
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<tbody>
<tr>
<td>New to Caregiving</td>
<td>19</td>
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<tr>
<td>Family and Relationships</td>
<td>29</td>
</tr>
<tr>
<td>Living with Family</td>
<td>18</td>
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<tr>
<td>Work Life Balance</td>
<td>7</td>
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<tr>
<td>Paying for Care</td>
<td>17</td>
</tr>
<tr>
<td>Home Safety</td>
<td>11</td>
</tr>
<tr>
<td>Financial Matters</td>
<td>20</td>
</tr>
<tr>
<td>Medicare and Medicaid</td>
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<tr>
<td>Tax Tips for Caregivers</td>
<td>9</td>
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<tr>
<td>Elder Law</td>
<td>29</td>
</tr>
<tr>
<td>Power of Attorney and Guardianship</td>
<td>29</td>
</tr>
<tr>
<td>Insurance Matters</td>
<td>9</td>
</tr>
<tr>
<td>Caregiver Burnout</td>
<td>46</td>
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<tr>
<td>Physical Wellbeing</td>
<td>10</td>
</tr>
<tr>
<td>Emotional Wellbeing</td>
<td>9</td>
</tr>
<tr>
<td>Tough Issues</td>
<td>15</td>
</tr>
<tr>
<td>Depression</td>
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### Appendix B

**Common Words and Phrases in Sample Questions**

<table>
<thead>
<tr>
<th>Category/Topics</th>
<th>Number of Questions 10/1/2017-10/29/2017</th>
<th>Common Words/Phrases in Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>New to Caregiving</td>
<td>19</td>
<td>Cope, Where do I begin?, Verbally abusive, Resources, Struggle</td>
</tr>
<tr>
<td>Family and Relationships</td>
<td>29</td>
<td>Siblings, Don’t trust, Asking for money, Emotional blackmail, Guilt, Disagreement, Withhold information from Sibling, Anxious</td>
</tr>
<tr>
<td>Living with Family</td>
<td>18</td>
<td>Miserable, Regret, Mistake, Marriage to change, Too much work, Supporting, Cope, Controlling parent, Can’t live w/mom anymore</td>
</tr>
<tr>
<td>Work Life Balance</td>
<td>7</td>
<td>Returning to fulltime work, Retire, Manage Full time Job, Focus on work, Take time for self, Updating resume</td>
</tr>
<tr>
<td>Paying for Care</td>
<td>17</td>
<td>Too much to qualify for Medicaid, Paid to be caregiver, No money for senior care, financial assistance, monetary support, VA benefits</td>
</tr>
<tr>
<td>Home Safety</td>
<td>11</td>
<td>Install, gun safety, smoking, smoke/natural gas alarms, affordable resource to fix A/C</td>
</tr>
<tr>
<td>Financial Matters</td>
<td>20</td>
<td>Money, Money runs out, Will, paid for services, Control of parents finances, burial contract, mortgage, Qualify for Medicaid, NH payment</td>
</tr>
<tr>
<td>Medicare and Medicaid</td>
<td>40</td>
<td>Medicare for free, Medicaid/Medicare cover cannabid oil, figure out Medicaid, Medicaid denied, qualify for Medicaid, Medicaid Rules, make too much for Medicaid, Medicaid process, Eligibility, Medicare Advantage,</td>
</tr>
<tr>
<td>Tax Tips for Caregivers</td>
<td>9</td>
<td>Deduction, report money, expenses, add parent</td>
</tr>
<tr>
<td>Elder Law</td>
<td>29</td>
<td>Spending down, NH admission without permission, Will executor, forged POA, invoke POA, Caregiver rights, eviction, Trust, refund check, No POA, NH legal rights</td>
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<tr>
<td>Power of Attorney and Guardianship</td>
<td>29</td>
<td>Financial POA, Durable POA, Contest guardianship, POA revoked, Override POA, Guardianship if still married, Sued for mishandling POA, Social Services</td>
</tr>
<tr>
<td>Insurance Matters</td>
<td>9</td>
<td>Life insurance policy, beneficiary, Open enrollment, Medicare supplement, Long term care</td>
</tr>
<tr>
<td>Caregiver Burnout</td>
<td>46</td>
<td>Stress, give up caregiving, destroy everything, guilty, demand, family dynamics, spouse of a caregiver, trapped, angry, burned out at 6 weeks, compassion fatigue, anxiety, prisoner, anger, bearing all the weight, personal life balance, miserable, isolated, mistreatment by care recipient.</td>
</tr>
<tr>
<td>Category</td>
<td>Count</td>
<td>Description</td>
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<td>-------------------</td>
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<td>-----------------------------------------------------------------------------</td>
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<tr>
<td>Physical Wellbeing</td>
<td>10</td>
<td>Can caregiving kill you? All questions were about the physical wellbeing of the care recipient.</td>
</tr>
<tr>
<td>Emotional Wellbeing</td>
<td>9</td>
<td>Caregiving is over, what to do now?, drudging up the past, taking a toll, feeling sad</td>
</tr>
<tr>
<td>Tough Issues</td>
<td>15</td>
<td>Abuse of caregiver, permanent disability from being a caregiver, alcohol dependence of care recipient, grandma constantly calling the fire department</td>
</tr>
<tr>
<td>Depression</td>
<td>1</td>
<td>How can I tell if I am feeling depression?</td>
</tr>
</tbody>
</table>