Caregiving for Love Ones in Wisconsin

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CHAPTER ONE: INTRODUCTION

The National Alliance for Caregiving (NAC) (2015), reports that during the past year, 65.7 million Americans, or 29 percent of the adult U.S. population (31 percent of all U.S. households) served as family caregivers for an ill or disabled relative. While this care is unpaid, its value has been estimated at 257 billion dollars annually. Family caregivers in Wisconsin provides 538 million hours of care, worth an estimated of $7 billion to their parents, spouses, partners, and other adult loved ones in 2013, according to American Association of Retired Persons (AARP), Public Policy Institute’s New Report, titled “Valuing the Invaluable: 2015.”

AARP Wisconsin, states in 2013, about 578,000 family caregivers in Wisconsin helped another adult, friend, or loved one carry out daily activities, such as but not limited to bathing, dressing, preparing meals, administering medications, driving to doctor visits, pay bills, and more. In this article family caregivers reported that the stress of caregiving, while working on a job, affects them physically, emotionally, and financially. These reports clearly show that we need to do more to assist the hundreds of thousands of caregivers across Wisconsin, and the entire country.

Caregiving in The (NAC) U.S (2015) states that nearly 40 million Americans provided unpaid care to an adult in the last year:

- Nearly 1 in 10 caregivers is 75 or older.
- Total caregiving hours are particularly high for those caring for a family member, or partner (an average of 44.6 hours a week).
- 40 percent of caregivers report a high burden of care; 18 percent report a moderate burden of care.
• When asked if they had a choice in taking on their caregiving role, over half of respondents said no.

Although caregiving is well needed, it can have a physical, emotional, and psychological effect on you. The stress of caregiving will leave you vulnerable to a wide range of problems, including depression, anxiety, and burnout. (NAC) 2015.

Statement of the Problem

According to the University of Oshkosh Center for Career Development (CCDET) (March 2010), caregiving for adult family members, or friends not only has important roles in assisting their loved one, but they also estimate that the number of caregivers will only continue to rise in Wisconsin. Two-thirds of the U.S. expect to be caregivers in the future, and 43 percent reported that it is very likely they will become a family caregiver (Opinion Research Corporation, 2005). Like many healthcare professionals, caregivers work hard and experience a wide range of emotions which can lead to stress and burnout. The National Alliance for Caregiving (NAC) reports:

• Half (53%) of caregivers said their health had gotten worse due to caregiving. They also stated the decline in their health has affected their ability to provide care (NAC, 2006).

• Caregivers said they do not go to the doctor because they put their family’s needs first (67% said that is a major reason), or they put the care recipient’s needs over their own (57%).

• More than half (51%) said they do not have time to take care of themselves and almost half (49%) said they are too tired to do so (NAC, 2004).
• 55% of family caregivers reported being overwhelmed by the amount of care their loved ones need to a point they find themselves worn out and unable to give the best care.

• 38% of family caregivers report a moderate (20%) to high degree (18%) of financial strain as a result of providing care.

• In 2014 60% of family caregivers had full, or part time jobs to besides caring for their loved ones.

**Definitions of Terms.**

**Caregiver:** The act of providing unpaid assistance, and support to family members, acquaintances or loved ones who have physical, psychological, or developmental need.

**Family Caregiving:** Is someone who is responsible for attending to the daily needs of another person’s physical, emotional, and often financial needs. They offer support to another person who is unable to care for him/herself due to illness, injury, or disability.

**Stress:** A state of mental emotional strain, or tension resulting from adverse, or very demanding circumstances

**Burnout:** Exhaustion of physical, or emotional strength, or motivation usually as a result of prolonged stress, or frustration.

**Respite Care:** Is a planned, or emergency, temporary care provided to caregivers of a child or adult. Respite provides a break for the family caregiver, which may prove beneficial to the health of the caregiver.
**Long term care:** Refers to a continuum of medical, and social services designed to support the needs of people living with chronic health problems that affect their ability to perform everyday activities.

**The Purpose of the Study**

According the Caregiving in the U.S. 2015 report when asked if they had a choice in taking on the responsibility to provide care for their loved one, half of caregivers self-reported they had no choice in taking on their caregiving responsibilities. In addition, the report suggests that in many ways, caregivers who feel they had no choice in taking on their role are different from those who feel they had a choice, often finding themselves facing complex care situations, and increased stress and strain. The purpose of this study is to assist caregiver in gaining an understanding of their loved one’s needs, and to seek potentially available caregiving resources to incorporate in both of their lives. Understanding, and leveraging these caregiving resources can help ensure that caregivers are not assuming all the caregiving responsibilities alone. Reaching out to other family, friends, and low, to no cost professional caregiving services for help, can allow caregivers time to relax and recharge.

**The Significance of Study**

In the industry of caregiving there are many current, and future demands on Caregivers. This warrants much needed research, in hopes to educate, as well as empower this population. The significance of this study is to provide evidence based practices, and resources to assist in supporting caregivers. The participants receiving different levels of care in the home need
reliable, healthy, and dependable caregivers. This is important because the client, rather family, friend, or loved one could be at risk.

In 2007, Wisconsin’s nursing homes had an occupancy rate of 88% due to high cost, and suspected elderly abuse. The average rate in Wisconsin for private pay home health aides ($20 an hour). Medicare-certified aides $30 an hour. (AARP Wisconsin). The trend for choosing nursing home for care is on a decline, especially for-profit nursing homes. Recent studies have found that non-profit nursing homes generally deliver higher quality of care. In 2009, 48% of Wisconsin nursing homes were for profit, while 36% were non-profit, these numbers are on the incline. (AARP Wisconsin) In addition, most family members prefer to receive long-term care at home; however, Wisconsin spends 72 percent of the state’s Medicaid funds on Institutional care (AARP Wisconsin).

AARP (2009) says that most Americans age 50+ (89%) want to stay in their homes if they can before they would consider care outside of the home. Nearly 988,000 Wisconsinites rely on Medicaid, and 13% are age 65+ (AARP WI.). Home and community-based services (HCBS) waivers allow Medicaid recipients to receive Medicaid funding for in home care. (AARP WI.) In Wisconsin, Medicaid allows some to choose in home care instead of nursing home care. (AARP WI.) In 2006, 21,067 Wisconsinites 65+ with disabilities received a waiver. (AARP WI.) There were 13,296 people 65+ with disabilities who waited to receive a waiver in 2008. (AARP WI.) However, 590,000 Wisconsinites are providing family caregiving to a loved one at home; which however, this care is valued at $6.6 billion a year (AARP WI.).
Delimitations of Research

In this study the research, and resources is limited to the best practices primarily throughout the State of Wisconsin, and its surrounding communities, as it relates to in home unpaid personal caregiving. in the home as it measuring such areas as affordability, and cost effectiveness outside of the home

Method of Approach

This review is based on caregivers in Wisconsin, and the surrounding areas statewide. This research will include a review of literature, articles, evidence, and statistics that highlights the significance of caregiving in United States as well as efforts/strategies being used to help caregivers. Primary focus is on statistics for Wisconsin.
Chapter Two: Literature Review

Recognizing the Need for Outside Help in Caregiving

According to Dr. Eboni Green (Sharecare.com), Caregivers play an important role in providing care for their sick or disabled loved ones. However, caregivers need support to increase their chances of having an effective and healthy caregiving experience over the long haul. She further provides the following top five reasons why caregivers need support:

- Caring for a sick or disabled loved one can be complicated. Caregivers must possess a variety of skills depending on the needs of their loved one. Some caregivers provide their loved ones with emotional support, others might aid physically, with such things as lawn care, grocery shopping, and the like. There are times where some caregivers provide total care, and help to their loved ones. Thus, caregivers must be versatile, as well as, prepared for many aspects of providing care for a sick, or disabled loved one.

- Not everyone knows, or understands all that is involved in caregiving; therefore, it may feel as if it is a thankless job. It is important for caregivers to educate themselves, family, and friends about the important details involved with caregiving, and if possible reach out and ask them for help.

- Care giving is easy to start but hard to quit. Caring for a close friend, or family member is not like a traditional job. In many instances the hours are not set, as the roles may change per the needs of that loved one. Often there are emotional ties in care giving that are incomparable to a typical, traditional workplace setting.
Often caregiving requires a long-term commitment. Most caregivers provide care for a loved one over an extended period.

In fact, in the 2009 Caregiver Wellness Survey, the average length of time caregivers spent caregiving was five years or more.

According to the National Care Planning Councils December 12th 2011. In many cases caregivers, don’t recognize when they are in over their heads, and often get to a breaking point. After a prolonged period of time, caregiving can, and will become too difficult to endure any longer. The article also states that Short-term, the caregiver can handle. Long-term, help is needed. At this point outside help is highly recommended. (www.longtermcarelink.net)

A typical pattern with an overloaded caregiver may unfold as follows:

- 1 to 18 months - the caregiver is confident, has everything under control and is coping well. Other friends and family are lending support.
- 20 to 36 months - the caregiver may be taking medication to sleep and control mood swing. The caregiver feels alone and helpless.
- 38 to 50 months - Besides needing tranquilizers, or antidepressants, the caregiver's physical health is beginning to deteriorate. Lack of focus and sheer fatigue clouds judgment, and the caregiver is often unable to make rational decisions, or ask for help. (www.longtermcarelink.net)

The National Care Planning Council (N.C.P.C) made mention, roughly, 11.1 million Americans of all ages is receiving formal, or informal care at any given time. This represents about 4% of the population and is comprised of about 9.5 million receiving care at home.
About 25.8 million family caregivers provide personal assistance to individuals 18 years, or older who have a disability, or chronic illness. And nearly one out of every four households (22.4 million households) is involved in giving care to persons aged 50 or older. About 43% of those receiving care are under the age of 65 and are evenly spread between ages 18 to 64. Children under 18, and receiving assistance because of disability are often characterized under different criteria of care giving. (www.longtermcarelink.net)

The (N.C.P.C.) says that certain diseases, disorders, accidents, or injuries result in disabilities that last longer than a few weeks or months. Many of these become permanent problems, and although the disabled person may eventually adapt to take care of himself, a caregiver is often needed. The location of where this care is given, is typically in the residential homes, or in an institution. The care is usually provided by informal, or formal caregivers, as it is dependent on the nature of the disability, as well as, the ability of the caregiver. (www.longtermcarelink.net)

Informal caregivers are family, friends, neighbors, or church members who provide unpaid care out of love, respect, obligation, or friendship to a disabled person. Without informal care giving, this country would have a difficult time formally funding the care giving needs of a growing number of disabled recipients.

Constraints on an informal caregiver are as follows:

- the amount of time needed to care for the disabled
- the need to balance a job with the demands of care giving
- the physical demands of moving the disabled
- Changing dirty diapers, or helping in the bathroom with toileting, and bathing.

(www.longtermcarelink.net)
Caregiving in the U.S. 2015, states that Policy makers, and care providers may be unable to change a caregiver’s perception of choice in taking his, or her role in caring for a loved one. The perception is closely tied to the relationship between the caregiver and care recipient, as well as the presence of other unpaid family caregivers; however, providing supportive services to caregivers who feel this sense of “obligation” may help mitigate some of the negative impacts arising from the complex care situations in which these caregivers find themselves. Reflecting this, caregivers who feel they had no choice in taking on their role are more likely to state that seeking outside support would be helpful. (www.aarp.org)

In the article, A Reappraisal of Effects on Caregivers, the author states there are literally thousands of scientific investigations that have attempted to assess the impact of informal (unpaid) care giving on the caregiver. Over the past three decades, data from these studies have suggested that individuals who tend to the needs of their elderly, sick, or disabled relatives, loved ones, and friends can feel burdened, and are at risk for psychological stress, health disorders, and increased mortality (Baronet, 1999; Pinquart & Sorensen, 2003, 2007; Schulz & Monin, 2012; Schulz & Sherwood, 2008; Vitaliano, Zhang, & Scanlan, 2003). (Social Issues & Policy Review, Vol. 8, No.1, 2014, pp. 74.)

The Advantages of seeking outside help as a caregiver

Dr. Linda Ercoli (sharecare.com) adds the outcomes of support for caregivers are very positive. Studies show that caregivers who receive support are less upset by a person’s memory problems. It can also relieve depression, and depression severity. In other words, when caregivers are happy with their social support, they feel less stressed. This in turn can benefit the people they are caring for. When a caregiver is supported and therefore less stressed, there is a
reduced rate of admission to nursing homes. People are also able to live at home more days before they are placed. In other words, the caregiver can tolerate the situation better.

**Wisconsin Statewide Programs and Resources**

The Wisconsin’s Aging and Disability Resource Center (ADRC) offers family members and other informal caregivers access to programming and education that can make being a caregiver more manageable. It provides free and unbiased information and assistance to connect families with in-home care providers, respite services and other caregiver resources in the area. ADRC staff is trained to navigate through immediate crises and provide decision-making counseling so that caregivers can make informed decisions. ADRC staff can also refer families to professionals that provide legal advice and financial planning services, including information about Social Security, Medicare and Medicaid benefits.

The Wisconsin Department of Health Services (DHS) website provides a list of the following caregiver support programs that are available in every community in Wisconsin (www.dhs.wisconsin.gov/aging/caregiver.htm).

The National Family Caregiver Support Program (NFCSP) provides services and supports that help family caregivers and informal caregivers, such as a neighbor or friend, care for older adults at home. The NFCSP is available to any person providing care to an adult age 60+. The program prioritizes services to low-income families and older adults with dementia, but one does not have to be low-income or have dementia to participate.

The program offers:

- Information about available services
• Assistance with gaining access to services
• Individual counseling to deal with depression and stress
• Caregiver support groups
• Training on providing safe and proper in-home care
• Temporary respite services, such as help with bathing, home repairs, snow removal or emergency in-home care
• Supplemental services, such as help making minor home modifications or providing adaptive equipment that allows a person to remain living safely at home

The Wisconsin Alzheimer's Family and Caregiver Support Program (AFSCP) is like the National Family Caregiver Support Program explained above, but only serves people with a diagnosis of Alzheimer's Disease or dementia.

To be eligible for AFCSP, the care receiver must meet three criteria:

1. Have a diagnosis of Alzheimer's Disease or other dementia
2. Reside in a community or home setting (not a facility)
3. Have an income of $48,000 or less (person and spouse)

Typical goods and services that can be provided through the AFCSP include:

• Respite care or household services
• Emergency response and home safety/alarm systems
• Home safety modification
• Specialized clothing for people with dementia
• Activities or hobby supplies
• Legal expenses related to establishing guardianship
• Caregiver counseling services
• Caregiver education classes
• Emergency housing and energy assistance

Wisconsin DHS also partners with community organizations across the state to offer the following caregiver support services:
o **Powerful Tools for Caregivers** - A six-week caregiver education class that teaches how to avoid injury when lifting a person, stress reduction techniques and the importance of self-care so that caregivers don't become sick or injured as a result of providing care to someone else. The class teaches skills applicable to all types of caregivers.

o **Savvy Caregivers** - An education class that may be provided by local Aging Offices, ADRCs, health care organizations and Alzheimer's groups. Savvy Caregiver is similar to Powerful Tools for Caregivers, but the focus is on dementia caregiving.

o **Share the Care™** - An informal system of care that helps organize family, friends, neighbors, co-workers, faith communities, social groups, volunteers and anyone else you can imagine, into a network of support for care recipients and their primary caregivers.

o WisconsinCaregiver.org Website
  [http://www.wisconsincaregiver.org](http://www.wisconsincaregiver.org) (link is external)

o Dementia-Friendly Employers Toolkit
  [https://www.dhs.wisconsin.gov/dementia/dfe-toolkit-home.htm](https://www.dhs.wisconsin.gov/dementia/dfe-toolkit-home.htm)

**Other Organizations**

Caregiver education and support is also available through local and nationwide organizations and groups that serve families coping with a new diagnosis or a chronic illness. Most condition-specific organizations, such as Alzheimer's Disease, cancer arthritis, etc., provide information and offer classes to support families and help prepare for the future. Below are a few common organizations:

o Alzheimer's Association - Wisconsin Chapter
  [http://www.alz.org/gwwi](http://www.alz.org/gwwi)

o Alzheimer’s and Dementia Alliance of Wisconsin
  [http://www.alzwisc.org](http://www.alzwisc.org)
- National Alliance for Caregiving
  http://www.caregiving.org/resources/
- AARP
  http://assets.aarp.org/external_sites/caregiving/index.html
- National Center on Caregiving
  https://caregiver.org/national-center-caregiving
- Wisconsin Parkinson’s Association
  http://www.wiparkinson.org/
- American Cancer Society
  http://www.cancer.org/treatment/index
- National Kidney Foundation
  http://www.kidneywi.org/
- Crohn’s and Colitis Foundation of America
  http://www.ccfa.org/chapters/wisconsin/
- Huntington’s Disease Society of America
  http://www.hdsawi.org/
Chapter Three: Conclusion & Recommendations

Caregiving can typically be considered a chronic, long term challenge for many. With nearly one out of every four households (22.4 million households) being involved in giving care to persons aged 50 or older; support to the caregivers is critical to these families (www.longtermcarelink.net). However, research by AARP and other groups has found that people who do not consider themselves to be caregivers often fail to take advantage of available aid. In addition, an AARP polling shows that while 51 percent of caregiver’s cope in part by praying, fewer than half ask others for help (Bein et.al, 2012). Conversely, studies show that these caregivers can experience emotional roller coasters, often feel overwhelmed, under paid and isolated. In addition, they can face years of caregiving responsibilities, and for some the disheartening reality that there is no hope for a love one to get better can be disheartening.

A Gerontologist-published study, led by UCLA researchers, supports a growing body of research that middle-aged people who assume full caregiving responsibility are likely to see the job negatively impact their own health. The team tracked about 6,000 caregivers and about twice as many non-caregivers, and found that the caregivers were more likely to take part in "negative health behavior" — defined by the study as smoking, consuming fast food and regular sodas, and being sedentary. Interestingly, the amount of time caregivers spent in the role did not make a significant difference in the study's results, an indication that the stress of caregiving has an impact on those who live with their parents as much as those who stop by once a week (Drevitch, 2013).

Drevitch (2013) reports many caregivers describe themselves as being tired or anxious, and the deterioration of their mental and even physical health is common (Brink, 2004;
In many cases, they may be obliged to cut back on leisure time or work hours, suffer loss of income, and may find that family conflicts develop or become aggravated (Chung, McLarney, & Gillen, 2008; Wakabayashi & Donato, 2006). This can result in marital problems, professional difficulties, anxiety, depression, and burn out (Frémontier, 2003).

Researchers have found that caregivers need:

- To maintain balance from day to day
- Continuously replenish themselves physically, emotionally, and spiritually.
- Carve out sometime to self-care.
- Establish a network of relatives, friends or people in the community
- Schedule a family meeting, or video chat about who does what, and convey your needs are.
- Join a local or online support group so you can connect with sympathetic ears, and glean ideas for coping better. (www.aarp.org/home-family/caregiving)

Based on this research, there needs to be a system to reach out to caregivers regularly to make them aware of the resources and support before they begin to experience negative effects of being a caretaker. They are a vital part of the health community and families are depended on their selfless help.
References


AARP. www.aarp.org


Institute on Medicine, Retooling for an Aging America: Building the Health Care Workforce, April 2008, www.nap.edu/catalog/12089.html


The National Alliance for Caregiving (NAC) and the AARP Public Policy Institute are proud to present *Caregiving in the U.S. 2015*.
