



2005

Maintaining A Balanced and Healthy Lifestyle for Caregivers

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MAINTAINING A BALANCED AND HEALTHY LIFESTYLE FOR CAREGIVERS

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A Scholarly Project

Submitted to the Occupational Therapy Department

of the

University of North Dakota

In partial fulfillment of the requirements

for the degree of

Masters in Occupational Therapy

Grand Forks, North Dakota

May

2005

To my caring mother, Donna. She was a dedicated and loving caregiver for her husband, my father. Without her, my father would not have experienced the quality of life that she provided. You are loved and respected by many.

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Chapter 1: Introduction

Individuals often become caregivers unexpectedly and are not fully prepared for this undertaking. Caregivers frequently do not receive adequate education and important information that will assist them in fulfilling the responsibilities. This may lead to clinical depression, burnout, and having a negative experience as a caregiver. This in turn hurts both the caregiver and the one receiving the care. Lim and Zebrack (2004) estimated that more than 25 million Americans serve as family caregivers. 52 million informal and family caregivers provide care to someone aged 20+ who is ill or disabled and nearly one out of every four households (23% or 22.4 million households) is involved in caregiving to persons aged 50 or over (Family Caregiver Alliance, n.d. b.). Approximately one-half of primary caregivers provide care with no outside assistance and only 10% to 20% of family caregivers use formal services through public or private agencies (Family Caregiver Alliance, n.d. b.). By not addressing the needs of the caregivers; they may experience burnout, depression, or provide inadequate care.

Previous literature has focused on what problems caregivers have and possible unmet needs (Brown & Mulley, 1997; Grant, Weaver, Elliot, Bartolucci, & Newman, 2004; Sharpe, Butow, Smith, McConnell, & Clark, 2005). Lack of caregiver training is a significant problem identified in the literature (Chen, Mann, Tomita, & Nochajski, 2000; Brown & Mulley, 1997). Caregivers are taking on this responsibility without much education and additional training. Training in patient diagnosis, transfers, medical equipment, adaptive equipment, and medication can all benefit caregivers and the care

recipient. Gaps found in the literature did not address potential ways of assisting caregivers or doing follow up studies on caregivers' resources to test effectiveness.

The information found is important to occupational therapists along with the healthcare community in many ways. Within the next decade the majority of Baby Boomers will be reaching retirement age and many will require healthcare assistance. The current trends in healthcare today are shortened inpatient hospital stays and increasing outpatient treatments. Due to these trends, there will be an influx of caregivers in America. Occupational therapy can assist the caregivers and the care recipients by providing instruction on transfers, adaptive equipment, ways to reduce stress, and how to maintain or introduce leisure activities in their lives. Occupational therapy can also provide community resources that may be beneficial to the caregiver.

The purpose of the scholarly project was to determine the literature findings concerning unmet needs and problems that caregivers experience along with ways to reduce the burden on caregivers. The data collected suggested that caregivers would benefit from an informational resource booklet on caregiving that could be given to them by a health care professional. Chapter 2 provides a comprehensive review of the literature. Chapter 3 describes the process used to design the educational resource manual for caregivers. Chapter 4 provides a summary of the resource manual with the complete product found in the Appendix. Chapter 5 summarizes the process, provides suggestions for implementing and indicates areas of future research.

Chapter 2: Review of Literature

Levy (2004) reported that caregiving is a stressful occupation. Taking care of a family member with Alzheimer's disease or a friend with AIDS is a tremendous responsibility that carries both its benefits and burdens. In today's society, the role of caregiving is increasing and becoming more important. This is due in part to shortened hospital stays, shortage of nursing staff, technological advances in the medical field, increased longevity in Americans, and the increasing number of elderly citizens. The roles of a caregiver may include assisting with activities of daily living (ADLs) and performing or aiding the patient in his/her instrumental activities of daily living (for example: money management, home management, and/or meal preparation). In addition, caregivers have responsibilities as a family member, spouse, and primary financial provider. By having so many roles, caregivers are experiencing added stress that may become detrimental to their health.

The recent trends in health care are shortened hospital stays and having the patients participate in outpatient therapy. With this current trend, more responsibilities are being placed on caregivers. Lim and Zebrack (2004) estimated that more than 25 million Americans serve as family caregivers. Fifty-two million informal and family caregivers provide care to someone aged 20+ who is ill or disabled and nearly one out of every four households (23% or 22.4 million households) is involved in caregiving to persons aged 50 or over (Family Caregiver Alliance, n.d. b). It is estimated the number of caregiving households in the U.S. for person's aged 50+ could reach 39 million by the

year 2007; 5.8 - 7 million people (family, friends, and neighbors) provide care to persons 65+ who need assistance with everyday activities, and 5 million informal caregivers provide care for someone aged 50+ with dementia. Considering the staggering amount of unpaid caregivers in the American culture, caregivers receive little or no professional assistance. Approximately one-half of primary caregivers provide care with no outside assistance and only 10% to 20% of family caregivers use formal services through public or private agencies (Family Caregiver Alliance, n.d. b).

This chapter provides a comprehensive summary of the literature on caregiving. Areas discussed include the psychological and physical impacts on caregiver well-being, the causes and effects of caregiver burnout, and strategies to assist caregivers through support and education. Outcomes of occupational therapy interventions and roles of occupational therapy are described. The Model of Human Occupation is applied to caregiver needs and training.

Caregiver well-being

One of the major occupations a caregiver has is to provide sufficient and beneficial care to the client. Caregivers often forget to take care of themselves which may lead to health related problems (Brown & Mulley, 1997; Grant, Weaver, Elliot, Bartolucci, & Newman, 2004; Sharpe, Butow, Smith, McConnell, & Clark, 2005). Being a caregiver is a rewarding occupation but typically demanding which may lead to health problems. Health and Human Services (1998) reported caregivers of people aged 50 and over spent an average of 17.9 hours per week providing care. This figure increased to 20 hours per week among those providing care for individuals aged 65 and older. The major

health related areas that caregiver may experience are their psychological and physical well-being.

Psychological conditions and symptoms

Caregiver's emotional and psychological healths are frequently strained throughout the tenure of the care they provide. Approximately one third of family caregivers of stroke patients will experience some difficulties with psychological adjustment over time (Hodgeson, Wood, & Langton-Hewer, 1996). Emotional and psychological strain may be caused by caring for a family member with a chronic or terminal illness, trying to accomplish all the caregiving tasks, managing family finances, not enough time in the day for caring for both the patient and themselves, and/or the demands placed on the caregiver by the patient.

When the strains become too difficult to handle, caregivers may experience psychological conditions that affect their lives. The conditions vary as do the degree depending on the caregiver's ability to cope with the strains, ranging from frustration to clinical depression (Grant et al., 2004; Lim & Zebrack, 2004; Roberts et al., 1999). Frustration occurs in everyone's life at one point or another. Caregivers may be exposed to excessive frustration while providing assistance to their loved ones. Frustration may be caused due to the lack of control over their loved one's illness, lack of support, and/or the change of lifestyle (Groff et al., 2004; Lim & Zebrack). Signs and symptoms of frustration may include: shortness of breath, stomach cramps, chest pains, headache, irritability, anger, resentment, mental confusion, fluctuating moods, being overly critical, compulsive eating, excessive alcohol consumption, increased smoking, and the desire to

strike out (Family Caregiver Alliance, n.d. a). Bergeron and Gray (2003) suggested that stressed and frustrated caregivers of elderly people are more likely to abuse the one they are caring for.

Depression is the most common psychological condition that may be experienced by caregivers. The Family Caregiver Alliance conservatively estimated in 2002 that 20% of family caregivers suffer from depression which is twice the rate of the general public. Between 18% and 58% of caregivers of cancer patients are estimated to experience clinical levels of depression (Sharpe et al., 2005). Yee and Schultz (2000) found that female caregivers are more likely than males to suffer from anxiety, depression, and other symptoms associated with emotional stress. Approximately 49% of female caregivers and 31% of male caregivers may experience depression due to their role of being a caregiver (Family Caregiver Alliance, n.d., b).

Signs and symptoms of depression include (1) depressed mood most of the day, (2) diminished interest or pleasure in most activities, (3) significant weight loss when not dieting or weight, or decrease or increase in appetite nearly every day, (4) insomnia or hypersomnia, (5) fatigue or loss of energy, (6) feelings of worthlessness or excessive or inappropriate guilt, (7) diminished ability to concentrate or being indecisive, and (8) recurrent thoughts of death or suicide (American Psychiatric Association, Diagnostic and statistical manual of mental disorders, 4th ed.-revised text).

Recent studies on caregivers have revealed a trend in caregiver depression and the effects it has on the care they provide. Grant et al. (2004) conducted a study that addressed caregivers of family stroke patients. The data suggested that 38% of the sample was at risk for depression based on Center for Epidemiologic Studies Depression

Scale (CES-D) profiles. These numbers were closely related to a previous study conducted by Grant, Bartolucci, Elliott, and Giger (2000) which resulted in finding 37% of family caregivers were at an increased risk of depression. Stetz and Brown (2004) found similar results in comparing cancer family caregivers and AIDS family caregivers in regards to their physical and emotional health. After collecting data from the family caregivers, the results demonstrated that the participants had depression levels higher than the community norm compared on the CES-D scores. Only 20% of the community samples scored 16 or more on the CES-D whereas the study reported 73% of the family caregivers had a score of 16 or higher. The caregivers' scores on the Symptoms of Stress Scale (SOS) were similar to scores of those seeking stress management treatments (Stetz & Brown, 2004). Schulz et al. (2004) reported similar results with 48.3% of caregivers for persons with dementia had CES-D scores that were indicative of at risk for clinical depression.

Physical conditions and symptoms

Caregivers not only experience psychological symptoms and suffer from depression, but they also may experience physical related conditions due to providing care. A study of seventy-seven caregivers conducted by Roberts et al. (1999) found 21% of caregivers were in poor-to-fair health while 47% were worried about their own health. A care recipient's illness or disease may affect various roles in their life including ADLs, more specifically dressing, grooming, toileting, and bathing. Many care recipients require physical assistance which may lead to caregivers experiencing back pain, fatigue, poor sleep, and possible early death (Brown & Mulley, 1997; Sales, 2003).

Patients that need assistance with transfers place a heavy burden on their caregivers. Back pain caused by overuse and strain is frequent amongst caregivers. Brown and Mulley (1997) conducted in-depth interviews of 46 informal caregivers of disabled elderly people about the occurrence of physical injuries. Of the 46, 31 or 67% reported an injury sustained while providing care which included lifting and handling their dependents. A total of 17 caregivers reported back pain and 8 caregivers were temporarily unable to provide care as a result of the sustained injuries. Only 19 of the caregivers reported they received formal instruction on patient transfers and handling (Brown & Mulley).

Caregivers spend on average 20 hours a week taking care of their loved one, this is approximately 20 hours less a week they have for themselves. Instead of resting and taking care of themselves, the caregivers will accomplish personal or caregiver oriented tasks. Even though the caregiver may not be able to get the care recipient to rest throughout the night, they should arrange to get much needed sleep.

As the caregiver experiences health related problems and does not seek medical assistance, a caregiver's life span may decrease. The majority of caregivers provide assistance for one to four years and approximately 20% provide care for five years or longer (Stone, Cafferata, & Sangl, 1987). On average, caregivers spend 4.5 years providing care (National Alliance for Caregiving & American Association of Retired Persons, 1997). The longer the caregiver provides assistance, there is an increased risk for serious health problems and medical complications. A study of elderly spousal caregivers (aged 66-96) found that caregivers who experience mental or emotional strain have a 63% higher risk of dying than non-caregivers (Schulz & Beach, 1999).

Caregiver Burnout

As the stresses and strains of caregiving become overwhelming and unmanageable, caregiver burnout may arise. Some of the more predominant causes of caregiver burnout are the burdens placed on the caregiver by the patient, the caregiver's and/or the care recipient's current health conditions, and the overall demands of being a family caregiver.

Causes of caregiver burnout

Burden, patient/caregiver health problems, and the demands of being a family caregiver are all reasons for caregiver burnout. Burnout has been defined as a “progressive loss of idealism, energy, and purpose experienced by people working in the human services” (Agius, Blenkin, Deary, Zeally, & Wood, 1996).

Current caregiving literature is exploring the important questions centering on the burdens family caregivers experience (Gennaro, 1999). Burden can be placed on the caregiver by care recipient in many ways including physically and mentally. Groff et al. (2004) studied the impact of outpatient commitment of persons with a mental illness on caregiver strain. Their data suggested caregivers were more likely to report decreased sense of burden when the care recipient became committed but the authors also noted the caregivers tended to feel responsible for having their loved one committed. Chumbler, Rittman, Van Puymbroeck, Vogel, and Qnin (2004) suggested that higher caregiver burden was associated with increased depression amongst caregivers of stroke survivors.

The health status of the caregiver or patient can lead to increased burnout. The more intense patients and the patients with illnesses that have unexplained prognosis place higher demands on the caregiver. Levy (2004) proposed in his article that “one

major source of stress in the caregiver-patient relationship is uncertainty: the uncertainty of the prognosis, the uncertainty of the illness, the uncertainty of death itself” (p. 544). Moraso et al. (1999) studied people diagnosed with lung cancer. They found 45% of primary caregivers had not been told the diagnosis by a medical professional but rather by the patient.

The physical and mental health of the caregiver also reflects on the course of burnout. If the caregiver maintains their personal health with exercise, rest, and proper diet; they are at less risk of burnout. With the added demands of being a caregiver plus having decreased health, burnout and other serious problems may be difficult to avoid.

Outside sources place additional demands on caregivers. Over half (51.8%) of all caregivers are employed full-time and over 12% are employed at least part-time (National Alliance for Caregiving & American Association of Retired Persons, 1997). Among working caregivers who provide assistance for a family member and/or friend aged 65+, two-thirds reported they needed to rearrange work schedules, decrease hours of employment, and/or take an unpaid leave of absence in order to meet caregiving responsibilities (Health and Human Services, 1998).

Effects of caregiver burnout

The effects of caregiver burnout not only affect the caregiver but also the care recipient and other family members. If the caregiver suffers from burnout, the effects transcend through the patient and family system (Ergh, Rapport, Coleman, & Hanks, 2002; Wade et al., 2002).

If burnout occurs, the caregiver may not be able to cope with demands placed on them either by the patient, family, friends, or work. Possible effects of burnout on the

caregiver are depression, lack of empathy for the patient, decreased motivation to accomplish daily tasks, being physically fatigued, depersonalization towards the care recipient, and absenteeism from their job (Levy, 2004).

Care recipients are also affected by caregiver burnout. With caregiver burnout, the patient may not receive the proper care. He/she may be abused, or neglected all together. The National Center on Elder Abuse (1998) estimated 449,924 elderly American citizens, aged 60 and over, experienced abuse and/or neglect in domestic settings in 1996. Care recipient abuse is grossly underreported. Many care recipients are under the care of a sole caregiver.

Caregiver burnout affects family members and family cohesion. Usually there is one family member responsible for taking care of the family's loved one. When the primary caregiver can no longer provide appropriate services, another family member must resume the role or the family must consider alternative placement. For family caregivers of persons with TBI, 60% to 68% reported family dysfunction due to caregiver distress (Ergh et al., 2002). Wade et al. (2002) found 17% of caregivers of children with severe TBI, 17% of caregivers of children with moderate TBI, and 8% of family caregivers of children with orthopedic disabilities met the criteria for family dysfunction on the McMaster Family Assessment Device (FAD).

Strategies to support caregivers

There are various ways to address the ongoing concern of lack of caregiver support. Caregiver support through community resources, discussing with the caregiver what unmet needs they may have, or simply educating the caregiver are a few means. Unmet needs for caregivers can be typically overlooked or misunderstood (Sharpe et al.,

2005). The needs that are not being met include the lack of support for the caregivers and properly educating the caregivers.

“Health care professionals were aware of greater levels of need than the patients reported, but still underestimated the needs of the patients and their family” (Sharpe et al., 2005 p. 110). Caregivers along with their families need assistance after inpatient rehabilitation and caregivers that receive adequate social support had a positive influence on caregiver well-being (Ergh et al., 2002). Ergh et al. noted social support was a direct predictor of caregiver distress, increased social support was related to decreased feelings of burden and distress. Sharpe et al. reported that lack of available support was consistently associated with negative feelings of being a caregiver. When a caregiver perceives their role as being worthless or negative, they tend to provide lackluster care and develop a sense of depersonalization towards the care recipient.

Social Support

One area of support that caregivers could benefit from is seeking assistance from community resources like hospice, occupational therapy, social services, and/or day treatment programs. Gaugler et al. (2003) addressed adult day services and how these affected the well-being of 400 dementia caregivers. Their research found by decreasing care demands for several hours per week through adult day services, caregivers had more time to complete other necessary demands thus leading to reduced feelings of exhaustion and overload. Specifically, the reduction of caregiver ADL hours was associated with decreased worries and strain over a three month span. Receiving outside assistance for even a few hours a week can be an effective way of preventing caregiver overload and sense of burden.

Caregiver education

Caring for the caregiver includes providing efficient and informative education. Many times caregivers leave the hospital with a general understanding of what responsibilities ensue but rarely are they provided with information that will possibly make their caregiving experience more rewarding and beneficial. Sales (2003) stated that families are playing an increased and integral role in patient care and professionals should take notice of this. Education may focus on their care recipient's illness, proper ergonomics for transfers, ways to cope with stress, or adaptive equipment training.

Roberts et al. (1999) studied the impact of effective problem-solving counseling on caregivers of persons with a mental illness or cognitive impairment. They offered nurse directed counseling for 77 caregivers taking care of a loved one with cognitive deficits. The conclusion was that although the counseling did not directly benefit all caregivers, the caregivers with poor coping strategies and inadequate problem-solving skills found the counseling beneficial. Coping strategies and problem-solving skills are sometimes taken for granted and assumed that every one has developed them. Roberts et al. findings show the need for further education and support to ensure that families receive needed education and resources.

For caregivers who are required to assist with physical activities like transfers, toileting, and dressing; education in proper ergonomics would be helpful. Physical injuries and caregiver fatigue could be reduced by providing correct training. Brown and Mulley (1997) found only a small percentage of caregivers were adequately trained and

had received instruction on manual handling. This caused a large portion of the caregivers in the study to suffer from physical ailments like back pain, hernias, general muscle aches, or knee problems.

Caregivers could benefit from instruction on adaptive and medical equipment. Much of the information on these items is given to the client during their stay in the hospital but often the caregiver is not present (Chen, Mann, Tomita, & Nochajski, 2000). Chen et al. found when caregivers participated in the decision making process including choosing and learning about assistive devices with the care recipient and professional, it increased the use and satisfaction with the assistive device.

Occupational therapy can assist in reducing caregiver strain and burden by providing recommendations to the client and caregiver for when the client goes home (Dooley & Hinojosa, 2004). Dooley and Hinojosa found that occupational therapy services for people with Alzheimer's disease appeared to be effective for both the caregiver and client in terms of caregiver burden and quality of life. Gitlin, Corcoran, Winter, Boyce, and Hauck (2001) found that recipients of occupational therapy that focused on the client's home environment maintained their IADL skills better than a control group over a three month study period. "Family caregivers represent a high-risk but underserved clinical group, they may greatly benefit from occupational therapy." (Corcoran & Gitlin, p. 18).

Little information was found addressing the issues of personal meaning and satisfaction amongst caregivers. Most literature found was not occupational therapy based and did not look at the caregiver's need for a healthy balance of work, leisure, and play.

Occupational therapy theory

The Model of Human Occupation (MOHO) seeks to explain how occupation is motivated, patterned, and performed. Its concepts address motivation for occupation, the routine patterning of occupational behavior, the nature of skilled performance, and the environment influence on occupations (Neistadt & Crepeau, 1998). By offering explanations of such diverse phenomena, MOHO offers a broad and integrative view of human occupation. Within MOHO, humans are conceptualized as being made up of three interrelated components: volition, habituation, and performance capacity (mind-brain-body performance). MOHO also emphasizes that to understand human occupation, we must also understand the physical and social environments in which it takes place. Therefore, this model aims to understand occupation and problems of occupation that occur in terms of its primary concepts of volition, habituation, performance capacity and environmental context.

Volition refers to the motivation for participation occupations. Many caregivers are placed in the role of caregiving without being asked but the motivation is typically there to provide the best possible care. Volition is comprised of three components: personal causation, values, and interests. Personal causation is a segment of volition and refers to “people’s capacities and effectiveness” (Neistadt & Crepeau, 1998 p. 528). This addresses the comfort of caregivers in his/her role and the responsibilities of being a caregiver. Values are caregiver beliefs and what they feel is important. Interests are the pleasures and enjoyments a caregiver experiences.

Habituation refers to the process by which occupation is organized into patterns or routines. Habituation is composed of habits and roles. Habits are learned ways of doing occupations. Caregiver habits may be positive such as responding to a stressful situation with healthy management techniques or negative as not taking time out of their day for themselves. Roles provide a sense of social identity and shape each individual's actions. A caregiver typically has many roles on top of being a caregiver like a spouse, friend, worker, and/or child.

Performance capacity or the mind-brain-body performance refers to the physical and mental abilities that inspire skilled occupational performance. This includes musculoskeletal, neurological, perceptual, and cognitive capabilities required to perform occupations.

The environment component comprises of the physical environment (mountains, walls, rivers, clothes, etc.) and the social environment (families, church groups, occupational forms, etc). Adaptive equipment, hospitals, home, and coworkers would be possible examples of caregiver's environment.

Caregivers may experience depression, burnout, and other problems that could possibly be prevented through the theory of MOHO. MOHO was selected to guide the development of the product because it addresses the habits, roles, motivation, and environment of the caregiver. If caregivers maintain unhealthy habits, his/her role of being a caregiver may become negative thus leading to lowered motivation to provide adequate care. The product focuses on what habits and roles the caregiver engages in and promotes a healthy caregiver experience through helpful and meaningful information.

Conclusion

The research on this topic suggests that caregiving can be a rewarding experience with periods of difficulty. How each caregiver responds to the challenges of caregiving is dependent on the social supports, resources, and education on providing care. More information received and resources are needed to assist caregivers in maintaining their psychological and physical quality of life.

Chapter 3 addresses the methodology and procedures used. Chapter 3 briefly discusses the product derived from the data collected and what unmet needs it addresses.

Chapter 3: Methodology/activities

Caregiving is affecting many individuals in today's society. Caregivers have played an integral role in American health care but now more individuals are being placed in the caregiver role. The current trends in health care are placing more pressure and emphasis on caregivers associating with this is an increase of health risks and burnout. The purpose of this chapter is to describe the process of designing an educational resource manual.

An extensive literature review was conducted to explore the perceived barriers of caregivers, areas of concern, and means to overcome these difficulties. The resulting caregiver resource manual was derived from reviewing this current literature as well as authors' clinical judgment, professional insight, and creativity.

The literature reviewed indicated many caregivers were lacking education and training needed to provided safe, efficient care. Specific areas where caregivers needed further education included transfers, client's diagnosis, symptoms of depression, and taking care of their own needs. The deficits in knowledge and skills were leading to physical injuries and psychological issues in many caregivers.

The procedure used in developing the product started with reviewing the literature and determining key unmet caregiver needs. The unmet needs discussed in the literature were compared to the experiences of a family member of the author who was a spousal caregiver for three years. This brought into perspective researchers' perceived caregiver needs and the actual unmet needs of familial caregiver. Once the list of unmet caregiver needs was developed, further research was conducted on what additional training would

alleviate caregivers' unmet needs. Data was gathered via professional literature, current caregiver resources, and credible Internet sites. The compiled data supported a need for education on depression, client's diagnosis, medication, medical equipment, transfers, adaptive equipment, and ways to cope with stress. These areas are the focal points of the resource manual. Tips were listed in the beginning and the end of the manual to reiterate the important key points.

The educational resource manual was designed to address the aforementioned issues. The manual provides helpful information to reinforce the instructions from a health professional. The goal is to reduce the perceived caregiver stress and burden. The manual offers suggestions for potential community and national resources that provide assistance for caregivers. The resource manual was organized to provide the caregiver with information to assist them while caregiving and potentially reduce perceived burden. Key information was emphasized and repeated to reinforce learning and allow for better integration into their lifestyle. The manual was evaluated for grade level reading. It is at approximately a 9th grade reading level according to Flesch-Kincaid Grade Level.

Chapter 4 provides an overview of the product. Each section is described with key points summarized. The complete manual can be found in the Appendix.

Chapter 4: Product

The purpose of this project was to design a manual to meet the needs of caregivers. After reviewing professional literature for deficits in caregiver resources and knowledge caregivers would benefit from, a caregiver reference and resource manual was developed. The focal points and headings in the manual are:

1. Maintaining Your Own Life

This section provides a brief introduction on maintaining a healthy lifestyle. Caregivers are encouraged to participate in prior activities.

2. Four Messages to Live By

This is adapted from National Family Caregivers Association and lists four important areas that caregivers should understand. This section also provides an overview of information in later sections of the manual.

3. Strategies for Providing Care: Diagnosis, Medication, Medical supplies, Transfers, and Adaptive Equipment

The strategies described are to provide caregivers with helpful information to alleviate some of the problems associated with caregiving. The order was determined as to what affects the caregiver first (diagnosis) and so forth. Caregivers need to know as much as possible about their loved one's condition and progression. This information decreases the possibility of unexpected problems and provides the caregiver with resources to increase confidence. Three websites are provided to allow caregivers to further research their loved one's illness or condition. Information on medication management is provided, including questions on purpose

of the medication, dosage, and side effects to ask the physician or nurse. The section on medical supplies urges the caregivers to gain knowledge on any medical supplies required for their loved one before leaving the hospital. Due to many clients needing assistance with physical transfers, a section was devoted on a few easy to follow suggestions on transfers. The goal is to decrease the chances of physical injuries to both the caregiver and care recipient. Finally, information on adaptive equipment is provided. These resources may increase the care recipient's independence and decrease the burdens placed on the caregiver.

4. Warning Signs of Caregiver Stress

The literature suggests that burnout and depression affect caregivers more than the general public (Grant, Bartolucci, Elliott, & Giger, 2000; Grant, Weaver, Elliot, Bartolucci, & Newman, 2004; Sharpe, Butow, Smith, McConnell, & Clark, 2005). Providing the caregiver with potential signs and symptoms of depression and frustration may decrease the chances of chronic and clinical depression. The list encompasses emotional, psychological, and physical symptoms to monitor.

5. Stress Management Techniques

Since the caregivers are informed on potential harmful symptoms of depression and burnout, the caregiver can incorporate new and/or previous stress management techniques. Numerous healthy techniques are listed to provide possible new ways of reducing stress and promoting a quality lifestyle.

6. Community Resources: home and personal care, meal services, hospice care, adult day centers, and respite care

This section provides six essential community resources that may be available to caregivers. Each resource is briefly defined with suggested organizations to contact. These community resources have the potential of reducing the burdens placed on the caregiver by sharing the work load and allowing the caregiver to rest and pursue personal goals.

7. Additional Resources

This section describes selected resources the caregiver may contact either by telephone, mail, or the Internet. Three caregiver organizations (Family Caregiver Alliance (FCA), National Family Caregivers Association (NFCA), and National Alliance for Caregiving) are listed. These organizations provide additional information and resources. The American Red Cross provides caregiver education training courses. References and contacts for hospice care, Easter Seals, and the American Association of Retired Persons (AARP) are resources frequently needed by caregivers.

8. 10 Tips for Family Caregivers

This is also adapted from the National Family Caregivers Association. The tips are intended to provide an easy to read list of important strategies to encourage caregivers to take care of themselves and increase the positives of being a family caregiver.

Chapter 5 summarizes the process, provides recommendations for implementation and limitations. Areas of future research are discussed.

Chapter 5: Summary

The findings in the literature suggest caregivers would benefit from additional training on transfers, client's diagnosis, symptoms of depression, and ways to maintain their own health. Based on this, an educational resource manual was designed to complement specific training by a health professional.

An easy to follow resource manual containing helpful information was developed so caregivers would be less likely to feel overwhelmed. The manual was designed to be an educational resource for caregivers. The goals of the resource manual were to decrease possible symptoms of depression while increasing physical, mental, and emotional health of the caregiver while providing care.

The caregiver resource manual does not replace information given to caregiver by health professionals. It is designed to reinforce information provided by professionals in an easy to follow manual where caregivers are able to quickly find answers. The manual will complement information provided by occupational therapists, physical therapists, physicians, nurses, and social workers.

Depression affects many caregivers throughout the United States (Grant, Weaver, Elliot, Bartolucci, & Newman, 2004; Lim & Zebrack, 2004; Sharpe, Butow, Smith, McConnell, & Clark, 2005). There is a need for an educational resource manual for caregivers that is effective in providing pertinent information that may decrease caregiver stress and burden. Future research needs to be done to evaluate the effectiveness of the resource manual and training in meeting the needs of caregivers.

Appendix

Maintaining a healthy lifestyle
while being a caregiver:
Information that every caregiver
should know.



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Maintaining Your Own Life

It is not hard to get caught up in caring for your loved one and forgetting about yourself. Even though you are taking care of someone else, you need to continue your life prior to becoming a caregiving as much as possible. This may include working, spending time with friends, doing things for you without the feeling of guilt, and participating in leisure activities.



Four Messages to Live By

1. Decide on taking charge of your own life.

The role of becoming a caregiver is often an unexpected event, but you need to step back and consciously say, "I choose to take on this caregiving role." This may help eliminating the feeling of being a victim.

2. Love, honor, and value yourself.

Self care shouldn't be a luxury but a right as a human being. Remember how important you are and that your good health is the best gift you can give your loved one.

3. Seek, accept and at times demand help.

Caregiving should not be a one person job. Asking for help is a sign of your strength while acknowledging your abilities and your limitations.

4. Stand up and be counted.

Realize that caregiving comes on top of being a parent, a child, a friend, and a spouse. Honor your caregiving role and speak up for your recognition and rights.

(Adapted from the National Family Caregivers Association, n.d.)

Strategies for Providing Care

Becoming a caregiver may be a totally new experience for you and you may feel overwhelmed. Being a caregiver should be rewarding and beneficial to both you and your loved one. Your caregiver role may be simplified and have increased safety with some helpful strategies. Five important areas are addressed and have strategies provided to assist you:

- Diagnosis
- Medication
- Medical Supplies
- Transfers
- Adaptive Equipment.

4

Diagnosis

The first item you should be familiar with is your loved one's diagnosis. Make sure you know the details and what to expect about your loved one's illness or disability from your physician. Ask for any handouts or possible ways to gather more information. The Internet is a valuable resource that can offer information about your loved one's illness or disability. The more you know about your loved one's illness or disability should decrease the chances of unexpected problems and worries.

Here is a brief list of Internet resources that may provide you with valuable information regarding your loved one's illness or disability.

- Healthopedia.com
(Medical encyclopedia)
www.healthopedia.com
- Mayo Clinic
www.mayoclinic.com
- WebMD
www.webmd.com

5

Medication

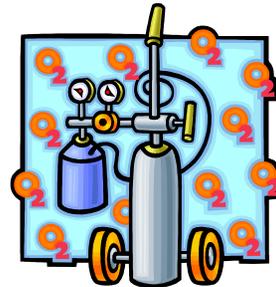
More than likely your loved one received medication(s) and will be taking them when they return home. Ask your doctor and/or pharmacist for information concerning the medication(s) especially when to take the medication(s), how many to take (dosage), and what possible side effects the medication(s) may have. Purchasing a pill organizer at your local drug store may be beneficial in simplifying the medication process. This will also increase the chances of giving the proper amount of medication at the right times of the day and reducing the chances of forgetting to give/take the medication.



6

Medical Supplies

If you are required to assist with medical supplies like IVs, giving shots to your loved one, maintaining oxygen tanks, etc.; you should be comfortable and knowledgeable in doing so. Before leaving the hospital, make sure you are familiar with all of the equipment your loved one will require and have a professional answer any questions you have. This should reduce your anxiety and increase the effectiveness of the medical supplies.



Transfers

Some care recipients require help transferring themselves (i.e. going from a wheelchair to the commode). The most important advice about transfers is using proper body mechanics:

- Lift with your legs and not your back
- Keep your back straight to prevent strain
- Don't lift more than you can handle
- Ask for help if you feel unsafe.

Before attempting to do a transfer for the first time, ask your occupational therapist, nurse, or physical therapist to demonstrate how to properly do the transfer.

Remember, poor transfers can lead to a heightened risk of back problems and increased chance of hurting your loved one and you!

8

Adaptive Equipment

Adaptive equipment like shower chairs and long handled reachers can assist you with your caregiving duties and to give your loved one more independence. You are encouraged to participate in the selection of the adaptive equipment along with your loved one. Just like transfers, adaptive equipment should be properly used to prevent injuries. Ask your occupational therapist for advice and training on adaptive equipment.



9

Warning Signs of Caregiver Stress!!

Caregiving is a rewarding job but it also can be stressful. Stress is a natural aspect of life but too much stress is unhealthy. Being overstressed can lead to various health problems like insomnia, poor eating habits, and depression if left untreated. The best way to prevent stress is to realize when you are becoming overstressed.

Here are some major signs and symptoms of being overstressed:

- Increased muscle spasms, headaches, fatigue, and shortness of breath
- Cloudy judgment
- Difficult for you to concentrate or to deal with distractions
- Sad, anxious, frustrated, and mad feelings
- Appetite changes (making you eat either less or more)
- Change in your sleeping habits (either causing you to sleep too much or not letting you sleep enough)
- Colds or the flu symptoms more often and causing other illnesses such as asthma, headaches, stomach problems, skin problems, and other aches and pains
- Sex life and performance affected
- Increased dependence on food, cigarettes, alcohol, or drugs
- Important things in life such as work, school, and even personal appearance are neglected

Stress Management Techniques

Stress should not be something that controls your life. There are various ways to cope with stress that are both healthy and effective. The following is a brief list of suggested healthy ways to relieve stress that you may want to explore and continue to use when you feel yourself becoming overstressed:

- Exercising (jogging, yoga, lifting weights)
- Massages or going to a day spa
- Light scented candles (vanilla and lavender are calming scents)
- Listening to relaxing music (sounds of the ocean, soft music, etc)
- Reading a book or magazine
- Taking a warm bubble bath
- Talking to friends and family
- Participating in religious activities
- Taking a short nap
- Learning a new craft or activity

Even though you feel you don't have a lot of time for yourself, you need to take care of yourself. These stress management techniques may offer new suggestions to maintain a healthy you!

Community Resources

Never feel alone when providing care to another or feel like there is nobody that can help you. There are resources organized to assist you with your responsibilities of being a caregiver and to make your life more manageable.

The following list provides general resources that may benefit you in your community that you may find in your local Yellow Pages:

- Home and personal care
- Meal services
- Home health care
- Hospice care
- Adult day centers
- Respite care



Home and Personal Care

Home care aides do chores such as cleaning the house, grocery shopping, or laundry. Personal care is non-medical help with such activities of daily living (ADLs) as bathing, dressing, or using the toilet. Home health care meets health care needs prescribed by a physician and provided by licensed professionals. This includes skilled nursing care, personal care, rehabilitative therapy, giving medicine, wound care, and medical help

- Hospitals, home health care services

Meal Services

Home-delivered meal programs offer nutritional meals to those who can no longer shop for groceries or cook.

- Meals on Wheels, senior citizen centers

Hospice Care

Hospice services include medical care, counseling, and pain control for terminally ill patients and their families. Hospice services are usually provided in patients' homes. They help the entire family, caregivers, and the patient cope with issues related to the terminal illness.

- Hospice, hospital home services

Adult Day Centers

For a client who needs supervised assistance, these centers offer many services in a group setting. Services may include health care, recreation, meals, and rehabilitative therapy. These centers meet the needs of people with mental or physical limitations. While there is usually a cost, many offer sliding rate scales or some financial assistance.

Respite Care

Respite care provides time off for family members who care for someone who is ill, injured or frail.

- adult day centers, home health care, assisted living facilities, nursing homes

Additional Resources

It's always a good idea to find out what your county and state have to offer for services, even if you think you don't qualify for them. Look in the blue pages in your local phone book for the numbers or go online. Counties and states should all have web sites. Type the name of your county and state into any major search engine i.e. North Dakota, or Orange County, NY. Go to the Department of Health and Human Services and to the specific office that relates to your needs such as elder affairs, disabilities, or child health.

Other good sources of information include your local hospital or clinic (social work department), area adult day centers, social service and faith-based agencies, and/or the local chapter of the health agency that focuses on your loved one's condition. It is by no means certain that any of these will offer caregiver support services, but they are good places to check, and they are good sources for information about services to directly support your loved one.

The following are possible online resources that may provide assistance and valuable information for you and your loved one:

Family Caregiver Alliance (FCA)

690 Market Street, Suite 600
San Francisco, CA 94104
415-434-3388
800-445-8106

<http://www.caregiver.org>

(Provides support and help to family caregivers through education, services, research and advocacy)

National Alliance for Caregiving

4720 Montgomery Lane, 5th Floor
Bethesda, MD 20814

<http://www.caregiving.org>

(Helps family caregivers with information, videos, pamphlets, etc. that have been reviewed and approved as providing solid information)

National Family Caregivers Association (NFCA)

10400 Connecticut Avenue, Suite 500
Kensington, MD 20895
800-896-3650

<http://www.thefamilycaregiver.org>

(Educates, supports, empowers and advocates for family caregivers of chronically ill, aged, or disabled)

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National Hospice and Palliative Care Organization

1700 Diagonal Road, Suite 625
Alexandria, VA 22314
800-658-8898

<http://www.nhpco.org>

(Provides information on hospice and services)

American Red Cross

2025 E Street, NW
Washington, DC 20006
202-303-4498

<http://www.redcross.org>

(Offers caregiver training courses at various locations)

American Association of Retired Persons

601 E Street, NW
Washington, DC 20049
800-424-3410

<http://www.aarp.org>

(Supplies information about being a caregiver, long-term care and aging, including publications and audio-visual aids for caregivers)

Easter Seals

230 West Monroe Street, Suite 1800
Chicago, IL 60606
800-221-6827

<http://www.easter-seals.org>

(Provides services to children and adults with disabilities and other special needs, and support to their families)

17

10 Tips for Family Caregivers

1. Reward yourself with breaks often. Caregiving is a job and taking a breather is your earned right.
2. Be aware for signs and symptoms of depression and don't delay in receiving professional help.
3. Educate yourself about your loved one's condition and how to communicate effectively with doctors and other health professionals.
4. Be open to technologies and ideas that promote your loved one's independence. There's a difference between caring and doing.
5. Trust your instincts because they usually lead you in the right direction.
6. Take care of your body especially your back. Caregivers often do a lot of lifting, pushing, and pulling.
7. Take time to grieve your losses and then allow yourself to plan for the future.
8. Accept the offer when people want to help and suggest specific things that they can do for you.
9. Seek support from other caregivers. There is great strength in knowing you are not alone and that there are people like you.
10. Stand up for your rights as a caregiver and a citizen.

(Adapted from National Family Caregivers Association, n,d.)

References

- Agius, R., Blenkin, H., Deary, I. J., Zeally, H. E., & Wood, R. A. (1996). Survey of perceived stress and work demands of consultant doctors. *Occupational and Environmental Medicine, 53*(4), 217-224.
- American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders* (4th ed.-revised text) Washington DC: Author.
- Bergeron, L. R., & Gray, B. (2003). Ethical dilemmas of reporting suspected elder abuse. *Social Work, 48*(1), 96-106.
- Brown, A. R., & Mulley, G. P. (1997). Injuries sustained by caregivers of disabled elderly people. *Age and Ageing, 26*, 21-23.
- Chen, T., Mann, W. C., Tomita, M., & Nochajski, S. (2000). Caregiver involvement in the use of assistive devices by frail older persons. *The Occupational Therapy Journal of Research, 20*(3), 179-199.
- Chumbler, N. R., Rittman, M., Van Puymbroeck, M., Vogel, W. B., & Qnin, H. (2004). The sense of coherence, burden, and depressive symptoms in informal caregivers during the first month after stroke. *International Journal of Geriatric Psychiatry, 19*, 944-953.
- Corcoran, M. A., & Gitlin, L. N. (2001). Family caregiver acceptance and use of environmental strategies provided in an occupational therapy intervention. *Physical & Occupational Therapy in Geriatrics, 19*(1), 1-20.
- Corradetti, E. V., & Hills, G. A. (1998). Assessing and supporting caregivers of the elderly. *Topics in Geriatric Rehabilitation, 14*(1), 12-35.

- Dooley, N. R., & Hinojosa, J. (2004). Improving quality of life for persons with Alzheimer's disease and their family caregivers: Brief occupational therapy intervention. *The Journal of Occupational Therapy, 58*(5), 561-569.
- Ergh, T. C., Rapport, L. J., Coleman, R. D., & Hanks, R. A. (2002). Predictors of caregiver and family functioning following traumatic brain injury: Social support moderates caregiver distress. *The Journal of Head Trauma Rehabilitation, 17*(2), 155-174.
- Family Caregiver Alliance. (n.d. a). *Dementia, Caregiving and Controlling Frustration*. Retrieved January 25, 2005, from http://caregiver.org/caregiver/jsp/content_node.jsp?nodeid=891.
- Family Caregiver Alliance. (n.d. b). *Selected Caregiver Statistics*. Retrieved January 23, 2005, from http://caregiver.org/caregiver/jsp/content_node.jsp?nodeid=439.
- Gaugler, J. E., Jarrot, S. E., Zarit, S. H., Stephens, M. P., Townsend, A., & Greene, R. (2003). Adult day service use and reductions in caregiving hours: Effects on stress and psychological well-being for dementia caregivers. *International Journal of Geriatric Psychiatry, 18*, 55-62.
- Genennaro, S. (1999). The core of caregiving. *Nursing Research, 48*(3), 199-201.
- Gitlin, L. N., Corcoran, M., Winter, L., Boyce, A., & Hauck, W. W. (2001). A randomized controlled trial of a home environmental intervention: Effect of efficacy and upset in caregivers and on daily function of persons with dementia. *Gerontologist, 41*, 4014.

- Grant, J. S., Bartolucci, A., Elliott, T. R., & Giger, J. N. (2000). Sociodemographic, physical, and psychosocial characteristics of depressed and non-depressed family caregivers of stroke survivors. *Brain Injury, 14*, 1089-1100.
- Grant, J. S., Weaver, M., Elliot, T. R., Bartolucci, A. A., & Newman, J. (2004). Family caregivers of stroke survivors: Characteristics of caregivers at risk for depression. *Rehabilitation Psychology, 49*(2), 172-179.
- Groff, A., Burns, B., Swanson, J., Swartz, M., Wagner, H. R., & Tompson, M. (2004). Caregiving for persons with mental illness: The impact of outpatient commitment on caregiving strain. *The Journal of Nervous and Mental Disease, 192*(8), 554-562.
- Health and Human Services. (1998, June). *Informal Caregiving: Compassion in Action*. Washington, DC: Department of Health and Human Services.
- Hodgeson, S. P., Wood, V. A., & Langton-Hewer, R. (1996). Identification of stroke carers 'at risk': A preliminary study of predictors of carers' psychological well-being at one year post stroke. *Clinical Rehabilitation, 10*, 337-346.
- Informal Caregiving: Compassion in Action. (1998, June). *National Survey of Families and Households (NSFH)*. Washington, DC: Department of Health and Human Services.
- Levy, M. M. (2004). Caring for the caregiver. *Critical Care Clinics, 20*(3), 1-6.
- Lim, J., & Zebrack, B. (2004). Caring for family members with chronic physical illness: A critical review of caregiver literature. *Health and Quality of Life Outcomes, 2*, 50-63.

- Moraso, G., Capelli, M., Viterbori, P., DiLeo, S., Alberisio, A., Constantini, M., et al. (1999). Psychological and symptom distress in terminal cancer patients with met and unmet needs. *Journal of Pain and Symptom Management*, 17(6), 402-409.
- National Alliance for Caregiving & American Association of Retired Persons. (1997, June). *Family caregiving in the U.S.: Findings from a national survey*. Bethesda, MD: National Alliance for Caregiving.
- National Center on Elder Abuse. (1998). *In National elder abuse incidence study: Final report* (Prepared by the National Center on Elder Abuse at the American Public Human Services Association in collaboration with Westat, Inc.). Washington, DC: Author.
- Neistadt, M. E., & Crepeau E. B. (1998). *Willard & Spackman's Occupational Therapy* (9th Edition). Philadelphia: Lippincott.
- Roberts, J., Browne, G., Milne, C., Spooner, L., Gafni, A., Drummond-Young, M., et al. (1999). Problem-solving counseling for caregivers of the cognitively impaired: Effective for whom?. *Nursing Research*, 48(3), 162-172.
- Sales, E. (2003). Family burden and quality of life. *Quality of Life Research*, 12(1), 33-41.
- Schulz, R., & Beach, S. R. (1999). Caregiving as a risk factor for mortality: The caregiver health effects study, *Journal of the American Medical Association*, 282(23), 2215-2219.
- Schulz, R., Belle, S. H., Czaja, S.J., McGinnis, K.A., Stevens, A., & Zhang, S. (2004). Long-term care placement of dementia patients and caregiver health and well-being. *The Journal of the American Medical Association*, 292(8), 961-967.

- Sharpe, L., Butow, P., Smith, C., McConnell, D., & Clarke, S. (2005). The relationship between available support, unmet needs and caregiver burden in patients with advanced cancer and their carers. *Psycho-Oncology, 14*(2), 102-114.
- Stetz, K. M., & Brown, M. A. (2004). Physical and psychosocial health in family caregiving: A comparison of AIDS and cancer caregivers. *Public Health Nursing, 21*(6), 533-540.
- Stone, R., Cafferata, G. L., & Sangl, J. (1987). Caregivers of the frail elderly; A national profile. *The Gerontologist, 27*(5), 616-626
- Wade, S. L., Taylor, H. G., Drotar, D., Stancin, T., Yeates, K. O., & Minich, N. M. (2002). A prospective study of long-term caregiver and family adaptation following brain injury in children. *The Journal of Head Trauma Rehabilitation, 17*(2), 96-111.
- Yee, J. L., & Schulz, R. (2000). Gender differences in psychiatric morbidity among family caregivers: A review and analysis. *The Gerontologist, 40*(2), 147-164.