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Critical Elements of Home Health Service Provision for Life Care Planners

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Abstract

The provision of home care in a life care plan is often the most costly area addressed by the life care planner (Pomeranz, Shaw, Sawyer, & Velozo, 2006; Weed, 1998). It has been reported that the provision of home care constitutes up to 44% of recurring disability-related rehabilitation costs (Harvey, Wilson, Greene, Stripling, & Berkowitz, 1992). It is imperative, therefore, that the life care planner fully understands how home care is provided, the cost associated with each type of service provision, how to identify resources for service provision and the indirect costs associated with family members providing home care. This article addresses each of those topics.

Critical Elements of Home Health Service Provision for Life Care Planners

The provision of in-home care in the United States is a model dating back to 1829 when the Charleston Ladies Benevolent Society organized the provision of home care (O'Dell, & Wheeler, 2012). Until the 1950s, this model of home-based service provision continued, with entities such as Metropolitan Life Insurance Company funding home visits through the Visiting Nurse Association (O'Dell & Wheeler, 2012). However, since the 1950s, the provision of medical care in the United States has become more specialized and technology driven, causing a shift away from a home-based model of care. With this shift, home care since the 1950s has largely been provided by allied health providers including physical, speech and occupational therapists or skilled nurses charged with providing wound care and medical monitoring (O'Dell, & Wheeler, 2012).

Home care services are utilized by many different populations, including: individuals recovering from surgery or accidents who may need short-term home care in addition to individuals who are elderly or have disabilities, who often require lifelong home care services (Marrelli, 2014). The Centers for Disease Control (CDC) reports that approximately eight million patients received home health care during 2012 (CDC, 2013), and the demand for personal care services is expected to double in the first half of this century (Kaye, Chapman, Newcomer, & Harrington, 2006). With the aging of the baby boomers, the U.S. Census Bureau projects that the population of citizens age 65 and older will more than double in size (from 46 million to 98 million) between 2014 and 2060, with the biggest increase (from 56 million to 74 million) occurring between 2020 to 2030 (Colby, & Ortman, 2015). As most home care services are provided to those over age 65, it is anticipated that the number of caregivers in the population will grow rapidly (Hong, & Casado, 2015; McCann, & Evans, 2002). Among patients receiving home health services as a Medicare benefit, 83% have three or more chronic conditions, 65% have incomes under 200% of the Federal Poverty Level, 36% live alone, and 29% have major functional limitations (Avalere Health, 2013). The Centers for Disease Control (CDC) reports that 82.3% of home health agency patients were over the age of 65 in 2011 and 2012 (CDC, 2013; Harris-Kojetin et al., 2013). Most care recipients prefer care at home as opposed to a nursing home, as do their families (Stone, 2011).

Individuals recovering from surgery or other medical procedures temporarily utilize home health care services to aid in the recovery process. Some need help cooking and cleaning, while others may need comprehensive care, such as: help with mobility, toileting, showering, eating, medication management, and even wound care. For this, a home health aide and/or nurse may be required to perform these activities until the patient has healed and is able to perform them independently.

People with disabilities also constitute a large number of consumers of home health care. Individuals with mental illness belong to this group. Children with special healthcare needs and/or medical complexities who require attendant care are a part of this group. Over 10 million children in the United States meet the definition for having special healthcare needs (Kogan, Strickland, & Newacheck, 2009). These children have constant needs and medical equipment that requires more assistance than the caregivers (parents, etc.) can provide. While all parents anticipate providing child care, for children without disabilities, the child's development with aging results in the parents providing less care for the child as they age. However, for children with disabilities, this diminishment of responsibility for parents does not occur and these children continue to require assistance with feeding, diaper changes, assistance with ambulation, and care and supervision throughout the day and night, throughout their lifetime (Curran, Sharples, White & Knapp, 2001; Roberts, & Lawnton, 2001). One study noted that children with disabilities required extra care in six areas of daily life (Roberts, & Lawton, 2001). Despite these ongoing needs, in one study three fourths of families of children with disabilities reported that they did not receive assistance from family members, even when those

individuals lived within 10 miles of their home (Curran, Sharples, White, & Knapp, 2001). These factors highlight the necessity of home care assistance for children with disabilities, even when parents are present. The role of home health is to provide respite and assistance for caregivers to allow the children to be able to remain in the home, without having to be hospitalized or institutionalized (Sherman, 1995). Not only does the provision of home care for children with disabilities improve outcomes for parents and families, it has also been found to decrease child maltreatment and strengthen family stability (Cowen, & Reed, 2002; Neufield, Query, & Drummond, 2001; Sherman, 1995).

Home Care Service Provision

The home health care field is made up of several types of job profiles and work responsibilities. It often takes a team of individuals to meet the needs of an individual requiring home health. Home health teams can include (but are not limited to): family caregiver, companion/sitter, certified nurse's aide (CNA)/personal care aide (PCA), and/or licensed practical nurses (LPN)/registered nurse (RN). Because nursing care poses a risk of harm if performed by individuals without proper training, most of these roles have laws and regulations that govern what the individual can and should do within the scope of their role. Each state's legislature has created a nurse practice act (NPA) that defines the scope of practice for nurses. Each NPA also establishes a board of nursing (BON) that has the authority to administer and enforce rules and regulations. It is dependent on the state's nurse practice act (NPA) to define the scope of practice for each job title. A scope of practice defines the specific tasks a nurse is allowed to perform within a given state. The following section will describe the typical roles and responsibilities of individuals who provide home health care services, as well as the educational and licensure requirements of these roles.

Family Caregiver

The most prevalent home care arrangement involves a family member providing care to a loved one, referred to as a family caregiver (Agree, 1999; Schulz, & Sherwood, 2008). According to a report issued by the National Alliance for Caregiving (NAC) and the American Association of Retired Persons (AARP), 43.5 million Americans provide unpaid care to a family member (NAC, & AARP, 2015). Less than one-third of caregivers report that their loved ones receive assistance from paid providers (e.g., housekeepers, aides, etc.). The majority of caregivers are women, although the number of male caregivers has grown in recent years to 40% (NAC, & AARP, 2015). The average age for adult caregivers is 49, but approximately 25% of caregivers in the United States are defined as millennials (NAC, & AARP, 2015). Approximately 5.5 million caregivers provide care to veterans or military members. While most family caregivers spend 24.4 hours a week providing care, almost one-quarter provide more than 40 hours of care (NAC, & AARP, 2015). Caregiving is the most time intensive role for someone providing care for a partner/spouse (44.6 hours a week) (NAC, & AARP, 2015). Common responsibilities for this role include personal care activities such as dealing with incontinence, bathing/showering, assisting with activities of daily living (ADLs), transportation, shopping, and housework.

Sitter/Companion

A sitter or companion generally serves a non-medical role in an individual's life. Companions do not provide actual hands-on patient care, but instead offer companionship, assist in meal preparation, perform light housekeeping, and escort the patient to appointments (Rizzolo, Friedman, Lulinski-Norris, & Braddock, 2013). While a sitter or companion can be someone who is paid to do this role, sometimes agencies have companion programs. For example, the Area Agency on Aging of West Central Arkansas has a program where volunteers who are aged 60 and older fulfill these roles of companionship in exchange for a small stipend and reimbursement for travel.

Home Health Aide

By 2020, the U.S. Department of Labor projects that home health aides will be one of the fastest-growing occupations in the United States, growing at a rate of 21% between 2012 and 2022 (Bureau of Labor Statistics, 2014). In 2014, there were 799,080 home health aides employed in the United States (Bureau of Labor Statistics, 2014). Home health aides are generally either a certified nursing assistant (CNA) or a personal care aide (PCA). These titles are sometimes used interchangeably because their roles are very similar. However, there are differences between them.

In most states, a personal care aide (PCA) is not required to be certified. A PCA helps with feeding, hygiene and some mobility needs such as pushing a wheelchair. Most states do not allow a PCA to administer medications. According to the U.S. Bureau of Labor Statistics (2014), the average annual salary for PCAs in the United States was $21,210, with a median hourly wage of $9.83.

In most states, a high school diploma and completion of a 75-hour training program is required to become a certified nurse's assistant (CNA). Training generally covers anatomy, physiology, functioning of the body, patient care and infection control. A CNA is typically expected to take vital signs and assist the client with personal care activities. According to the U.S. Bureau of Labor Statistics (2014), the average annual salary for CNAs in the U.S. was $26,250, with a median hourly wage of $12.07.

Unfortunately, there is a fairly high turnover rate for home health staff. In the United States, the three-month turnover rate is reported to be near 19% (Donoghue, 2010; Temple, Dobbs, & Andel, 2009). The six-month turnover rate ranges from 13-64% (Castle, 2008; Pillemer et al., 2008).

This may be explained by the rate of pay offered for the significant responsibilities held by these workers, as more than 30% of working health care aides receive public assistance, and 11-14% use food stamps (Harmuth, 2002; Khatutsky, Wiener, & Anderson, 2010; Squillace et al. 2009). Recently passed legislation may increase the income of aides. In 2013, the Fair Labor Standards Act was passed to extend overtime coverage and minimum wage requirements to home aides. Historically, home health aides in most states did not qualify for overtime and minimum wage requirements because of a federal exemption from wage-and-hour laws for "companion services" that dated back to 1938 (Biklen, 2003). This legislation, however, excludes live-in home-care workers from being eligible for overtime pay.

Skilled Nurse

Most home health care nurses are employed by a home health care agency. Examples of skilled home health services that are provided by a home health care nurse include: wound care for pressure sores (or other wounds), patient/caregiver education, intravenous or nutrition therapy, injections, and monitoring of serious illness and unstable health status (Centers for Medicare & Medicaid Services, 2015).

Each state board of nursing is responsible for determining which tasks fall under the Registered Nurse (RN) license and which can be performed by a licensed practical nurse (LPN). In general, the RN scope of practice includes more complex and potentially dangerous tasks (i.e., titrating or adjusting a dose of medication; inserting a central venous catheter; or giving intravenous chemotherapy). Typically, an LPN works under the supervision of a RN or physician, a requirement if skilled nursing services are paid for by Medicare.

Licensed practical nurses, also known as licensed vocational nurses (LVN) in some states, provide 19% of home health agency services (U.S. Department of Health & Human Services, 2014). Most LPNs have completed approximately one year of nursing education. Some go on to complete a longer degree program such as an Associate of Applied Science (AAS). In 2014 there were 78,810 LPNs working in the home health sector in the United States (BLS, 2014). According to the U.S. Bureau of Labor Statistics (2014), the average annual salary for LPNs working in the home health field was $45,370, with a mean hourly wage of $21.81.

Registered nurses (RNs) are required to have a minimum of an associate's degree; however, a growing number employers are now requiring a bachelor's degree for many nursing positions. In one survey of employers, it was found that an associate's degree was sufficient for approximately 58% of available nursing-related jobs, while a Bachelor of Science in Nursing (BSN) qualified an individual for nearly 92% of all nursing vacancies in 2014 (Erstad, 2015). According to the U.S. Bureau of Labor Statistics (2014), there were 168,970 RNs working in the home health sector in the United States earning an average annual salary of $67,880 and a mean hourly wage of $32.64.

Annual Cost

Although home health care is a widely used service which is provided at costs typically cheaper than institutional care, the exact costs of home health has not been rigorously studied (Disler, Roy, & Smith, 1993; O'Dell & Wheeler, 2012). The most recent report providing hourly home care costs located by these authors was the *Genworth Cost of Care Survey* (2015). The Genworth data were obtained through approximately 3,700 interviews with home health care providers throughout the United States. The report provides cost information both nationally and broken down by state. These data indicate the median hourly rate for homemaker services is $20, a 2.63% increase over 2014. The median cost for home health aide services is also $20 per hour which reflects only a 1.27% increase over 2014 costs. By contrast, the growth rate for assisted living facilities and nursing homes is estimated at 2.86%-4.17% (Genworth Financial, 2015). Another source of home health care cost is the Met Life Survey, which was last published in 2012 (MetLife, 2012). This report shows a national median hourly cost of a home health aide in the United States of $21 per hour and median hourly cost for homemaker services of $19 per hour (MetLife, 2012).

In addition to the direct cost incurred in personal healthcare spending, the provision of care has indirect costs to family members. Approximately 60% of caregivers report being employed while also serving as a caregiver, with the average hours of employment per week reported at 34.7 (NAC, & AARP, 2015). Caregivers report a higher rate of self-employment (17%) compared with general population (9.4%), which may be explained by the caregiver needing more work-related flexibility than can be found in traditional employment environments (NAC, & AARP, 2015). Alternatively, this higher rate of self-employment may be found among caregivers because self-employed family members may be tasked with the role of caregiver due to their unique employment situation as 50% of family caregivers report they had no choice in taking on the role of caregiver (NAC, & AARP, 2015).

Caregivers who are employed report that caregiving often impacts their employment situation. Caregiving costs American employers $17.1-$33.6 billion dollars in lost productivity each year in the form of employee absenteeism, workday interruptions, supervisory time, and employee turnover (MetLife, 2006). Caregivers report that their caregiving duties cause them to take early retirement or depart the labor market entirely, reduce their work schedules from full-time to part-time, or make other work-related adjustments (MetLife, 2011; NAC, & AARP, 2015). It is estimated that caregivers lose $300,000-$600,000 over their lifetimes in lost wages and pension benefits (MetLife, 2011). The value of the caregiving duties provided by family

caregivers is estimated at $450 billion dollars annually, nearly four times the amount of Medicaid spending on LTSS services in 2009 (Feinberg, Reinhard, Houser, & Choula, 2011).

For women of children with disability, 67% report that they are unable to work after the birth of their child (Curran, Sharples, White, & Knapp, 2001). One Canadian study found that parental caregivers for children with cerebral palsy worked less and earned less when compared to parents of children without disabilities, even if the parents had the same level of education (Brehaut et al., 2004).

Payment Sources

There are a variety of payment sources for home health care, including private pay, Medicare, Medicaid, Long-Term Care Insurance (LTC), commercial insurance/managed care/third party payers, Workers' Compensation, and Veterans Aid. Out-of-pocket/private pay is the most predominant personal funding source for home care services with 63% of home care payments coming from personal sources alone (Janus, & Ermisch, 2015). Almost 9 in 10 personally financed caregivers are private pay, fewer than 5% are paid by private insurance and approximately 2% are paid for by a family member of the person receiving care (Janus, & Ermisch, 2015). Families with incomes over $75,000 pay for home care services personally 97% of the time and are reported to receive 8.5 more hours of weekly home care overall than families with incomes of less than $15,000 (Janus, & Ermisch, 2015).

Long-Term Care Insurance (LTC)

Some individuals purchase long-term care insurance (LTC) to help cover potential long-term care expenses. Most buy this coverage through an insurance agent; however, some employers and organizations also offer such coverage. Some insurance companies have rules requiring an individual to use services from a certified home care agency or a licensed professional, while others allow you to hire independent or non-licensed providers or family members. Depending upon the policy, there is generally a waiting period before an individual can use their benefits. Typical waiting periods are 60 to 90 days after a "benefit trigger," an event that causes an inability to independently perform certain activities of daily living (ADLs) (Braverman, 2013). The most common ADLs defined in these policies include requiring assistance with bathing, eating, dressing, using the toilet, walking and remaining continent (AARP, 2015). Most often benefit periods are for three to five years, have a lifetime benefit cap, and have daily benefit limits of $100-$250 (AARP, 2015; Braverman, 2013). According to the American Association for Long Term Care Insurance (2015), the average cost of an individual long-term care insurance policy is $2,007 per year.

Private Health Insurance

Private health insurance policies will generally pay for home health home care services for acute needs (such as after a surgery) up to a limited time period (U.S. Department of Health & Human Services, 2015). Private insurance will typically cover services such as an aide, a skilled nurse, and allied health including respiratory, physical, speech and occupational therapists. This type of insurance will seldom pay 100% of any home care service. Most health insurance policies also require a prescription for skilled services and will not pay for these services when performed by a family member (USDHHS, 2015).

Medicare

Medicare is a federal insurance program for individuals 65 or older and younger people with certain disabilities. Medicare typically covers home health care for 60 days at a time, although it can be renewed with a physician's prescription. To be eligible to receive home health care, an individual must be housebound and require a certain level of skilled care. For example, Medicare will not pay for personal or homemaker services only. An individual must also require skilled care in order to receive aide services. Medicare will cover a maximum of eight (8) hours of care a day, or 28 hours a week (Braverman, 2013). In some circumstances, Medicare will cover 35 hours a week (Braverman, 2013). In 2013, Medicare paid for 29% of nursing home and home health care in the United States (Janus, & Ermisch, 2015).

Medicaid

Medicaid is a state-managed program that is financed by both the federal government and the state. There are many different programs under Medicaid available for individuals who either meet certain financial eligibility or disability criteria. Eligibility criteria varies among states but many of those eligible for Medicaid have incomes below the poverty level (Janus & Ermisch, 2015). Medicaid is the main payer source for publicly funded long-term supports and services (LTSS). In 2009, Medicaid paid for 75% of all publicly funded LTSS for individuals with intellectual and developmental disabilities in the United States (Rizzolo et al., 2013). The majority of this spending was for the Home and Community Based Services (HCBS) Waiver program. The HCBS Waiver program was first authorized by Congress in 1981 as a way for states to target groups of individuals at risk of institutionalization, including individuals with intellectual and developmental disabilities who would otherwise need care in an intermediate care facility (Rizzolo et al., 2013). While the amount of assistance varies by state, generally Medicaid pays for two to eight hours of service per day. However, the total cost of services cannot exceed the price of a nursing home (Braverman, 2013). It is noted that the Affordable Care Act does not provide for home health services directly, but some states have expanded Medicaid coverage and this must be considered on a state-by-state basis.

Some states have programs that allow Medicaid recipients to hire almost anyone for home care, including

relatives. The Medicaid Waiver program, Alternatives for Adults with Physical Disabilities (AAPD), provides home and community-based services to adults with physical disabilities between the ages of 21 and 64 years old. An individual may receive up to eight hours a day, seven days a week of attendant care by either an attendant they personally hire or through an agency they chose. While the attendant may be a family member, they cannot be a spouse or other person legally responsible for the client. In 2013, Medicaid paid for 32% of nursing home and home health care in the United States (Janus, & Ermisch, 2015).

Individualized Education Plans (IEP)

The Individuals with Disabilities Education Act (IDEA) guarantees that all children with disabilities have a free, appropriate public education to meet their unique needs and prepare them for further education, employment, and independent living (IDEA, 1997; Turnbull, 2005). While IDEA provides financial support for state and local school districts, the school is required to try to obtain reimbursement from private or public health insurance for health services written in a student's Individualized Education Program (IEP). These services can include: nursing services, personal care assistants (PCA), physical therapy, occupational therapy, speech language pathology, mental health services, special transportation, and assistive technology devices.

While a child with a disability may be receiving home care services outside of school, when such services are provided through the school, they are considered IEP services and billed as such (Pacer, 2015). The school can only bill the child's parent's insurance for IEP services with their written consent. However, even if the parent does not permit the school to bill their insurance company, the child must still receive all of the services in the IEP at no cost to the family. IEP services are not considered or billed as home care, therapy or waiver services. The IEP services do not count against the limits for home care services by most insurance companies. For example, IEP services are not counted against the waiver cap or affect the amount of services available under the waiver program (Pacer, 2015).

Advantages and Disadvantages of Care Provision

When deciding on how home care services will be provided, those involved must weigh the pros and cons involved in various avenues of service delivery. In general, it is believed that home care services are least expensive when provided by a family member and most expensive when provided by a home care agency. It is reported, however, that privately hiring home care can be the most challenging option for most individuals (Butler, Brennan-Ing, Wardamasky, & Ashley, 2014; Dahlberg, 2001).

One element of this choice involves cost. It is estimated that private-pay services are 20-30% lower than agency provided care (Elder Options of Texas, 2015), with one study demonstrating the average daily cost of agency provided care at $151 per day, compared with $129 per day for privately managed care (Prince, Manley, & Whiteneck 1995). Another element of this choice involves control, with some consumers of private hire care reporting that they feel they have greater control over the duties and responsibilities of the caregiver (Beatty, Richmond, Tepper, & DeJong, 1998; Prince et al., 1995).

It is important, when considering cost, that an informed decision is being made about exactly what privately hire versus agency hired services include. While there may be perceived hourly savings for in-home care derived from private pay sources (when compared to agency care), the comparison between private pay and agency care is oftentimes comparing apples to oranges. Home health agency costs, for example, include costs for interviewing, background screens, workers' compensation, insurance, licensure, bonding and providing back-up care (Dahlberg, 2001; Thomas, & Kitchen, 1996). Agency provided care involves the development of a comprehensive care plan, and coordination with the family and medical treatment team. Additionally, the home health agency is responsible for administrative details including payroll, taxes, screening, hiring/firing, and supervision (often by a skilled nurse). AARP advises those considering hiring through private pay sources learn about background checks, Social Security and Medicare taxes, workers' compensation, liability insurance for the home where the care is provided and advises consideration of how to handle situations when the caregiver is not available to work (AARP, 2015).

Thomas and Kitchen (1996) compared the cost of private-hire attendant care compared to agency hire. They also advised consumers to make provisions for back-up care when private-hire attendants are ill, take vacations or are otherwise not available for work. After factoring in costs of background checks, taxes, insurance, licensure, bonding, payroll services as well as back-up services, they concluded that a private-hire rate of $7.00 per hour could easily amount to $14 per hour when the administrative, supervisory and back-up services inherent in agency care was added to the private-hire model (Thomas, & Kitchen, 1996).

Another element of the home care choice involves the use of unpaid family members. While family members may be available to provide caregiving/attendant care services without financial remuneration, there is a vast body of literature addressing the true cost of such services. As mentioned above, there is often an economic impact to the income stream of the caregiver when they reduce their paid employment hours, leave the labor market to provide caregiving services or are prevented from promotional consideration due to the caregiving obligations (NAC, & AARP, 2015). The caregivers' relinquishment of their paid employment to provide caregiver services is also a worry for those receiving care (McCann, & Evans, 2002). In addition, caregivers often report absorbing the medical costs for the family member for which they provide care, an estimated cost

of $5,531 per year (MetLife, 2011).

Perhaps the biggest cost associated with caregiving is the physical and psychological toll that it takes on the service provider, often referred to as caregiver stress (Leonardi, Giovanetti, Pagani, Raggi, & Sattin, 2012; McCluskey, 2000; Raina et al., 2005; Sherman, 1995; Smith et al., 2010). Wilks and Croom (2008) defined caregiver stress as the product of mental, physical, financial and/or interpersonal demands perceived by caregivers. Common complaints of caregivers include limited access to the outdoors, being socially isolated and not having personal time (Leonardi et al., 2011; Palisano et al., 2009).

Almost 60% of caregivers surveyed reported that their health has become "moderately" to "a lot" worse because of their caregiving role (Evercare, 2006). More caregivers (17%) describe their own health as "fair" or "poor" when compared to 10% in the general U.S. population (10%) (NAC & AARP, 2015). This trend has been identified in similar studies in Italy (Leonardi et al., 2011), Canada (Brehaut et al., 2004), Fiji (Gajraj-Singh, 2011) and Ireland (Byrne, Hurley, Daly, & Cunningham, 2009). Caregivers report higher levels of physical and psychological distress with conditions including gastrointestinal, renal, and cardiac conditions as well as stroke, migraines and/or orthopedic problems (including back problems) (Brehaut et al., 2004; Byrne et al., 2009; McCann, & Evans, 2002; Smith et al., 2010). Caregivers report taking medication for conditions including anxiety, cardiac conditions, depression and sleep disturbance (Smith et al., 2010). Both household income less than $30,000 per year and duration of caregiving tasks correlate with poor health reports (NAC, & AARP, 2015).

In addition to physical problems, caregivers report higher levels of psychological problems than is found in the general population, both in the United States and in other countries (Byrne et al., 2010; Cowen, & Reed, 2002; Leonardi et al., 2011; Smith et al., 2010). Studies have found that 34% to 59.5% of caregivers report moderate to severe depression (Leonardi et al., 2011; Smith et al., 2010), with the symptoms of depression and somatization in one study of caregiving parents reaching that of psychiatric patients (Sherman, 1995). Smith et al. (2010) reported that 15% of caregivers in their study reported receiving counseling for depression.

While the caregiver population is reported to be at high risk for experiencing caregiver stress, certain variables appear to be more strongly associated with caregiver stress. Variables that are associated with higher levels of caregiver stress include being female, with female caregivers reporting 14.6% more caregiver stress than male caregivers, perhaps because they are performing more caregiving duties (Byrne et al., 2010; Neufield et al., 2001). Additionally, the higher the level of the caregiver's education, the higher the level of caregiver stress (Hong, & Casado, 2015), with a one unit increase in education being associated with a 4.7% increase in caregiver stress. Caring for an individual who has a greater number of limitations (Hong, & Casado, 2015) also results in higher levels of caregiver stress, with a one unit increase in number of Instrumental Activities of Daily Living (IADL) limitations being associated with a 3.3% increase in caregiver stress. Physical strain also increased levels of caregiver stress reported, with a one unit increase in physical strain resulting in a 32.6% increase in caregiver stress (Hong, & Casado, 2015). Finally, economic hardship increased caregiver stress with a one unit increase in economic hardship being associated with a 16.6% increase in caregiver stress (Hong, & Casado, 2015). Those caregivers reporting the most negative health effects included higher-hour caregivers (29% worse health), caregivers for someone with a mental health issue (34%), co-resident caregivers (30%), those doing medical/nursing tasks (27%), and primary caregivers (25%). Over 50% of those who feel they have no choice but to assume caregiving responsibilities report high levels of emotional stress (Byrne et al., 2009; Gajraj-Singh, 2011; NAC, & AARP, 2015). Those providing caregiving services to a close relative (e.g., spouse or parent) report higher levels of caregiver stress than those who provide care to distant relatives or non-relatives (NAC, & AARP, 2015).

In addition to the physical and psychological stress that is caused by caregiving, caregivers report financial strain or economic stress as a result of their caregiving duties, with those providing a higher number of hours of care and those who have provided care for long periods of time reporting the highest levels of financial strain (NAC, & AARP, 2015; Smith et al., 2010). Commonly cited concerns include the costs of insurance, co-payments and out-of-network costs, maximum lifetime coverage provided, and general healthcare costs. The inability to access affordable services is reported by 25% of caregivers (NAC, & AARP, 2015). These concerns cause some individuals to downsize their home and/or delay treatment.

Life Care Planning Implications

From a life care planning perspective, fully understanding the various services available for home care, as well as the state nurse practice act that governs home health service provision for the client, is critical. Without the understanding of the level of service required and the availability of such services in the client's geographic region, the home care portion of the life care plan may inadvertently be underfunded.

Consideration of inclusion of respite care for caregivers in the life care plan should be undertaken, as such services have been shown to reduce the burden and stress of care providers (McCann, & Evans, 2002; Neufield et al., 2001; Sherman, 1995). In a study of 73 families who provided caregiving services to children (ages 0-19) with chronic illness who were provided experimental respite services over a period of three years, such services decreased the number of patient hospitalizations, decreased the risk of unintentional neglect, decreased sibling strain, decreased caregiver

somatization and increased family stability (Sherman, 1995). This study concluded that respite services serve not only the patient but provide a family centered approach to service provision that benefits the entire family of the patient (Sherman, 1995). The only complaints from family members involved in the study concerned the desire for emergency respite services and the need for more hours of respite services than the study provided, a complaint that is seen elsewhere in respite care literature (Neufield et al., 2001; Sherman, 1995). It is cautioned, however, that the provision of respite care is very different from the provision of child care or babysitting (when provided to pediatric patient) as those terms disregard the skill and knowledge required by care providers and diminish the difficulty parents report in finding properly trained respite care services for their children (Neufield et al., 2001).

Of interest, in one study of parents of children with cerebral palsy, 68% of parents expressed a need for information about services their child might receive in the future while 57.7% of parents expressed a need for information about planning for their child's future wellbeing (Palisano et al., 2009). This theme of needing additional information about future needs and care of the patient is reflected throughout the caregiving literature. This finding highlights the importance of the educational role that the life care plan can serve in addressing the lifelong needs of the client. The planning and educational role of the life care planner may reduce the stress for parents of children with disabilities.

It is important for the life care planner to advise family caregivers of the availability of resources for their support. Information designed to educate and support caregivers is readily available online, including a Caregivers Bill of Rights that encourages the caregiver to seek help from others and take time for themselves (Caregiver.com, 2015). Other online resources exist to explain what level of care may be necessary to provide home care and the estimated cost for services in one's state.

For life care planners also serving as a vocational consultant, an awareness of workplace-related resources may also be valuable. As of 2006, approximately one-third of large American employers had eldercare programs available to serve their employees who also provide caregiving duties (MetLife, 2006). Literature is available to managers of employees who are caregivers to provide workplace supports that minimize the disruption in the workplace. Workplace suggestions offered by some employers include flexible work hours, paid time off and/or telecommuting.

An awareness of legislative developments is important to the life care planner. As mentioned previously, the work of home health aides was impacted by the 2013 Fair Labor Standards Act expanding protection to those workers who provide home care services. In 2015, President Barack Obama issued a Presidential Proclamation in honor of National Family Caregivers Month explaining that military caregiver leave, for those providing care to veterans, will be expanded to up to five years.

Having a command of the caregiving literature is important to educate all parties on how using formal services can alleviate caregiver stress and improve quality of life (Empeno, Raming, Irwin, Nelesen, & Lloyd, 2011; McCluskey, 2000; Montgomery, & Borgatta, 1989; Sherman, 1995; U.S. Department of Health & Human Services, 2014). Such services allow family members to resume work and become more fully engaged in social networks (McCluskey, 2000). Some state systems provide reimbursement for respite services, which have been shown to reduce inpatient hospitalization costs (Sherman, 1995). Particularly for life care planners who work in multiple states, exploring the programs for each client may be important in the development of the life care plan.

Having the availability of resources, including the provision of attendant care, is foundational for quality of life for individuals with disabilities (Boswell, Dawson, & Henninger, 1998; Hammell, 2004). Prior life care planning follow-up studies have found that attendant care is frequently consumed after a life care plan is developed (Kendall, & Casuto, 2005; Rutherford-Owen, 2011), with higher satisfaction levels reported by those who had funding to purchase the necessary levels of attendant care (Rutherford-Owen, 2011). Prior to life care plan development, approximately 70% of individuals with spinal cord injuries surveyed reporting receiving unpaid attendant care, compared with only 20% after the life care plan was developed, revealing a shift away from family provided care when a life care plan was developed and funded (Rutherford-Owen, 2011). In this study, only 27% of individuals who received life care plan funding utilized unpaid family care, while the majority (73%) purchased paid attendant care for assistance including bathing, grooming, transportation and housekeeping. When provided open-response questions in describing their day, the critical role of personal assistant services was noted by almost all individuals in their daily routine. This study demonstrates the important changes that occur in attendant care arrangements following the intervention of a life care planner.

Conclusion

The provision of home care in a life care plan is a critical element that enhances the lives not only of the person with the disability but also of their family members. Having a full understanding of the unique needs of the individual with a disability is critical in developing a plan of care that adequately addresses the needs of the whole person and their family. With a full understanding of the differences in the levels of home care required by the individual and the associated cost with both agency provided and privately hired personnel, the life care planner is in a unique position to educate all parties about the home care required on a lifelong basis by the person for whom the life care plan is developed.

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