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Attendant Care and Spinal Cord Injury: Usage Patterns and Perspectives for Those with Life Care Plans

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Abstract

The provision of attendant care services is one of the costliest services needed by many individuals following a spinal cord injury (SCI). The current study examined consumption patterns of 55 adults with SCI who had a life care plan developed. Respondents were asked about various aspects of attendant care including number of hours utilized, satisfaction, level and type of care, (i.e. unpaid care versus private hire), received prior to and following life care plan development and settlement. Respondents provided open responses to explain reasons for satisfaction and dissatisfaction with attendant care. Results indicated more respondents received attendant care services following life care plan development than prior to plan development. A greater percentage relied more upon unpaid care from family and friends prior to a settlement or receipt of funding, and less so following receipt of funding and plan development. Finally, differences in usage patterns of attendant care services were noted between the group of individuals who did not receive a settlement/funding when compared to those who did. Participants without funding more often relied upon unpaid attendant care following life care plan development.

Those with Life Care Plans

Personal attendant care services are defined by the World Institute of Disability as "assistance, under maximum feasible user control, with tasks aimed at maintaining well-being, personal appearance, comfort, safety, and interactions within the community and society" (Pomeranz, Shaw, Sawyer & Velozo, 2006 p. 8). Among individuals with spinal cord injuries (SCI), attendant care is often cited as the most basic need related to quality of life (Boswell, Dawson & Henninger, 1998).

It is estimated that attendant care services can comprise up to 44% of the total recurring rehabilitation costs for individuals with spinal cord injuries (Havey, Wilson, Greene, Berkowitz & Stripling, 1992 as cited in Harrell & Krause, 2002; Pomeranz, Shaw, Sawyer & Velozo, 2006). Unfortunately, most individuals who have sustained a traumatic SCI do not have the resources to pay for personal assistance (Harrell & Krause, 2002). As some state government

programs do not provide in-home care and others require indigent status to qualify for services, the cost for in-home care for those with SCI can be staggering. These services are often the most critical and costly services included in the life care plan (LCP) (Deutsch, Weed, Kitchen & Sluis, 1989; Harrell & Krause, 2002; Pomeranz, Shaw, Sawyer & Velozo, 2006; Weed, 1998). As a result, it is often the one item in the LCP that is debated within the litigation arena with typically the defense arguing that family members are available to provide attendant care services, theoretically negating the need for paid assistance.

Since the cost of in-home personal assistance is in most cases cost prohibitive, approximately 80% of all caregiving in the U.S. is provided by unpaid family members, totaling an estimated $300 billion per year (National Alliance for Care-giving and American Association of Retired Persons, 2004). The average caregiver is a female in her mid-40s in over 50% of cases, and is often caring for a loved one or aging parent over the age of 50. Approximately 14% of caregivers are caring for their disabled child in 55% of cases (National Alliance for Caregiving and American Association of Retired Persons, 2004). Caregiving is generally broken down into two types. Activities of daily living (ADL) typically includes assistance with personal hygiene, grooming, dressing, feeding, transferring, bowel and bladder care, and assistance ambulating. Instrumental activities of daily living (IADL) includes providing money management, meal preparation, grocery or related shopping, and medication management. Additional services may be included, and depending on care needs, may range from less than one hour to 24 hours per day.

The literature reveals that when family members provide personal attendant care services to their loved one with a disability, disruption in the natural family relationship can occur (Harrell & Krause, 2002). The life care planner is often responsible for explaining the discrepancy between care recommended in the life care plan and what is currently being provided to the client. Regardless, there is a plethora of literature regarding the potential physical and mental implications of caregiving, especially in instances where the primary caregiver has: (a) little or no assistance; (b) the intensity of the care-giving required is extensive (e.g., ventilator, feeding tube); (c) the number of direct care contact hours required; (d) the loved one being cared for is abusive or aggressive; and, (e) the caregiver has poor coping skills (Grosse, Flores, Ouyang, Robbins & Tilford., 2009; Imran et al., 2010; Marini, 2011; Mulvihill et al. 2005; Roth, Perkins, Wadley & Temple, 2009).

Life care planners, as a result, spend a significant amount of time researching the need for services and educating the parties involved about the availability and costs for these services. Under representation of attendant care needs in a life care plan may lead to inadequate services being received, more frequent hospitalizations and painful complications (Weed, 1998). In contrast, over representing personal care attendant needs in the life care plan may result in an inflated and costly plan that is unfair to all parties involved (Weed, 1998). Life care planners are often questioned about long-term use of items included in the life care plan, including attendant care consumption. A quantitative life care planning follow-up study conducted by Kendall and Casuto (2005), found that attendant care was implemented consistently at the level that was recommended in 86.7% of the 15 life care plans they reviewed.

A review of literature suggests that individuals with spinal cord injuries who manage their attendant care services report fewer preventable complications, hospitalizations and overall better health and life satisfaction than those who rely on agency provided care (Harrell & Krause, 2002; Pomeranz, Shaw & Sawyer, 2006). The provision of attendant care services, according to Harrell and Krause (2002), is impacted by housing, social support, proximity to caregivers, financial resources, availability of family members and geographic location.

Attendant care services have been found to directly impact quality of life by changing access to community, including work, which has been found to correlate with higher quality of life reports (Arango-Lasprilla et al., 2009; Boswell, Dawson & Henninger, 1998; Harrell & Krause, 2002; Krause, 1992; Meade, Lewis, Jackson & Hess, 2004).

The present study was part of a larger scale study exploring a variety of life care planning implementation factors pertaining to persons with spinal cord injuries involved in litigation for whom a life care plan was developed. Since attendant care services are often the most expensive aspect of the life care plan and the most critical in ensuring quality of life, a more thorough exploration of the topic was deemed necessary. This analysis was primarily an exploratory endeavor with descriptive statistics; however, qualitative comments were solicited from participants regarding pre and post life care plan attendant care and satisfaction with the care received. The research questions specifically addressed were:

1) What are the pre and post life care plan implementation patterns of attendant care services with/without a successful litigation outcome?

2) How satisfied were respondents with their ability to pay for attendant care services and direct their attendant care?

Methods

Participants

Participants for the study were referred by 15 practicing life care planners who obtained permission to contact these former plan recipients with spinal cord injuries. In total, 55 of 372 referred cases eventually participated after 238 could not be contacted. Respondents with SCI were primarily male (n=33, 60%) and 40% (n=22) female. The majority (n=47, 85%) were White/Caucasian, with 7% (n=4) African American, 5% (n=3) Hispanic and 2% (n=1) Asian. The average age at injury was 30.6 (SD= 14.26). Respondents resided in 18 states throughout the U.S., with over 90% residing in non-rural geographic locations. Motor vehicle accidents were the most frequently reported cause of injury, followed by an on the job injury and sports related injury. Type of injury included 13% (n=7) who reported C2-C4 lesion, 49% (n=26) reported a C5-T1 level injury, 32% (n=17) a T2-T12 lesion, and 5.7% (n=3) and L1-L5 SCI. Criteria for eligibility to participate included individuals who are 18 years or older, and had no other co-morbid disability (e.g., traumatic brain injury).

Instruments

A 39-question life care plan fixed and open question survey was adapted to collect information from respondents regarding demographic information, life care plan item consumption and information pertaining to the number of hours and level of attendant care services received. Additionally, respondents were queried with open-ended questions about their level of satisfaction/ dissatisfaction with attendant care received. The questions were adapted from the World Health Organization-International Classification of Functioning (WHO ICF) model which considers the impact of the disability, environmental conditions, social and interpersonal factors. Previous research regarding life care plan reliability included a study of home health and/or facility care because this item is common to most life care plans and has been cited as one of the costliest single items in a life care plan (Sutton, Deutsch, Weed, & Berens, 2002). Questions were broken down in relation to pre-injury versus post-injury services utilized, and settlement/monetary award versus no award.

Aside from customary demographic questions previously described in the participants' section, the pre-life care plan assistance section included receipt of daily assistance including

paid/ unpaid, number of hours per day, provider of care and level of care (home health, LPN, RN, other). Additional items include the individual's satisfaction with the authority they have to direct assistance and the amount of money available to pay for assistance. Reponses to these items were on a 5-point Likert scale from "not at all satisfied" to "extremely satisfied." In this section as well, open response questions were provided to explain reasons for satisfaction or lack of satisfaction.

Procedures

Permission to carry out the study was obtained through the human subjects internal review board (IRB) at the University of Arkansas. A convenience sample was used by soliciting life care planners using several sources, including the Foundation for Life Care Planning Research, the International Association of Rehabilitation Professional listserv, the Life Care Planner Forum listserv, the Certified Life Care Planner listserv, and the International Academy of Life Care Planners listserv. Aside from electronic listserves, additional solicitations were conducted in person at the 2010 Life Care Planning Summit, through individual email and telephone contact with individuals designed as a certified life care planner through the International Association of Rehabilitation Professionals directory, and an advertisement in the Journal of Life Care Planning. Of the approximate 614 life care planners contacted individually by email, electronically, and/or by telephone, 545 did not respond and 32 were not willing to participate.

The 15 life care planners who decided to participate were provided several options to do so. They could either supply names and telephone number or email addresses for adults with SCI for whom they have previously prepared plans, send a link to the survey (on Surveymonkey.com) to their former evaluated cases, or direct mail hardcopy surveys for those who could not be reached by telephone or elected to complete the survey by mail. The Foundation for Life Care Planning Research funded the mail-out of approximately 300 post cards with the announcement and instructions on how to link to the study. In addition, the International Commission on Healthcare Certification announced the study on their listserv and provided 10 CLCP CEUs for all life care planners who participated. Finally, life care planners who decided to participant were entered into a drawing for a free life care planning conference registration fee worth $400.

Upon receipt of potential participant's contact information, the researcher contacted each to discuss participation in the study. Each individual was provided IRB disclosure information about the purpose of the study, voluntary participation, and any risks and benefits. Of those who agreed to participate, informed consent was obtained. Participants were provided the option of completing the survey online with SurveymonkeyTM, a hardcopy by mail with a self-addressed stamped return envelope, or by telephone. A five dollar gift card was mailed to everyone who completed the survey online, by phone, or by mail. For those who agreed to participate, a maximum of six follow-up reminder telephone calls were made with no further contact thereafter.

Results

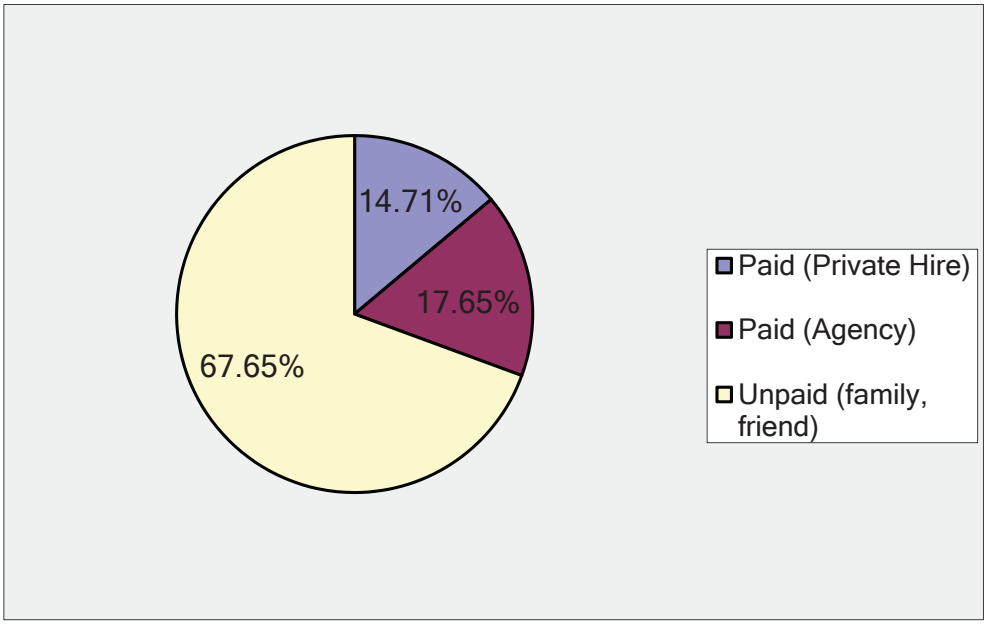
Regarding research question one: "What are the pre and post life care plan implementation patterns of attendant care services with/without a successful litigation outcome." Attendant care utilization and funding sources were determined using SAS Software version 9.2 frequency statistics.

Pre-Life Care Plan Attendant Services Received

In this sample, 34 (of 52) respondents (65.38%) indicated that they received personal assistance prior to life care plan development. The most frequently reported source of assistance was unpaid care provided by family and friends for 23 (of 34) or 67.65% respondents, followed by paid agency care for six respondents (17.65%) and paid private-hire care for five respondents (14.71%). This information is shown in Figure 1.

Figure 1

Pre Life Care Plan Attendant Care Received



The average number of unpaid daily hours of attendant care received by respondents prior to life care plan development was 12.92 hours (SD=9.80) with a range of zero to 24 hours. The average number of paid daily attendant care hours received was 5.81 hours (SD=7.73), with a range of zero to 24. The level of care received included unskilled personal attendant care for 10 respondents (34.48%), licensed practical nurse (LPN) for two respondents (6.90%), registered nurse for three respondents (10.34%) and 'Other' for 14 respondents (48.28%). All of the respondents who chose 'Other' indicated that family members provided their care. The most frequently cited specific caregiver was one's mother (n=6).

Although respondents were not specifically queried about sources of funding for attendant care services prior to LCP development, they were asked the source of payment for all pre-life care plan items. Sources of payment included out-of-pocket private pay for 31 respondents (47.69%), private insurance for 16 respondents (24.62%), Medicare for seven respondents (10.77%), Medicaid for six respondents (9.23%) and Workers' Compensation for five respondents (7.69%). It is noted that respondents could choose more than one category, so the total response to this item (n=65) exceeded the total sample size (n=55). Other open responses

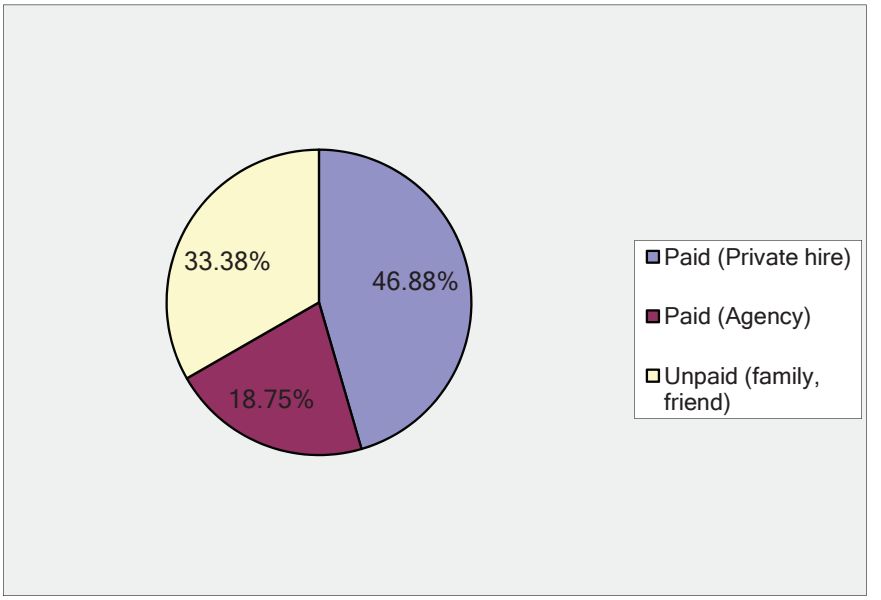
indicated that respondents utilized loans (n=2), rehabilitation services and independent living (n=6), Veteran's Administration (n=1), funding from family members (n=3) and donations (n=1) to pay for life care plan goods and services.

Post Life Care Plan Attendant Care Services Received

In this sample, 35 respondents (70.00%) indicated that they received personal assistance following life care plan development. Sources of assistance included out-of-pocket paid private-hire care for 15 respondents (46.88%), paid agency care for 6 respondents (18.75%), and unpaid care provided by family or friends for 11 respondents (34.38%). This information is contained in Figure 2. It is noted that this sample includes both those who did and did not have a successful litigation outcome.

Figure 2

Post Life Care Plan Received



The average number of daily unpaid attendant care hours received by respondents following life care plan development reduced from pre-injury to 10.88 (SD = 7.32) whereas the average number of daily paid attendant care hours received increased from pre-injury to 7.89 (SD = 7.85), with a range of zero to 24 hours. Overall, in addition to the number of daily funded attendant care hours having increased for the successfully financially settled, those who hired private pay attendants tripled compared to pre-injury (15 versus 5), whereas none of the individuals who did not receive a settlement hired their own private care.

Table 1

Post Life Care Plan Attendant Care Received with and without Funding

Life Care Plan Item	Post-LCP-funding (%) N (27)		Post-LCP-without funding (%) N (5)	
Assistance – Agency	5	(18.52%)	1	(20%)
Assistance-Private Hire	15	(55.56%)	0	(0%)
Unpaid/Family	7	(25.93%)	4	(80%)

Qualitative Analysis Summary - Pre Life Care Plan

Research question two queried how satisfied respondents were with their ability to pay for attendant care services and direct their attendant care. Selected comments summarizing overall responses are briefly addressed. When asked about level of satisfaction with the amount of authority the individual with SCI had to direct their personal assistants prior to life care plan development, the majority (67.65%) responded that they were "very satisfied" or "extremely satisfied." However, when asked about satisfaction with the amount of money available to pay for attendant care, 20 of 32 respondents (62.50%) indicated that they were "not at all" or only "slightly satisfied."

Twenty-one of the respondents provided open-ended comments regarding their level of satisfaction with attendant care services received before the life care plan process. Of the 21 who responded, 10 (47.6%) of comments cited a lack of funding as the primary factor regarding the amount of attendant care services received. Representative of typical responses pertaining to limited financial resources included "No money paid prior to life care plan, did not have an income except Social Security disability" (Respondent 3). Citing both limited funds and benefit restrictions, Respondent 5 noted "I was told as long as there was a family member in the home that could take care of my needs I was not eligible for any monetary assistance." One respondent (Respondent 20) noted receipt of attendant care services through a combination of family care and limited benefit funds: "Parents provided care and Medicaid provided some care." Overall, limited resources, lack of income and lack of benefits coverage were all cited as reasons for dissatisfaction with attendant care.

Conversely, eight of the 21 respondents (38%) noted positive comments about the family members who provided their care. Respondent 1 noted; "Care provided by those who love me with little or no compensation." Similar comments were noted among other respondents including Respondent 3 who wrote "I have an amazing mom who was there every roll of the way. She was understanding and supportive!"

Qualitative Analysis- Post Life Care Plan

Respondents were also asked the same series of questions pertaining to post life care plan attendant care received. When asked about level of satisfaction with the amount of authority the individual with SCI had to direct their personal assistants, the majority (82.86%) responded that they were "very satisfied" or "extremely satisfied." However, when asked about the

satisfaction with the amount of money available to pay for attendant care, 12 respondents (41.38%) indicated that they were "not at all satisfied", while 11 (37.93%) responded that they were "very" or "extremely satisfied." Of the five respondents who did not receive any funding to purchase LCP services, four of five (80%) reported that they were "not at all satisfied" or only "slightly satisfied" with the amount of money available to pay for attendant care.

Again, respondents were asked to provide open-ended responses regarding their reasons for being satisfied or not regarding attendant care. Use of settlement or annuity funding to pay for attendant care services was noted by four of 17 respondents. Several respondents noted the need for involving family members to help pay for care including "my husband's retirement" (Respondent 6). This comment was made by a respondent who had received a financial settlement. Respondent 5 commented "I'm always worried about running out of money in the future because of my care expenses." The same sentiment was reported by several respondents, overall citing that despite having prevailed in receiving a settlement or verdict, they perceived they would not have enough funds to support them for the rest of their lives.

Discussion

The issue of personal care attendant (PCA) services in life care plans will likely remain one of the most contested and scrutinized services in litigation due to the high costs involved in more severe type injuries (Weed, 1998). The present study represents the largest empirical inquiry to date investigating pre and post injury PCA utilization, sources of funding, type of services, and satisfaction with PCA services. Thirty-four of the 52 respondents to this question utilized PCA services in this study.

Summarizing the present findings, virtually all respondents who reported needing PCA services prior to their injury continued to require such care post injury. Only one additional respondent indicated using PCA services post life care plan. More significant; however, is the finding that prior to the life care plan and settlement, over 67% of the respondents were receiving PCA services by unpaid family or friends. This statistic is somewhat consistent with national statistics indicating approximately 80% of all PCA services in the US is performed by unpaid significant others (National Alliance for Care-giving and American Association of Retired Persons, 2004). After life care plan settlement, however, only 34% or half of the pre-settlement respondents reported to be continuing to obtain PCA services from unpaid family members. As such, settlement monies were directly being used to hire a personal attendant.

Sources of payment for those fortunate enough to have some type of funding source remained diverse both prior to and following life care plan implementation. Prior to the life care plan, approximately half or 47% of respondents were spending their own money to hire their own care as noted in the qualitative responses such as utilizing retirement accounts. Post life care plan and settlement, this statistic remained the same; however, respondents were now using their settlement monies as needed. And although the greatest concern both prior to and following life care plan implementation was not having enough financial resources to fund PCA services over a lifetime, respondents were paying for more hours of daily attendant care than they were before their settlement. Several of the subjective complaints or comments by respondents regarding funding pertained to the restrictions or limitations in number of hours allowed by the funding source (e.g., Medicare, Medicaid, Workers' Compensation). It is noteworthy that many respondents with some collateral source paid attendant care also reported needing additional hours provided by unpaid family members.

Overall, although 63% of respondents were either not satisfied or only slightly satisfied with the amount of money available to pay for PCA services pre-settlement, this number

dropped to 48% post-settlement, and 38% indicated being very or extremely satisfied with the amount of money available. Of the six individuals who did not receive a settlement, all of them reported being very dissatisfied with amount of money available to pay for PCA services despite two of them having a collateral source, albeit restrictive.

The mental-health as well as quality of life implications for having adequate care-giving services continues to show fairly consistent findings (Arango-Lasprilla et al., 2009; Boswell, Dawson & Henninger, 1998; Harrell & Krause, 2002; Krause, 1992; Meade, Lewis, Jackson & Hess, 2004; Pomeranz et al., 2006; Marini, 2011; Owen & Marini, 2011). Overall, such studies are suggesting under certain circumstances caregiver burnout can occur, care receivers can experience lower levels of life satisfaction and quality of life. Conversely, with adequate PCA support, individuals can maintain greater levels of independence which can include employment. Additionally, those individuals who are able to manage their own care as previously noted report fewer hospitalizations and secondary complications as well as life satisfaction as opposed to relying on potential restrictions of agency care (Harrell & Krause, 2002; Pomeranz et al., 2006). The merits of private hire versus agency care become an excellent line of inquiry for further future research as explored by Pomeranz and associates.

There are several study limitations that readers should be aware, the first of which concerns generalizability of findings. Respondents for this study were a convenience sample of former life care plan recipients from 15 life care planners, and therefore not a random sample. Another instrument limitation is that the life care plan survey was not field tested. The instrument was designed by combining common elements of previously developed life care plan follow-up surveys and having the content reviewed by a panel of life care planning experts. Finally, respondents were not specifically asked about the source of payment for attendant care services following life care plan development.

Life care planners when addressing PCA services are often faced with decisions and subsequent questions regarding family provided care, agency care, skill level needed, nursing or residential home care and more recently private hire care. Although the collateral source rule is fairly consistent across all venues, life care planners continue to be questioned by attorneys regarding the need for paid PCA services if family members are performing care adequately and safely. The present study showed respondents who received a settlement did pay for their care at twice the level prior to their award, and opted for more private hire care than that from an agency. Reliance on unpaid family caregivers decreased following settlement, likely due to funding availability to purchase attendant care services.

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