

The impact of Spinal Cord Injury on the employment of family caregivers

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Abstract. This paper describes and explores the impact of spinal cord injury (SCI) on the employment of family members, especially those who act as primary caregivers, of individuals with SCI. Using individual interviews and a focus group, nine caregivers were interviewed to gain a better understanding of the challenges these caregivers face, the needs and concerns they have, and what services and programs would enable them to continue to balance their many roles. Our participants included both parents and spouses/partners of individuals with SCI, who varied significantly across age (teenager through adult) and level of injury. Four primary themes emerged from our study: (1) caregivers had to create flexibility in their employment situation in order to successfully maintain employment, especially immediately after the injury; (2) while many of our caregivers felt that they needed to work for financial reasons, there were times when the two responsibilities of work and caregiving conflicted; (3) responsibilities left little time for the caregivers to engage in leisure, maintain social connection, spend time with their spouse, or take time to care for their own personal needs; and (4) caregivers' employment was affected by the lack of available Certified Nursing Aides. This study points to the need for more community supports for this population of caregivers and the need for more research on employed caregivers of persons with SCI.

Keywords: Spinal cord injury, family, caregiver, employment

1. Introduction

Approximately 250,000 individuals in the United States are living with SCI [20]. This number is expected to increase, as surgical procedures and medical interventions continue to improve both quality of life and life expectancies [16,19,20]. Today, 88.1% of persons who are discharged with SCI return to private residences, usually where they resided prior to the injury [20]. While some individuals can successfully live alone following a SCI, those with more severe injuries often need assistance with personal care in order to remain in the community. Frequently, this

care is provided informally by family members who are unpaid for their assistance and support [14]. It is estimated that 40% of all individuals with SCI have at least some assistance with personal care and that over half of these individuals receive assistance from family members [9].

While adjustment and coping strategies of individuals with SCI have been extensively studied, their caregivers and family members have received less attention. However, the research that has been done has documented the importance of the family caregiver in facilitating the adjustment, community integration and continued health of an individual with SCI [2,18,24]. Research has also documented that the combination of the physical demands, emotional demands and impact on the individual's lifestyle often put these individuals at risk for problems with physical and psychological health (often stress related) [2,8,13,17,19,24]. Chwalisz has described caregivers as "hidden patients" be-

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cause of their tendency to develop their own physical and emotional problems within two years of their spouse's illness or injury [6, p. 91].

An extensive body of literature exists on the employment of family caregivers of the elderly, including persons with Alzheimer's, which can inform the study and discussion on caregiving of individuals with SCI. This research is especially important to consult when examining employment of family caregivers of individuals with SCI, as the authors do not know of any articles or research examining this topic.

2. Background and problem statement

2.1. Definitions

In this paper, "family caregiver" is defined as a family member or other significant individual who provides unpaid personal care assistance and/or emotional support to an individual with a physical or mental disability. While the research on "caregivers" is plentiful, little attention has been focused on the amount of time or types of assistance that must be provided in order to be considered a "caregiver".

In understanding the role of the caregiver, it is necessary to understand the perceptions of the caregiver themselves. The concept of "burden" is used to describe how caregivers perceive their responsibilities. "Burden" has been described in different ways, such as: "the accumulation of specific problems in caregivers' lives, including mental and physical health, financial status, social activity participation, financial status, giving the elderly care when the caregiver is not well enough and providing constant attention to the impaired elderly" [1, p. 64]; or "the negative subjective experience" or "perceived stress" of the caregiver [6, p. 93]. "Burden" has been found to be higher for female caregivers, those with lower incomes, caregivers who reside with the "impaired elderly person", those who experience more conflicts between their caregiving and employment responsibilities, those providing care for individuals with cognitive and/or behavioral problems, and those who provide assistance with personal care [1, p. 65]. However, many caregivers describe their experience in very positive terms, reporting that these responsibilities are satisfying and fulfilling [4,11].

Females are significantly more likely to act as caregivers than males, for both persons with SCI and for other groups of disabled and elderly individuals [3], although -according to the website of the National Fam-

ily Caregivers Association (NFCA) – the percentage of male caregivers is increasing [4]. One study found that, among adult children, daughters served as primary caregivers three times more often than sons [13]. This has significant implications for employment, as women have a labor force participation rate of 59.2% and represent 46% of the total US Labor Force [22], though they tend to be paid significantly less than their male counterparts. In the case of SCI, the predominance of female caregivers is also a reflection of the disproportionate number of males who are injured (about 80%) and the associated higher number of wives providing assistance to their husbands [18,20]. In contrast, females with SCI are more likely to have a paid attendant while males are more likely to have their spouse or parent acting as a caregiver [18].

2.2. Caregivers and employment

Research on family caregivers (usually adult daughters) of geriatric patients can provide insight into the issues of employment of family caregivers of persons with SCI. Approximately 30% of informal and unpaid caregivers to disabled older adults hold full or part-time jobs [16]. Employment can enable the caregiver to get respite from the routine of caregiving and be a source for social contacts; however, it can also add to the stress that the caregiver experiences. Two opposing theories have been postulated to explain the impact of employment on the emotional health of family caregivers [5, 15]. A "role enhancement" [15] perspective or "expansion hypothesis" [5], emphasizes the benefits of filling the role of caregiver. This theory suggests that fulfilling the role of caregiver would be a potentially positive aspect in a their life and might enhance their self-esteem and feelings of competence and self worth. This is in contrast to the "role strain" perspective [15] or "scarcity hypothesis" [5] which theorize that employment has a negative impact on the caregiver as it adds to the stress inherent in the caregiver role.

The illness or injury of a loved one results in family caregivers needing to choose one of three options with regard to their own employment. They can find or continue to work with no adjustments or changes to their schedule or responsibilities; they can make employment accommodations (e.g., take unpaid leave, decreased their hours or rearranged their schedules); or they can remain or become unemployed [21]. Many factors influence this decision, including the needs of the family member, the employment situation, and availability of other support resources. Family care-

givers who are younger, white and more highly educated are more likely to be employed. It also appears that individuals with more control over their jobs, such as those higher socioeconomic classes, are more likely to remain employed and have more financial incentive to do so [21]. Caregivers who find it necessary to leave work in order to fulfill their caregiving responsibilities are often unable to return to work later because of these responsibilities [3].

Racial and ethnic differences appear to exist in both the frequency and perception of caregiving. Research shows that African American caregivers perceive less "burden" and provide more care than non-Hispanic White caregivers [1,3,11]. African Americans caring for an elderly family member have also been found to be more likely than their non-Hispanic, White counterparts to rely on informal support systems, such as extended family, rather than community resources or paid assistants [3]. Because African Americans tend to be among the more economically disadvantaged, this has a potential impact on the economic condition of the individual filling the role as caregiver.

Caregiving involves, to varying degrees, the disruption of usual activities, the addition of new responsibilities, and new financial concerns. While this is true both for caregivers of the elderly and persons with Alzheimer's as well as caregivers of persons with SCI, significant differences between these groups exist, making it difficult to generalize findings from one population to the other. Primary differences include the age of the person with the chronic condition/disability and the type of onset, as well as both the role of and relationship to the individual with disability. The average age of injury for persons with SCI is 37.6 years old, which is – by definition – significantly younger than that of the elderly who need care. At the time of the spinal cord injury, many individuals are in school or working and may be supporting a spouse and children. Both the injury and any resulting change in employment status for the individual with SCI are therefore likely to have a significant and immediate economic impact on the family. If the person who obtained the SCI is the primary wage earner of a family, it may become necessary for the spouse, or even a parent, to enter or return to the workforce for economic reasons, perhaps requiring the need for job training. In addition, SCI often results in significant direct financial costs related to the need for special transportation, medical supplies, and housing modifications.

Further, the individual providing care is likely to be different. Family caregivers for individuals with

SCI are most often parents and spouses, as opposed to adult daughters, which is usually the case with the elderly. Research has shown that "spousal care is a much stronger predictor of depressive symptoms than is parent care" even when similar tasks are involved [5]. Furthermore, in the case of SCI, the unexpectedness and the length of the caregiving role are potential factors leading to more stress. It has been suggested that the occurrence of SCI in the life of a younger individual constitutes a "non-normative" life event for the person with SCI and the family member in the caregiver role [18] and so is associated with greater depression and stress. Researchers have pointed out that the amount of time spent providing care each week [4,5] and the duration of responsibilities (in years [10]) are significant factors in depression. With the increasing life expectancies of individuals with SCI, caregiving may last for decades rather than being more time-limited, as it is with the elderly leading this population to be at considerable risk.

Finally, acting as family caregiver for the elderly often involves gradually evolving and increasing responsibilities. As a parent gets older, he or she often needs more assistance with various aspects of their lives—such as transportation to shopping and medical appointments, assistance with financial matters, errands, and sometimes assistance with personal care. When an individual obtains a SCI, the change in their ability to perform self-care is sudden and often dramatic.

3. Methodology

The objective of this study was to describe and explore the impact of SCI on the employment of family members, especially those who act as primary caregivers for individuals with SCI. Data from this project was extracted from that collected as part of a larger study – a Needs Assessment of Virginians with SCI. The larger study used a mixed method design with both qualitative and quantitative components. We collected and assessed data generated from focus group and individual interviews to identify and present the perspectives of the participants. Individuals with SCI were recruited through the use of advertising methods approved in our research protocol, including direct mailings, cards and brochures left at hospitals, service agencies, and community organizations, and notices in newspapers and magazines targeting the disability community. In particular, advertisement cards were sent to individuals listed on the Virginia Spinal Cord In-

jury Registry. This aspect of the *Needs Assessment* was designed to gather information on underserved populations of individuals with SCI (e.g., women, children and individuals from racial/ethnic minority background). Caregivers were recruited through follow-up letters to project participants, asking them to invite a family caregiver to participate/ All participants (both individuals with SCI and family caregivers) were paid \$50.

The qualitative data used in this study comes from caregivers who were interviewed either individually or as part of a focus group to determine their needs, strengths, challenges and recommendations. At the start of the interview, informed consent and HIPAA documents were distributed, explained, and signed. These are kept in files separate from the actual interviews.

All interviews were audio-taped, transcribed and 'cleaned' of identifying data. The cleaned transcripts were reviewed by the actual interviewers and by all members of the research team in weekly meetings. Discussions of the data provided opportunities to check interpretations and information, and to code the data. Data and information from the qualitative interviews with family caregivers were examined to determine themes related to employment in order to provide increased understanding of the topic.

4. Results

A total of nine caregivers were interviewed. Five of these were women who took part in a single focus group while the other four individuals were interviewed individually in their homes. The caregivers interviewed were primarily women (89%), and non-Hispanic White (55%). Six participants (67%) were parents, while three (33%) were spouses.

4.1. Case descriptions

Case #1: Married African American female; mother, focus group participant

Mrs. K. is the primary caregiver for her son, R., a young adult with high level tetraplegia who is ventilator-dependent and requires 24 hour care. Mrs. K. works full-time for an employer whom she describes as very flexible. Her son has full-time, paid nursing assistance with the exception of the 6:00 pm–11:00 p.m. time period, when she provides the personal care assistance. Mrs. K's husband acts as a back-up when nurses

do not show up. Mrs. K. manages to successfully fill multiple roles, including those of wife, mother, caregiver, and employee. In addition to ensuring that her son's personal care needs are met, Mrs. K also tries to meet his emotional needs, attempting to keep him from feeling hopeless and encouraging his involvement in community activities. Between her job and her son's needs, Mrs. K has little time for herself. In speaking of her son's accident, she stated, "I just went on and did what I had to do."

Case #2: Partnered, Non-Hispanic White female; partner/spouse; focus group participant

Ms. D. is the partner of Mr. B, an African American male in his late 40s with high level tetraplegia. He is not ventilator dependent but requires almost total assistance with personal care. Ms. D. made a commitment to staying with and caring for him following his accident approximately 10 years ago. She had been employed in the same industry for many years and was able to utilize her skills to start her own business, which she operates out of her home. However, she is concerned because the amount of respite care Mr. B receives is limited to 720 hours a year and she must travel for her job. She has CNAs doing some of his nursing care but has no support from his siblings despite their proximity.

Case #3: Married African American male; father; individual interview

Mr. R. works part time in his church and his wife works full-time in an administrative job. The two provide care and assistance for their son, M., a 30 year old African American male with tetraplegia. The couple work different schedules in order to be able to provide more continuous care for their son. Mr. R. changed positions and reduced his work hours in order to meet his son's needs. He describes his wife's employer as very flexible and supportive. Mr. R also reported that his daughter dropped out of school and "put her life on hold" to help with her brother's care immediately following his injury, and that she still helps out. Mr. and Mrs. R. are very supportive of their son and also assist with the care of his young children. Mr. R talks about the change in lifestyle and the very limited time he and his wife have for themselves or to do things with each other.

Case#4: Divorced, Non-Hispanic, White female; mother, individual interview

Mrs. N is the divorced mother of a teenage daughter with paraplegia which resulted from a motor vehicle accident approximately two years prior. She spoke of numerous challenges and interruptions in her job as a result of her daughter's injury, including: trying to

spending time with her daughter during inpatient rehabilitation when the facility was over a two hour drive from her home; coordinating structural changes in her house to insure that it was accessible to her daughter when she returned home; dealing with the school system to insure that they could accommodate her daughter's needs; and managing the many appointments her daughter had once she returned home. Working for a social service agency, Mrs. N. said that it was likely she was more prepared than many people to deal with the Department of Rehabilitation Services and issues related to Medicare and Medicaid. She also has a supportive, understanding employer. Despite this, Mrs. N. felt frustration over needing to work full-time in order to maintain her benefits. Mrs. N. spoke about her difficulty concentrating on her job as she attempted to plan for her daughter's return home following rehabilitation. She also felt that her role as caregiver limited her opportunities for professional advancement because of her inability to travel overnight or take on new responsibilities. Mrs. N. also reported a lack of time to make social connections at work.

Case #5: Non-Hispanic, White female; mother; focus group participant

Mrs. M, who works full-time, has a young adult daughter who was injured in her late teens and has paraplegia. Her daughter is now a part-time student and is independent with all activities. Mrs. M., who stated she has no support system, talked about the challenges she experienced immediately following her daughter's accident, when her daughter returned to live at home. She expressed feeling continual frustration and worry about her daughter's present and future needs as well as with her inability to afford the most advanced equipment.

Case # 6: Married Non-Hispanic White female, individual interview

Mrs. O has a teenage son who was recently obtained a SCI resulting in paraplegia. While her husband is the primary source of income for the family, she works part time and runs a business out of their home. When her son was injured, she took a leave of absence from job so that she could be with him during his rehabilitation. Mrs. O described her husband's employer as very flexible and supportive, providing him with a laptop so he that he could spend time with his son during inpatient rehabilitation while still continuing to work. Mrs. O appears to have a strong social support system, which consists of her in-laws (who live nearby), her mother, and members of the community such as parents of her son's friends. Mrs. O has now returned to her part-time job and resumed her own business.

Case #7: Married Non-Hispanic, White, female; mother individual interview

Mrs. G. is the mother of a young adult female with paraplegia resulting from a motor vehicle accident that occurred the previous year. Her daughter lives at home but is now fairly independent and employed full-time. Mrs. G. is not employed, though her husband is a professional with a good job. She spoke about the profound changes in her life as a result her daughter's injury. Immediately following the injury, "We didn't continue our life." Among the many challenges were trying to continue to meet the needs of her other children; coping with the loss of leisure and avocational activities that were important to her (e.g., church and social activities); and trying to find a balance between allowing her young adult daughter be independent and providing continual support and assistance.

Case #8: Married African American female; spouse; focus group-participant

Mrs. T is in her 40s and married to an African American male with tetraplegia. Her husband obtained his SCI as a teenager and is completely independent. The two married several years after his accident. Both of them are employed full-time and lead active lives. Mrs. T reports that she does not have flexibility in her job, as she works in a very busy office, but feels that right now, that is not an issue. However, she expressed concerns about the future, aging, and how this might impact her husband's functioning and need for assistance.

Case #9: Married African American female; spouse; focus group participant

Mrs. K and her husband, who has paraplegia, are both in their mid 20's. Mr. K is independent and requires little assistance of any kind. They were married several years after his injury. At the time, both were working. Mr. K stopped working due to a long hospitalization resulting from complications from a bedsore. Following the hospitalization, transportation problems limited his ability to continue employment. Mrs. K stopped working when she became pregnant, at the recommendation of her physician, because of the potential strain caused by her job. Now that she has a young child, the couple plans for Mrs. K to stay home and for her husband to once again seek employment.

4.2. Themes

Four primary themes emerged from the case studies and interviews.

Theme 1. Caregivers had to have or create flexibility in their work schedules to meet the various needs of

the injured family member. They needed to spend time with the injured individual immediately following the accident, to handle details related to discharge, insurance coverage, home adaptations, and many other issues. For a few participants, a job change was necessary. Other participants had the ability to take time off work either to spend time with their loved one during inpatient rehabilitation or stay home to provide assistance when paid caregivers fail to show. All of our participants felt that this flexibility enabled them to maintain both the work and caregiving responsibilities and to control the level of stress that these circumstances can cause, particularly early in the adjustment, recovery and reintegration process.

I was working at an office as a purchasing analyst for like a construction company. Then, the first week of June, he told me that, "Well, we had this comptroller come in and kind look over the budgets and stuff and we're going to discontinue your job." So, that was in '96. "R" had the accident the end of June. So, I ain't got no job. Now I ain't got no car. Now I got a paralyzed son. But it gave me the chance to go down to the hospital. So, I was with him. So, then after I got a real good nurse when we first came home. Anyway, I thought maybe I'll just take something part-time. I wasn't really ready to let go and let him stay with a nurse. So, I took this little part-time job at the school, working in the afternoon with the after school program. Then the following year, the principal wanted me to work full-time. I said, well, I don't know. So, it kinda worked out by me going back to school working full-time and know that if I get a phone call, I can go home right now. They're very flexible with that. I can work full-time and get benefits and stuff and then go be with him.

I'm doing the same type of work. The only problem that I had was when [my daughter] had her injury. And I wanted to be at [the hospital]. I wanted to be there every day. My job would not give me time off to be with her. So, I went to a psychiatrist and they took me out of work under that. That was my biggest problem. I left that company shortly after that.

... it's trying to keep up a certain level of professionalism when you really can't concentrate on what you're doing a lot of times.

Theme 2. Family caregivers struggled to balance work, caregiving responsibilities and their own, per-

sonal needs. Their loved one's injury impacted significantly on their jobs and the combination could sometimes become overwhelming. However, because of the financial costs associated with the SCI, work was often a necessity for the caregiver.

I've had to watch my annual leave and things a lot, like to do vacations and stuff because there's been so much that's been having my time off has got to go to where she has doctor's appointments. Um, I don't have time for a personal relationship. . . when I got home in the evenings while she was still in rehab, I had some peace, kind of, some lay-down time, quiet time. When [my daughter] came home, there was no time between work and taking care of her needs. So, that got kinda pushed on the back burner. I used to be involved in a few things out at church that I'm not involved in anymore. An organization at work I was active in. I'm not active in that anymore. Conferences. Even conferences from work that required being overnight, I mean, I couldn't do it.

I have one paycheck. Everything they need is so expensive. And insurance ain't going to pay but for the most minimal of what they can get by with. And then I feel guilty. I'm thinking, why can't I make enough money to give her these specialized things that I see on the Internet, you know, that helps them out so much, a power-assisted wheelchair because her wrists are hurting so bad now. Or the TEMS machine which may or may not work. And the ones that'll stand them up to keep their bones solid. And that's my fears. What if I drop dead tomorrow? What's going to happen to my daughter?

Theme 3. Another common theme was a lack of leisure and personal time. Those family members providing care for young adult or adult children reported having few opportunities to spend leisure time with spouses. Participants with other teenaged children discussed the challenge of continuing to meet their needs. Single parents felt they had no time for themselves. A few caregivers stated that they had limited time to visit physicians for routine health care.

The demands that are on my wife and I are for constant monitoring. He really needs 24-hour supervision, so to speak, or availability of someone around him because of some of the things that he could experience. And so that gives us no time at all. She's off on a one-day trip with the Bible class. And so we have to trade off. All my family's out of

this area, either in Kentucky or Maryland or elsewhere. And so if something comes up where either one of us has to be out of town, we really can't do it together because somebody has to be here to care for him.

My office is in my home and I could go out if I wanted to, but we moved up here in spring of 1995. And in July is what [B] got mugged. By November, he was quad. And before that, I fell and broke my [leg] in the backyard, so "B" took care of me before he got the way he is. We basically just have each other. The two nurses we have now we've gotten to be very close with. And I have the clients that might come in and out. And [my son] comes down from New York and his girls come down from [northern Virginia], and that's it. That's it. And the neighbors that are immediately around us, that's it. I'm a homebody anyway, so it really doesn't make any difference. And I do have to travel with my work. I have to go down to North Carolina and West Virginia. And I have to go out of town quite often. So, I don't feel like I'm coped.

So, it was a big turmoil. Between that (trying to make changes in her daughter's school to make it accessible) and insurance companies and Social Security and trying to take care of a kid, her twin brother, and trying to hold down a job – it was hell. Because all of the paperwork stuff fell to me. So, on a personal level, it was pretty rough. Like I didn't know. . . . Some days I got up and didn't know what day it was. You planned your day about who you had to call and what arrangements you had to make.

Theme 4. The family caregiver's employment was affected by the difficulty finding and retaining qualified Certified Nursing Aides (CNAs) to assist in providing care for the individual with SCI. All participants who used paid caregivers had negative experiences with them. Some CNAs were unreliable, others stole, were abusive or failed to complete assigned tasks.

We had a lot of issues with nursing. I've had money stolen, I've had jewelry stolen, I've had food stolen. I've had them all not show up. . . . We had one nurse that we referred to as "the nurse from hell". She's the one that stole the food.

I work full-time and my husband is retired. [My son] requires 24-hour care because he is on a ventilator and sometimes the nurses don't come. So,

he's there just in case the nurses don't come. But I do a lot of his care because when I get home it's 6:00 in the evening. I have a nurse that comes in at 11 at night to 7 in the morning. And I have one at 7 in the morning to 3 in the evening. So, from 6 p.m. until 11 p.m., there's no nurse. So, I usually do all his care, bathroom and all that. So, it's just a lot of confinement to the house a lot of time. You can't go, like go away for the weekend. You have to have good nurses and make sure they can come. And then they pick up the phone and say I can't come and it just mess up your full plan for whatever you have. But I'm kinda used to it now.

5. Discussion

The family caregivers who participated in this study represent a broad range of circumstance reflecting different ages, relationships, lengths of time since injury, and intensity of care and assistance they provide. All of these factors impact on the caregiver's ability to become and remain employed. The nine family members participating in this study are not a random sample; however, the case descriptions and themes reflected by this self-selected group provide insight into some of the key issues related to combining employment and caregiving. As we review the themes, we can connect these findings to the existing literature and propose strategies, programs and policies that might meet their needs and enable them to succeed in their dual roles.

Family caregivers needed to find or create flexibility in their employment situation in order to successfully maintain employment. In our sample, flexibility by employers allowed at least some of the caregivers to continue in their jobs. The most difficult time period appears to be immediately following the onset of the SCI, during the inpatient rehabilitation phase when the need to be with their loved one and the need to get tasks completed (insurance, home adaptations, etc.) were the most intense [2].

The potential for the employment situation to add to the caregivers' stress is high. One of our participants, who lacked family support yet felt a need to be with her child, felt compelled to leave her job because her employer would not accommodate her need to spend significant amounts of time at the hospital and rehabilitation center. This mother benefited from receiving treatment from a psychiatrist who helped her deal with her stress and cope with her burdens. In contrast, another participant sought out psychological assistance

Table 1
Summary of study participants and the individual they provide care for

Case#	Relationship to Individual With SCI	Age of Individual with SCI	Race	Level of Injury	Years Since Injury
1	Parent	Young Adult	African-American	Paraplegia	> 9
2	Partner	Adult	African-American	Tetraplegia	> 9
3	Parent	Adult	African-American	Tetraplegia	3–9
4	Parent	Teenager	Non-Hispanic, White	Paraplegia	3–9
5	Parent	Young Adult	Non-Hispanic, White	Paraplegia	3–9
6	Parent	Teenager	Non-Hispanic, White	Paraplegia	< 3
7	Parent	Young Adult	Non-Hispanic, White	Paraplegia	< 3
8	Spouse	Adult	African-American	Paraplegia	> 9
9	Spouse	Young Adult	African-American	Paraplegia	> 9

Teenager: 13 to 20 years old; Young Adult: 20 to 29 years old; Adult: At least 30 years old.

to support her during the stressful period, but was able to remain in her job. She was able to do so primarily because of the flexibility afforded by her employer as well as the assistance and involvement of other family members who were able to spend time with her daughter in inpatient rehab while she handled plans for her daughter's return home.

Employers could benefit from a better understanding of the needs of families under stress, and such education could be a useful means to bring about attitudinal changes in employers. This issue also needs to be addressed at the policy level. Policy-makers need to find incentives to encourage employers to support persons who are acting as caregivers. These may include flexible employment and benefits for part-time workers acting as caregivers. Tax incentives might be an alternative to help smaller employers provide provisions of the Family and Medical Leave Act (FMLA), which might at the least enable caregiver to take time off after the onset of the SCI without worrying about losing their jobs.

The second theme was associated with the conflicts created between work and caregiving. While many of our family caregivers felt that they needed to work for financial reasons, there were times when the two responsibilities came into conflict. While none of our study participants stopped working as a result of taking on the role of caregiver, one participant reduced his hours, one changed to a more accommodating job, and a third started her own business so she could work from home. Our examples reflect the need for internal flexibility the family caregiver; however, they also speak to the emotional impact and mental health needs that are common among family caregivers of persons with SCI [2,4,16,23,24].

As discussed earlier in the article, these individuals often experience considerable stress and may be at risk for health problems [19]. Our limited sample

of spouses who provide care for individuals with SCI does not allow us to reach any conclusions about either the positive benefits of work (e.g., feelings of competence and a social outlet [15]) or its negative consequences (e.g., increased stress [5]). Future research should specifically focus on the impact on employment on the physical and emotional health of family caregivers of individuals with SCI. These studies should consider the work of Cannuscio and colleagues [5] that found that intensity of caregiving and number of social ties were related to level depressive symptoms, independent of work intensity while whether she was fully, partially or unemployed.

While the majority of family members of persons with SCI do not express interest in or seek out counseling services, it might be beneficial to make such supportive services available early following the injury, in the context of SCI rehabilitation programs. Helping caregivers anticipate problem areas such as the potential conflicts between work and caregiver responsibilities and the emphasizing the importance of social supports might mitigate problems early in the adjustment process. The benefits of creating peer support groups for caregivers has also been suggested as a useful addition to the rehabilitation process [23]. According to the SCI Information Network (University of Alabama), "Caregivers are often the forgotten half of the rehabilitation process." [4, p. 182].

The third theme reflected how these multiple responsibilities leave little time for the caregivers to participate in leisure, establish and maintain social connections, reinforce marital ties, or address their own personal needs. However, there were significant differences in the roles and issues of family caregivers who were parents and those who were spouses.

The study participants who were caring for children with SCI expressed concerns regarding their children's immediate and long-term needs as well as feel-

ings about how their own lives have changed. The injury altered the developmental timeline of the teenager or young adult who was just beginning to gain independence and separate from their family, adding to the stress the family experiences. Parents of teenagers and young adults with paraplegia spoke about the struggle to balance between encouraging their child to become both emotionally and physically independent, and treating them like a child who needs to be cared for. Our two parents of individuals with higher level injuries (both in their late 20's) struggled with the need to meet their children's emotional needs and struggle with their children's social isolation while also maintaining jobs and finding time for spouses. The parents acted as facilitators, providers and advocates. The roles these parents fill is in contrast to our participants who were spouse/partner to the person with SCI. In these couples seemed to reflect a partnership among equals, even in the case of the partner needing extensive personal care.

The potential influence of culture in moderating the caregiving experience and expectations was also reflected by our participants. In one of the African-American families included in the study, caregiving became a responsibility of several family members, with both parents and a sibling (all employed) sharing the responsibilities. While one example can certainly not be generalized, this demonstrates what several researchers presented about the caregiving style of the African-American community, who tend to provide more family care and rely on less hired care. This tends to be true even for those caregivers who are employed [3,11].

On the program level, these families, who expressed the frustration of having little time for their own needs or to connect with each other could benefit from the availability of respite care (which could be in the home, or outside of the home, such as day care, short-stay facilities, etc). This might allow them time to take care of personal needs, including their own health care, leisure time, and time for an able-bodied spouse or child, thus alleviating stress and possibly facilitating continued employment.

This connects with the fourth theme that caregivers' employment, and in fact their entire lives, was affected by the lack of available, qualified and trustworthy Certified Nursing Aides (CNAs). Two of our participants reported being occasionally unable to work when CNAs were not available. The quality of available CNAs was also a major concern. The best approach to this problem is a policy/systems approach. We need to increase focus on insuring both the quality of and funding for certified nursing aids. It is crucial that the pool of

available and qualified CNAs is increased, most probably by a combination of better training and increased pay, in order to minimize the unplanned disruptions of caregivers' employment.

6. Conclusions

Family caregivers often play a critical roles in enabling the person with SCI to integrate into the community by providing assistance with personal care, managing details related to insurance, home accommodations, CNAs and many other details. These family members frequently must balance caregiving responsibilities with employment because of economic necessity. This study has begun to identify and address the unique needs of this population and to make suggestions about steps that can be taken to support them. However, additional research is needed to determine who these employed caregivers of persons with SCI are, how they juggle these competing responsibilities and what their needs and concerns are.

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