Family Caregivers of Individuals with Spinal Cord Injuries Receiving Medicaid/Medicare: How Are They Faring?

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**BACKGROUND**

- People with traumatic spinal cord injuries (SCI) have complex health care needs.
- Persons with SCI often need assistance with activities of daily living such as eating, bathing, dressing, and bowel/bladder management.
- SCI care is more complex and physically demanding than care for other disabling conditions.
- Family caregiving can be a long-term responsibility.
- Families of public-insured consumers with SCI often lack the sufficient material, financial, and social resources to provide the level and quality of care for their relative needs and are often poorly compensated for their efforts.
- Compared to families with private health insurance, family caregivers for public-insured consumers with SCI may be more vulnerable to physical and psychological morbidity.

**STUDY OBJECTIVES**

1. To assess family caregivers’ burden related to their public-insured family member with SCI using a standardized measure.
2. To compare the narratives of family caregivers’ whose responses on the standardized measure fall in the first quartile and in the fourth quartile.

**DESIGN & METHOD**

This cross sectional study employed a mixed-method (qualitative and quantitative) approach to data collection and analysis that combined in-depth interviews and the Montgomery Caregiver Burden Scale (CBS).

**Study population**: 16 family caregivers of SCI consumers who received Medicaid/Medicare.

**Recruitment**: conducted through professional contacts and a media outreach campaign at the Rehabilitation Institute of Michigan outpatient departments, the Braza Center, the Developmental Disabilities Institute of Michigan, the Michigan Disability Networks, and the Visiting Nurse Association.

**Main outcome measure**: Montgomery CBS. The total CBS score includes three components:

1. **Objective Burden (OB)** – the perceived infringement or disruption of tangible aspects of a caregiver’s life (e.g., amount of time available for one’s self, work, friends, etc.).
2. **Subjective Demand Burden (SDB)** – the extent to which the caregiver perceives responsibilities to be overly demanding (e.g., unreasonable or excessive requests).
3. **Subjective Stress Burden (SSB)** – the emotional impact of caregiving responsibilities on the caregiver (e.g., stress and depression related to the relationship with the consumer).

**PRELIMINARY FINDINGS**

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“Understanding the health care needs of publicly insured recipients with tetraplegia: A family perspective” funded by Blue Cross Blue Shield of Michigan Foundation. Grant no. 1051.11

**CONCLUSIONS & NEXT STEPS**

- Family caregivers with low and high total CBS scores do not have corresponding low and high scores on all the subscales.

**NEXT STEPS**

- Conduct a comprehensive analysis to determine which factors influence variations in caregiver burden, with themes of stress, burden, and quality of life embedded in the narratives.
- Disseminate findings to health care financing policy makers emphasizing the unmet needs of family caregivers and recommend the provision of specific services.

**QUOTES FROM CAREGIVERS**

High total CBS scores

- “I stay stressed most of the time...trying to have home have as close to a normal life as he can, trying to make things the best I can...even if not getting any help.”
- “They said, you can have executive care if you didn’t work. Well, that’s why I’m trying to keep our life better (by working!).”
- “She felt like God took her, you know, at the wrong time...everything was taken out on me.”

Low total CBS scores

- “That’s my role (caring). Sure, I’m tired, but it’s good.”
- “...I can’t leave them like this...and it’s kind of rough.”
- “...I let him go through it (anger) and after that, just started our lives with him being paralyzed.”

Quality of life

- “My belief and prayer keep me going.”
- “But, I just dedicated my life to him...he lived so I got to be happy about that.”
- “God and my kids keep me going...I’m a lot happier now ‘cause I had a little time to myself.”

Special thanks to all the caregivers who graciously gave their time and shared their experiences with the goal of helping other family caregivers.