Objective: Youth with spinal cord injury (SCI) have complex health and daily living needs, which caregivers, most often parents, have increasingly managed over the years due to the decrease in lengths of inpatient rehabilitation stays. Attention and support of the health and life experiences of caregivers is vital to the overall health of the caregiver child, and is imperative for the family's well-being. However, little is known about the experiences of caregivers of youth with SCI. This study sought to examine caregiver perspectives on unmet needs and support preferences in the context of caring for their children with SCI.

Participants/Methods: A total of 26 primary caregivers participated in 1 of 4 focus groups stratified by their child’s injury severity (Table 1).

Results

Unmet Needs: Several kinds of unmet needs emerged, and needs differed by phase of care (initial vs. ongoing). While a central aim was to explore caregiver unmet needs, caregivers most commonly began by discussing their children’s and families unmet needs and more effort was needed by moderators to ask caregivers to explore their personal unmet needs. For the purpose of this study we focused on individual and family unmet needs. Systemic unmet needs will be the topic of a subsequent study.

Acute unmet needs: isolation, trauma, chaos
Isolation and coping with trauma were themes from discussions of acute care experiences. Caregivers also described this context as overwhelming and chaotic. They described having trouble understanding and emotionally coping with their children’s care needs and multiple providers.

Ongoing unmet needs: Persistent Isolation, coping with injury, balancing family and caregiving roles, and physical and emotional stamina of caregivers

After the initial phase, caregivers spoke of experiencing isolation from others living with SCI, for both themselves and their child.

My son doesn’t have any peers his age or close to his age that he can look to...like my son, he was so young. He knew nothing different. But he has come to...I think the hospital is great. We...You have to put so much energy in so many different directions...It was scary, you going into and like, ‘Okay, why can he move his legs? What is going on?’...You are not sure if your child is going to live or die...

Caregivers also reported ongoing emotional challenges for themselves and their family and caregiving roles, and physical and emotional stamina of caregivers.

Support Preferences: Two primary support preferences emerged.

Professional Support
Caregivers desired more support from professionals during both the initial and ongoing phases of care. Early on, they reported needing help finding appropriate pediatric SCI rehabilitation centers and processing the large amount of information and emotions.

Peers
Caregivers were unanimous in the need for more peer support as soon as possible and over the “long haul.” They spoke of the power of hearing and receiving support from others who have “been there and done that.”

Conclusions

By employing focus group methodology, caregivers were able to not only express their needs in their own words, but they were able to interact and share their experiences with one another. As such, in addition to providing critical information to clinicians and researchers alike, this methodology can offer comfort to those speaking and listening that others are experiencing similar journeys.

Results suggest that caregivers have many unmet needs and that additional professional and peer social support would be welcomed as caregivers navigate the different phases of caring for their child with SCI. For instance, professional support could include making available additional psychological support during the acute phase, and family-focused interventions to ease trauma and isolation. Ongoing professional and peer support could be provided to support families during new stages of coping with injury, balance family roles and bolster caregiver self-care. Having formal and informal opportunities to connect with others living with SCI was highly desired.

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