

Author Year; Country Score Research Design Total Sample Size	Methods	Outcome
<p>Guilcher et al. 2012 Canada Cross-sectional/Qualitative Level 5 N=14</p>	<p>Population: 14 participants with SCI (6M 8F); median age of 47.5 years, median time post-injury was 18 years. 8 used electric wheelchairs, 6 manual. Treatment: No treatment. Purpose was to describe the structure of informal networks and to understand their influence on the prevention and management of secondary health conditions (SHCs). Outcome Measures: The Arizona Social Support Interview Survey (6 domains including social support, physical assistance, positive feedback, advice, material assistance and intimate relations) and open-ended questions.</p>	<ol style="list-style-type: none"> 1. 10 individuals identified only family and/or friends rather than formal health care providers within their social networks. 2. The largest networks were for social support (median 6.5 persons) and physical assistance (median 4), with smallest networks for material assistance and intimate relations (median 2.5). 3. Available network sizes were larger than utilized networks. Majority of respondents reported decreased social network following SCI. 4. There was variation in the perception of needs, with median scores ranging from 1.0 (no need for material assistance) to 5.0 (great need for social support and physical assistance). 5. Informal networks engaged in a variety of roles, including: advice/validating concerns, knowledge brokers, advocacy, preventing SHCs, assisting with finances, and managing SHCs.
<p>Rutherford Owen and Marini 2012 USA Cross-sectional/Qualitative Level 5 N=55</p>	<p>Population: 55 participants with SCI (33M 22F); predominantly Caucasian (85%); residing in 18 different states. Treatment: Investigated the type and amount of attendant care between individuals before and after completion of life care planning. Outcome Measures: 39 question life care survey consisting of fixed and open-ended questions.</p>	<ol style="list-style-type: none"> 1. Pre-life care plan, 67.65% unpaid attendant care (family and friends), 17.65% paid (agency), 14.71% paid (private hire) 2. Post-life care plan, 33.38% unpaid (family and friends), 46.88% paid (private hire), 18.75% paid (agency) 3. After completion of life care planning, number of daily unpaid attendant hours decreased from 12.92 (pre) to 10.88 (post); paid hours increase from 5.81 (pre) to 7.89 (post) 4. Participants without funding were more reliant on unpaid attendant care.
<p>Gajraj-Singh 2011 Fiji Cross-sectional Level 5 N=30</p>	<p>Population: 30 family (primary) caregivers (10M 20F); mean age 39.2yrs (range 21-70yrs); 13 spouses; 5 mothers; 5 siblings; 4 children, 3 others; mean 6.1 hrs (SD=2.19) per day of caregiving. Treatment: No treatment. Purpose of the study was to explore the psychological response and to assess the burden of caregiving for SCI persons living in the community in Fiji. Outcome measures: The Index of Psychological Well-Being (IPWB), Caregiver Burden Inventory (CBI), Barthel Index (BI).</p>	<ol style="list-style-type: none"> 1. Psychological well-being of caregivers (IPWB mean score 4.5/ 7) was not affected by caregiver age, number of hours spent caregiving, number of years of caregiving, level of lesion or severity of disability. Poorer psychological well-being was significantly associated ($r=0.52$) with higher caregiver burden (CBI). 2. The breakdown of caregiver burden (CBI mean score 47.6/100) found participants scored highest in time-dependent burden (mean 13.6) followed by development burden (mean=11.9). 3. A significant association ($r=0.46$) was found between total CBI and age, indicating older caregivers experienced greater burden. 4. Total CBI was significantly associated with the number of hours caregiving per day ($r=0.35$), suggesting burden increased with the increasing amount of time spent providing care.

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<p>Arango-Lasprilla et al. 2010 Colombia Cross-sectional Level 5 N=37</p>	<p>Population: 37 family caregivers (5M 32F); mean age 44.9 years (SD_16.4); 11 spouses, 18 parents; mothers, 6 siblings, 2 others; mean educational level of 8.4 years (SD_4.2). Treatment: No Treatment. The purpose of this survey was to determine the most frequent needs of family caregivers of individuals with SCI; to describe caregivers' psychosocial functioning; and to examine the relationship between caregiver needs and psychosocial functioning. Outcome measures: Caregiver Needs Questionnaire (9 support sub-scales indicating family needs; emotional, psychological, information, economic, sleep, rest, household, community, own physical health), Zarit Burden Interview, Patient Health Questionnaire, Satisfaction with Life Scale, Interpersonal Support Evaluation List.</p>	<ol style="list-style-type: none"> 68% report being overwhelmed with caregiving responsibilities, 43% some level of depression and dissatisfaction with life. Greater economic, emotional, informational, sleep, psychological, and physical needs were significantly and positively correlated with depression (r ranged 0.35-0.56) and burden (r ranged 0.42 -0.56) Greater economic, household, physical, sleep and psychological needs were significantly and negatively correlated with satisfaction with life (r ranged -0.35 to -0.41) and social support (r ranged from -0.39 to -0.59). Greater community support and respite needs were negatively correlated with social support (r ranged -0.41 to -0.52), and more emotional needs were negatively correlated with satisfaction with life (r=-0.45). Higher needs for respite were significantly and positively correlated with burden (r=0.51), and more household needs were significantly and positively correlated with depression (r=0.52).
<p>Van Loo et al. 2010 The Netherlands Cross-sectional Level 5 N=453</p>	<p>Population: 453 / 999 possible respondents from the Dutch SCI Patient Organization; 295M 158F; mean age 47.7 yrs (range 18-82); mean YPI 13.3 (range 0.6-62 yrs); 19.9% complete and 14.4% incomplete tetraplegia, 46.3% complete and 19.4% incomplete paraplegia. Treatment: No treatment. Purpose to describe the care needs according to persons with long-term SCI who were living at home. Outcome Measures: Postal questionnaire with numerous variables including socio- demographic and injury characteristics, frequency of SCI-related contacts with caregivers, and other professionals.</p>	<ol style="list-style-type: none"> 72% indicated a need for additional care with needs ranging from outpatient visits to rehabilitation centres or home consultation (phone or home visiting). 19.0% needed support for incidental activities of daily living, 18.5% for incidental housekeeping and 8.6% for other interventions. In 14.6% of all participants, another caregiver was preferred, mainly peers, home help or care manager/coach.
<p>Bushnik et al. 2007 USA Observational Level 5 N=203</p>	<p>Population: 203 individuals with SCI; Mean age =47.0 (SD 10.7 yrs); 19 (SD 4.1) years post injury (YPI); 58 with complete tetraplegia; 58 with incomplete tetraplegia; 44 with complete paraplegia; 7 with incomplete paraplegia. Treatment: No treatment. Purpose was to examine factors which may influence personal care attendant (PCA) turnover and the impact of high PCA turnover (≥ 2</p>	<ol style="list-style-type: none"> The high turnover (HT) group had significantly fewer PCAs reported as relative or friend compared to the low turnover group (LT). Both groups were equally satisfied with the skill level of PCA. The HT group was significantly less satisfied with the quality of care. On the quality of life assessment, the HT group felt their PCA restricts daily life

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	<p>attendants in the past 6 months) on individuals with SCI.</p> <p>Outcome Measures: Personal Attendant Care Questionnaire, a measure of the amount of personal assistance utilized as well as the satisfaction with the care.</p>	<p>significantly more than LT group.</p>
<p>Foster et al. 2005 Australia Observational Level 5 N=179</p>	<p>Population: 179 individuals who provide care to a family member with SCI. SCI population was 140 male; 39 with complete tetraplegia; 60 with incomplete tetraplegia; 43 with complete paraplegia; 33 with incomplete paraplegia. Treatment: No treatment. Purpose was to examine family caregiving in relation to individuals with SCI.</p> <p>Outcome Measures: Spinal Cord Injury Questionnaire (SCIQ) designed to collect information about the family caregiver, and the Family Caregiver Questionnaire (FCQ) completed by the family caregiver and covers description of caregiving and services required.</p>	<ol style="list-style-type: none"> 1. Family caregivers were predominately female (84.4%), a partner or spouse (62.0%), most were 40 years of age and older (72.5%), with 87% residing in the same house as the individual with SCI. 2. Practical care (running errands, getting groceries) was the most reported type of care (92.7%). 3. Emotional care (discussion of problems) was reported in 87.6% of surveys, and physical care (assisting with transfers, dressing) was reported in 67.0%. 4. 55.3% of family caregivers spent 3hrs or more per day providing care.
<p>Robinson-Whelan & Rintala 2003 USA Observational Level 5 N=348</p>	<p>Population: 348 veterans with SCI; mean age = 54.8; paraplegia = 177; low tetraplegia = 122; high tetraplegia = 49.</p> <p>Treatment: No treatment. Purpose was to gain information on the informal care (unpaid assistance by caregiver) received by veterans.</p> <p>Outcome Measures: Hours of informal assistance, likelihood care provided will remain the same in 5 years, and assistance provided if current caregiver is unable to continue caring.</p>	<ol style="list-style-type: none"> 1. 37% (n=130) reported receiving some form of informal unpaid care. 2. Mean hours of informal care per day was 11.6 hours. 3. Of the 130 people receiving informal care, 59% identified a spouse or partner as their primary caregiver, 17% a parent, 9% a sibling, 8% a child, 2% a friend, 3% other. 4. 88% of the caregivers were women. 5. 25% reported that their caregiver would be able to provide the same amount of care in 5 years. 6. 54% do not have anyone else willing and able to assist them if their caregiver became unable to care for them.
<p>Weitzenkamp et al. 2002 USA Observational Level 5 N=2154</p>	<p>Population: 2154 people with SCI (1723M 431F); mean age at injury 33.3 yrs; mean age at time of study 36.9 (SD 11.4) yrs; C1-4 AIS A n=201; C5-8 AIS A n=281; T1-L1 AIS A or B n=993 L2-S5 AIS A or all levels AIS D or E n=679.</p> <p>Treatment: No treatment. Purpose was to assess the predictors of personal care assistance (PCA) use in people with SCI.</p> <p>Outcome Measures:</p>	<ol style="list-style-type: none"> 1. 58.2% of PCA was unpaid. 2. Having more neurological impairment was significantly associated with requiring more care. 3. Each additional point of the interval measure of the motor FIM was associated with needing 7.3 fewer paid minutes and 5.8 fewer unpaid minutes. 4. Those who were further post injury required less PCA.

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	Daily hours of paid, unpaid and occasional PCA services (items taken from the CHART); activities of daily living measured by the FIM.	
Berry et al. 1995 USA Observational Level 5 N=22	<p>Population: 22 participants with SCI (17M 5F); age range 20-36; Level of injury = C3 to C7.</p> <p>Treatment: No treatment. Purpose was to gain information on the attendant care arrangements among poor persons with SCI.</p> <p>Outcome Measures: Number of attendants, number of hours per day with an attendant, tenure of the attendant, training of the primary attendant.</p>	<ol style="list-style-type: none"> 1. 13 had one regular attendant, 7 had two attendants, and 2 had four attendants. 2. Hours per day with an attendant ranged from 1 to 24. Of the attendants, 5 were spouses, 2 were cohabitators, 13 were other relatives, and 2 were friends. 3. Tenure in years of the attendants ranged from less than one year to 22 years. 4. 15 primary attendants were trained during inpatient rehabilitation, 9 were trained by the participants, 6 by nurses or occupational therapists, 8 by others. One attendant was paid by Medicare; all other primary attendants were unpaid. 5. 15 were very satisfied with the quantity, quality, dependability of care they received; 3 were somewhat dissatisfied. 6. Attendants rated their clients as less independent in functioning and self-care than the consumers. 7. Both consumers and attendants agreed control and substance abuse were not problems.
Cockerill & Durham 1992 Canada Qualitative N=66	<p>Population: <i>Current residents</i> (n=37) 22 were male; mean age= 29 years; 20 were disabled as a result of an SCI or cerebral palsy. <i>Prior residents</i> (n=24) 14 were male; average age = 34 years; 15 were disabled as a result of an SCI or CP. Attendants (n=29) had an average tenure of 18 months; mean age 32.6 yrs. Coordinators had been in their position for an average of 3.2 years, serving an average of 26 clients.</p> <p>Treatment: No treatment. Purpose was to examine role of attendants in independent and transitional living centers and obstacles experienced in transitional living centers.</p> <p>Outcome Measures: Self-administrated questionnaire with open and closed-ended questions.</p>	<ol style="list-style-type: none"> 1. Attendants identified a lack of clear guidance from either agency of individual or the individual as to who should set priorities and working conditions. 2. Attendants identified experiencing high levels of burnout and stress. Factors such as inability to measure success, low pay, few opportunities for promotion were listed as contributors. 3. Attendants identified a lack of communication in transitional living centers regarding methods of teaching independence with personal care to individuals with disabilities.