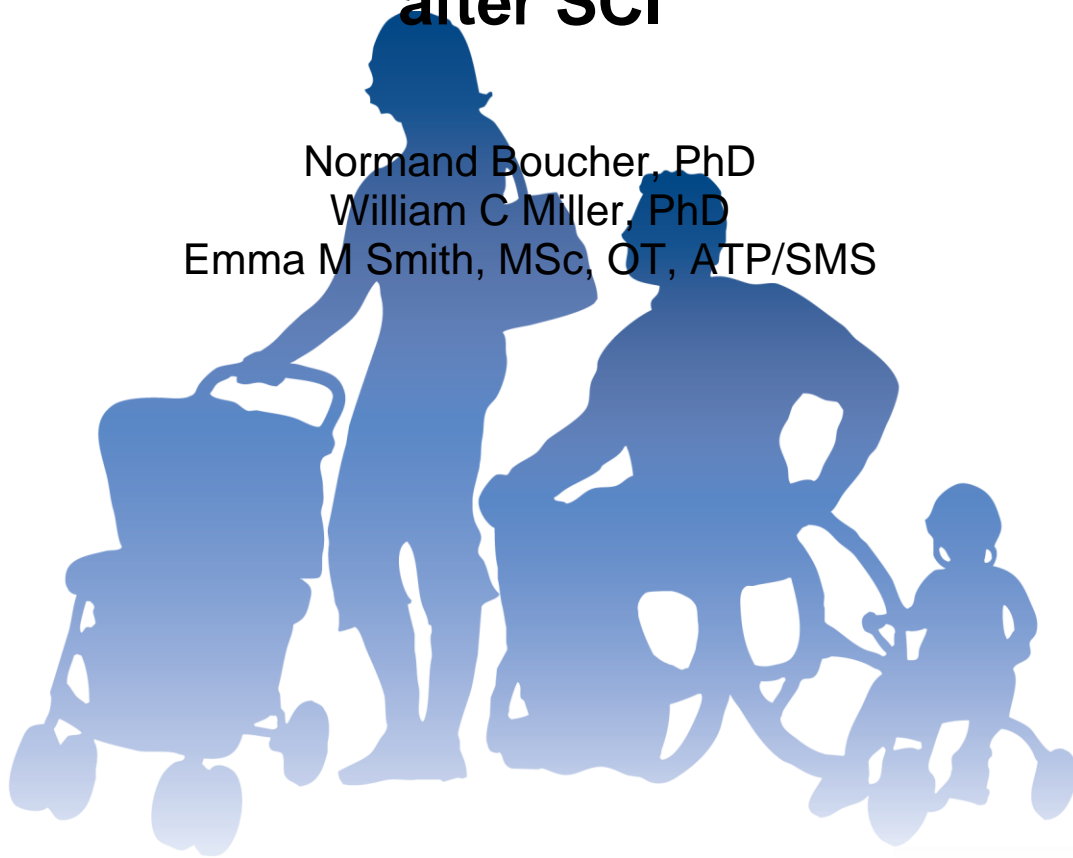


SCIRE

SPINAL CORD INJURY REHABILITATION EVIDENCE

Housing and Attendant Services: Cornerstones of Community Reintegration after SCI

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Key Points

In many cases, discharge from hospital is delayed for SCI patients due to lack of accessible housing, which leads to unnecessary increase of cost of care.

ILCs with MRP relationships serve more clients than those without, and the most frequently serviced individuals are those with SCI who attend for peer counseling, skills training and discharge planning.

Living with a spouse and/or children, living alone, or living with unrelated persons are more desirable arrangements than living with parents and spouse/children together, living with distant family (i.e. grandparents), or living with parents and siblings.

Marital status, transportation barriers, education level, medical supervision requirements, economic disincentives, services received, and severity of disability are predictors of independent living.

Choice and control are important when planning living situations and setting goals with clients with SCI because they are directly related to residential and life satisfaction.

Individuals with SCI have lower perceived life satisfaction, locus of control, and satisfaction with certain aspects of housing than a normative sample.

Accommodation options for a person with a disability are limited. The preferred accommodation is a private house or apartment.

Living with someone prior to SCI, having insurance or private funding for equipment, and being young decreases the risk of being discharged to an extended care facility following SCI rehabilitation.

Individuals with SCI have a need for assistance with fire safety to increase their perception of home safety.

Individuals with SCI move multiple times after injury. In most cases, they start living with their parents and/or in an institution before moving into their own homes.

Most informal caregivers are female spouses of individuals with SCI who require assistance in fulfilling and maintaining services.

There is substantial burden to family caregivers who report feeling overwhelmed, decreased psychological well-being and decreased satisfaction with life.

There is general satisfaction with informal attendant services.

The most significant predictors of personal care assistance use are motor function, days spent in rehabilitation, and length of stay in a nursing home.

Personal attendant turnover is positively correlated with higher injury level and increased need for assistance in exercise and transfers.

Directing one's care, establishing roles and boundaries for PCA, and improving training may facilitate consumer independence.

Goal-directed occupational therapy can achieve gains in role performance and improvements in life satisfaction.

Counselling on proper technique and hygiene for at least one session might reduce the risk of UTI to below threshold for individuals at risk for UTIs.

Re-hospitalization might be reduced after participation in an educational intervention involving a workshop, a collaborative home visit, and access to follow-up.

Skills development educational workshops for attendants and consumers can increase knowledge about spinal cord injury, wellness, and communication.

Directing, training, and financing one's personal attendant care may lead to financial savings, better health outcomes, and increased life satisfaction.

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Abbreviations

AIS	ASIA Impairment Index
BI	Barthel Index
CBI	Caregiver Burden Inventory
CIC	Clean Intermittent Catherization
ECU	Extended Care Unit
FIM	Functional Independence Measure
ILC	Independent Living Centre
LOS	Length of Stay
MRP	Medical Rehabilitation Program
PAS	Personal Assistance Services
PCA	Personal Care Assistance/Assistant
QoL	Quality of Life
SHC	Secondary Health Condition
SNF	Skilled Nursing Facility
UTI	Urinary Tract Infection
YPI	Years Post-Injury

Housing and Attendant Services: Cornerstones of Community Reintegration after SCI

1.0 Introduction

Individuals go through a demanding functional rehabilitation process following a spinal cord injury (SCI). Having an SCI involves taking into account important issues (e.g., financial support, insurance, technological devices or equipment, etc.) when planning for discharge home. Appropriate housing and attendant care are cornerstones of successful community reintegration. In cases where individuals are more vulnerable, the quality of these resources, in particular in terms of functionality and availability, can make the difference between whether an individual can live independently or not.

For the past three decades, these issues have been of interest to both the academic and disability communities and have been addressed to some extent. The work done by the disability community has been oriented towards increasing access to more specific resources such as support and equipment, as well as to mainstream resources such as transportation, housing, health, and educational services. These advocacy actions have been undertaken to increase choice and control over issues related to the living arrangements of persons with disabilities, in particular those with SCI. Within the academic community many of the studies related to independent living have focused largely on impact research relating to several dimensions of the life of persons with disabilities, as well as on the community as a whole. In this chapter, we present the findings involving persons with SCI.

Housing is a fundamental need of all people. Finding appropriate living arrangements within the community can be difficult for many individuals with SCI after they are discharged from rehabilitation, yet housing is key to successful community reintegration. Because of the cost associated with altering the physical environment to accommodate an individual with an SCI, housing presents a financial challenge and therefore can be a significant obstacle limiting one's opportunities to resume an active role and fully integrate within the community. This issue is also connected to two other important factors: 1) community resources related to availability and capacity to provide support, and 2) opportunity to choose one's living environment. Both factors have been documented as playing an important role in the quality of community reintegration and residential satisfaction.

Attendant care services are a resource designed to provide a person with SCI with support so they can engage in activities of daily living that are considered important. This support is usually put into place after discharge from rehabilitation when the individual returns to his/her community. Several important decisions are required when considering attendant care services, such as who will provide the support, how it will work, who will pay for it, etc. At the same time, the relationship between rehabilitation services and community resources must be also considered in the context of the built environment to ensure the best opportunities for independent living among individuals with SCI. For example, the quality of the built environment, particularly housing adaptations, is very important because it can influence how the attendant care services will be provided in terms of the intensity and frequency of care.

In this chapter we provide a review of literature related to housing and attendant care services, and the influence of these factors on the quality of life of individuals with SCI living in the community. In order to develop a more comprehensive analysis of this material, the literature selection and review methods used have been expanded beyond those traditionally used for the other SCIRE reviews (see SCIRE Methods). Specifically, two new databases with a focus on the social sciences were searched

(Social Sciences Abstracts and Social Work Abstracts), and the inclusion criteria were broadened to include any study (including qualitative studies) that was at least partially community-based which examined factors influencing satisfaction with housing and attendant care needs after SCI, issues with access, and/or interventions improving outcomes.

2.0 Housing

Housing is a primary need for all individuals. The necessity of having a safe home compatible with one’s personal needs increases when an individual is vulnerable. One of the first questions asked when a person has sustained and survived an SCI is where he/she will be able to live. Successful community reintegration is intimately linked to housing within the background of the person’s needs, the attributes of relevant environmental factors, and the preferred choice of living environment of the person with the injury. Until recently, SCI authors generally only discussed the issue of the suitability of a home regarding its physical accessibility and adaptations (Heywood, 2004; Forrest and Gombas 1995; McAweeney et al. 1996). Forrest and Gombas (1995) showed that a lack of accessible housing increases a person’s length of stay on the rehabilitation unit, thus increasing the overall cost of healthcare services after SCI.

The choice of living environment for people with SCI is critical because of their increased need for human and environmental support, requiring them to carefully consider who they will live their life with and where. In some cases, individuals with SCI do not have a choice because of the lack of accessible housing inventory. Having a range of choices of housing likely hastens and enhances the transition from rehabilitation to community while improving the personal match to the living environment. Sixteen non-intervention housing articles are presented below. Given stable housing is a basic human need, ethical research practice precludes the development of intervention studies in this research area.

Table 1: Housing Articles

Author Year; Country Score Research Design Total Sample Size	Methods	Outcome
Scovil et al. 2012; Nepal Observational N=37	<p>Population: 24 individuals (14M 10F) mean age: 33 yrs (range 14-59); YPI: 2 days to 14 yrs; injury level: lumbar: 9; thoracic: 11; cervical: 4. Subjects were visited 11-27 months post discharge. 84% had been injured through falling, 15 were wheelchair users, 4 required walking aids and 5 could walk unassisted.</p> <p>Treatment: No treatment. The purpose was to evaluate the ongoing health and community reintegration of patients with SCI.</p> <p>Outcome Measures: Semi-structured interview to evaluate health, independence in daily living, community participation and barriers due to socioeconomic issues, housing, accessibility, and availability and use of mobility aids.</p>	<ol style="list-style-type: none"> 1. Inappropriate wheelchairs, inadequate housing and rugged terrain restricted accessibility. 2. 80% of wheelchair users could not enter their homes independently. 3. Half of those interviewed had no accessible toilet, access to a water source, or road access to their home. 4. 19 owned their own home, 5 rented.
Dickson et al. 2011; UK Qualitative N=17	<p>Population: 17 SCI subjects (14M 3F); mean age: 46 yrs (range 26-62); YPI: 17 months to 32 yrs; injury level C5-C7.</p> <p>Treatment: No treatment.</p> <p>The purpose of the study was to capture the experience of SCI from the perspective of the individuals with it.</p>	<ol style="list-style-type: none"> 1. Subjects reported ongoing difficulties in adjusting to home life: 3 recurrent themes were: <ul style="list-style-type: none"> - “loss of camaraderie” - “lack of post-discharge care” - negative experiences with other people related to being in a wheelchair

Author Year; Country Score Research Design Total Sample Size	Methods	Outcome
	<p>Outcome measures: Analysis of recurring themes concerning difficulties adjusting to life post-hospital discharge: loss of camaraderie, lack of post-discharge care, other people's reactions to SCI.</p>	
<p>Kuipers et al. 2011; Australia Qualitative N=270</p>	<p>Population: 270 SCI subjects (218M 52F); mean age: 43 yrs, (range 20-76); mean YPI: 16 yrs (range 0.75-55 yrs); injury level: 107 with complete quadriplegia; 100 with complete paraplegia; 63 with spared ambulatory ability. Treatment: No treatment. The purpose of the study was to explore and clarify the differing personal perspective of what a 'community' is. Outcome measures: Telephone interviews were conducted to analyze core themes concerning patients' communities, such as social integration, independence, and occupation.</p>	<ol style="list-style-type: none"> 1. In addition to descriptions of community as 'place', findings echoed the three dimensions commonly included in measures of community integration; "social integration", "occupation" and "independent living". 2. Participants who described their community in social and relationship terms reflected generally positive views about that community, whereas those who described their community in terms of physical space and access expressed a relatively greater proportion of negative views when describing their community.
<p>Mazurek et al. 2011; USA Retrospective cohort- Quantitative N=149</p>	<p>Population: 149 SCI patients (111M 38F); mean age at injury: 36.3 yrs; 113 rural & 36 urban living Treatment: No treatment. Purpose was to assess the differences in injury-related factors, rehabilitation services and costs, and rehabilitation outcomes in individuals with SCI in rural areas vs. those in urban areas. Outcome measures: Demographic and injury-related variables, rehabilitation services received, length of stay (LOS) in acute and rehabilitation settings, and costs.</p>	<ol style="list-style-type: none"> 1. Urban and rural residents did not differ in terms of costs of acute care and LOS. 2. Urban residents experienced significantly longer rehabilitation hospitalization stays. 3. No differences between urban and rural residents in terms of the number of hours of physical therapy, occupational therapy or psychological services received.
<p>Gulati et al. 2010; UK Retrospective Cohort N=30</p>	<p>Population: 30 of 39 surviving traumatic SCI patients; mean age 73 yrs (range 65-88); 24 incomplete; 21 cervical, 3 thoracic, 6 lumbar level Treatment: no treatment. The purpose of this study was to describe functional outcome and discharge destination of elderly patients with traumatic SCI. Outcome measures: Data from the National Injuries Unit database (2000-2005) included the following variables : demographics, cause of injury, level of injury, type of cord injury, associated injuries, discharge outcome and hospital stay, American Spinal Injury Association impairment scale, Functional Independence Measure Score (FIM).</p>	<ol style="list-style-type: none"> 1. 11 patients (37%), all with incomplete injuries, were discharged home and had significantly higher FIM scores at the onset and discharge from rehabilitation compared to those discharged to a nursing home or other hospital. 2. Those discharged home also had a significant improvement in their FIM score from the onset of rehabilitation to discharge.
<p>Kennedy et al. 2010; UK Cross-sectional N=80</p>	<p>Population: 80 individuals with SCI; ratio of 2:1 (men: women); mean age = 50.37 yrs (range 18–81 yrs); 3–18 months post discharge; 8 complete and 23 incomplete tetraplegia; 17 complete and 23 incomplete paraplegia; 9 unknown.</p>	<ol style="list-style-type: none"> 1. The majority of participants (67.9%) felt there were issues after discharge that made transition difficult, mostly due to accommodation and adaptations (29%). 2. 49% of respondents experienced a delay in acquiring the necessary adaptations.

Author Year; Country Score Research Design Total Sample Size	Methods	Outcome
	<p>Treatment: No treatment. The purpose was to assess the needs and perceived environmental barriers of SCI patients living in the community 3–18 months after discharge.</p> <p>Outcome Measures: A postal survey using a number of standardized measures and open ended comments.</p>	<p>3. The lack of resources making transition most difficult were, in order, adaptations (35%), equipment (27%), and poor access (19%).</p>
<p>Bergmark et al. 2008; USA Qualitative N=22</p>	<p>Population: 22 traumatic SCI subjects; 16 male; mean age at injury 29.2 yrs (range 17-49); mean YPI: 14.4 yrs (range 2-37); injury level C1-C7.</p> <p>Treatment: No treatment. The purpose of study was to describe the factors which influence tetraplegic subjects' residence decisions and the general pattern of residence among tetraplegic individuals.</p> <p>Outcome Measures: 15 open-ended questions, administered in an interview, either in person or on the phone.</p>	<ol style="list-style-type: none"> 1. Subjects lived in 5 kinds of places post-injury: own or friends' homes, parents' home, group home/board and care, skilled nursing facilities (SNF), and rehabilitation facilities. 2. Subjects moved on average 3.3 times after discharge. 3. Factors influencing residence moves include information, money, accessibility, insurance, intimate relationships, personal assistance and caregiving. 4. Subjects living in parents' home or institutions thought it was their "only option", and is seen as a "stepping stone" towards moving into their own homes, which is their goal.
<p>Anzai et al. 2006; Canada Observational N=52</p>	<p>Population: 52 subjects (40M 12F); mean age 45.3; 33 subjects had a C4 lesion; 31 were categorized as AIS – A.</p> <p>Treatment: No treatment. The purpose of the study was to identify and describe the factors associated with whether individuals with high lesion SCI were discharged from rehabilitation to an extended care unit (ECU) versus other settings, including private homes, group homes, and acute care.</p> <p>Outcome measures: Location to where subjects were discharged; individual characteristics, health-related characteristics; personal context, hospitalization factors; and health resources.</p>	<ol style="list-style-type: none"> 1. 21 subjects were discharged to an ECU (12 as a permanent destination, 9 as interim placement). Of the 9, 3 subjects eventually returned to the community. 2. 25 subjects were discharged to a home; 2 to a group home; 1 to a shared care apartment; and 3 to acute care. 3. Univariate analyses revealed 7 factors significantly associated with discharge to an ECU versus community: age, employment at time of injury, pre-existing medical conditions, social support, pre-injury living situation; and insurance or private funding for equipment. 4. Multivariate analysis revealed 4 factors significantly related to location of discharge: insurance; private funding for equipment; age; pre injury living situation.
<p>Cesar et al. 2002; USA Observational N=69</p>	<p>Population: 69 individuals (55M 14F); ≤5 years post injury; 31 paraplegia and 38 with tetraplegia; living in the community.</p> <p>Treatment: No treatment. Purpose was to assess the living situation of recently injured individuals, to identify any safety concerns, and to address potential solutions to eliminate the concerns.</p> <p>Outcome Measures: Safety in the home Environment.</p>	<ol style="list-style-type: none"> 1. Most perceived themselves relatively safe in their environment (safe from crime in home, safe going out in neighborhood, feel safer when go out with friends than alone). 2. 45 felt prepared for a fire in their home; 24 expressed a need for assistance with fire safety concerns. 3. No statistical difference in overall perceptions of safety between those with paraplegia and those with tetraplegia.

Author Year; Country Score Research Design Total Sample Size	Methods	Outcome
Boschen. 1996; Canada Observational N=82	<p>Population: 82 individuals (66M 16F) with traumatic SCI (age range = 18 – 35); ≥1 year post- injury; 46 subjects with tetraplegia</p> <p>Treatment: No treatment. The purpose of this study was to evaluate the correlates of life satisfaction, residential satisfaction, and locus of control among individuals with SCI.</p> <p>Outcome Measures: self-administered questionnaire (Living with Spinal Cord Injury): residential choices; perceived activities choice scale, activities choice congruence scale; and Locus of Control Scale.</p>	<ol style="list-style-type: none"> 1. 57 lived in private houses or apartments (often with parents), 8 in apartment projects with shared attendant services, and 4 in institutions. 2. >50% had to move to new residence due to injury. 3. Half of the respondents reported their current accommodations were determined by them having a physical disability. 4. The greatest single predictor of residential satisfaction is perceived current residential choice. 5. Residential satisfaction was correlated to life satisfaction; one's living accommodations are central to one's life situation.
Forrest & Gombas 1995; USA Observational N=105	<p>Population: 105 acute SCI subjects (80M 25F); mean age 42 yrs (range 17-83); 63 with paraplegia and 42 tetraplegia</p> <p>Treatment: No treatment. The purpose of study was to determine the frequency with which lack of accessible housing delays the discharge of an SCI subject, and the related costs of the delay.</p> <p>Outcome Measures: Frequency and length of delay of discharge due to lack of accessible housing; cost of the delay.</p>	<ol style="list-style-type: none"> 1. Of the 105 subjects included in the study, 11 stayed on the rehabilitation unit between 6-210 days longer than was medically necessary because of lack of accessible housing; the average delay in discharge was 60 days. 2. The average cost of a 60-day stay at the institution was \$29,280, compared to \$1,620 at a transitional living unit, which translates to an average saving of \$27,660 per patient.
Boschen 1990; Canada Observational N=82	<p>Population: 82 individuals with traumatic SCI (aged 18-35); mostly male with tetraplegia; age-matched data from the Institute of Behavioural Research Canadian Quality of Life data-bank (1981).</p> <p>Treatment: No treatment. The purpose of the study was to compare life satisfaction, housing satisfaction, and locus of control between individuals with SCI and non-disabled individuals.</p> <p>Outcome Measures: Living with a Spinal Cord Injury questionnaire composed of 29 items from the Canadian Quality of Life Survey and 60 items from Locus of Control Scale.</p>	<ol style="list-style-type: none"> 1. Life satisfaction and locus of control were significantly lower for individuals with SCI than for the normative sample. 2. There was no significant difference in overall residential satisfaction; however those with SCI rated their housing problems as more serious, most often related to environmental barriers. 3. Individuals with SCI who lived in private residences had significantly greater residential satisfaction than those in apartment projects; however life satisfaction was not impacted.
Fuhrer et al. 1990; USA Observational N=71	<p>Population: 46 independent living centers (ILCs) which have relationships with one or more medical rehabilitation programs (MRPs); 25 MRPs which have relationships with at least one of the 46 ILCs recruited.</p> <p>Treatment: No treatment. Purpose was to identify types and scope of relationships which exist between ILCs and MRPs and to identify barriers and facilities of these relationships.</p> <p>Outcome Measures: Types of contacts which exist between the respondent's center and MRPs, and perceived barriers to a workable relationship with MRPs.</p>	<ol style="list-style-type: none"> 1. Most ILCs and MRPs reported making 'referrals to or providing information about' the other; and most ILCs reported 'peer counselling of MRP patients' and 'training in daily living skills'. 2. 92% of MRPs reported use of ILC services to address housing, 84% for attendant care, 79% for transportation, and 67% for personal/ psychosocial problems, during discharge planning or outpatient follow-up. 3. ILCs with MRP relationships served significantly more people monthly than those without MRP relationship. 4. The use of ILC services was most frequent for individuals with SCI; >70% of individuals

Author Year; Country Score Research Design Total Sample Size	Methods	Outcome
		with SCI required ILC peer counselling services, >60% required skills training and >55% required discharge planning services.
Boschen et al. 1988; Canada Observational N=82	<p>Population: 82 persons (65M 17F); mean age = 28 (age range =18-35); 46 with tetraplegia.</p> <p>Treatment: No treatment. The purpose of the study was to examine current accommodations, housing options, and preferences.</p> <p>Outcome Measures: Questionnaire to identify factors influencing choices of accommodation; preferences of types of housing; and number of housing options perceived to have been available.</p>	<ol style="list-style-type: none"> 1. Seventy percent live in a private house or apartment, 19% live in an apartment project with shared attendant care services, 5% live in an institution, and 6% live in other accommodations; 69% live with one or more people and 31% live alone. 2. Most important accommodation deciding factors in order are: location, wheelchair accessibility, family ties, finances, vacancy, and attendant care availability. 3. Preferred accommodation was own house or apartment.
DeJong et al. 1984; USA Case Series N=75	<p>Population: 75 individuals (63M 12F); 71% <35 years old; 51 had SCI ≥3 years,</p> <p>Treatment: No treatment. The purpose was to determine factors that predict the ability of persons with SCI to live independently following discharge from rehabilitation.</p> <p>Outcome Measures: Overall independent living (IL), socio-demographics, disability (Barthel Index and 4 other factors), environmental aspects (attendant care, housing, transportation, work disincentives, services received), and interface variables bridging functional limitations and environmental barriers (unmet equipment needs).</p>	<ol style="list-style-type: none"> 1. Significant predictors of living arrangement outcome were marital status, age at onset, sex (female was associated with greater independence), transportation barriers, medical supervision, and services received. 2. Seven variables explained 63% of the variance in IL outcome; the greatest predictors are marital status; transportation barriers; education level; degree of medical supervision required; economic disincentives; services received; and severity of disability.
DeJong & Hughes 1982; USA Observational N=33	<p>Population: Retrospective population of 111 persons with SCI who were discharged from rehabilitation; Current population of 33 members (20M 13F) of the Massachusetts Interagency Council on Independent Living (ICIL) (19 under 35 years old; 18 not disabled). Treatment: No treatment. The purpose of this study was to develop a long-term outcome measure of independent living by identifying outcomes from previous research and ranking and weighing their relevance to current independent living.</p> <p>Outcome Measures: Retrospective extraction of data relating to living environment and productivity; New survey for ranking and weighing living arrangements and productivity.</p>	<ol style="list-style-type: none"> 1. A greater weight is allocated to productivity (57%) than living arrangement (43%) when determining independent living. 2. 'Living with spouse/significant other and/or children', 'living alone', and 'living with friends, unrelated persons, and/or siblings' were ranked and weighted as most positive living arrangements. 3. 'Living with parents and with spouse and/or children', 'living with relatives such as grandparents, uncles, aunts, or adult children', and 'living with parents or with parents and siblings', were ranked and weighted as less desirable living arrangements. 4. Living in an institution was ranked and weighted as least positive.

Discussion

From the onset of SCI, the rehabilitation services and the resources required for independent living remain two of the key elements for successful community reintegration. This is particularly true for people with spinal cord injury who use more services (particularly related to housing) than other consumers with disabilities such as TBI or Stroke (Fuhrer et al. 1990). According to Tate and

Forchheimer (1998) participation in an independent living program (e.g. peer counseling, group support, etc.) can provide better knowledge of the resources needed and may lead to better personal control and adjustment upon return to the community. However, a follow-up study of an independent living program revealed it had little or no impact on life satisfaction or personal control of participants with SCI (Forchheimer and Tate 2004). Marital status and transportation barriers are the most important predictors related to living arrangement post-SCI (DeJong et al. 1984). Boschen (1996) found the best predictor of residential satisfaction was having the perception of choice of residence, and satisfaction with residential placement was correlated with life satisfaction. Boschen (1988, 1990) found the level of satisfaction with the home is also related to difficulties encountered living in the home, primarily because of environmental barriers. Moreover, the level of satisfaction was higher among persons with SCI living in their own apartment. In previous work, Boschen (1988) revealed having one's own apartment was preferred by the individuals with SCI and their choice is determined by the quality of the environment, particularly in terms of accessibility. The choice of residence is limited by many factors and the limitations are magnified as the severity of disability increases. Therefore individuals with tetraplegia are at a significant disadvantage. The findings indicate those with tetraplegia move several times after discharge from rehabilitation. The moves are influenced by factors such as information, money, accessibility, insurance, personal assistance, etc. Individuals with SCI who eventually end up living with their parents or in an institution consider such living arrangements as their last option (Bergmark et al. 2008). Anzai et al. (2006) found certain social and personal factors (e.g. age, having insurance or private funding) reduce the risk of moving to a nursing home after discharge from rehabilitation. A low FIM score appears to increase the risk to move to a nursing home amongst individuals with SCI after rehabilitation discharge (Gulati et al. 2010). Living in an environment considered to be minimally restrictive which enables active participation in daily decisions according to the principles of independent living is more likely to contribute to improved quality of life (DeJong and Hughes 1982). Finally, safety at home is important to persons with SCI, particularly related to fire. Many participants indicated they would need assistance with this dimension of home safety (Cesar et al. 2002).

The evidence reveals the importance of the continuity of services between rehabilitation and return to the community (Fuhrer et al. 1990). The lack of accessible housing is an important barrier which may have an impact on the community reintegration process as well as on rehabilitation service costs. According to the findings by Kennedy et al. (2010), the transition process is difficult because of the lack of resources, mainly in terms of adaptation, accommodation and equipment. Community services play an important role, especially in housing and peer support to return to independent living (Fuhrer et al. 1990; Tate and Forchheimer 1998). Finally, the quality of the built environment is one of the key determinants of the ability to find housing which meets the needs of persons with SCI, which also affects their level of satisfaction with respect to where they reside. Freedom of choice related to selecting where they will live constitutes a salient feature of life satisfaction for many. However those individuals who encounter obstacles (related to accessibility, financial support and so on) will likely have little choice when it comes to selection of housing (Boschen 1988; 1990). Scovil et al. provide evidence of chronic housing problems for individuals with SCI in Nepal, finding approximately 80% of individuals are unable to enter their homes independently (Scovil et al. 2012). Some qualitative findings revealed individuals with SCI experienced some difficulties when they returned home. Those difficulties are related to loss of camaraderie, lack of post discharge care and negative experiences with other persons related to being a wheelchair user (Dickson et al. 2011). Drawn on a qualitative study, individuals with SCI who described their community in social and relationship terms presented a more positive perspective of the community than those who described it in terms of physical space and access (Kuipers et al. 2011). Despite opportunities to participate in transitional or independent living programs before discharge from rehabilitation, the common finding of this body of work is the move back into the community following SCI seems to be a real test of both the supportiveness of the environment and the resilience and resourcefulness of the individual in determining the success of the reintegration.

Conclusion

There is level 5 evidence (Forrest and Gombas 1995) that discharge from hospital was delayed for a significant portion of SCI patients due to lack of accessible housing, which leads to unnecessary increase of cost of care.

There is level 5 evidence (Fuhrer et al. 1990) that ILCs with MRP relationships serve more clients than those without, and that the most frequently serviced individuals are those with SCI who attend for peer counseling, skills training, and discharge planning.

There is level 5 evidence (DeJong and Hughes 1982) that living with a spouse and/or children, living alone, or living with unrelated persons were more desirable arrangements than living with parents and spouse/children together, living with distant family (i.e. grandparents), or living with parents and siblings.

There is level 4 evidence (DeJong et al. 1984) that marital status, transportation barriers, education level, medical supervision requirements, economic disincentives, services received, and severity of disability are predictors of independent living.

There is level 5 evidence (Boschen 1996) that issues of choice and control are important when planning living situations and setting goals with clients because they are directly related to residential and life satisfaction.

There is level 5 evidence (Boschen 1990) that individuals with SCI have lower perceived life satisfaction, locus of control and satisfaction with certain aspects housing than a normative sample.

There is level 5 evidence (Boschen 1988) that accommodation options for a person with a disability are limited. The preferred accommodation is a private house or apartment.

There is level 5 evidence (Anzai et al. 2006) that living with someone prior to SCI, having insurance or private funding for equipment, and being younger decreases the risk of being discharged to an extended care facility following SCI rehabilitation.

There is level 5 evidence (Cesar et al. 2002) that individuals with SCI have a need for assistance with fire safety to increase their perception of home safety.

There is qualitative evidence (Bergmark et al. 2008) that suggests individuals with SCI move multiple times after injury. In most cases they start living with their parents and/or in an institution before moving into their own homes.

There is qualitative evidence that suggest individuals with SCI have difficulties adjusting to life at home (Dickson et al. 2011). Reported difficulties are related to the loss of camaraderie, lack of post-discharge care and negative experiences with other people related to being in a wheelchair.

There is qualitative evidence (Kuipers et al. 2011) that suggest individuals with SCI who described their community in social and relationship terms reflected more positive views about this community compared to those who described their community in terms of physical space and access.

In many cases, discharge from hospital is delayed for SCI patients due to lack of accessible housing, which leads to unnecessary increase of cost of care.

ILCs with MRP relationships serve more clients than those without, and the most frequently serviced individuals are those with SCI who attend for peer counseling, skills training and discharge planning.

Living with a spouse and/or children, living alone, or living with unrelated persons are more desirable arrangements than living with parents and spouse/children together, living with distant family (i.e. grandparents), or living with parents and siblings.

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Choice and control are important when planning living situations and setting goals with clients with SCI because they are directly related to residential and life satisfaction.

Individuals with SCI have lower perceived life satisfaction, locus of control, and satisfaction with certain aspects of housing than a normative sample.

Accommodation options for a person with a disability are limited. The preferred accommodation is a private house or apartment.

Living with someone prior to SCI, having insurance or private funding for equipment, and being young decreases the risk of being discharged to an extended care facility following SCI rehabilitation.

Individuals with SCI have a need for assistance with fire safety to increase their perception of home safety.

Individuals with SCI move multiple times after injury. In most cases, they start living with their parents and/or in an institution before moving into their own homes.

3.0 Attendant Care

Advances in medical technology have increased survival rates for traumatic injuries and as a result, more people are living longer with an SCI (Adams and Beatty 1998). However, functional impairment due to SCI may necessitate the use of attendant care or personal assistance services (PAS). Attendant care can be broadly defined as home-based support which assists individuals to perform tasks they would otherwise not be able to perform themselves. Attendant care service providers are usually either non-paid family members or paid workers who help with everyday personal or self-care tasks such as bathing, dressing, grooming, and transfers (Berry et al. 1995; Cockerill and Durham 1992; Meyer et al. 2007). They may also assist with instrumental activities of daily living such as cooking, chores, and shopping (Berry et al. 1995; Cockerill and Durham 1992). In this way, personal assistance or attendant care facilitates community integration and social participation (previously known as independent living), and which may also include accommodated employment and/or adapted sports and recreation (Adams and Beatty 1998). In addition, home-based attendant care, which is typically provided only part-time and not on a full-day basis, has long been recognized as more cost-effective when compared to institutional costs (Hoeman and Winters 1990).

It should be noted that independent living does not require a person be able to carry out their routine tasks alone without help from someone else. While tasks are completed with some assistance, the emphasis of independent living is placed on the individual's right to decide when, where, and how tasks are performed (Litvak et al. 1987). Indeed, recipients of paid personal care assistance (PCA)

have emphasized the importance of being in control of training the assistant. How the assistance is to be provided is discussed with the attendant at the outset of the professional relationship (Meyer et al. 2007). Some individuals prefer untrained attendants so they can train and direct them to suit their own particular needs. Being able to direct attendants to assist with managing personal care post-SCI maximizes the ability to promote good health and enables the person with the SCI to live more independently and productively. Personal care attendants may be skilled or unskilled workers, licensed or unlicensed, registered nurses, nursing assistants, nurse's aids, home health aids, or paid or unpaid family members (Berry et al. 1995; Pomeranz et al. 2006). Typically, individuals with tetraplegia in need of 24-hour care will require such care from nurses with specialized training, whereas persons with lower-level injuries may be fairly self-sufficient and require less-skilled assistance with daily tasks.

Attendant care is a common and essential aspect of daily living for many individuals with an SCI (Berry et al. 1995). The United States Federal Bureau of Statistics predicted the number of personal care attendants would be 827,000 in 2005 (Frost et al. 1999). Attendant care services can be expensive and are therefore an important financial as well as social consideration. In 1992, the average individual yearly cost of attendant care services for all levels of SCI combined was \$14,359 USD two years after injury (Johnson et al. 1996). However, costs ranged dramatically and these data are now outdated. For comparative purposes it is instructive to know the annual mean cost of PAS for individuals with high tetraplegia (C1-C4) was \$92,441 while average costs were \$2,184 for persons with paraplegia (T1-S5). Another study found a range of \$38-\$798 spent per day on attendant care (Mattson-Prince 1997). A third costing study, also from the 1990's, found 44% of total costs related to SCI were for attendant care (Harvey et al. 1992). A recent report by Krueger et al. (2013) reported that estimated lifetime attendant care costs in Canada for tetraplegia are: \$\$1,021,420 (complete SCI) and \$797,590 (incomplete SCI), for paraplegia are: \$294,418 (complete SCI) and \$422,548 (incomplete SCI).

Regardless of cost, PCA is essential for many individuals with SCI, and is correlated with a variety of factors. Previous studies have found gender may influence PCA use; men tend to rely on family members whereas women are more likely to pay for services from an outside agency (Shackelford et al. 1998). A 1992 study revealed approximately two-thirds of individuals with SCI received an average of 25 hours of paid or unpaid weekly PCA; more than half received 40 hours per week or less. The majority of this care was provided voluntarily (Harvey et al. 1992). Family caregivers tend to be female, a spouse, and over 40 years of age (Foster et al. 2005). It is important to understand the patterns of PCA use, the characteristics of family support providers, and the impact of this role on these lifelong assistants (Boschen et al. 2005a, 2005b). Families often play a central role in providing home services, which is beneficial to the injured person but has significant health, career, social, and other personal consequences for the informal provider (Boschen and Gargaro 2009). One generic rehabilitation study documented family caregivers may experience poorer health, higher rates of anxiety and depression, and possibly develop more long-term health problems (Holicky 1996). The evidence base from the above studies of these family caregiver consequences is crucial for justifying healthcare and social support direct service allocation to SCI families, and highlights the need for promoting self-care for all PCA providers to improve stability of services.

Despite using a broad definition of attendant care or personal assistance there are very few high-quality academic articles on this topic. Although most of the literature reviews use the words "attendant care" or "attendant care services", the term "attendant services" now appears to be the preferred term, especially among many SCI consumers. The articles reviewed in Table 2 below focus both on the characteristics of attendant care for the adult SCI population and on the promotion of their independent function and behaviours which will maintain or improve their health. Specifically, articles were included if they addressed the effectiveness of in-home attendant care services, factors influencing the use of and access to attendant care, and/or future interventions to improve outcomes. Qualitative data were included in this review due to the paucity of intervention articles and the utility of

the data obtained from these studies which met the chapter inclusion criteria. Most of the research evidence comes from observational studies, with few randomized controlled trials (RCTs). All intervention studies involving facilitation of the individual to direct their own attendant care have been included in Table 3 in this chapter.

3.1 Non-Intervention Attendant Care Studies

This attendant care literature review for non-intervention attendant care articles includes five peer-reviewed observational and four cross-sectional articles all classified at Level 5, and one qualitative article. A summary of the findings can be found in Table 2.

Table 2: Non-Intervention Articles

Author Year; Country Score Research Design Total Sample Size	Methods	Outcome
<p>Guilcher et al. 2012; Canada Cross-sectional/Qualitative N=14</p>	<p>Population: 14 subjects 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 only identified 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>Owen and Marini et al. 2012; USA Cross-sectional/Qualitative N=55</p>	<p>Population: 55 subjects 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 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</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

Author Year; Country Score Research Design Total Sample Size	Methods	Outcome
	<p>the burden of caregiving for SCI persons living in the community in Fiji.</p> <p>Outcome measures: The Index of Psychological Well-Being (IPWB), Caregiver Burden Inventory (CBI), Barthel Index (BI).</p>	<p>scored highest in time- dependent burden (mean 13.6) followed by development burden (mean=11.9).</p> <ol style="list-style-type: none"> 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.
<p>Arango-Lasprilla et al. 2010; Columbia Cross-sectional 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).</p> <p>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.</p> <p>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"> 1. 68% report being overwhelmed with caregiving responsibilities, 43% some level of depression and dissatisfaction with life. 2. 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) 3. 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). 4. 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 ($r=-0.45$). 5. 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 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.</p> <p>Treatment: No treatment. Purpose to describe the care needs according to persons with long-term SCI who were living at home.</p> <p>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"> 1. 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. 2. In 14.6% of all participants, another caregiver was preferred, mainly peers, home help or care manager/coach.

Author Year; Country Score Research Design Total Sample Size	Methods	Outcome
Bushnik et al. 2007; USA Observational N=203	<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.</p> <p>Treatment: No treatment. Purpose was to examine factors which may influence personal care attendant (PCA) turnover and the impact of high PCA turnover (≥ 2 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>	<ol style="list-style-type: none"> 1. The high turnover (HT) group had significantly fewer PCAs reported as relative or friend compared to the low turnover group (LT). 2. Both groups were equally satisfied with the skill level of PCA. 3. The HT group was significantly less satisfied with the quality of care. 4. On the quality of life assessment, the HT group felt their PCA restricts daily life significantly more than LT group.
Foster et al. 2005; Australia Observational N=179	<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.
Robinson-Whelen & Rintala 2003; USA Observational N=348	<p>Population: 348 veterans with SCI; mean age = 54.8; paraplegia = 177; low tetraplegia = 122; high tetraplegia = 49. 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.
Weitzenkamp et al. 2002; USA Observational N=2154	<p>Population: 2154 individuals 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>	<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

Author Year; Country Score Research Design Total Sample Size	Methods	Outcome
	<p>Treatment: No treatment. Purpose was to assess the predictors of personal care assistance (PCA) use in people with SCI.</p> <p>Outcome Measures: Daily hours of paid, unpaid and occasional PCA services (items taken from the CHART); activities of daily living measured by the FIM.</p>	<p>7.3 fewer paid minutes and 5.8 fewer unpaid minutes.</p> <p>4. Those who were further post injury required less PCA.</p>
<p>Berry et al. 1995; USA Observational SCI n=22</p>	<p>Population: 22 subjects 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 subjects, 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.
<p>Cockerill & Durham 1992; Canada Qualitative N=66</p>	<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.

Discussion

Two observational studies identified correlates of PCA turnover and service use. In one study, a large sample of participants with SCI reported the number of new assistants within the past six months, how

often they worked, and how satisfied they were with received service (Bushnik et al. 2007). Individuals with high turnover (HT) rates were compared to those with low turnover (LT) rates. The majority of the sample (over 80%) was very or extremely happy with received services, with greater happiness associated with unpaid rather than paid work. There was no difference in turnover rates in relation to injury level. However those with HT had more needs regarding exercise and transfers than those with LT. Individuals with LT had significantly more unpaid attendant care by family members or friends, with higher reported skill level and satisfaction ratings than those with HT. Those with HT were more likely to rate attendant care as restricting their life. No differences were found for QOL, functioning, or rates of secondary complications.

The second observational study identified predictors of PCA use in a large sample of SCI participants by retroactively examining health records from a national SCI database (Weitzenkamp et al. 2002). The motor portion of the Functional Independence Measure (FIM) was the strongest predictor of PCA use, followed by days spent in a nursing home. Length of rehabilitation stay only predicted PCA use for individuals who paid for services. Surprisingly, age, gender, years since injury, and service payer were non-significant variables in predicting attendant care use.

There were four observational studies that described the characteristics of informal caregivers. The first investigated caregivers of a large sample of veterans to obtain a better understanding of future care needs of those aging with an SCI, determine the number of veterans receiving care from family, describe those caregivers, and assess perception of stability of that care (Robinson-Whelan and Rintala 2003). A total of 22% of participants reported receiving only unpaid assistance and received on average 12.9 hours of daily care. Sixteen percent received both unpaid and paid care with an average of 10.4 and 4.8 daily hours respectively. Those with high tetraplegia were more likely to use both paid and paid PCA. Of those who used unpaid care ($n = 130$), over half (59%) primarily received care from a spouse or partner, followed by parent, sibling/spouse of sibling, and child/spouse of child, most of whom were women. One quarter of participants were not sure their primary caregiver could continue to provide the same care five years in the future, and more than half did not have a suitable alternate person.

A related study of informal caregivers found similar results (Foster et al. 2005). PCA were mostly female spouses of the SCI consumer. The most common services provided by unpaid caregivers were practical, emotional, and physical care. Over half of the participants spent more than three hours per day providing care or support. In terms of required services, family caregivers required assistance in six areas: respite/care support (concerns about health problems of caregiver); personal support (managing stress); information services (medical updates and information regarding equipment/aids); health professional services (PT or massage); home help and practical support (housework, yard maintenance); and lifestyle services (employment support for consumer).

A cross-sectional qualitative study of informal care networks found 10 out of 14 individuals interviewed identified only family members or friends rather than formal health care providers as part of their social network. The majority reported a decrease in size of their social network following SCI. Self-assessed needs varied widely between individuals, with caregivers providing advice/validating concerns, acting as knowledge brokers, advocating on the behalf of affected individuals, helping with finances, and helping to prevent secondary health conditions (Guilcher et al. 2012). The last cross-sectional study evaluated the influence of life care planning on use of attendant services. They found a greater proportion of attendant care was paid (rather than unpaid) following life care planning. In total, the average number of daily unpaid hours for individuals with a life-care plan fell from 12.92 to 10.88 per day, while the average number of paid hours with a life-care plan increased from 5.81 to 7.89 (Owen and Marini, 2012).

Two cross-sectional studies explored burden issues amongst the caregivers of individual with SCI (Arango-Lasprilla et al. 2010). A majority of caregivers indicated to be overwhelmed with their caregiving responsibilities. According to the findings by Gaijraj-Singh (2011), the poorer level of psychological well-being is associated with a higher caregiver burden. The increased family caregiver

burden is associated with a number of hours of care provided per day and with increased age of caregivers (Gaijraj-Singh 2011). The results provided by Arango-Lasprilla et al. (2010) indicated there is a relationship between the increased family caregiver burden and the support needs in domains such as respite, information, emotional, economic, physical health, etc. Finally, a survey looking to describe the needs of individuals with long term SCI who live at home suggested a significant portion of unmet care-needs is related to the incidental activities of daily living and housekeeping support (Van Loo et al. 2010).

A survey compared consumers and attendants with few financial resources on their perceptions of care, satisfaction, independence, and control (Berry et al. 1995). Injury level ranged from C7-C3 and most consumers had one regular attendant who worked on a daily basis. Most attendants were family members or friends, as the majority of the sample only had Medicaid to pay for healthcare expenses with no secondary insurance. Most attendants received training during the consumer's inpatient rehabilitation and were trained by the consumer, nurses, and occupational therapists. The majority of consumers felt assistance was always available in a timely fashion and meals were on time. All participants felt they were in control of their financial affairs. Most (68%) felt very satisfied with quantity, quality, dependability and overall impression of care. In contrast, attendants often rated their clients as less independent in functioning and self-care than the consumers. They also thought timeliness of care and meals was more of a problem than the individuals with SCI, and they rated their clients' satisfaction as lower than what clients rated. However, all agreed control and substance abuse were not problems.

A qualitative study obtained information from attendants and consumers regarding the role of personal assistive services in independent living (Cockerill and Durham 1992). Consumers described the difficulty of obtaining reliable and affordable attendant care services. Attendants struggled with determining whether their agency or the consumer should set priorities and direct care. Burnout was quite common and attributed to little performance appraisal, low pay, and few opportunities for advancement. In terms of transitional centres, both consumers and attendants agreed the emphasis of care should be promoting consumer independence. However, there was little reported on training for how this was to be accomplished. As a result, attendants created their own methods for educating the client. Obstacles in transitional centers included a lack of tailored skill development for consumers, establishing boundaries for consumer independence, and teaching consumers to direct their attendant care.

Conclusion

There is level 5 evidence (Guilcher et al.) indicating size of available networks decrease following SCI for most individuals, and informal care networks engage in a variety of roles, including advice/validating concerns, knowledge brokers, advocacy, preventing secondary health conditions (SHCs), assisting with finances, and managing SHCs.

There is level 5 evidence (Foster et al. 2005; Robinson-Whelan and Rintala 2003) indicating that most informal caregivers are female spouses of SCI consumers who required additional assistance in fulfilling and maintaining provided services.

There is level 5 evidence (Berry et al. 1995) suggesting general satisfaction with informal attendant services from both clients and attendants although there are variations with some aspects of care.

There is level 5 evidence (Weitzenkamp et al. 2002) that the most significant predictors of PCA use are motor function, days spent in rehabilitation, and length of stay in a nursing home.

There is level 5 evidence (Bushnik et al. 2007) indicating that personal attendant turnover is positively correlated with higher injury level and increased need for assistance in exercise and transfers.

There is level 5 evidence (Gajraj-Singh 2011) that increased family caregiver burden is associated with poorer levels of psychological well-being. Level 5 evidence (Arango-Lasprilla et al. 2010) indicates that poorer psychological well-being is associated with greater information, emotional, economic, physical health, sleep and psychological support needs.

There is level 5 evidence (Arango-Lasprilla et al. 2010) that the majority of family caregivers are overwhelmed with their caregiving responsibilities.

There is level 5 evidence (Gajraj-Singh 2011) that increased family caregiver burden is associated with the number of hours of care provided per day and with increasing age of the caregiver.

There is level 5 evidence (Arango-Lasprilla et al. 2010) that increased family caregiver burden is associated with greater respite, information, emotional, economic, physical health, sleep and psychological support needs.

There is level 5 evidence (van Loo et al. 2010) that substantial unmet care needs requiring support for incidental activities of daily living and housekeeping support.

There is level 5 evidence (Owen and Marini 2012) that the use of life care planning may decrease use of unpaid attendant care, and increase the use of paid attendant care.

There is qualitative evidence (Cockerill and Durham 1992) that both consumers and attendants agree that the emphasis of care in transitional centres should be placed on facilitating consumer independence which may be accomplished by delineating the role of attendants.

Most informal caregivers are female spouses of individuals with SCI who require assistance in fulfilling and maintaining services.

There is substantial burden to family caregivers who report feeling overwhelmed, decreased psychological well-being and decreased satisfaction with life.

There is general satisfaction with informal attendant services.

The most significant predictors of personal care assistance use are motor function, days spent in rehabilitation, and length of stay in a nursing home.

Personal attendant turnover is positively correlated with higher injury level and increased need for assistance in exercise and transfers.

Directing one's care, establishing roles and boundaries for PCA, and improving training may facilitate consumer independence.

3.2 Intervention Studies for Attendant Care

Maintaining good health practices can lead to a greater level of independence. Moreover maximizing health is an important goal for both the person with the SCI and family caregivers, and is important for the healthcare system since complications and hospitalizations are costly. Most importantly, healthy individuals are more likely to be maintained in community settings and more likely to be productive.

Attendants are often required to perform tasks such as transfers and bowel and bladder care, all of which involve knowledge, skill, and effective communication (Berry et al. 1995; DeVivo et al. 1989). If not done properly, secondary complications such as pressure sores and urinary tract infections (UTIs) may occur. These issues underscore the need for proper training and assessment of that training.

Personal care assistance services can be obtained through agencies or can be hired, trained, and paid independently by the consumer. The effects of these two approaches in terms of health outcomes and satisfaction is largely unknown. The impact of the type of payer on psychological functioning of SCI consumers has been investigated, and the amount of assistance and payer type may influence self-esteem (Tate et al. 1994a). Those with more psychological distress are more dependent on attendant care and tend to pay for it rather than rely on informal support (Tate et al. 1994b). A total of 6 intervention articles were reviewed which included one Level 1 RCT, a Level 2 prospective study, two Level 4 pre-post studies, one Level 4 case series, and a Level 4 observational study. A summary of the methods and outcomes can be found in Table 3.

Table 3: Intervention-based Research Specific to Attendant Care

Author Year; Country Score Research Design Total Sample Size	Methods	Outcome
Cohen & Schemm 2007; USA PEDro=6 RCT N=21	<p>Population: 21 subjects (19M 2F); age range 17-59 yrs; 16 with complete injury, 5 with incomplete injury.</p> <p>Treatment: Subjects received either 8 in-home visits with an occupational therapist or 8 social visitors over a 6-month period. 7 occupational therapists were recruited and given 6 hours of additional training in SCI, home-care and client-centered therapy. 3 people with no rehabilitation experience were recruited to be social visitors; they received training in in-home safety, rapport building and active listening.</p> <p>Outcome Measures: Functional Independence Measure (FIM), Craig Handicap Reporting and Assessment Technique (CHART), the Role Checklist.</p>	<ol style="list-style-type: none"> 1. No significant difference between groups in FIM or CHART scores. 2. OT group showed significant gain in average LSIA score, SV group did not. 3. Subjects in OT group took on more new roles following intervention compared to social visitor group.
Schopp et al. 2007; USA Prospective controlled trial N=140	<p>Population: <i>Consumer group</i> (n=87, 72% with SCI); 34 in the intervention; 53 in the control group. Mean age = 40.1; 52 male. <i>Personal assistant group</i> (n=53), 31 in the intervention, and 22 in the control group. Mean age = 45.2; 6 male.</p> <p>Treatment: 6- hour personal assistance services (PAS) training program which: 1) provided information on the health threat; 2) severity of commonly occurring secondary conditions and health behaviours to prevent these conditions; and 3) promoted consumer/assistant professional relationship.</p> <p>Outcome Measures: Knowledge of secondary conditions; nature of the consumer/assistant relationship.</p>	<ol style="list-style-type: none"> 1. Consumers and personal assistants in the PAS program had significantly higher knowledge about secondary conditions at both 3 and 6 months after the intervention than those in the control group. 2. There were no significant differences in either the consumer or personal assistant ratings of their working relationship. 3. Consumers who changed personal assistance during the data collection reported being less comfortable advising what needs to be done, less choice over what duties were done; and less satisfied with the way their needs were being met.

Author Year; Country Score Research Design Total Sample Size	Methods	Outcome
Beck & Scroggins 2001; USA Post-test N=19	<p>Population: 19 subjects: 3 with tetraplegia and 16 long-term health care provider.</p> <p>Treatment: Health Maintenance Education Program made up of 3 phases: 1. 1-day interdisciplinary workshop to provide research-based knowledge on care; 2. Collaborative home visit to provide individualized assessment, education and intervention; 3. 12-months of on-going support to the consumer and care provider relationship.</p> <p>Outcome measures: Program evaluation forms.</p>	<ol style="list-style-type: none"> 7 evaluations returned indicating 100% satisfaction with program. Statistically significant increase in knowledge of: prevention of respiratory complications; prevention & treatment of autonomic dysreflexia prevention of spasticity; reportable symptoms; effects of aging; availability of community resources. Benefits included: demonstration of skills, on-site evaluation, awareness of resources. Suggested modifications: educational content regarding client vulnerability, client advocacy, discussion of role of agencies.
Barber et al. 1999; USA Pre-Post N=17	<p>Population: 17 subjects, all presenting with 2+ UTIs in a 6-month period, seen at an outpatient SCI clinic.</p> <p>Treatment: Intensive counselling by clinic nurse to learn proper clean intermittent catheterization (CIC) technique, daily external catheter application and care, appropriate cleansing of supplies and daily perineal hygiene. If subjects continued to exceed 2+ UTIs in the following 6 months they were started on either nitrofurantoin or methenamine mandelate with ascorbic acid or given more instruction on proper techniques.</p> <p>Outcome Measures: Compliance with regime, number of UTIs.</p>	<ol style="list-style-type: none"> 11 subjects responded to counselling sessions; 8/11 refused suppressive therapy and received multiple sessions. 4 subjects started on methenamine mandelate and ascorbic acid to treat UTI; 2/4 developed 1 UTI. 3 subjects placed on nitrofurantoin; none developed UTIs. Compliance found to be a problem in patients in both regimes after 1 year of treatment.
Frost et al. 1999; USA Case Series N=8	<p>Population: 8 individuals with tetraplegia (5M 3F); C4-C8; age range 21-66 years.</p> <p>Treatment: Project (Linking Employment, Abilities, and Potential (LEAP) provided training to individuals with mental health/ABI, mental retardation, seizures, drug alcohol rehabilitation to work as PCA for individuals with tetraplegia living in the inner city.</p> <p>Outcome Measures: Number of individuals with SCI receiving care from a trained LEAP individual at follow-up.</p>	<ol style="list-style-type: none"> Had little to no success in pilot project. 8 individuals with tetraplegia were identified as potential candidates over a period of 2 years. Upon follow-up, only one candidate was continuing to receive care from a LEAP project graduate.
Mattson-Prince 1997; USA Observational N=71	<p>Population: Agency-based care group (n=29) (27M 2F): mean age = 35.3; mean years since injury = 7.9. Self-managed care group (n=42) (40M 2F): Mean age = 37.1; mean years since injury = 11.48.</p> <p>Treatment: Independent living model or agency-based care. Purpose was to compare agency-based care and self-managed care.</p> <p>Outcome measures: Patient function and well-being (RAND-36); current satisfaction against life satisfaction prior to SCI (LSI-A); physical independence, mobility, occupation, social integration and</p>	<ol style="list-style-type: none"> There was a significant difference between the groups with respect to income and employment (self-managed care group earned and worked more). People in the agency-based care group had lower spinal cord lesions (<C2) The self-managed care group received significantly more hours of paid care. Satisfaction with care being received was significantly higher in the self-managed care group. No difference between the groups in current life satisfaction relative to life satisfaction before injury. The self-managed care group reported a

Author Year; Country Score Research Design Total Sample Size	Methods	Outcome
	economic self-sufficiency (CHART); level of satisfaction with care being received (PASI).	significantly higher level of health

Discussion

Health promotion is an important area for maintenance of individuals in the community. Only three intervention studies were identified in this area and only one is of a high quality; the other two are observational studies. Cohen and Schemm (2007) conducted an RCT with a convenience sample of persons with SCI in the early phases of rehabilitation. The occupational therapist visits were intended to be client goal-focused, structured, and individualized. Their purpose was to help participants increase their functional independence and the depth and breadth of their social roles. No statistically important differences were noted in the participants' independence level or handicap level based on this intervention.

Barber and colleagues (1999) studied the effectiveness of skills-focused counseling for persons at risk of developing UTIs and found the risk can be reduced below threshold levels. It should be noted a majority of the participants required multiple sessions, suggesting skill-based interventions such as this must be repeated over sessions and time to achieve change. The authors stressed this is a simple and cost-effective intervention when compared to the medical interventions required with chronic UTIs.

The Beck and Scroggins (2001) post-test study has several interesting aspects. A health maintenance education program was developed to deal with a multitude of re-hospitalizations due to spinal cord dysfunction with tetraplegia. The program was comprised of: a one-day workshop consisting of evidence-based education; a collaborative home visit; and ongoing support provided via telephone. Healthcare providers and family members were included, in recognition that the larger healthcare system needs to be educated regarding SCI consequences and available resources. A one-year follow-up and a collaborative home/facility visit after the workshop provided individualized "real-world" follow-up to the concepts discussion in the workshop (strategies, educational resources, and supervised practice).

Attendant care training was discussed in a prospective controlled trial (Schopp et al. 2007) and a case series (Frost et al. 1999). Schopp et al. (2007) evaluated a PAS training program with 87 consumers and 53 personal assistants in a longitudinal study designed to improve the relationship between consumer and caregiver in addition to increasing knowledge of health and wellness. Both groups attended a workshop that provided information about health threats, severity of various secondary conditions, and specific health behaviours to prevent complications such as pressure sores and UTIs from arising. A physician provided training for bowel and bladder management, nutrition, and weight-loss strategies. A second component to this intervention was interactive sessions involving role-playing discussions on effective listening and communication skills, and assertiveness training. Training was completed as one large group and then separate groups consisting of caregivers and consumers. The results revealed no change in the working relationship between the two groups. However, knowledge among participants significantly increased.

A case series investigated the utility of training persons with disabilities to provide PCA for SCI consumers in an inner city via the Linking Employment, Abilities and Potential (LEAP) PVA Training Program (Frost et al. 1999). Unsafe work environments, changing discharge locations, and limited verbal abilities of the attendants, hampered obtaining preliminary results. However, one female client

with a C5 injury used LEAP services and was doing well with both the agency and family help. More data must be collected to determine client satisfaction and success of the intervention.

Despite the common use of attendant care services, there have been few studies which investigate the utility of various types of personal care. One observational study compared agency-provided PCA with self-managed attendant care. Seventy-one participants with high-level tetraplegia were interviewed about their experiences with either approach using measures of health status, life satisfaction, functional ability, service satisfaction, locus of control, and cost (Mattson-Prince 1997). Results indicated significant savings using non-agency attendants (\$156 per day if using 24-hour care) and are higher when non-agency nurses are used. Furthermore, those not using agencies had better health outcomes, fewer re-hospitalizations, and greater life satisfaction and locus of control than those using agency-based attendant care services. It should be noted that paid attendant services were often complemented by attendant care provided by family members.

Conclusion

There is level 1 evidence (Cohen and Schemm 2007) indicating that client-centred visits by an occupational therapist can increase the number of life roles performed and improve life satisfaction.

There is level 4 evidence (Barber et al. 1999) that suggests recurrent UTIs can be reduced below threshold levels through a simple cost-effective educational intervention by a clinical nurse.

There is level 4 evidence (Beck and Scroggins 2001) that suggests that health can be maintained after participation in an educational intervention focused on skill development and support in the “real world.”

There is level 2 evidence (Schopp et al. 2007) that a skills training project can improve knowledge in both consumers and personal assistants up to six months post-training.

There is insufficient evidence (Frost et al. 1999) to determine the efficacy of training persons with disabilities to provide SCI attendant care.

There is Level 4 evidence (Mattson-Prince 1997) suggesting that an independent living self-managed model for attendant care results in decreased costs, better health outcomes and life satisfaction, and fewer re-hospitalizations than agency-based care.

Goal-directed occupational therapy can achieve gains in role performance and improvements in life satisfaction.

Counselling on proper technique and hygiene for at least one session might reduce the risk of UTI to below threshold for individuals at risk for UTIs.

Re-hospitalization might be reduced after participation in an educational intervention involving a workshop, a collaborative home visit, and access to follow-up.

Skills development educational workshops for attendants and consumers can increase knowledge about spinal cord injury, wellness, and communication.

Directing, training, and financing one's personal attendant care may lead to financial savings, better health outcomes, and increased life satisfaction.

4.0 Summary

There is level 5 evidence (Forrest and Gombas 1995) that discharge from hospital was delayed for a significant portion of SCI patients due to lack of accessible housing, which leads to unnecessary increase of cost of care.

There is level 5 evidence (Fuhrer et al. 1990) that ILCs with MRP relationships serve more clients than those without, and that the most frequently serviced individuals are those with SCI who attend for peer counseling, skills training, and discharge planning.

There is level 5 evidence (DeJong and Hughes 1982) that living with a spouse and/or children, living alone, or living with unrelated persons were more desirable arrangements than living with parents and spouse/children together, living with distant family (i.e. grandparents), or living with parents and siblings.

There is level 4 evidence (DeJong et al. 1984) that marital status, transportation barriers, education level, medical supervision requirements, economic disincentives, services received, and severity of disability are predictors of independent living.

There is level 5 evidence (Boschen 1996) that issues of choice and control are important when planning living situations and setting goals with clients because they are directly related to residential and life satisfaction.

There is level 5 evidence (Boschen 1990) that individuals with SCI have lower perceived life satisfaction, locus of control and satisfaction with certain aspects housing than a normative sample.

There is level 5 evidence (Boschen 1988) that accommodation options for a person with a disability are limited. The preferred accommodation is a private house or apartment.

There is level 5 evidence (Anzai et al. 2006) that living with someone prior to SCI, having insurance or private funding for equipment, and being younger decreases the risk of being discharged to an extended care facility following SCI rehabilitation.

There is level 5 evidence (Cesar et al. 2002) that individuals with SCI have a need for assistance with fire safety to increase their perception of home safety.

There is qualitative evidence (Bergmark et al. 2008) that suggests individuals with SCI move multiple times after injury. In most cases they start living with their parents and/or in an institution before moving into their own homes.

There is qualitative evidence that suggest individuals with SCI have difficulties adjusting to life at home (Dickson et al. 2011). Reported difficulties are related to the loss of camaraderie, lack of post-discharge care and negative experiences with other people related to being in a wheelchair.

There is qualitative evidence (Kuipers et al. 2011) that suggest individuals with SCI who described their community in social and relationship terms reflected more positive views about this community compared to those who described their community in terms of physical space and access.

There is level 5 evidence (Guilcher et al.) indicating size of available networks decrease following SCI for most individuals, and informal care networks engage in a variety of roles,

including advice/validating concerns, knowledge brokers, advocacy, preventing secondary health conditions (SHCs), assisting with finances, and managing SHCs.

There is level 5 evidence (Foster et al. 2005; Robinson-Whelan and Rintala 2003) indicating that most informal caregivers are female spouses of SCI consumers who required additional assistance in fulfilling and maintaining provided services.

There is level 5 evidence (Berry et al. 1995) suggesting general satisfaction with informal attendant services from both clients and attendants although there are variations with some aspects of care.

There is level 5 evidence (Weitzenkamp et al. 2002) that the most significant predictors of PCA use are motor function, days spent in rehabilitation, and length of stay in a nursing home.

There is level 5 evidence (Bushnik et al. 2007) indicating that personal attendant turnover is positively correlated with higher injury level and increased need for assistance in exercise and transfers.

There is level 5 evidence (Gajraj-Singh 2011) that increased family caregiver burden is associated with poorer levels of psychological well-being. Level 5 evidence (Arango-Lasprilla et al. 2010) indicates that poorer psychological well-being is associated with greater information, emotional, economic, physical health, sleep and psychological support needs.

There is level 5 evidence (Arango-Lasprilla et al. 2010) that the majority of family caregivers are overwhelmed with their caregiving responsibilities.

There is level 5 evidence (Gajraj-Singh 2011) that increased family caregiver burden is associated with the number of hours of care provided per day and with increasing age of the caregiver.

There is level 5 evidence (Arango-Lasprilla et al. 2010) that increased family caregiver burden is associated with greater respite, information, emotional, economic, physical health, sleep and psychological support needs.

There is level 5 evidence (van Loo et al. 2010) that substantial unmet care needs requiring support for incidental activities of daily living and housekeeping support.

There is level 5 evidence (Owen and Marini 2012) that the use of life care planning may decrease use of unpaid attendant care, and increase the use of paid attendant care.

There is qualitative evidence (Cockerill and Durham 1992) that both consumers and attendants agree that the emphasis of care in transitional centres should be placed on facilitating consumer independence which may be accomplished by delineating the role of attendants.

There is level 1 evidence (Cohen and Schemm 2007) indicating that client-centred visits by an occupational therapist can increase the number of life roles performed and improve life satisfaction.

There is level 4 evidence (Barber et al. 1999) that suggests recurrent UTIs can be reduced below threshold levels through a simple cost-effective educational intervention by a clinical nurse.

There is level 4 evidence (Beck and Scroggins 2001) that suggests that health can be maintained after participation in an educational intervention focused on skill development and support in the “real world.”

There is level 2 evidence (Schopp et al. 2007) that a skills training project can improve knowledge in both consumers and personal assistants up to six months post-training.

There is insufficient evidence (Frost et al. 1999) to determine the efficacy of training persons with disabilities to provide SCI attendant care.

There is Level 4 evidence (Mattson-Prince 1997) suggesting that an independent living self-managed model for attendant care results in decreased costs, better health outcomes and life satisfaction, and fewer re-hospitalizations than agency-based care.

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