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The health and life priorities of individuals with spinal cord injury: A systematic review

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Abstract

Determining the priorities of individuals with spinal cord injury (SCI) can assist in aligning research priorities which ultimately improve these individuals' quality of life. This systematic review examined studies that directly surveyed people with SCI to ascertain their health priorities and life domains of importance. Twenty-four studies (combined sample of 5262) that met the inclusion criteria were identified using electronic databases (Medline, EMBASE, CINAHL, PsycINFO). The questionnaire methods and domains of importance were reviewed and described. While the questionnaires varied across the studies, a consistent set of priorities emerged. Functional recovery priorities were identified for the following areas: motor function (including arm/hand function for individuals with tetraplegia and mobility for individuals with paraplegia), bowel, bladder and sexual function. In addition, health, as well as relationships emerged as important life domains. The information from this study, which identified the priorities and domains of importance by individuals with SCI, may be useful for informing healthcare and research agenda-setting activities.

Keywords

SCI; consumer priorities; quality of life; well-being

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INTRODUCTION

The consequences of sustaining a spinal cord injury (SCI) can be overwhelming and can impact many areas of one’s life. Impairments in bowel and bladder function, mobility and autonomic functions along with secondary conditions such as pressure ulcers and pain are just some of the consequences that can directly impact one’s health (McKinley et al., 1999). The impact of SCI on domains such as employment and social participation has also been well documented (Anderson et al., 2007; Noreau & Fougeyrollas, 2000). Diminishing the negative impact of impairments, promoting full participation in life domains and ultimately increasing the well-being of individuals with a SCI is the goal of clinicians and researchers alike. Indeed, well-being or quality of life (QoL) has become an important outcome within SCI research.

Quality of life among people with SCI is complex however, and is an area that is not well understood despite a growing amount of literature amassed over the last few decades (Dijkers, 2005; Hammell, 2010; Hill et al., 2010). It has been postulated that after SCI, individuals change their expectations and values and thus their markers with which they judge their quality of life (Duggan &Dijkers 2001). Thus, there have been increasingly more calls for the use of measures that capture subjective QoL (Dijkers, 2005; Hammell, 2010; Hill et al. 2010).

Dikjers (2005) created a model that conceptualizes individual subjective quality of life as three different inter-related elements (Figure 1): 1) an individual’s expectations and/or priorities; 2) an individual’s subjective evaluations and reactions and 3) an individual’s achievements. Accordingly, the model explains that subjective QoL is shaped by the subjective evaluations and reactions that one forms through the process of comparing reality (achievements) to his or her priorities or expectations. Dikjers (2005) further explains that priorities are the important aspect of subjective QoL that are often missing from measures proposing to capture this exact construct. The author suggests that expectations and/or priorities can be evaluated through the examination of such factors as individuals’ needs, wants, and perceived importance of various domains. In essence, this model implies that if the ultimate goal of interventions is to increase the well-being of these individuals, then it is essential to recognize those life domains or areas consumers perceive as important. Moreover, it has been recognized that frequent and occasionally dramatic mismatches in health research priorities exist between consumers and professionals (e.g., health care professionals, researchers), in part due to limited input and participation from consumers (Grant-Pierce et al., 1998). A better understanding of consumer priorities can help shape and enrich the process of research priority-setting.

There is a growing body of literature examining the preferences or values of individuals with SCI. Estores (2003) conducted a limited literature review that included six studies examining consumers’ concerns and interests. This review highlighted the importance of mobility and aging to individuals with SCI. This was not a systematic review however, and given the growing interest in understanding consumers’ perceptions and concerns, a systematic review is warranted. A systematic review is intended to have a transparent and rigorous methodology which permits replication of the findings. Thus the purpose of this paper is to conduct a systematic review that will shed light on the domains that people with SCI perceive as important.

MATERIALS AND METHODS

A systematic review of electronic databases (Medline, CINHAL, EMBASE, PsycINFO) was conducted on studies published from 1948 through April 2011. The keyword ‘spinal cord injury’ and its related terms tetraplegia, paraplegia and quadriplegia were combined with ‘preferences’, ‘priorities’, ‘perceptions’, ‘importance’, ‘need’ and ‘quality of life’ or ‘well-being’ with all terms mapped to subject headings. Articles were limited to the English language and human subjects. A hand search of the reference list from reviews and selected articles was also conducted to ensure a complete search (Hopewell et al. 2007).

To be included in the review, articles had to meet the following inclusion criteria: 1) comprised a sample of individuals with SCI who were 17 years or older, 2) obtained the perceived priorities, needs and important domains by direct questioning of consumers with SCI, 3) reported SCI specific data, and 4) published in a peer-reviewed journal. Exclusion criteria excluded: 1) samples that consisted entirely of individuals with non-traumatic SCI, 2) articles that ascertained the domains of importance to QoL through statistical analysis of the relationship between different measures (i.e. cross-sectional studies using functional and QoL measures as opposed to direct questioning or self-report of participants), 3) studies which examined the relationship between interventions to QoL, 4) studies using qualitative design (rationale is provided in the Discussion section), 5) conference proceedings, and 6) studies with sample sizes less than 10.

The intention of this review was to increase our understanding of the perceived importance of life domains and priorities that contribute to well-being for individuals with SCI. Namely, we focused our review on papers that examined the ‘priorities’ element of Dijkers (2005) model of subjective QoL. With this focus in mind, articles exploring satisfaction in life areas or perceived difficulty with SCI consequences (subjective evaluation and reactions element according to Dijker’s model), or the current functional or health status (achievements element according to Dijker’s model) of SCI consumers were excluded. Articles which focused on a single domain were also excluded. We categorized articles based on the domains included in their questionnaires (i.e. health or broader life domains). After deleting duplicate articles, titles and abstracts were screened and non-relevant articles were removed. Relevant articles were read by two reviewers (LAS, JJE) who independently generated a final article list along with their respective categories. Discrepancies involving article inclusion/exclusion or classification were resolved through discussion and consensus.

RESULTS

The search strategy generated 656 articles of which 359 abstracts were reviewed. Figure 2 outlines the process used to select the 24 articles that met the inclusion criteria. Articles were categorized based on the content of their questionnaires and resulted in two categories: life domain priorities (n=13) and health priorities (n=11).

Summary of subject characteristics

The 24 articles represented a combined total of 5262 subjects. The age of participants in the studies ranged from 17 to 98 years and time since injury ranged from less than a year to 52 years. The majority of studies that reported the duration of injury of their samples included individuals with chronic injuries (16/20). The majority of studies that reported the gender of their samples comprised a mix of males and females with the percentage composition of males ranging from 50–88%. Sixteen studies utilized a combination of individuals with paraplegia and tetraplegia while 4 studies did not provide details about the lesion level.

Life domain priorities

Thirteen studies examined the importance across a cross-section of life domains (Table 1). These studies comprised a total of 2075 participants with a median of 54 individuals per study. The number of domains in the surveys ranged from 12 to 39 with a median of 15 items per study. The most frequent domains considered by the studies were leisure (n=11), relationships with family/friends (n=11), employment (n=11), general health/physical function (n=10), social activities (n=8) and psychological health (n=8). Table 2 lists the number of studies that ranked the domains in the top 25%.

Health or physical function were ranked in the top 25% in 8/10 studies that included these domains in their questionnaires (Benony et al., 2002; Boschen, 1997; Boswell, 1997; Cox et al., 2001; Cushman and Scherer, 2002; Kennedy and Rogers, 2000; Weitzenkamp et al., 2000; White et al., 1992; White et al., 1993). Relationships with family/friends was ranked in the top 25% in 8/11 studies that included this domain (Benony et al., 2002; Boschen, 1997; Boswell, 1997; Kennedy and Rogers, 2000; Weitzenkamp et al. 2000; White et al., 1992; White et al., 1993; Yerxa and Locker, 1990).

Employment was among the top 25% most frequently endorsed need in the four studies that included this domain and ascertained perceived life area needs (Backman et al. 2007; Cox et al. 2001; Cushman & Scherer, 2002; Kennedy et al. 2006). In addition, employment was the most frequently identified life goal in the study by Yerxa and Locker (1990). However, the “importance” of employment did not rank as high as its “need”. Studies that asked participants to rank or rate the importance of employment found that work was ranked 8/12 and 12/12 in the studies by White et al. (1992 and 1993 respectively) and was ranked 6/15 or lower in three other studies (Kennedy and Rogers, 2000; Weitzenkamp et al., 2000; Boschen, 1997). This was despite the finding that work was identified as important or very important for 82–87.5% of individuals in the studies by Kennedy and Rogers (2000) and Weitzenkamp et al. (2000).

The community domains of leisure, transportation and housing were included in 11, 7 and 6 studies, respectively. They were consistently ranked lower than social or physical health domains, however, leisure and transportation were ranked in the top 25% in 2/11 and 2/7 studies respectively. Finally, although only included in one study each, 3 domains related to environmental supports (home support, access to services and lobbying for financial policy) were identified as important needs in these studies (Backman et al., 2007; Cox et al., 2001). The apparent need for home support is consistent with the perceived importance of daily living tasks and personal care found in the studies by White et al.(1993) and Cushman and Scherer (2002).

Health Priorities

Eleven studies examined the priorities within the health domain (Table 3). These studies comprised a total of 3187 individuals with a median of 94 individuals per study. The number of functions participants were asked to rate ranged from 3 to 39. The functions considered by the largest number of studies were: bowel/bladder function (n=9), sexual function (n=7), upper extremity function (n=6) and pain (n=5). One study focused entirely on mobility items (Brown-Triolo et al. 2002) and another entirely on activities using the upper limbs (Anderson et al. 2009). Table 4 shows the frequency of functions ranking within the top 25% most important.

Bowel/bladder function, upper and lower extremity function and sexual function were perceived priorities for functional recovery over the general SCI population (not separated by lesion level). For instance, walking and bowel and bladder function were all selected as priorities for recovery early in the trade-off game in the study by Ditunno et al. (2008) while movement was rated among the top five highest rated important health dimensions in the study by Kannisto et al. (1998). Use of hands and control of the bladder and bowel had among the highest mean ratings over 39 health functions rated important by 25 individuals (Laman and Lankhorst 1994). Finally, in one study with 454 participants, bowel, bladder and sexual function were ranked among the top five most important functions (Bloemen-Vrencken et al. 2005).

Common impairments such as pain, pressure sores, spasms and fatigue were not frequently included as items among the eleven health priority studies. Five studies included pain (Anderson, 2004; Bloemen-Vrencken et al. 2005; Kannisto et al. 1998; Laman&Lankhorst, 1994; Snoek et al. 2004), two studies included spasms and pressure sores (Bloemen-Vrencken et al. 2005; Snoek et al. 2004) and no study included fatigue in its questionnaire. Pain was endorsed as important by 40.1% (n=454) of individuals in Bloemen-Vrencken et al. (2005), 40–50% (n=1475) of individuals in Snoek et al. (2004) and received an importance rating of 8.16/10 in the study by Laman and Lankhorst (1994). Relative to other items among the health priority studies however, these ratings or endorsements did not place pain in the top 25%. Pain was among the lowest ranked items when participants were asked to directly rank their functional recovery priorities (Anderson, 2004; Kannisto et al. 1998).On the other hand, pain was ranked in the top 25% most important needs in both of the studies that included this item in the life area studies (Table 2). Snoek et al. (2004) found that pressure sores were ranked higher in importance than pain and muscle spasms among 1475 individuals whereas Bloemen-Vrencken et al. (2005) found that pressure sores and spasms were rated similarly in terms of importance and both were less important than pain.

Seven of the eight studies that explored functional recovery priorities provided results based on level of injury (Anderson, 2004; Anderson et al., 2009; Brown-Triolo et al., 2002; Hanson & Franklin, 1976; Snoek et al. 2004; Snoek et al. 2005; Wagner et al., 2007). In 4 of the 5 studies that included arm and hand function as an option, individuals with tetraplegia most wanted to restore this function (Anderson 2004; Hanson and Franklin 1976; Snoek et al. 2004; Wagner et al. 2007). However, Snoek et al. (2005) was unable to find a preference for arm and hand function when using a novel time tradeoff method. In 4 of the 5 studies that provided results for individuals with tetraplegia, restoration of bowel and bladder function was found to be the second highest priority after arm and hand function (Anderson, 2004; Hanson and Franklin, 1976; Snoek et al. 2004; Wagner et al. 2007). It was among the first or second choice in 40% of individuals in Anderson (2004), 47% in Hanson & Franklin (1976) and received an importance rating on par with arm and hand function in the study by Snoek et al. (2004) which examined a sample of 565 individuals with tetraplegia.

Among the 4 studies that presented results for individuals with paraplegia, the greatest functional priorities for individuals with paraplegia were sexual function, walking/lower extremity function and bowel and bladder function (Anderson 2004; Brown-Triolo et al. 2002; Hanson and Franklin 1976; Snoek et al. 2004). Snoek et al. (2004) found that bowel and bladder function received the highest mean importance rating among 941 individuals with paraplegia. Anderson (2004) found that sexual function was the first or second priority for 45% of the sample. This was followed closely with recovering the ability to walk which was selected as the first or second choice by 38% of the sample. When asked to prioritize use of legs, sexuality, bladder and bowel function, Hanson and Franklin (1976) found that 51.9% of individuals with paraplegia selected use of legs as their first priority while bladder and bowel function was the second priority among 46.3% of participants. Finally, participants in the study by Brown-Triolo (2002) selected walking as the top priority for restoration among four mobility functions.

DISCUSSION

Patterns of importance within and across categories

Despite the heterogeneity in the purposes of and measurement methods used in the included studies, several patterns did emerge with respect to the priorities of individuals living with SCI. Indeed, Froberg and Kane (1989) assert that it is generally accepted among the psychosocial measurement literature that different types of response scales should produce the same rank order of items. Figure 3 provides a summary of the important health and life domains identified from this systematic review that are considered priorities by individuals with SCI.

Four areas of function emerged as particularly important among individuals with SCI: bowel, bladder, sexual and motor (which includes walking and arm/hand function). Arm and hand function was especially important to people with tetraplegia. Arm and hand function is associated with independence in many activities, and impairments in upper extremity function can compound difficulties in many other areas such as bowel and bladder management. Thus, it is not surprising that restoring arm and hand function was found to be a priority for individuals with tetraplegia among the majority of included studies.

Restoring mobility, sexual function, and bowel/bladder function emerged as priorities for individuals with paraplegia with no clear priority emerging among these functions. The two functions that have received the greatest attention in the literature to date are motor function and reducing complications associated with bladder function (Furlan & Fehlings, 2006; Tate et al., 2011). Accordingly, greater research on bowel management and sexual function is warranted especially as the importance of quality of life issues and patient preferences are receiving recognition (Tate et al., 2011).

The inclusion of secondary conditions such as pain, pressure sores and spasms were less prominent among the surveys. Pain was identified as an important condition in the studies in which it was present, albeit less important than recovering motor and bladder/bowel function. It was also identified as one of the top 25% most important needs in the life area studies that included pain. Our results suggest that the relative importance of pain is affected by the context in which the question of importance is asked.

Interestingly, the importance of fatigue was not investigated in any of the studies included in the review. Fatigue is a common consequence of SCI (as in other chronic conditions) and has been shown to have a negative impact on QoL (Suzuki et al., 2007). Future research examining the health priorities of individuals with SCI should consider inclusion of this frequently-reported secondary condition.

Health, in addition to relationships, emerged as two salient factors in people's lives among the life area studies. The importance of both psychological and physical aspects of health appeared to be endorsed by participants. Emotional health domains were not well represented in the surveys used within the health domain studies (n=3). Future studies exploring the importance of more specific emotional as well as physical states might increase our understanding about the specific health factors perceived important to persons with SCI. Furthermore, the perceived importance of relationships found in this review is consistent with the finding that social support is an important determinant of life satisfaction for individuals with SCI (van Leeuwen et al., 2011).

The relative priority of employment depended on the context in which the question was posed and ranked high when "needs" were assessed, but ranked low when "importance" was assessed. Employment after SCI is a topic that has been well studied in the literature and has been associated with life satisfaction in other studies (Lidal et al. 2009). Our results provide some support that there are unmet needs in the area of employment following SCI.

Limitations

The studies in this review utilized quantitative methods which incorporate predetermined domains in their surveys and thus it could be argued that participants only prioritized the domains believed to be important by the researchers. Conversely, qualitative methods do not start with a predetermined set of variables and allow individuals to generate their own domains of importance. The depth of information obtained in qualitative studies however limits the feasibility of large sample sizes. Our review was able to capture a total number of 5262 participants while the qualitative meta-synthesis by Hammell (2006) that reviewed articles examining determinants of quality of life for individuals with SCI included a total number of 120 participants. Although this review did not include qualitative studies, our findings concerning the life domains of importance were consistent and complementary to the qualitative meta-synthesis by Hammell (2006) as she identified 6/10 themes directly related to physical, social and psychological areas. Future quantitative studies in the area of

SCI consumer preferences should use qualitative studies to inform their methods as suggested by Hammell (2010). Finally, our review did not include articles that examined aspects of consumer satisfaction or fulfillment in different life areas. Subjective evaluations of and reactions to one's circumstances is another important element of quality of life (Dijkers, 2003; 2005). A review of work examining this topic would provide a useful contribution to the literature.

Summary and Implications

This systematic review was able to uncover patterns in the importance that individuals with SCI ascribe to different life areas (Figure 3). This review summarized the resulting rankings of 24 studies (Tables 2 & 4) while also considering the context in which the study results were obtained. Health, in addition to relationships, were shown to be important life areas to consumers. Within the health domain, consumers identified restoration of motor, bowel, bladder, and sexual function as priorities for recovery. Restoration of arm and hand function was a specific priority for individuals with tetraplegia, whereas mobility function was more important to individuals with paraplegia. As consumer priorities and expectations have been identified as a major component of subjective quality of life, consistency between research and consumer priorities is an important goal.

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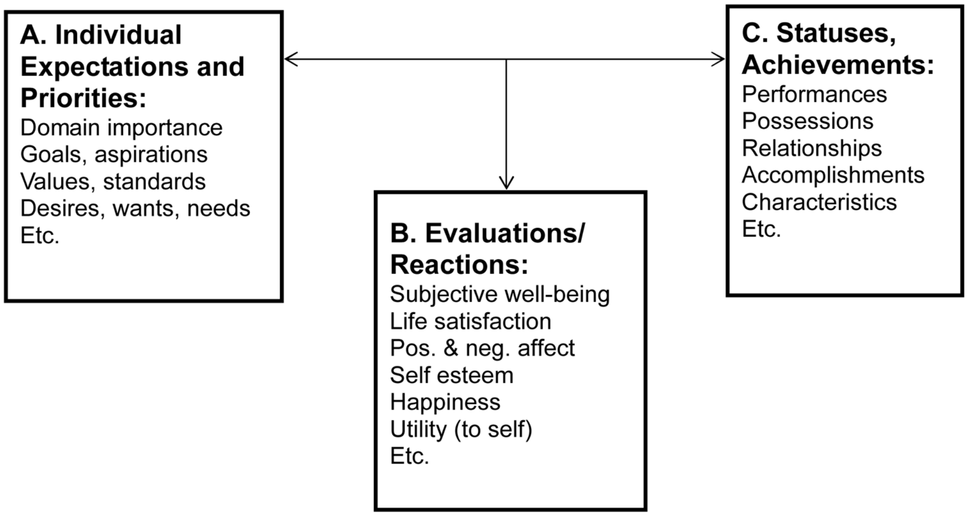

Figure 1.

Model of subjective QOL (adapted from Dijkers MP. (2003) Individualization in quality of life measurement: Instruments and approaches. Arch Phys Med Rehabil, 84(4 suppl 2), S3–14.)

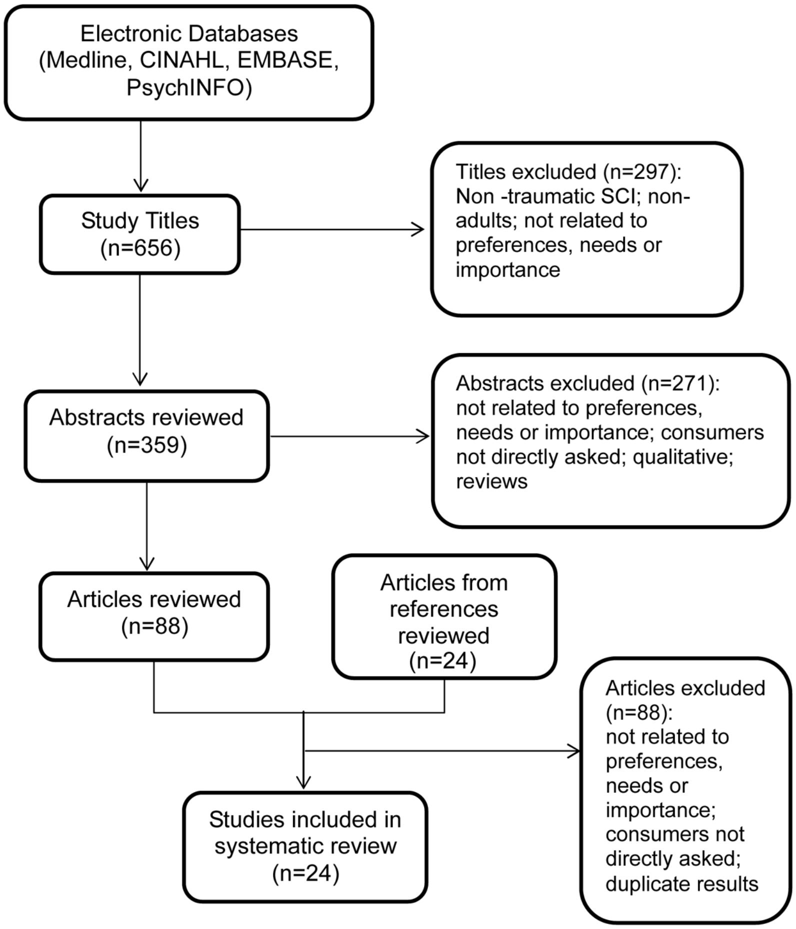

Figure 2.

Flowchart of article selection process

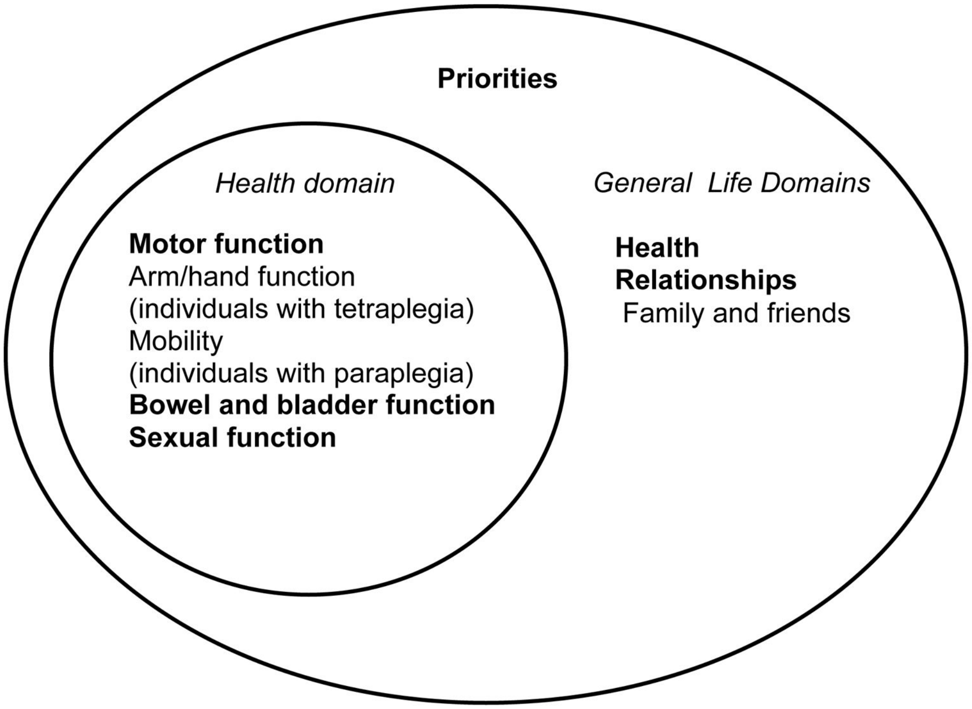

Figure 3.
Summary of review findings

Table 1

Life domain priority studies

Study	N	Results: Domains ranked in the top 25%
Backman et al. 2007	357	(1) home support (2) income policy (3) educate employers
Benony et al. 2002	33	(1) friends (2) physical state (3) free time (4) family (5) hobbies
Boschen 1997	547	(1) health (2) family (3) spouse
Boswell 1997	12	(1) family (2) physical well-being (3) psychological aspects
Cox et al. 2001	54	(1) physical changes (2) ongoing education (3) exercise (4) work (5) transport (6) pain mng. (7) obtaining services
Cushman & Scherer 2002	22	(1) personal care (2) transport (3) assistive technology
Kennedy et al. 2006	350	(1) sexual activity (2) work (3) pain relief
Kennedy & Rogers 2000	24	1 month post d/c: (1) health (2) family (3) work (4) friends 6 months post d/c: (1) health (2) family (3) spouse (4) material comforts
Lin et al. 1997	347	All 39 items rated important
Weitzenkamp et al. 2000	195	(1) health (2) family (3) spouse
White et al. 1992	79	(1) health (2) family (3) emotional well-being
White et al. 1993	40	(1) health (2) ADLs (3) family
Yerxa and Locker 1990	15	(1) miscellaneous (2) earn living/new job (3) family relations

d/c: discharge; ADLs: activities of daily living

Table 2

Life Domain questionnaire domains and top ranking results

Item[a]	**# studies that include item (total 12**[b]**)**	**# of times in top 25%**
Friends/family relationships[c]	11	8
General Health/physical function	10	8
Employment issues[c]	11	5
Leisure/recreation[c]	11	2
Psychological health[c]	8	2
Transportation[c]	7	2
ADL/personal care	4	2
Pain	2	2
Income policy/financial matters[c]	7	1
Sexual function[c]	7	1
Education/school	5	1
Equipment[c]	4	1
Material comforts	3	1
Fitness/exercise	2	1
Access to services	1	1
Home support	1	1
Social activities[c]	8	0
Housing[c]	6	0
Parenting	5	0
Participating in community[c]	5	0
Helping others	4	0
Communicating	3	0
Accessibility-home and community	3	0

ADL: activities of daily living;

[a] only items in 25% of questionnaires or in top 25% of 1 study were included;

[b] only 12 studies as 1 study asked open ended question;

[c] includes study from Lin et al. (1997) which found all items endorsed as important and meaningful rankings could not be determined

Table 3

Health priority studies

Study	N	Results: Functions ranked in the top 25%
Anderson 2004	681	*Tetraplegia:* (1) arm/hand function (2) bowel/bladder *Paraplegia*: (1) sexual function (2)bladder/bowel/AD
Anderson et al. 2009	137	(1) dressing (2) feeding oneself
Bloemen-Vrencken et al. 2005	454	(1) bladder (2) bowel (3) pain (4) spasms (5) sexuality (5) pressure sores
Brown-Triolo et al. 2002	94	(1) walking
Ditunno et al. 2008	31	(1) bowel/bladder (2) walking (3) toileting (3) bathing
Hanson & Franklin 1976	128	*Tetraplegia*:(1) arms/hands (2) bowel/bladder (3) use of legs (4) sexual function *Paraplegia*:(1) use of legs (3) bowel/bladder (3) sexual function
Kannisto et al. 1998	65	*Recent injury*: (1) mental function (2) breathing (3) moving (4) seeing (5) communicate *Long standing injury*: (1) mental function (2) breathing (3) communicate (4) moving
Laman & Lankhorst 1994	25	All 39 items were rated important
Snoek et al. 2004	1475	*Tetraplegia*: (1) hand (1) bowel (1) bladder (2) sexual function *Paraplegia*: (1) bladder (1) bowel (2) pressure sores
Snoek et al. 2005	47	UE function, bowel/bladder, sexual function, standing/walking received same preference weights
Wagner et al. 2007	50	(1) UE function

Table 4

Health Priority questionnaire functions and top ranking results

Item[a]	# studies that include item (total 11)	# of times in top 25%
Bowel/bladder[b]	9	4
UE function[b]	6	4
Sexual function	7	2
Walking[b]	4	2
Pain	5	1
Transfers[b]	4	1
Eating[b]	4	1
LE function	3	1
Dressing[b]	3	1
Mental functions	2	1
Spasms	2	1
Pressure sores	2	1
Breathing	2	1
Communicating[b]	2	1
Psychosocial problems	3	0
Stairs	3	0
Standing[b]	3	0

[a] only items in 25% of questionnaires or in top 25% of 1 study were included;

[b] includes study from Laman & Lankhorst (1994) which found all items endorsed as important and meaningful rankings could not be determined