ORIGINAL ARTICLE

Health-related outcomes of people with spinal cord injury—a 10 year longitudinal study

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Study Design: Longitudinal panel design over 10 years.

Objectives: To describe the health outcomes for people with spinal cord injury and identify how indicators of health change over time.

Setting: Queensland, Australia.

Methods: A structured interview consisting of measures of perceived health, medical service utilization, hospitalization and pressure sore occurrence was administered on six occasions over 10 years after discharge from the hospital following the initial rehabilitation episode.

Results: The majority of respondents were relatively healthy over the course of the 10-year study and required minimal medical interventions or hospitalization. There was however a group of up to 20% of respondents who required extensive medical intervention, including hospitalization and pressure sore management.

Conclusion: The findings have significant implications for health-care policy and strategic planning for the ongoing management of spinal cord injury. A biopsychosocial approach combining patient education, cognitive behavioral interventions, screening and treatment for affective disorders and environmental interventions is recommended to facilitate optimal health outcomes for people with spinal cord injury over the long term.

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Introduction

Although life expectancy for people who sustain spinal cord injury (SCI) has improved, the risk of premature death is high in the first and second year after injury and remains elevated until the fifth year after injury.¹ In addition, secondary medical complications intensify the experience of disability for people with SCI by negatively impacting on long-term health, quality of life, dignity, mobility and independence. Health complications following SCI are also costly, in terms of limited health-care resources and quality of life.²

The literature highlights the fact that persons with SCI use medical and/or health-care services at a significantly higher rate than the general population and are at increased risk of developing secondary complications and being rehospitalized.³ Dryden *et al.*⁴ found that people with SCI were 2.7 times more likely to contact a physician than the general

population. The rate of hospital admissions after initial SCI rehabilitation ranges from 19 to 57%^{4–11} with the highest rate of rehospitalization occurring in the first 5 years after discharge.^{3,5,9–11} One Australian study⁷ reported readmission rates ranging from 41 to 55%, whereas another found that 31% of the participants had been readmitted to the hospital at least once in the first 2 years following initial discharge.¹²

Pressure sores are the most common medical complications following SCI. The incidence of pressure sores in SCI populations varies between 15 and 66%.^{13–21} Twenty-five to thirty percent of individuals with SCI will have at least one pressure sore within the first 5 years after injury²² and as many as 80% may experience pressure sores that require medical intervention throughout their life.²³

The aim of this study is to describe the incidence and pattern of health outcomes in a cohort of people with SCI over 10 years. Outcome measures include injury demographics, mortality, perceived health problems, utilization of medical services, hospitalization and the occurrence of pressure sores. This study was part of a larger study investigating a range of rehabilitation, adjustment, psychosocial, environmental and coping outcomes.

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Methods

Participants

The sample comprised all adult patients with acute traumatic SCI consecutively discharged from the Spinal Injuries Unit of the Queensland Spinal Cord Injuries Service following the initial hospitalization episode between November 1992 and March 1994. A total of 53 patients met the inclusion criteria. Fifty-one patients (96%) agreed to participate in the study.

Five (10%) individuals were from an indigenous background and were eventually dropped from the sample because the data collection methods proved culturally inappropriate for this subgroup, leaving a final participant group of 46 individuals.

In the Australian context, the sample is approximately half of the annual acute admissions to Queensland Spinal Cord Injuries Service and approximately 15% of the Australian total SCIs per year.

Demographics and injury characteristics of the sample presented in Figure 1 show that age, gender, cause and type of injury are consistent with the trends in SCI populations in Australian²⁴ and international literature.²⁵

Procedures

Ethics. All procedures were approved and monitored by the Human Research Ethics Committee of the relevant institution. Informed consent was obtained from participants prior to discharge from hospital.

Design. A longitudinal panel design was used to collect health outcome data over 10 years. There were six data

collection points at discharge from hospital ($n=46$) at 6 months ($n=44$), 12 months ($n=40$), 24 months ($n=35$), 36 months ($n=33$) and 10 years ($n=32$) after discharge. At each interview, a structured questionnaire was administered by the principal investigator. A combination of face-to-face and telephone interviews was used owing to the geographical spread of the respondents. Participants were asked to provide information related to the 6- or 12-month period immediately prior to the interview.

Measures

Mortality. The number of deaths and cause of death as recorded in the participant's medical record are reported.

Self-perceived health. Self-perceived health is reported using a single item from the life problems subscale of The Life Situation Questionnaire.²⁶ The Life Situation Questionnaire is a self-report measure that collects data on the long-term outcomes of an SCI-specific population. Participants were asked to rate the extent to which health problems were experienced on a 5-point scale with higher scores indicating more problems.

Medical service utilization. Medical service utilization was recorded as the self-reported number of times participants had consulted a medical practitioner for a medical problem, excluding routine medical reviews, and sub-grouped as no medical consultations, 1–9 consultations or >10 medical consultations.

Hospital admission. Participants reported the number of hospitalizations, reason for hospitalization (categorized as either related or unrelated to SCI) and loss of stay (LOS). Treatment of pressure sores, urinary tract infections, kidney or bladder stones, pneumonia, bowel obstructions, loss of function, surgical removal of spinal instrumentation and respite were categorized as related to SCI. All other admissions were categorized as unrelated to SCI.¹²

Occurrence of pressure sores. Participants provided a self-report count of the number of pressure sores they had experienced in the preceding 12 months.

Analysis

Repeated measure regression models were fitted to consider the significance of changes over time in outcome variables. Multiple linear regression models were fitted to continuous outcome variables, binary logistic regression models to dichotomous outcomes and multinomial logistic regression models to polytomous outcomes. A generalized estimating equations approach was used to derive these estimates, and assumed an independent correlations matrix. This approach permitted the use of all collected data, including those for subjects who were not available for all six assessments.

Demographic and injury characteristics	Number (%)
Gender	
Male	42 (91%)
Female	4 (9%)
Age at injury, years	
16–19	11 (24%)
20–29	15 (31%)
30–39	9 (20%)
40–49	3 (6%)
50–59	4 (9%)
60+	4 (9%)
Range	16–72 years
Mean (median)	32 years (27)
Level of injury	
Paraplegia	19 (41%)
Tetraplegia	27 (59%)
Degree of impairment	
Complete	16 (35%)
Incomplete	30 (65%)
Aetiology	
Road trauma	20 (44%)
Falls	7 (15%)
Sports/recreational activities	9 (20%)
Acts of violence	2 (4%)
Other	8 (17%)

Figure 1 Participant demographic and injury characteristics ($N=46$).

Results

Mortality

Four participants (9%) died during the course of the study. Two participants (4.5%) committed suicide. One died from septicemia associated with a urinary tract infection and one ventilator-dependent participant died from myocardial infarction. The overall mortality rate was 9%, with all deaths occurring in the first 3 years of the study.

Self-perceived health

For the majority of participants, health problems were only a minor concern. The mean scores remained relatively stable over 10 years and ranged from 2.0 to 2.2 out of a possible high score of 5, indicating the most substantial concerns. There was a slight non-significant increase in perceived health problems at the tenth year.

Medical service utilization

Figure 2 shows the number of medical consultations by frequency grouping. In the first 6 months following discharge from hospital, 23% ($n=10$) of the respondents had not consulted a medical practitioner, whereas 11% ($n=5$) had consulted a medical practitioner on 10 or more occasions. By the 10th year, only 3 (9%) respondents reported not requiring medical consultation, the lowest of any period. The percentage of respondents who required 10 or more consultations peaked at 24 months.

The mean number of medical consultations per participant is shown in Figure 3. Medical consultations were lowest in the first 6 months and peaked at 2 years after discharge (7.7 per participant). The changes in the number of medical consultations over time were significant (Wald $F=3.47$, 4 df, $P=0.015$).

Hospitalization

Forty-eight percent ($n=22$) of the participants did not require hospitalization. There were a total of 47 hospital admissions with an average of 2 admissions for each participant hospitalized. Fifty-two percent ($n=24$) had at least one hospital admission, with 24% ($n=9$) having more

Figure 2 Percentage of participants requiring medical consultations.

Figure 3 Mean number of medical consultations.

Figure 4 Percentage of respondents rehospitalized for any cause.

than one admission. The overall rehospitalization rate was 32.6% in the first 2 years and 52% by the tenth year. Figure 4 demonstrates that the percentage of participants requiring hospitalization was maximal at the tenth year.

The majority of admissions were brief with LOS less than 7 days. However, 11% ($n=5$) of participants required hospital treatment with LOS in excess of 28 days. Overall, there were no significant changes over time in the number of hospitalizations or LOS.

Reason for hospitalization. Twenty-seven (57.4%) of the 47 hospital admissions were classified as being related to SCI. Hospitalization for reasons related to SCI was highest at 24 months. The major reasons for hospitalizations throughout the period of the study were pressure sores, urinary tract infections, bowel obstructions, pneumonia, surgical removal spinal instrumentation, fractures and renal tract calculi.

Figure 5 Reason for hospital readmissions.

Figure 6 Respondents reporting pressure sores.

By the tenth year, there were an increasing number of hospitalizations for conditions not directly related to the SCI (Figure 5).

Occurrence of pressure sores. In the first 6 months following discharge, 80% ($n=35$) reported that they had not developed any pressure sores (see Figure 6). However, 7% ($n=3$) had three or more pressure sores. The percentage of patients reporting no pressure sores remained steady over the period of the study.

At 24 months, the number of pressure sores was the highest for any follow-up period. Twenty-two percent ($n=8$) reported at least one pressure sore and 11% ($n=4$) reported more than three pressure sores. There was no statistically significant change in the number of pressure sores over time.

Essentially, the same group of participants were able to avoid pressure sores throughout the 10-year study period. Of the 32 participants with complete data sets, 50% ($n=16$) reported no pressure sores throughout the 10-year study period. Those who developed pressure sores tended to have them at multiple points of follow-up, with 30% ($n=13$) reporting pressure sores at two or more points of follow-up.

Discussion

The results of this study reveal that the majority of respondents were relatively healthy throughout the course

of the 10-year follow-up and required minimal medical interventions or hospitalization. However, a group of up to 20% of respondents required extensive medical intervention, including hospitalization and pressure sore management.

Mortality

The mortality outcomes for this group are similar to those in the other Australian studies (7% over the first 10 years after injury, excluding the initial acute phase²⁷) and those in the United States (9% at 10 years²⁸). As in other studies, the risk of premature death was highest in the early years after injury, with all deaths occurring in the first 3 years. The high risk of suicide is highlighted, with suicide accounting for half of the deaths in this sample. Septicemia has also been found to be a significant contributor to premature death in other SCI populations, accounting for 9.8% of deaths.²⁹ DeVivo and Stover³⁰ report that individuals with SCI had a nearly 5 times higher risk of death from suicide and a 64 times higher risk of death from septicemia than did the general population.

Self-perceived health

Overall, the perceived health problems were not a major concern for the participants. However, there was a slight nonsignificant increase in perceived health problems at the tenth year, suggesting an increase in medical concerns as participants aged and time since injury increased.

Medical service utilization

In this study, approximately 10% of the respondents required 10 or more non-routine medical consultations at each point of the follow-up, and by the 10-year follow-up 91% of participants required a non-routine medical consultation in the preceding 12 months. The utilization of health-care services by people with SCI living in the community is not well documented. However, in a population-based sample of SCI,⁴ the median number of contacts with the physician per respondent (including those during hospitalization) was 22 in the first year, 8 in the second year and declined to 4 in the sixth year, which is lower than in the present study.

Hospitalization

More than half of the sample in this study had medical concerns serious enough to warrant hospital admission, and 24% required multiple hospital admissions. The rehospitalization rate was 32.6% in the first 2 years and 52% of all participants by the tenth year. This finding is consistent with the findings of other Australian studies¹² but lower than the rate in the USA, where the readmission rate in the first 2 years after discharge ranges from 36–51%.^{8,9} Dryden *et al.*⁴ found that the chance of being hospitalized in SCI populations is 2.6 times greater than that of the general population.

Eleven percent of the present cohort required admission to hospital with LOS in excess of 28 days, suggesting a serious or chronic medical condition. There is great variability in

reported LOS and the number of admissions.⁴ Mean LOSs ranging from 4 to 34 days are reported.^{1,3-5,10,13,31} In a comprehensive Australian review of hospital readmissions, 58.6% had been readmitted to hospital for an SCI-related episode on one or more occasions over 10 years with an average LOS of 15.5 days.³¹

The reasons for hospitalization are similar in all studies, with respiratory, skin and urinary complications contributing to the majority of admissions. Many of these admissions are considered to be potentially avoidable. Pershouse *et al.*¹² found that 81% of LOS was for conditions classified as directly related to SCI and 21% of LOS was for conditions classified as preventable. The most common reason for admission for preventable conditions was for pressure sores, which accounted for 25% of LOS.¹² Pressure sores accounted for 6.6% of all hospital readmissions in another Australian SCI sample ($n = 253$) but contributed to 28% of the total bed days for all SCI admissions.³¹

Pressure sores

Although it is encouraging that this study found that 50% of individuals reported no pressure sores over the 10 years, there was a group of up to 30% of participants who had recurring or persistent pressure sores. This again confirms the findings of many other studies that there is a significant subgroup of people with SCI who experience recurrent problems with pressure sores requiring frequent hospitalization, and there is an increased risk in case of a prior history of pressure sores.^{17,31,32}

Although this study found that there was no statistically significant change in the number of pressure sores over time, other researchers have found that the prevalence of pressure sores increases with time since injury.^{11,13,32}

Further research is required to identify demographic, personal or environmental factors that contribute to the development of pressure sores, especially in those cases where pressure sores persist or continually recur. Increasingly, it is being suggested that a complex interaction of psychosocial and physical factors may be involved.^{13,15-17,33} Krause and Broderick¹⁷ have suggested that the study of coping strategies and how these relate to pressure sores using a longitudinal design may be particularly enlightening.

Others have suggested that there may be a group of individuals who, because of prior socioeconomic disadvantage or for other reasons, do not have adequate life skills, self-esteem or a framework from which they can develop coping skills or appropriate problem-solving skills to live successfully with an SCI.³⁴ The resulting self-neglect behaviors result in medical complications that have serious implications for the quality of life, health and even survival of the injured person.

The determination of causal factors relating to health and medical problems is often difficult; however, in many cases, causation is a complex interplay of biopsychosocial factors, which need to be considered to achieve optimal management. An approach that combines patient education,^{17,35} training in cognitive behavioral and coping strategies, screening and adequate treatment for affective disorders⁷

and environmental interventions that facilitate outcomes such as improved social and personal support and adequate resources is likely to be most effective.

The health outcomes in this study provide indirect evidence that the psychosocial care and self-care of the person with SCI may be important targets for intervention strategies. The current authors suggest that the next serious step in developing effective interventions for the management of health-related outcomes will involve investigating the role of coping strategies and developing interventions that support effective coping efforts in the SCI at-risk population.

Limitations

This study is limited by the use of self-report measures and is therefore subject to retrospective recall bias. Another potential limitation of the study is that many of the measures have categorical responses, thus reducing the sensitivity to change over time. This limitation, inherent in the Life Situation Questionnaire, is discussed by Krause and Broderick³⁶ in a recent report. This study reports only those events that occurred in the 12-month period immediately prior to the interview. Additionally, there is a large gap between the 3-year report and the 10-year report, which diminishes the continuity of the data and its sensitivity to change over time. However, considering these limitations, it is reassuring that the findings are essentially consistent with the findings of other studies, suggesting that the data are robust.

Conclusion

The findings of this study have significant implications for health-care policy and planning relating to the management of SCI. Health-policy planners must have a comprehensive picture of the health outcomes following SCI, if adequate strategies to promote health and minimize further disabling experiences are to be developed.

Further research to identify high-risk groups and factors that are amenable to intervention are clearly warranted. The long-term consequences of living with SCI escalate as life expectancy increases, making it important to know what secondary conditions are experienced and to identify risk factors that are amenable to intervention to enhance the effectiveness of health promotion and preventative strategies. The increasing cost of health care for the person with SCI, as well as the personal, vocational and family impacts, makes it urgent that we fully understand these issues and develop strategies that will decrease the risk of complications and subsequent rehospitalizations.

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