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Published

2008

Journal Title

Spinal Cord

DOI

[10.1038/sj.sc.3102159](https://doi.org/10.1038/sj.sc.3102159)

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TITLE PAGE

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

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ABSTRACT

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

Setting: Queensland, Australia

Study Design: Longitudinal panel design over 10 years

Methods: A structured interview consisting of measures of perceived health, medical services utilisation, hospitalisation, and pressure sore occurrence was administered on six occasions over 10 years post discharge from 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 hospitalisation. There was however a group of up to 20% of respondents who required extensive medical intervention including hospitalisation and pressure sore management.

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

Keywords: spinal cord injury; hospital readmission, pressure sores; health services; mortality

INTRODUCTION

While life expectancy for people who sustain spinal cord injury (SCI) has improved, the risk of premature death is high in the 1st and 2nd year post injury and remains elevated until year 5 post injury. ⁽¹⁾ In addition, secondary medical complications intensify the experience of disability for people with spinal cord injury (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 utilise 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 rehospitalised. ⁽³⁾ Dryden et al found that that people with SCI were 2.7 times more likely to have a physician contact than the general population. ⁽⁴⁾ Reported rates of hospital admissions post initial SCI rehabilitation range from 19% to 57% ⁽⁴⁻¹¹⁾ with the highest rates of rehospitalisation occurring in the first 5 years post discharge. ^(3, 5, 9-11) One Australian study reported readmission rates ranging from 41% to 55% while another found that 31% of the participants had been readmitted to hospital at least once in the first 2 years following initial discharge from. ⁽¹²⁾

Pressure sores are the most common medical complication following SCI. The incidence of pressure sores in SCI populations has been reported as varying between 15% and 66%. ⁽¹³⁻²¹⁾ It has been reported that 25-30% of individuals with SCI will have at least one pressure sore within the first 5 years post injury ⁽²²⁾ and that as many as 80% may

experience a pressure sores which require medical intervention over the course of their lifetime.⁽²³⁾

The aim of this study is to describe health outcomes for people with SCI and to identify how indicators of health change over time. The study will describe the incidence and pattern of health outcomes including; injury demographics, mortality, perceived health problems, utilisation of medical services, hospitalisation, and the occurrence of pressure sores in a cohort of people with SCI over ten years. This study was part of a larger study investigating a range of rehabilitation, adjustment, psychosocial, environmental and coping outcomes.

METHODS

Participants

The sample comprised all adult patients with acute traumatic SCI consecutively discharged from the Spinal injuries Unit (SIU) of the Queensland Spinal Cord Injuries Service (QSCIS) in 1993 following the initial hospitalisation episode. 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 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 QSCIS and approximately 15% of the Australian total SCI's per year.

Demographics and injury characteristics of the sample presented in Figure 1 show age, gender, cause and type of injury are consistent with the trends in SCI populations reported in Australian⁽²⁴⁾ and international literature.⁽²⁵⁾

[Insert Figure 1 here]

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 ten 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 ($n = 32$) post discharge. At each interview, a structured questionnaire was administered. Participants were asked to provide information related only to the six 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 (LSQ).⁽²⁶⁾ The LSQ is a self-report measure, which collects data on the long term outcomes of a 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 Services Utilisation

Medical service utilization was measured by a single question, asking how many times participants had consulted a medical practitioner for a medical problem, excluding routine medical reviews. Actual numbers of non-routine consultations were recorded and sub-grouped as: no medical consultations, 1-9 consultations or > 10 medical consultations.

Hospital Admission

Participants reported the number of hospitalisations, reason for hospitalisation and LOS. Reasons for hospitalisation were categorised as either related or unrelated to SCI. 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 categorised as related to SCI. All other admissions categorised as unrelated to SCI.⁽¹²⁾

Occurrence of Pressure Sores

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

RESULTS

Mortality

Four participants (9%) died during the course of the study. Two participants (4.5%) committed suicide. One died from septicaemia 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 three years of the study.

Self-Perceived Health

The majority of participants reported that health problems were only a minor concern. Mean scores remained relatively stable over 10 years and ranged from 2.0 – 2.2 out of a possible high score of five indicating the most substantial concerns. There was a slight non-significant increase in perceived health problems at the 10th year.

Medical Services Utilisation

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

[Insert Figure 2 Here]

[Insert Figure 3 Here]

Hospitalisation

Forty eight percent ($n=22$) of the participants did not require hospitalization. There were a total of 47 hospital admissions reported; an average of 2 admissions for each participant hospitalised. Fifty two percent ($n=24$) had at least one hospital admission with 24% ($n=9$) having more than one admission. The overall rehospitalisation rate was 32.6% in the first two years and 52% by year ten. Figure 4 demonstrates that the percentage of participants requiring hospitalisation was maximal at year 10.

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 hospitalisations or LOS.

[Insert Figure 4 here]

Reason for Hospitalisation

Twenty seven (57.4%) of the 47 hospital admissions reported were classified as being related to SCI. Hospitalisation for reasons related to SCI was highest at 24 months. The major reasons for hospitalisations throughout the period of the study were pressure sores, urinary tract infections, bowel obstructions, pneumonia, surgical removal spinal instrumentation, fractures, and renal tract calculi. By the 10th year there were an increasing number of hospitalisations for conditions not directly related to the SCI.

[Insert Figure 5 here]

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 reported was at 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 reported over time.

Essentially the same group of participants were able to avoid pressure sores throughout the ten year study period. Of the 32 participants with complete data sets, 50% (n=16) reported no pressure sores at all over the 10 years. Those who developed

pressure sores tended to have them at multiple points of follow-up, with 30% (n= 13) reporting pressure sores at 2 or more points of follow-up.

[Insert Figure 6 here]

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 hospitalisation. However a group of up to 20% of respondents required extensive medical intervention including hospitalisation and pressure sore management.

Mortality

The mortality outcomes for this group are similar to those reported in other Australian studies (7% over the first ten years post injury excluding the initial acute phase⁽²⁷⁾) and those reported in the USA (9% at 10 years⁽²⁸⁾).

As in other studies the risk of premature death was highest in the early years post injury with all deaths occurring in the first three years. The high risk of suicide is highlighted with suicide accounting for half of the deaths in this sample. Septicaemia has also been found to be a significant contributor to premature death in other SCI populations, accounting for 9.8% of deaths.⁽²⁹⁾ DeVivo reports that individuals with SCI had a nearly 5 times increased risk of dying from suicide and a 64 times risk of dying from septicaemia than that of the general population.⁽³⁰⁾

Self-Perceived Health

Overall perceived health problems were not a major concern for the participants. However, there was a slight non-significant increase in perceived health problems at the 10th year suggesting an increase in medical concerns as participants aged and time since injury increased.

Medical Services Utilisation

In this study, approximately 10% of respondents required 10 or more non-routine medical consultations at each point of follow-up and by the 10 year follow-up 91% of participants required a non-routine medical consultation in the preceding 12 months. The utilisation 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 physician contacts per respondent (including those during hospitalisation), were 22 in the 1st year, 8 in the 2nd year and declined to 4 in the 6th year which is lower than in the present study.

Hospital Admission

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 rehospitalisation rate was 32.6% in the first 2 years and 52% of all participants by year ten. This finding is consistent with the findings of other Australian studies ⁽¹²⁾ but is somewhat lower than rates reported in the USA where readmission rates in the first 2 years post discharge are reported as ranging from 36% to 51%. ^(8, 9) Dryden et al ⁽⁴⁾ reported that the chance of being hospitalised 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 numbers of admissions.⁽⁴⁾ Mean LOS's ranging from 4 to 34 days to four days have been reported.^(1, 3-5, 10, 13, 31) In a comprehensive Australian review of hospital readmissions it is reported that 58.6% had been readmitted to hospital for a SCI related episode on one or more occasions over ten years with an average LOS of 15.5 days.⁽³¹⁾

The reasons for hospitalisation 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⁽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

While 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 again confirming the finding of many other studies; that there is a significant subgroup of people with SCI who experience

recurrent problems with pressure sores, requiring frequent hospitalisation and that risk is increased if there is a prior history of pressure sores. ^(17, 31, 32)

While this study found that there was no statistically significant change in the number of pressure sores reported over time, other researchers have found that the prevalence of pressure sores increases as time since injury increased. ^(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 suggested that a complex interaction of psychosocial and physical factors may be involved. ^(13, 15-17, 33)

Krause has suggested that the study of coping strategies and how these relate to pressure sores using a longitudinal design may be particularly enlightening. ⁽¹⁷⁾

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

Determination of the causal factors relating to health and medical problems is often difficult, however in many cases causation is complex interplay of biopsychosocial factors which all need to be considered to achieve optimal management. An approach that combines patient education ^(17, 35), training in cognitive behavioural and coping

strategies, screening and adequate treatment for affective disorders ⁽¹⁹⁾ and environmental interventions that facilitate such outcomes as improved social and personal supports and adequate resources, is likely to be most effective.

The health outcomes reported 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 which 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 used have categorical responses and thus reducing the sensitivity to change over time. This is a limitation, inherent in the LSQ, is discussed by Krause in a recent report. ⁽³⁶⁾ This study only reports events which occurred in the 12 month period immediately prior to interview and there is also a large gap between the three year report and the ten 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 findings of other studies, suggesting the data is 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 minimise further disabling experiences are to be developed.

Further research to identify high risk groups and factors which are amenable to intervention are clearly warranted. Long term consequences of living with SCI escalate as life expectancy increases, making it ever more important that we know what secondary conditions are experienced and 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 make it urgent that we fully understand these issues and develop strategies which will decrease the risk of complications and subsequent rehospitalisations.

Acknowledgements

We would like to acknowledge the support of the Princess Alexandra Foundation for a grant that supported the final stages of this study and acknowledge the assistance of Dr Dianna Battistuta, Queensland University of Technology, in the preparation of statistical data for this report.

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