

A comparison of independent living outcomes following traumatic brain injury and spinal cord injury

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This study compares independent living outcomes in persons with traumatic brain injury (TBI) and spinal cord injury (SCI). Both injuries represent life-altering events that are known to have a negative impact on independent living and are predominantly experienced by members of the same demographic group. However, the types of resultant impairments and disabilities experienced by the two populations differ substantially. The TBI participants were recruited consecutively from Canada's largest tertiary care trauma centre and followed prospectively for four years. The SCI participants were recruited via a mailed survey to members of a provincial branch of the Canadian Paraplegic Association. Independent living outcomes were measured using DeJong and Hughes' (1982) classification system of productivity status, the Reintegration to Normal Living Index, and questions on assistance from environmental supports in the form of wheelchair use and paid/unpaid personal assistance. The TBI group was found to be significantly more productive, have higher levels of satisfaction with their current experience of community integration, and use fewer environmental supports than their SCI counterparts ($P \leq 0.0001$). Methodological and demographic differences between the samples are discussed in relation to the results. The results suggest that various aspects of independent living in these two defined groups (TBI and SCI) although highly related require specific attention and that clinicians and researchers working with TBI and SCI might benefit from further collaborative efforts.

In dieser Studie wird das Maß an Unabhängigkeit bei Patienten mit traumatischen Hirnverletzungen (TBI) und Rückenmarksverletzungen (SCI) verglichen. Beide Verletzungen stellen Ereignisse dar, die das Leben verändern und sich negativ auf die unabhängige Lebensweise auswirken und von denen überwiegend Angehörige derselben demographischen Gruppe betroffen sind. Jedoch unterscheiden sich die Arten der resultierenden Beeinträchtigungen und Behinderungen in den beiden Kollektiven erheblich. Die Teilnehmer mit Hirntraumata wurden fortlaufend aus Kanadas größtem Traumazentrum der Spezialversorgung rekrutiert und prospektiv 4 Jahre lang beobachtet. Die Teilnehmer mit Rückenmarksverletzungen wurden mittels Fragebogen rekrutiert, der an Mitglieder eines regionalen Zweiges der Canadian Paraplegic Association verschickt wurde. Die Parameter der unabhängigen Lebensweise wurden anhand des Klassifikationssystems des Produktivitätsstatus (Reintegration to Normal Living Index) nach DeJong und Hughes (1982) und Fragen zur Unterstützung aus der Umgebung in Form von Rollstuhlbenutzung und bezahlter/unbezahlter persönlicher Pflege bestimmt. Es zeigte sich, dass Mitglieder der Hirntraumagruppe signifikant produktiver waren, einen höheren Zufriedenheitsgrad mit ihrer aktuellen gesellschaftlichen Integration hatten und weniger Unterstützung aus der Umgebung beanspruchten als die Mitglieder der Gruppe der Rückenmarksverletzten ($P \leq 0,0001$). Im Zusammenhang mit diesen Ergebnissen werden methodologische und demographische Unterschiede zwischen den Stichproben diskutiert. Die Ergebnisse legen den Schluss nahe, dass trotz des starken Zusammenhangs verschiedene Aspekte der unabhängigen Lebensweise in diesen beiden definierten Gruppen (Hirntrauma und Rückenmarksverletzung) besondere

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Aufmerksamkeit verlangen und dass Ärzte und Forscher, die mit diesen Patienten arbeiten, von weiteren gemeinsamen Ansätzen profitieren könnten.

Cette étude compare l'évolution de l'indépendance du mode de vie de patients victimes de lésions cérébrales traumatiques (LCT) et de lésions médullaires (LM). Ces deux types de lésions ont des répercussions vitales et sont connus pour retentir de façon négative sur un mode de vie indépendant et être essentiellement l'apanage des membres d'un même groupe démographique. Toutefois, les altérations et les handicaps qui en résultent diffèrent notablement selon le type de lésion. Les participants de cette étude atteints de LCT ont été recrutés de façon consécutive dans le plus important centre canadien de soins tertiaires pour traumatisme et ont été suivis de façon prospective pendant 4 ans. Les patients atteints de LM ont été recrutés au moyen d'un sondage par courrier parmi les membres d'une section provinciale de l'Association des Paraplégiques Canadiens. L'indépendance du mode de vie a été évaluée au moyen du système de classification de l'état productif de DeJong et Hughes (1982), de l'indice de reprise d'une vie normale (Reintegration to Normal Living Index) et de questions sur le recours à des aides extérieures, telles que chaises roulantes et assistants rémunérés ou non. Les membres du groupe LCT se sont montrés significativement plus productifs, ont exprimé des degrés de satisfaction plus élevés concernant leur intégration au sein de la communauté et ont nécessité moins d'aides extérieures que les patients du groupe LM ($p < 0,0001$). Les différences méthodologiques et démographiques sont discutées à la lumière des résultats obtenus. Cette étude suggère que, bien que très liés, les différents aspects d'un mode de vie indépendant pour ces deux groupes définis de patients (LCT et LM) imposent une attention spécifique et que les cliniciens et les chercheurs oeuvrant dans le domaine des LCT et des LM ont tout à gagner à conjuguer leurs efforts dans l'avenir.

En este estudio se compararon los resultados en cuanto a la vida independiente conseguidos por personas con traumatismo craneoencefálico (TCE) y lesión de la médula espinal (LME). Ambas lesiones representan acontecimientos vitalmente perturbadores que afectan de forma negativa a la vida independiente y son experimentados sobre todo por miembros del mismo grupo demográfico. Sin embargo, los tipos de deficiencia y discapacidad resultantes presentan diferencias distanciales entre los dos grupos. Los participantes con TCE fueron reclutados de manera consecutiva en el mayor centro terciario canadiense de traumatología, y sometidos a seguimiento prospectivo durante 4 años. Los participantes con LME fueron reclutados mediante una encuesta por correo realizada entre miembros de una delegación provincial de la Asociación de Paraplégicos de Canadá. Para medir los resultados de la vida independiente se utilizó el sistema de clasificación del estado de productividad de DeJong y Hughes (1982) (índice de reintegración en la vida normal) y se hicieron preguntas sobre la asistencia recibida del entorno en forma de sillas de ruedas y de ayuda personal remunerada o voluntaria. Se observó que los miembros del grupo de TCE eran significativamente más productivos, presentaban niveles superiores de satisfacción en su experiencia de integración en la comunidad y hacían menos uso de la asistencia del entorno que los miembros del grupo de LME ($P \leq 0,0001$). Se comentan las diferencias metodológicas y demográficas entre las muestras en relación con los resultados. Los resultados indican que, aunque están muy relacionados, diversos aspectos de la vida independiente de estos dos grupos (TCE y LME) requieren atención específica, y que los médicos e investigadores que trabajan con uno y otro podrían beneficiarse de la colaboración en el futuro.

Keywords: community integration; independent living; productivity; spinal cord injury; traumatic brain injury

Introduction

Successful independent living is a key outcome for persons who have experienced various illnesses or sustained various injuries including traumatic brain injuries and/or spinal cord injuries. Independent living includes having control over one's own life, fulfilling a range of social roles (including family responsibilities, employment in one's community), and having minimal dependence on others for the performance of routine, everyday activities (Frieden *et al.*, 1979). However, it involves not only one's participation in activity but also one's subjective experience of integration into the community. As such, aspects of successful independent living are associated with an

increased quality of life (DeJong and Hughes, 1982; Boschen, 1997; Dawson *et al.*, 2000) and with a decreased reliance on public financial support (DeJong and Hughes, 1982). Consequently, independent living is a primary outcome of interest for individuals with disabilities, service-providers, researchers, and policy makers.

Traumatic brain injury (TBI) and spinal cord injury (SCI) are events in peoples lives that are well known to have catastrophic effects on many injured persons' abilities to return to successful independent living in the community (Dikmen *et al.*, 1994; Boschen *et al.*, 2000; Friedland and Dawson, 2001; Boschen and Gargaro, in press; Dawson *et al.*, submitted). The percentage of persons returning to productive activity

(paid employment and/or school) following TBI depends on cohort and study methods, but generally ranges from about 25% to 65% (Stambrook *et al.*, 1990; Dikmen *et al.*, 1994; Dawson and Chipman, 1995) with one study reporting rates as high as 80% (Dawson *et al.*, submitted). Following SCI, return to productivity rates are generally reported as being quite low, that is between 25% and 30% (Castle, 1994; Krause and Anson, 1996). A high proportion of persons with SCI and TBI also require assistance with various basic and instrumental activities of daily living (ADL) following their injury. Drewes *et al.* (1989) reported that 65% of persons with quadriplegia required basic ADL assistance (e.g., bathing, dressing) and more than 80% required assistance with instrumental ADL (e.g., housecleaning). Data derived from the largest survey of community dwelling adults with TBI in Canada revealed that two thirds required assistance with some type of basic and/or instrumental ADL (Dawson and Chipman, 1995). Studies of persons with either SCI or TBI have also found substantially decreased participation in recreational and leisure activities enjoyed pre-injury (Kennedy and Smith, 1990; Ponsford *et al.*, 1995). Similarly, we know that longstanding psychosocial distress is extremely prevalent among both SCI and TBI survivors (Caplan *et al.*, 1984; Brown and Vander-goot, 1998; Dawson *et al.*, submitted).

These reports of apparently unsuccessful independent living following injury are made more poignant by the fact that individuals who sustain these injuries are generally young. In both the TBI and SCI groups, the highest incidence rates are among young males aged approximately 15 to 24 years (Kraus and McArthur, 1996). Further, the incidence rates for these injuries, particularly TBI are high. Annually, approximately 375,000 Americans sustain TBI's and an additional 10,000 sustain SCI's (Krause, 1991; Kraus and McArthur, 1996; DeVivo, 1997). These numbers are startling even for persons familiar with the epidemiology of these injuries. Clearly, the associated personal and societal costs are enormous and warrant efforts being directed at reducing these costs.

Despite similarities in the epidemiology and potential independent living outcomes of TBI and SCI, researchers, clinicians and TBI and SCI individuals have done little work together. This may be because the immediate effects and rehabilitation interventions are quite different, more physically oriented for SCI individuals and more cognitively oriented for TBI individuals. Nevertheless, we believe that there are potential benefits to working more collaboratively and that combining resources to work towards maximizing

successful community living would be helpful. One suggestion for the benefits of working together is illustrated by conceptual and empirical work done on independent living. Many more studies have been done on independent living in the SCI population than the TBI population stemming from DeJong and Hughes' landmark studies in the late 70's and early 80's (DeJong, 1979; DeJong and Hughes, 1982; DeJong *et al.*, 1984). In their initial survey of individuals two years post-SCI, DeJong and Hughes (1982) developed a classification system to objectively measure independent living that incorporated seven levels of living arrangement and 12 levels of productivity status. This classification system has been tested empirically and is useful for describing outcome, determining predictors of outcome, and potentially for measuring the impact of rehabilitation. Boschen and Gargaro (1998) have replicated the original work among the Ontario SCI population. Although the broader concept of independent living has been studied in the TBI population (e.g., McColl *et al.*, 1999), despite its obvious relevance DeJong and Hughes' model remains virtually unexplored in this group with one notable exception (Vogenthaler *et al.*, 1989).

A second suggestion for potential benefits in collaboration is provided by work we are doing on post-injury changes in psychological factors such as locus of control, coping style, and life orientation (Boschen and Gargaro, 1999; Dawson *et al.*, 2001–2004). It has been hypothesized that following TBI, injured persons develop maladaptive coping strategies and a more externalized locus of control which in turn contribute to negative experiences in community reintegration (Moore and Stambrook, 1995). A similar model could be valid for SCI. We have independently started to investigate these psychological factors in the TBI and SCI populations and offer this as an example of one area where combining resources might well be fruitful. In brief, we believe that persons interested in TBI and persons interested in SCI have much to learn from each other.

Purpose of the study

Consequently, we compared these two groups in order to increase knowledge particularly in relation to the degree of independent living attained by individuals following their injuries. Specifically, we undertook to compare these groups on three aspects of independent living: (1) participation in productive activity using DeJong and Hughes' (1982) methodology, (2) the

subjective experience of community reintegration, and (3) the amount and type of assistance needed for completion of ADL including physical (e.g., wheelchairs) and personal (weekly hours of paid/unpaid) assistance. In addition, we examined the relationship between participation in productive activity and the subjective experience of community reintegration among both groups. The overall goal of this study was to provide an opportunity to consider the value of studying outcomes among persons with TBI and SCI in concert.

Materials and Methods

Sample

The present study used samples from two larger studies on SCI and TBI (Boschen and Gargaro, 1998; Stuss *et al.*, 1999; Dawson *et al.*, submitted). The original SCI study was cross-sectional in design, the TBI study prospective in design.

SCI Sample

Data were collected via a mailed survey to all community-residing individuals with SCI on the 1992 mailing list of the Canadian Paraplegic Association – Ontario Division ($n=1769$). Details of the sampling are published elsewhere (Boschen, 1995; Boschen and Gargaro, in press). Inclusion criteria for this study were: at least one-year post SCI, traumatic cause for SCI (as opposed to disease or congenital) resulting in complete or incomplete para- or quadriplegia, and ages 16 to 65 years. Of 547 returned surveys, data from 440 participants (80.4%) met the inclusion criteria for this study.

TBI Sample

Participants were recruited consecutively at time of injury from Canada's largest regional trauma centre, the Sunnybrook Health Science Centre, Toronto ($n=94$). Exclusion criteria included: non-English speaking, penetrating TBI, age less than 16 or older than 65 years, a significant secondary hypoxic or hypotensive event, and history of previous neurological disorder, substance abuse, and/or psychiatric illness. Details of the sampling are published elsewhere (Stuss *et al.*, 1999; Dawson *et al.*, submitted). At approximately four years post-injury, 47 of 88 (53.4%) eligible participants completed face-to-face follow-up interviews. Participants in follow-up interviews were not significantly different from non-participants except for a longer length of stay in the acute trauma unit (22.4 days compared to 15.2 days, $p \leq 0.05$) (Dawson *et al.*, submitted).

Measurement

Participation in productive activity was measured using the Independent Living Questionnaire (ILQ) (Boschen and Gargaro, 1999; Boschen, 1993, 1995). This composite instrument includes the Personal Independence Profile (Nosek and Fuhrer, 1992; Nosek *et al.*, 1992), the Interpersonal Support Evaluation List (Skinner and McColl, 1991), and the Flanagan Quality of Life Scale (Flanagan, 1978, 1982). Additional questions on housing and daily activities were added to provide more detailed information about independent living. Each of the component measures of the ILQ has been shown to have reasonable psychometric properties. On the basis of responses to questions included in the ILQ, participants were classified according to DeJong's levels of productivity (see Appendix A).

The subjective experience of community reintegration was measured using the Reintegration to Normal Living Index (RNL) (Wood-Dauphinee *et al.*, 1988). This measure asks people to rank their experience with 10 aspects of community reintegration (e.g., I spend most of my days occupied in a work activity that is necessary and/or important to me.) The RNL has been shown to have good psychometric properties and has been used previously in both the SCI (Boschen, 1995) and the TBI (Friedland and Dawson, 2001) populations.

The amount and type of assistance in ADL were measured using questions from the ILQ in the SCI sample. The face-to-face interview with the TBI sample included the Craig Handicap Assessment and Reporting Technique (CHART, Whiteneck *et al.*, 1992), the Community Integration Questionnaire (Willer *et al.*, 1993) and the Functional Independence Measure (FIM) (Hamilton *et al.*, 1987). Items from these measures provided the necessary details about the amount and type of ADL assistance.

Statistical Analyses

Data analysis was conducted in three steps. Descriptive statistics were used to document participant characteristics, the component variables of the productivity status scores, the RNL scores, and the amount and type of assistance utilized by the two groups (TBI and SCI). Comparative analysis was then conducted using Wilcoxon 2-sample (rank sum) tests, chi-square tests of proportion, and Kruskal-Wallis tests (depending on the type of independent variable) to determine if differences existed between the two groups. Lastly, Spearman correlation coefficients were calculated between productivity status categories and RNL scores to determine the degree of association

between community integration and productivity. Non-parametric tests were used due to the ordinal nature of the data.

Results

Demographic and injury-related characteristics of participants are reported in Table 1. Significant differences between the groups were found for age ($p < 0.0001$), gender ($p < 0.0001$), marital status ($p < 0.0001$), level of education ($p < 0.0001$), and number of years post-injury ($p < 0.0001$). The SCI group was on average, eight years older, and had higher proportions of males, of persons who were separated, divorced or widowed, and of persons who had not completed high school. In terms of injury characteristics, the SCI group was almost eight years longer post-injury than the TBI group. More than 40% had complete quadriplegia, the most serious classification of SCI, and almost 32% of the TBI sample fell into the severely injured category.

The TBI group had higher levels of independent living in each of the four areas investigated (See

Table 2). Participants with TBI were significantly more productive than participants with SCI. As all TBI participants were in the top six of the 13 levels of productivity (See Appendix A), the levels were grouped into three categories for comparative analyses (DeJong and Hughes, 1982). Almost three-quarters of the TBI group was in the most productive category versus less than one-third of the SCI group. Further, none of the TBI group fell into the least productive category whereas more than twenty percent of the SCI group was in this category. Sixty-eight percent of the TBI group was engaged in full or part-time paid employment compared to 26% of the SCI group. Details of the classification are found in Appendix A (employment status, participation in school, homemaking, formal organizations, and active leisure).

In contrast, both groups reported good levels of community reintegration as measured by the RNL with mean scores over 80 out of 110.

In terms of the type and amount of environmental assistance needed, substantial differences were reported. The vast majority of participants with SCI reported using wheelchairs (94.50%) as compared to none of the TBI participants. Correspondingly, almost

Table 1. Demographic and Injury Profile of Participants

	TBI Participants (n=47)	SCI Participants (n=440)
Age in Years*		
Mean (SD)	31.78 (9.69)	39.69 (11.76)
Range	19–64	19–65
Gender** (Percent males)	53.0%	74.3%
Marital Status**		
Married/Common Law	46.8%	42.1%
Single/Engaged	48.9%	37.1%
Divorced/Separated/Widowed	4.3%	20.8%
Education**		
Less than High School Diploma	19.1%	25.9%
Obtained High School Diploma	34.0%	37.3%
1–4 Years Post-Secondary	46.8%	34.3%
Graduate School	0.0%	2.5%
Years Post-Injury		
Mean (SD)*	4.36 (0.90)	12.30 (9.86)
Range	2.89–5.83	1.0–50.0
Age in Years at time of Injury		
Mean (SD)	27.43 (9.69)	27.45 (12.17)
Range	16–60	0–62
6-hour GCS		
13–15 (Mild)	51.1%	
9–12 (Moderate)	17.0%	
3–8 (Severe)	31.9%	
Incomplete Paraplegia (Mild)		41.6%
Incomplete Quadriplegia (Moderate)		48.1%
Complete Paraplegia (Moderate)		4.9%
Complete Quadriplegia (Severe)		5.5%

* $p \leq 0.0001$ (Wilcoxon 2-sample (rank sums) test). ** $p \leq 0.0001$ (Chi-square).

Table 2. Independent Living Outcomes

	<i>TBI Participants (n=47)</i>	<i>SCI Participants (n=440)</i>
Productivity Status Categories*		
Most Productive (Levels 1–3)**	74.5%	28.9%
Moderately Productive (Levels 4–8)	25.6%	48.1%
Least Productive (Levels 9–13)	0.0%	23.0%
Reintegration to Normal Living* RNL Summed Score (/110)		
Mean (SD)	97.0 (17.1)	84.3 (18.1)
Range	45–110	19–110
Environmental Assistance*		
Using Wheelchairs	0.0%	94.50%
Weekly Hours of Paid and Unpaid Assistance*		
0hours/Week	85.1%	33.8%
<5hours/Week	6.3%	15.8%
5–10hours/Week	4.3%	14.0%
11–20hours/Week	2.1%	12.3%
21–30hours/Week	0.0%	9.9%
>30hours/Week	2.1%	14.2%

*Chi-square $p \leq 0.0001$; **See Appendix A for details of each level.

Table 3. Correlations Between the RNL Index Scores and Productivity Status

<i>Correlation* of RNL and Productivity Status</i>	
All Participants	–0.4567 ($p \leq 0.0001$)
TBI Participants Only	–0.4920 ($p \leq 0.0007$)
SCI Participants Only	–0.4013 ($p \leq 0.0001$)

*Spearman correlation coefficients.

70% of the SCI participants reported receiving paid or unpaid assistance weekly compared to less than 15% of TBI participants.

Table 3 shows the positive correlations between two aspects of independent living: productivity status and the subjective experience of community integration scores as measured by the RNL for all study participants, for the TBI participants only, and for the SCI participants only. That is, persons who reported higher levels of productivity also reported more satisfaction with their community integration status. In each case, the correlations were moderate in size and significant. Further, the size of correlation was very similar in each analysis.

Discussion

The two main findings in this study enhance our understanding of independent living among persons with TBI and SCI. First, we found a strong and significant relationship between participation in productive activity and the subjective experience of community reintegration in both groups. Individuals

with higher levels of involvement in productive activity reported more satisfaction with their overall community reintegration. Second, our results clearly separated the two groups (TBI and SCI) in terms of independent living outcomes. Successful independent living (participation in productive activity and the subjective experience of community reintegration) is a significantly larger problem among persons with SCI than those with TBI.

The highly significant correlations we found between participation in productive activity and the subjective experience of community reintegration confirm that these aspects of independent living are related. However, the moderately sized correlation coefficients show that they are not the same things. Engagement in paid employment is an important aspect of community integration but it is not the only aspect. We would now like to consider whether participation in productive activity is a primary determinant of satisfaction with community reintegration or vice versa. A prospective study following persons with TBI and persons with SCI would provide important data. Regardless, these findings provide impetus to clinicians and researchers to consider various aspects of independent living both in developing rehabilitation interventions and designing research studies.

Persons with TBI reported substantially higher levels of independent living in terms of participation in productive activity with almost three-quarters falling into the most productive category. In contrast, more than 70% of the SCI survivors were in the moderately or least productive categories. These results are likely due to a combination of factors

including study design, response bias and participant demographics. Nevertheless, the difference is substantial and could well represent a real variation between the groups as our findings confirm previously reported results (Brown and Nell, 1992; Castle, 1994; Dikmen *et al.*, 1994; Krause and Anson, 1996).

Why would such a large difference exist? Our primary hypothesis is that environmental barriers play a highly significant role in return to productivity particularly following SCI. Not surprisingly, we found that persons with SCI are more restricted physically and require more assistance to complete daily tasks and activities. Castle (1994) found that individuals with SCI deemed access to buildings as the key barrier in consideration of participation in employment. These facts mean that their choices of productivity, household, and leisure activities are limited. In contrast, individuals with TBI are less likely to require assistance from others for completion of daily tasks and activities, leaving them with a greater degree of freedom to choose various employment, household, and leisure activities. Persons with TBI often require other forms of environmental assistance to compensate for cognitive impairments (e.g., personal digital assistants or memory notebooks). However, these are generally highly portable and more easily incorporated into day-to-day and work-related activities than the wheelchairs used by almost 95% of the SCI sample in this study.

A second hypothesis for the difference in independent living outcomes is differences in rehabilitation approaches. For example, a common rehabilitation approach used with persons with TBI is supported employment. This is often thought to be necessary to address the problems facing a person with TBI with cognitive impairments. It might be fruitful to investigate the value of such an approach with the SCI population as well.

As mentioned earlier, the differences we found in independent living outcomes among persons with SCI and TBI might also be related to methodological differences in the way data on these two groups were collected. The TBI participants were recruited consecutively at time of injury and followed prospectively. The SCI participants were recruited from an existing database and represent a cross-section of persons living with SCI in the province of Ontario. Thus, we have incidence data on TBI and prevalence data on SCI. Further, although demographically consistent with the overall SCI population, the sample in this study represents responses from only one-quarter of the surveys mailed. Respondents may have been biased in some way: we do not know if their responses are representative of the SCI population as a whole.

This was not the case for TBI participants, as they did not differ from non-participants except that the participants had a slightly longer length of stay in the acute care hospital. It is however possible that this TBI group may be less severely injured than some TBI samples as those with a secondary hypoxic or hypotensive event were excluded from the study. Finally, the socio-demographic characteristics of the SCI sample (older, higher proportion of males, loss of marital partner, less education) were significantly different from those in the TBI group. It is possible that marital status changed as a result of the SCI (divorce, separation) and that individuals left school because of their SCI. This would represent aspects of less successful independent living in the SCI group if this were the case. It is also possible that the group was made up of more single people with lower levels of education compared to the TBI group and that these factors (along with age and gender) contributed to lower levels of productivity status as these factors are known to be related to productivity.

In addition to highlighting important differences and similarities between outcomes among the TBI and SCI groups, this study also demonstrated the merit of comparing these two groups. First, we were able to draw from important work in the SCI literature on measuring productivity outcomes and apply this to the TBI group. At present, there is no consensus in the literature on how productive activity should be measured. The most common approach in the TBI literature is to focus on whether or not an individual has returned to paid employment. Such assessments neglect many important aspects of productivity. DeJong and Hughes' (1982) classification provided a valuable model for looking at productive activity. This more detailed and comprehensive way of assessing productive activity may prove fruitful for other TBI studies.

Research on independent living during the current era of fiscal restraint in health and rehabilitation expenditures can be used to justify programs and services of highest priority within differing populations. Our comparison of independent living and community integration measures between two groups with disabilities reveals important perspectives in understanding "real life" outcomes. Although this study has shown that persons with TBI have higher levels of community integration and productivity than a comparison group of SCI individuals, it is important to remember the large difference in incidence rates of the two types of injuries. Examining annual U.S. prevalence rates, approximately 3,000 persons with SCI may return to productivity, leaving 7,000 individuals requiring considerable assistance and

experiencing poor integration into their communities. In contrast, even if three-quarters of those persons with TBI are able to return to work and/or school, over 90,000 newly injured individuals remain unable to do so each year. It is thus imperative to continue to work in the area of facilitating the highest possible levels of independent living for both persons with TBI and SCI.

The strong relationship we found between productive activity and the subjective experience of community reintegration confirms the importance of addressing various aspects of independent living in rehabilitation. As well it provides the impetus for future exploration of common factors that contribute to overall successful independent living. The discrepancies in rates of return to productive activity between persons with TBI and SCI provide an impetus for investigating the reasons for this and an impetus for sharing effective 'return to work' rehabilitation strategies. An example of potential benefits in studying TBI and SCI together is our use of DeJong and Hughes' (1982) productivity classification that was drawn from the SCI literature and proved valuable and relevant to the TBI group as well. Further work will determine if additional benefits can be realized.

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REFERENCES

- Boschen, K. A. (1993). Variables that influence independent living. *Canadian Journal of Rehabilitation*, **7**(1), 50–1.
- Boschen, K. A. (1995). Variables affecting independent living for persons with physical disabilities: Final report (unpublished).
- Boschen, K. A. (1997). Measuring quality of life of adults with spinal cord injuries: Lessons for developmental disabilities research. *Journal of Developmental Disabilities*, **5**(1), 91–5.
- Boschen, K. A. and Gargaro, J. (in press). Characteristics of people with spinal cord injury who live independently in the community. *Canadian Journal of Occupational Therapy*.
- Boschen, K. A. and Gargaro, J. (1999). The Independent Living Questionnaire: A long-term outcome measurement tool. *Journal of Rehabilitation Outcome Measurement*, **3**, 1–9.
- Boschen, K. A. and Gargaro, J. (1998). Independent living long-term outcome variables in spinal cord injury: A replication of DeJong. *International Journal of Rehabilitation Research*, **21**, 285–300.
- Boschen, K. A., Tonack, M. and Gargaro, J. (2000). Measuring successful rehabilitation of adults with spinal cord injury. *American Journal of Physical Medicine & Rehabilitation*, **81**, 1618.
- Brown, D. and Nell, V. (1992). Recovery from diffuse traumatic brain injury in Johannesburg: A concurrent prospective study. *Archives of Physical Medicine and Rehabilitation*, **73**, 758–70.
- Brown, M. and Vandergoot, D. (1998). Quality of life for individuals with traumatic brain injury: Comparison with others living in the community. *Journal of Head Trauma Rehabilitation*, **13**(4), 1–23.
- Caplan, B., Gibson, C. J. and Weiss, R. (1984). Stressful sequelae of disabling illness. *International Rehabilitation Medicine*, **6**(2), 58–62.
- Castle, R. (1994). An investigation into the employment and occupation of patients with a spinal cord injury. *Paraplegia*, **32**, 182–7.
- Dawson, D. and Chipman, M. (1995). The disablement experienced by traumatically brain-injured adults living in the community. *Brain Injury*, **9**(4), 339–53.
- Dawson, D. R., Levine, B., Escobar, M. D., Schwartz, M. L. and Stuss, D. T. (submitted). *The relationship of acute traumatic brain injury characteristics to functional outcome at one and four years post-injury: A prospective study*.
- Dawson, D. R., Stuss, D. T., Winocur, G., and Schwartz, M. L. (2001–2004). *The stability of psychological factors following traumatic brain injury: A prospective study*. Grant #01056-0, Ontario Neurotrauma Foundation.
- DeJong, G. (1979). Independent living: From social movement to analytic paradigm. *Archives of Physical Medicine and Rehabilitation*, **60**, 435–46.
- DeJong, G., Branch, L. G. and Corcoran, P. J. (1984). Independent living outcomes in spinal cord injury: Multivariate analyses. *Archives of Physical Medicine and Rehabilitation*, **65**, 66–73.
- DeJong, G. and Hughes, J. (1982). Independent living: Methodology for measuring long-term outcomes. *Archives of Physical Medicine and Rehabilitation*, **63**, 68–73.
- DeVivo, M. J. (1997). Causes and costs of spinal cord injury in the United States. *Spinal Cord*, **35**, 809–13.
- Dikmen, S. S., Temkin, N. R., Machamer, J. E., Holubkov, A. L., Fraser, R. T. and Winn, R. (1994). Employment following traumatic head injuries. *Archives of Neurology*, **51**, 177–86.

- Drewes, A. M., Olsson, A. T., Slot, O. and Andreasen, A. (1989). Rehabilitation outcome for patients with spinal cord injury. *International Disability Studies*, **11**(4), 178–80.
- Flanagan, J. C. (1978). A research approach to improving our quality of life. *American Psychologist*, **33**, 138–47.
- Flanagan, J. C. (1982). Measurement of quality of life: Current state of the art. *Archives of Physical Medicine and Rehabilitation*, **63**, 56–9.
- Frieden, L. and Cole, J. A. (1985). Independence: The ultimate goal of rehabilitation for spinal cord-injured persons. *American Journal of Occupational Therapy*, **39**(11), 734–9.
- Frieden, L., Richards, L., Cole, J. and Bailey, D. (1979). ILRU Source Book: A Technical Assistance Manual on Independent Living. Houston: The Institute for Rehabilitation and Research.
- Friedland, J. and Dawson, D. R. (2001). Function after motor vehicle accidents: A prospective study of mild head injury and posttraumatic stress. *Journal of Nervous and Mental Disease*, **189**, 426–34.
- Hamilton, B. B., Granger, C. V., Sherwin, F. S., Zielezny, M. and Tashman, J. S. (1987). A uniform national data system for medical rehabilitation. In: *Rehabilitation Outcomes: Analysis and Measurement*. (edited by Fuhrer, M.J.), pp. 137–47. Baltimore: Paul H. Brookes.
- Kennedy, D. W. and Smith, R. W. (1990). A comparison of past and future leisure activity participation between spinal cord injured and non-disabled persons. *Paraplegia*, **28**, 130–6.
- Kraus, J. F. and McArthur, D. L. (1996). Epidemiologic aspects of brain injury. *Neurologic Clinics*, **14**(2), 435–50.
- Krause, J. S. (1991). Survival following spinal cord injury: A fifteen-year prospective study. *Rehabilitation Psychology*, **36**(2), 89–98.
- Krause, J. S. and Anson, C. A. (1996). Employment after spinal cord injury: Relation to selected participant characteristics. *Archives of Physical Medicine and Rehabilitation*, **77**, 737–43.
- McCull, M., Davies, D., Carlson, P., Johnston, J., Harrick, L., Minnes, P. and Shue, K. (1999). Transitions to independent living after ABI. *Brain Injury*, **13**(5), 311–30.
- Moore, A. D. and Stambrook, M. (1995). Cognitive moderators of outcome following traumatic brain injury: A conceptual model and implications for rehabilitation. *Brain Injury*, **9**, 103–30.
- Nosek, M. A. and Fuhrer, M. J. (1992). Independence among people with disabilities: I: A heuristic model. *Rehabilitation Counseling Bulletin*, **36**, 6–20.
- Nosek, M. A., Fuhrer, M. J. and Howland, C. A. (1992). Independence among people with disabilities: II. Personal Independence Profile. *Rehabilitation Counseling Bulletin*, **36**, 21–36.
- Ponsford, J. L., Olver, J. H. and Curran, C. (1995). A profile of outcome: 2 years after traumatic brain injury. *Brain Injury*, **9**(1), 1–10.
- Skinner, H. A., and McColl, M. A. (1991). Measuring social support, coping and adjustment in a disabled population: Final report (unpublished).
- Stambrook, M., Moore, A. D., Peters, L. C., Deviaene, C. and Hawryluk, G. A. (1990). Effects of mild, moderate and severe closed head injury on long-term vocational status. *Brain Injury*, **4**(2), 183–90.
- Stuss, D. T., Binns, M. A., Carruth, F. G., Levine, B., Brandys, C. E., Moulton, M. J., Snow, W. G. and Schwartz, M. L. (1999). The acute TBI recovery period: Post-traumatic amnesia or post-traumatic confusional state? *Journal of Neurosurgery*, **90**, 635–43.
- Vogenthaler, D. R., Smith, K. R. and Goldfader, P. (1989). Head injury, a multivariate study: Predicting long-term productivity and independent living outcome. *Brain Injury*, **3**(4), 369–85.
- Whiteneck, G. G., Charlifue, S. W., Gerhart, K. A., Overholser, J. D. and Richardson, G. N. (1992). Quantifying handicap: A new measure of long-term rehabilitation outcomes. *Archives of Physical Medicine and Rehabilitation*, **73**, 519–26.
- Willer, B., Linn, R. and Allen, K. (1993). Community integration and barriers to integration for individuals with brain injury. In: *Brain Injury Rehabilitation: Clinical Considerations*. (edited by Finlayson, M. A. J. and Garner, S.). Baltimore, Maryland: Williams and Wilkins.
- Wood-Dauphinee, S. L., Opzoomer, M. A., Williams, J. I., Marchand, B. and Spitzer, W. O. (1988). Assessment of global function: The Reintegration to Normal Living Index. *Archives of Physical Medicine and Rehabilitation*, **69**, 583–90.

Appendix A. Classification of Participants Using DeJong and Hughes' (1982) Levels of Productivity Status

<i>Productivity status category</i>	<i>Level</i>	<i>Employment status</i>	<i>Attending educational facility</i>	<i>Participation in formal organizations</i>	<i>Participation in homemaking</i>	<i>Participation in active leisure</i>	<i>TBI Sample (n=47)</i>	<i>SCI sample (n=438)</i>
Most Productive	1	FT	May or may not be participating in these 3 areas. Must participate in at least 2 of these 3 areas			Yes	51.1 (24)	7.3 (32)
	2	PT	May or may not be participating in these 3 areas. Must participate in at least 2 of these 3 areas			Yes	17.0 (8)	5.0 (22)
	3	No	Yes	Yes	Yes	Yes	6.4 (3)	5.9 (26)
Moderately Productive	4	No	Yes	No	Yes or No	Yes	4.3 (2)	18.5 (81)
	5	No	No	Yes	Yes	Yes	14.9 (7)	5.5 (24)
	6	No	No	No	Yes	Yes (≥ 15 times/month)	4.3 (2)	7.8 (34)
	7	No	No	Yes	No	Yes	0.0 (0)	7.3 (32)
	8	No	No	No	Yes	Yes (< 15 times/month)	2.1 (1)	5.9 (26)
Least Productive	9	No	Attend school or participate in formal organizations but not both		No	No	0.0 (0)	1.6 (7)
	10	No	No	No	No	Yes (≥ 6 times/month)	0.0 (0)	4.6 (20)
	*11	No	No	Yes or No	Yes or No	No or Yes (< 6 times/month)	0.0 (0)	19.2 (54)
	12	No	No	Yes	Yes	Yes (< 6 times/month)	0.0 (0)	0.7 (3)
	13	No	No	No	No	No	0.0 (0)	10.7 (47)

*Category 11 added by Boschen and Gargaro (1998).