

ORIGINAL ARTICLE

A comparison of patients' and physiotherapists' expectations about walking post spinal cord injury: a longitudinal cohort study

LA Harvey¹, R Adams², J Chu¹, J Batty³ and D Barratt⁴

Study design: A longitudinal cohort study.

Objective: The primary objective of this study was to compare the expectations that patients with recent spinal cord injury (SCI) had about walking 1 year from injury with the expectations of their physiotherapists.

Setting: Two Sydney SCI units.

Methods: A consecutive series of 47 patients admitted to the metropolitan SCI units was recruited. Using the Mobility Scale, expectations of the patients and their physiotherapists about walking at 1 year from SCI were recorded at the time of admission to rehabilitation. Ability to walk was then assessed at 1 year from the SCI.

Results: On admission to rehabilitation, 31 patients expected to walk about their homes at 1 year post SCI, but only 18 (58%) of these patients did so. In contrast, physiotherapists expected 21 patients to be able to walk about their homes at 1 year post SCI, with 17 (81%) of these patients doing so. Similarly, whereas 21 patients expected to walk about the community at 1 year post SCI, only 11 (52%) of these patients did so. Physiotherapists expected 8 patients to walk about the community at 1 year post SCI and 7 (88%) of these patients did so. The differences between patients' and physiotherapists' expectations about walking were statistically significant ($P < 0.001$).

Conclusion: There is a high degree of disagreement between patients' and physiotherapists' expectations about walking at 1 year post SCI. Differences between patients' and physiotherapists' expectations about walking are potentially problematic and requires research to identify appropriate management strategies.

Spinal Cord (2012) **50**, 548–552; doi:10.1038/sc.2012.1; published online 7 February 2012

Keywords: spinal cord injuries; rehabilitation; outcome assessment; physical therapy

INTRODUCTION

Effective therapy following spinal cord injury (SCI) relies on a working partnership between patients and physiotherapists. Together they must set goals and plan the focus of therapy. It is therefore potentially problematic for the working relationship if patients and physiotherapists have markedly different expectations about likely outcomes, particularly if they have different expectations about likely outcomes for the fundamental motor skill of walking. A discrepancy between patients' and physiotherapists' expectations about walking can lead to problems during rehabilitation and for the patients' adjustment to SCI. For example, if patients expect to walk, they may be unwilling to learn wheelchair and transfer skills because they perceive these motor skills as not being relevant to them. In addition, patients' expectations about walking can prompt them to forgo standard rehabilitation while pursuing programs that focus primarily on gait. However, the results of a recent study indicate that patients who primarily focus on walking after SCI, but never attain it, have a lower quality of life, higher dependence and more depression at 1 year after SCI than their counterparts who master independence from a seated position.¹

Clinical observations suggest that patients, regardless of the severity of their SCI, increasingly expect to walk following SCI. There may be

several explanations for this expectation, including patients' need for hope.^{2,3} In addition, patients may be increasingly expecting to walk because of the current media and scientific attention^{4–7} given to neural plasticity, locomotor training and 'recovery' programs. Such media exposure may heighten the expectations of walking in patients with serious motor complete SCI. Physiotherapists, however, have access to relatively accurate information about the likelihood of patients walking following SCI.^{1,8–17} For example, a recent large cohort study found that a combination of age, motor scores in the quadriceps and gastrocnemius muscles, and the presence of light touch sensation in the L3 and S2 dermatomes at 2 weeks post SCI could accurately discriminate between independent walkers and non-walkers at 1 year post SCI with the level of accuracy given by the area under the receiver–operator curve being 0.96 (95% confidence interval (CI) 0.94–0.98).¹⁷ We were interested in obtaining a better understanding of the patients' and physiotherapists' expectations about walking after SCI. A previous study in 2000 from the Netherlands has examined a similar issue.¹⁸ This study included 44 patients and found that they had expectations similar to the rehabilitation team about future walking. However, this retrospective study looked only at mobility following discharge, and not at 1 year following SCI. In addition, it

¹Rehabilitation Studies Unit, Northern Clinical School, Sydney School of Medicine, University of Sydney, Sydney, New South Wales, Australia; ²Discipline of Physiotherapy, Faculty of Health Sciences, University of Sydney, Sydney, New South Wales, Australia; ³Spinal Injury Unit, Prince of Wales Hospital, Sydney, New South Wales, Australia. and ⁴Spinal Injury Unit, Royal North Shore Hospital, Sydney, New South Wales, Australia
Correspondence: Associate Professor LA Harvey, Rehabilitation Studies Unit, Northern Clinical School, Royal Rehabilitation Centre Sydney, PO Box 6, Ryde, New South Wales 1680, Australia. E-mail: lisa.harvey@sydney.edu.au

Received 13 September 2011; revised 23 December 2011; accepted 31 December 2011; published online 7 February 2012

was conducted before the recent media and scientific interest in neural plasticity and recovery following SCI. The purpose of the present study, therefore, was to compare patients' and physiotherapists' expectations about walking at 1 year from SCI in a cohort longitudinal study.

MATERIALS AND METHODS

This study was part of a larger project in which groups of contact physiotherapists and non-contact physiotherapists were asked, shortly after patients' admission to rehabilitation, to predict what patients' mobility and equipment needs would be in 3 months, 1 year and 5 years time. The methodology and accuracy of physiotherapists' predictions about mobility at 3 months have been published elsewhere.¹⁹ A second paper has looked at the importance of direct face-to-face contact between physiotherapists and patients for setting realistic goals. The present work evaluates the discrepancy between patients' and physiotherapists' expectations about walking at 1 year after SCI.

All patients admitted to two Sydney SCI units between March 2009 and March 2010 were screened ($n=93$) for inclusion. Patients were eligible for inclusion if they had an American Spinal Injury Association (ASIA) Impairment Scale (AIS) A at the neurological level of C5 or below, or if they had an AIS B, C or D lesion at any neurological level, provided they were receiving their first episode of rehabilitation following recent SCI. Patients were excluded if they were under the age of 18, were diagnosed with a deteriorating medical condition, had commenced rehabilitation elsewhere before admission to the SCI unit or had an AIS E lesion. The study received ethical approval from the appropriate institutions and informed consent was obtained from all patients and physiotherapists. The institutional and governmental regulations concerning the ethical use of human volunteers were followed during the course of this research.

At a median of 45 days (31–73) after SCI and 25 days (14–41) after commencement of rehabilitation, patients and their physiotherapists were separately asked about their expectations of walking at 1 year post SCI. The physiotherapists ($n=5$) had a median (interquartile range) of 5 years (5–10) clinical experience in SCI. Patients and physiotherapists did not together openly discuss their expectations as part of this study although they may have discussed their expectations as part of the rehabilitation process. Specifically, patients and physiotherapists were asked to predict future scores on the Mobility Scale.²⁰ Then, one year later (median, 1 year after SCI; interquartile range, 1.0–1.1 year), an independent physiotherapist assessed patients' ability to walk using the Mobility Scale. The assessor was blinded to all predictions and was not involved in the patients' rehabilitation.

The Mobility Scale categorised walking as follows:

1. Physiological walker (that is, stands or walks for exercise only): Walks for exercise only either at home or in parallel bars during physical therapy.
2. Limited household walker: Relies on walking to some extent for home activities.
3. Independent household walker: Walks for all household activities without any reliance on a wheelchair.
4. Most-limited community walker: Can enter and leave home independently; independent in at least one moderate community activity (that is, appointments, restaurants) but needs assistance or is unable to walk for most community activities (that is, walking about in the neighbourhood, visiting a friend).
5. Least-limited community walker: Independent in all moderate community activities without assistance or use of wheelchair.
6. Independent community walker: Independent in all home and community activities.

For the purposes of this study, non-walkers and predictions of not walking were scored 1 on the Mobility Scale. The Mobility Scale was selected as it captures the usefulness of walking about the home and community, and because patients could readily understand the scoring system. In addition, it reflects the range of patients' expectations about walking in their day-to-day lives. The Mobility Scale was dichotomised in two ways for analysis; first, walking was dichotomised by the ability to walk about the house in a limited way (that is, a

Mobility Score of $\geq 2/6$); second, walking was dichotomised by the ability to walk about the community in a limited way (that is, a Mobility Score of $\geq 5/6$). Dichotomising the data in this way reduced the implications of errors in scoring because it was relatively simple for all to distinguish between a score of 1 and 2, and between a score of 4 and 5, all that was required to accurately dichotomise walking ability.

Stata software (version 11; Texas, USA) was used for all analyses. Patients' and physiotherapists' expectations about walking were compared using χ^2 . All analyses were repeated with a subgroup of patients, namely those with AIS A and B lesions. These *post-hoc* analyses were performed to explore the possibility that most of the discrepancies between patients' and physiotherapists' expectations about walking were due to patients with motor complete SCI (AIS A and B) expecting to walk—expectations that were not realised or shared by their physiotherapists.

RESULTS

Ninety-three patients were admitted to the two SCI units and screened for inclusion over the 1-year study period. In all, 36 of the 93 screened patients were excluded because they were under the age of 18 ($n=2$), were diagnosed with deteriorating medical conditions ($n=3$), had commenced rehabilitation elsewhere before admission to the SCI unit ($n=17$), had sustained an AIS A injury at $\geq C4$ ($n=9$), or had an (AIS) E lesion ($n=5$). An additional seven potentially eligible patients declined to be involved and three patients were recruited and made predictions but were lost to follow-up at 1 year. The characteristics of the remaining 47 patients included in the study are shown in Table 1. In total, 41/47 patients were unable to walk in any way on admission to rehabilitation and 20/47 patients were able to at least walk in a limited way about their homes, at 1 year post SCI.

Tables 2 and 3 provide patients' and physiotherapists' expectations about walking compared with walking ability at 1 year. Table 4 provides the positive and negative likelihood ratios reflecting the realisation of patients' and physiotherapists' expectations about walking at 1 year, and Table 5 compares patients' and physiotherapists' expectations about walking. On admission to rehabilitation, 31 patients expected to walk about the homes at 1 year post SCI, but

Table 1 Characteristics of patients on admission to rehabilitation ($n=47$)

Age (years), median (interquartile range)	42 (25–58)
Sex (male:female), n (%)	43:4 (91:9)
AIS, n (%)	
AIS A	16 (34)
AIS B	9 (19)
AIS C	9 (19)
AIS D	13 (28)
Neurological level, n (%)	
C1–C8	28 (60)
T1–T12	15 (32)
L1–L5	4 (8)
The Mobility Scale, n (%)	
1	41 (87)
2	4 (9)
3	1 (2)
4	0 (0)
5	0 (0)
6	1 (2)

Abbreviation: AIS, Asia Impairment Scale.

Table 2 Patients' expectations about walking about the house (a) and walking about the community (b) on admission to rehabilitation versus walking ability at 1 year (n=47)

	<i>Does not walk</i>	<i>Walks</i>	<i>Total</i>
<i>(a)</i>			
Does not expect to walk	14	2	16
Expects to walk	13	18	31
Total	27	20	47
<i>(b)</i>			
Does not expect to walk	26	0	26
Expects to walk	10	11	21
Total	36	11	47

Bolding indicates that patients' expectations about walking matched their walking ability at 1 year.

Table 3 Physiotherapists' expectations about patients' walking about the house (a) and walking about the community (b) on admission to rehabilitation versus walking ability at 1 year (n=47)

	<i>Does not walk</i>	<i>Walks</i>	<i>Total</i>
<i>(a)</i>			
Does not expect to walk	23	3	26
Expects to walk	4	17	21
Total	27	20	47
<i>(b)</i>			
Does not expect to walk	35	4	39
Expects to walk	1	7	8
Total	36	11	47

Bolding indicates that physiotherapists' expectations about walking matched the patients' walking ability at 1 year.

Table 4 Positive and negative likelihood ratios reflecting the realisation of patients' and physiotherapists' expectations about walking or not walking at 1 year (n=47)

	<i>Patients</i>	<i>Physiotherapists</i>
<i>Walk about the home</i>		
+ive likelihood ratio	1.9 (1.2–2.8)	5.7 (2.3–14.4)
–ive likelihood ratio	0.2 (0.1–0.8)	0.2 (0.1–0.5)
<i>Walk about the community</i>		
+ive likelihood ratio	3.6 (2.1–6.1)	22.9 (3.2–167.0)
–ive likelihood ratio	0 (not calculable)	0.4 (0.2–0.8)

only 18 (58%) of these patients did so. The corresponding positive likelihood ratio was 1.9 (95% CI, 1.2–2.8). In contrast, physiotherapists expected 21 patients to walk around their homes at 1 year post SCI, with 17 (81%) of these patients doing so. The corresponding positive likelihood ratio was 5.7 (95% CI, 2.3–14.4). The difference between patients' and physiotherapists' expectations of walking about their homes was statistically significant ($P=0.000$). The contrast between patients' and physiotherapists' expectations about walking about the community was similar. Whereas 21 patients expected to walk about the community at 1 year post SCI, only 11 (52%) of these

Table 5 Patients' versus physiotherapists' expectations about walking about the house (a) and walking about the community (b) (n=47)

<i>Physiotherapists' expectations</i>	<i>Patients' expectations</i>		<i>Total</i>
	<i>Does not expect to walk</i>	<i>Expects to walk</i>	
<i>(a)</i>			
Does not expect to walk	15	11	26
Expects to walk	1	20	21
Total	16	31	47
		(χ^2 , $P=0.000$)	
<i>(b)</i>			
Does not expect to walk	25	14	39
Expects to walk	1	7	8
Total	26	21	47
		(χ^2 , $P=0.007$)	

Bolding indicates that patients' expectations about walking matched physiotherapists' expectations about walking.

patients did so (positive likelihood ratio 3.6; 95% CI, 2.1–6.1). Physiotherapists expected 8 patients to walk about the community at 1 year post SCI and 7 (88%) of these patients did so (positive likelihood ratio 22.9; 95% CI, 3.2–167.0). The difference between patients' and physiotherapists' expectations of walking about the community was statistically significant ($P=0.007$).

There was discrepancy between the expectations of patients with AIS A and AIS B lesions and physiotherapists' expectations about future walking. In all, 12 patients with AIS A and AIS B lesions expected to walk about the home but only 2 (17%) did so, and 6 patients expected to walk about the community but only 1 (17%) did so. In contrast, physiotherapists expected three patients with an AIS A or AIS B lesion to walk about the home and one patient to walk about the community, with all except one doing so. The expectations of patients and physiotherapists about walking about the home and community were not significantly different ($P>0.05$).

DISCUSSION

The results of this study indicate that there is a discrepancy between patients' and physiotherapists' expectations about future walking. The results raise for the first time the mismatch between patients' and physiotherapists' expectations about recovery and walking post SCI. It is difficult to know whether this discrepancy is an age-old phenomenon, or a recent consequence of the current scientific and media attention about neural plasticity, locomotor training and 'recovery' programs. A previous study²¹ has addressed the discrepancy between occupational therapists' and patients' expectations, but only in the area of self-care and only in 25 patients with recent tetraplegia. It found that patients' expectations about independence with self-care at 1 year post injury were notably higher than those of their occupational therapists. For example, 70% of the patients expected to gain independence with feeding, but only 20% of the occupational therapists shared their patients' expectations.

While the sample size in the present study was modest, it was sufficient to enable detection of statistically significant differences between patients' and physiotherapists' expectations about walking. The modest sample size did, however, lead to some imprecision associated with the estimates of the positive likelihood ratios (reflected

in the width of the 95% CI). In contrast, the negative likelihood ratios were very precise, indicating that the patients' and physiotherapists' expectations were good at ruling out the possibility of walking. The modest sample size may partly account for our failure to detect statistically significant differences between the expectations of patients with AIS A and AIS B lesions and those of physiotherapists about walking. This *post hoc* analysis was included to explore the hypothesis that most of the discrepancy between patients' and physiotherapists' expectations about walking is due to patients with AIS A and AIS B lesions expecting to walk, expectations that are not realised or shared by their physiotherapists. We also explored the possibility that the way in which we dichotomised the data affected the results by way of repeating the analyses with community ambulation defined by a score of $\geq 4/6$ on the Mobility Scale (rather than a score of $\geq 5/6$). However, this made no difference to the findings.

A consecutive and representative sample of people with recently acquired SCI from a defined catchment area in Australia was recruited for this study. This was possible to achieve because the public health-care system in Australia ensures that all people with traumatic SCI within the state of New South Wales are admitted to one of the two SCI units. The results therefore are unlikely to reflect sampling bias. They do, however, only reflect the attitudes and expectations of patients and physiotherapists along with typical outcomes from this region of the world.

It is not known how much guidance and counselling patients received before making their predictions about their future potential to walk from the physiotherapists or members of the rehabilitation team. However, all predictions were made after patients had participated in at least one goal-planning meeting with their rehabilitation team. At this time, goals about walking may have been discussed. Patients would have also received, from the time of injury, ongoing advice about their prognosis from their medical physicians and others. While it is unlikely that patients would have received misinformation or overly optimistic information about their future potential to walk, different members of the rehabilitation team may have taken different approaches to patients with overly optimistic expectations. Some members of the team may have been more open and upfront about the realities of walking than others. This is always a difficult issue for the rehabilitation team and requires members of the rehabilitation team to tread the fine line between helping patients be realistic about their outcomes and undermining their need for hope.^{2,3} Hope is often a strong source of motivation for patients. Further guidance for rehabilitation teams on this important issue would be valuable.

It would be interesting to know if patients' expectations about walking change with time. It is generally assumed that patients who initially have unrealistically high expectations about walking ultimately lower their expectations when walking is not achieved and after they have exhausted all treatment options. This may be a reasonable coping strategy for some patients; however, it is not without potential problems. Patients who expect to walk can become discontented with the focus of rehabilitation if their physiotherapists do not share their expectations. For example, these patients are not always interested or willing to learn skills essential for independence from a wheelchair. Often these patients will pursue other rehabilitation providers who offer the type of therapy that matches their expectations about walking. However, initial work in this area suggests that when walking does not eventuate, these patients can have high levels of depression and dependence, and a low quality of life.¹ It is therefore not within patients' best interests for health-care providers and scientists to encourage unrealistic expectations about walking and recovery following serious motor complete SCI.

It is possible that our results reflect the type of rehabilitation provided in Australia and that our patients' expectations about walking may have been realised if they had received a different type of rehabilitation in another country. This interpretation implies that the discrepancy between patients' and physiotherapists' expectations about walking reflects the type of therapy and rehabilitation provided in Australia rather than unrealistic patient expectations. However, our outcomes align closely with the outcomes of one of the largest and most recent prognostic studies focusing on walking at 1 year post SCI.¹⁷ In addition, patients received comprehensive rehabilitation consisting of 3–5 months of inpatient rehabilitation. Rehabilitation was goal directed and focused on attaining independence, while at the same time optimising patients' potential for neurological recovery. Therapy included locomotor training on treadmills with overhead suspension and over-ground gait training, although this was only provided to patients with some signs of voluntary muscle activity in the lower limbs. Some patients, including those with motor complete SCI, received regular electrical stimulation of the lower limbs with cycling. All patients were closely monitored for any signs of lower limb voluntary activity and therapy was adjusted accordingly.

The results of this study indicate that patients expected more than what is typically achieved within the Australian context. This is unfortunate because disparity between patients' and physiotherapists' expectations about walking can lead to patients being discontented about the focus of therapy. In addition, if patients expect to walk but do not, they may ultimately have lower quality of life and greater depression.¹ They may also never attain their optimal level of independence in a wheelchair because they miss early rehabilitation opportunities while pursuing goals of walking. These issues require careful management by the rehabilitation team. A mismatch between patients' and physiotherapists' expectations about something as fundamental as walking may negatively impact on the success of rehabilitation and future quality of life.

DATA ARCHIVING

There were no data to deposit.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

ACKNOWLEDGEMENTS

We thank the patients and physiotherapy staff from the two Sydney SCI units who participated in the study. This study was funded by the Rehabilitation and Disability Research Foundation and by the NSW Lifetime Care and Support Authority.

- 1 Riggins MS, Kankipati P, Oyster ML, Cooper RA, Boninger ML. The relationship between quality of life and change in mobility 1 year postinjury in individuals with spinal cord injury. *Arch Phys Med Rehabil* 2011; **92**: 1027–1033.
- 2 Babamohamadi H, Negarandeh R, Dehghan-Nayeri N. Coping strategies used by people with spinal cord injury: a qualitative study. *Spinal Cord* 2011; **49**: 832–837.
- 3 Lohne V, Severinsson E. Hope during the first months after acute spinal cord injury. *J Adv Nurs* 2004; **47**: 279–286.
- 4 Barbeau H. Locomotor training in neurorehabilitation: emerging rehabilitation concepts. *Neurorehabil Neural Repair* 2003; **17**: 3–11.
- 5 Rossignol S, Frigon A. Recovery of locomotion after spinal cord injury: some facts and mechanisms. *Annu Rev Neurosci* 2011; **34**: 413–440.
- 6 Dietz V. Spinal cord pattern generators for locomotion. *Clin Neurophysiol* 2003; **114**: 1379–1389.
- 7 Dobkin BH, Havton LA. Basic advances and new avenues in therapy of spinal cord injury. *Annu Rev Med* 2004; **55**: 255–282.
- 8 Scivoletto G, Di Donna V. Prediction of walking recovery after spinal cord injury. *Brain Res Bull* 2009; **78**: 43–51.

- 9 Burns SP, Golding DG, Rolle WA, Graziani V, Ditunno JF. Recovery of ambulation in motor incomplete tetraplegia. *Arch Phys Med Rehabil* 1997; **78**: 1169–1172.
- 10 Lazar RB, Yarkony GM, Ortolano D, Heinemann AW, Perlow E, Lovell L *et al*. Prediction of functional outcome by motor capability after spinal cord injury. *Arch Phys Med Rehabil* 1989; **70**: 819–822.
- 11 Waters RL, Adkins R, Yakura J, Vigil D. Prediction of ambulatory performance based on motor scores derived from standards of the American Spinal Injury Association. *Arch Phys Med Rehabil* 1994; **75**: 756–760.
- 12 Welch RD, Lohley SJ, O'Sullivan SB, Freed MM. Functional independence in quadriplegia: critical levels. *Arch Phys Med Rehabil* 1986; **67**: 235–240.
- 13 Woolsey RM. Rehabilitation outcome following spinal cord injury. *Arch Neurol* 1985; **42**: 116–119.
- 14 Saboe L, Darrah J, Pain K, Guthrie J. Early predictors of functional independence 2 years after spinal cord injury. *Arch Phys Med Rehabil* 1997; **78**: 644–650.
- 15 Hillier S, Fisher PH, Stiller K. The timing and achievement of mobility skills during SCI rehabilitation. *Spinal Cord* 2011; **49**: 416–420.
- 16 Kay ED, Deuschle A, Wuermser LA. Predicting walking at discharge from inpatient rehabilitation after a traumatic spinal cord injury. *Arch Phys Med Rehabil* 2007; **88**: 745–750.
- 17 Van Middendorp JJ, Hosman AJ, Donders ART, Pouw MH, Ditunno Jr JF, Curt A *et al*. A clinical prediction rule for ambulation outcomes after traumatic spinal cord injury: a longitudinal cohort study. *Lancet North Am Ed* 2011; **377**: 1004–1010.
- 18 Schönherr M, Groothoff J, Mulder G, Eisma W. Prediction of functional outcome after spinal cord injury: a task for the rehabilitation team and the patient. *Spinal Cord* 2000; **38**: 185–191.
- 19 Chu J, Harvey LA, Ben M, Batty J, Avis A, Adams R. Physiotherapists' ability to predict future mobility for people with spinal cord injury. *J Neurol Phys Ther*, (in press).
- 20 Perry J, Garrett M, Gronely JK, Mulroy SJ. Classification of walking handicap in the stroke population. *Stroke* 1995; **26**: 982–989.
- 21 Lysack CL, Zafonte CA, Neufeld SW, Dijkers MPJM. Self-care independence after spinal cord injury: patient and therapist expectations and real life performance. *J Spinal Cord Med* 2001; **24**: 257–265.