
Emotional Consequences of Delays in Spinal Rehabilitation Unit Admission or Discharge: A Qualitative Study on the Importance of Communication

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Objective: To explore the influence of health communications on the emotional consequences of delays in transfer from acute hospital into a spinal rehabilitation unit (SRU) or delays in discharge from SRU. **Methods:** Semi-structured interviews were conducted in this exploratory, thematic qualitative research design in an SRU, Melbourne, Australia. **Results:** Six patients experienced delay in admission to ($n = 4$) or discharge from ($n = 3$) the SRU, with one person experiencing both an admission and discharge delay. Median admission delay was 41.5 days, primarily related to bed availability and staffing issues. Participants experiencing a delay in transfer from the acute hospital reported feelings of uncertainty, frustration, disappointment, and concern due to a perception that their functional recovery was compromised because of delayed access to specialist rehabilitation. Psychological issues were less common than emotional responses. One participant spent some of the delay period waiting for admission to the SRU in a non-spinal rehabilitation unit and reported no concerns about his recovery. Median discharge delay was 27 days, largely due to a wait in obtaining funding for equipment. Emotional and psychological responses to delayed discharge, particularly frustration, appeared to be influenced by having a sense of control over the discharge process. **Conclusion:** Patients' experiences during the delay periods partially mitigated the emotional and psychological consequences of a delayed admission or discharge on their psychological well-being. Locus of control, where participants reported being able to effect some influence on their situation, appeared to moderate their emotional state. The findings suggest that clinicians can draw on the concept of control to better support patients through periods of delay. **Key words:** *delivery of health care, health services accessibility, patient discharge, qualitative research, rehabilitation, spinal cord diseases*

Many countries encounter challenges meeting the demand for hospital services and dealing with patient flow problems.¹⁻³ These problems are also relevant to rehabilitation; one survey reported 54% of rehabilitation physicians (physiatrists) perceiving problems with timely access to inpatient rehabilitation and 90% reporting problems with barriers to discharge after completion of the necessary inpatient rehabilitation.⁴

A number of reports have highlighted problems for people with spinal cord damage (SCD) achieving timely access to a specialist spinal

rehabilitation unit (SRU).⁵⁻⁹ In a recent survey of 10 SRUs in different countries, 4 reported moderate or worse barriers to timely access to the SRU and 7 had moderate or worse barriers to discharge from the SRU.¹⁰ In quantifying barriers to rehabilitation patient flow, notable delays have been reported, particularly in terms of transfer from an acute hospital into rehabilitation: 12% for general rehabilitation patients¹¹ and 34% for patients with SCD.^{12,13} Barriers to discharge after completion of the necessary inpatient goals have been reported to occur in 16% of general rehabilitation patients, accounting for 21% of their inpatient rehabilitation

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length of stay (LOS).¹⁴ Discharge delays are more common (37%) for SCD patients, accounting for 18% of the inpatient LOS.¹⁵

Unnecessary time in hospital increases the risk of iatrogenic complications.¹⁶ Equally important, delays in the timely transfer of patients with SCD from acute hospital to SRU may reduce functional outcomes^{8,9} and can increase LOS,⁹ possibly as a result of increased complications. In addition, it is well known that mental health problems, such as depression and anxiety, occur in significantly higher rates among patients with SCD compared with the non-disabled population.¹⁷ This potentially increases their susceptibility to mental health problems when faced with admission or discharge barriers.

Good communication between individual providers and patients offers a way of mitigating these effects.¹⁸ Significant gains have been demonstrated in patient outcomes and LOS where efforts aimed at enhancing communication in longer term care settings, including rehabilitation, have been made.^{19,20} Greater patient psychosocial outcomes – especially empowerment and satisfaction – are reported where clear and open communication occurs.²¹ However, the influence of communication on the emotional responses to delays to admission or discharge from rehabilitation have not been considered in research examining the psychological effects of SCD or in research on rehabilitation patient flow, although the need to consider this has been noted.¹⁵ The impact of delayed discharge into the community for older patients has been studied using qualitative methodology in the United Kingdom, where it was noted that patients with a delay reported feeling disempowered, had a lower mood, felt dependent, and perceived a lack of information.²²

The current article focuses on emotional responses, rather than diagnosed psychopathologies, because emotions provide insight into the phenomenological effects of delays²³ and provide pathways to social support and enhanced coping.²⁴⁻²⁷ Emotional responses are also able to capture situational variables associated with rehabilitation stays and are therefore responsive to subclinical levels of reduced affect.^{26,28} By attending to the relationship between emotions and coping,

appropriate advice can be developed for members of multidisciplinary health teams as well as providers of family or social support, facilitating reduced psychosocial distress and enhanced coping. The aim of this project was therefore to qualitatively explore the emotional responses to delays in transfer from acute hospital into an SRU or delays in discharge from the SRU for patients after SCD.

Methods

Study design

An iterative thematic analysis²⁹ study design was employed.

Setting

The project was based in an Australian Spinal Rehabilitation Service, which provides a 12-bed adult inpatient service for patients referred from private and public hospitals across the state.

Participants

Patients who experienced a delay in their admission into the SRU (after they were deemed ready for transfer from acute hospital) or a delay in discharge (after the treating team established that all inpatient rehabilitation goals had been met) were purposively recruited. Further details about the admission procedure and definition of discharge barriers are provided elsewhere.^{12,15} Only patients with a delay of 2 weeks or longer were included, because it was deemed that shorter delays would be less likely to result in adverse responses.

Potential participants were identified by the head of the SRU and given a brief explanation about the project by another doctor in the SRU. Patients who expressed interest in participating were given relevant written information and the contact details of one author (K.W. or A.S.) who subsequently obtained informed consent and conducted the interview.

Prospective recruitment for this project started in June 2012 and ceased in September 2012. Retrospective recruitment of potential participants

included those who met the criteria and were inpatients between January 2011 and June 2012. Interviews were conducted between July and September 2012. Patients with an admission delay were interviewed while in the SRU, whereas those with a delay in discharge were either interviewed in the SRU or at their place of residence after discharge.

Patients were excluded if they did not have a recent onset of SCD, had cognitive problems (determined by clinical assessment of ward medical staff and formal neuropsychological assessment if required) or inadequate English language skills to give informed consent or participate in the interview, or had a major active psychological disorder and/or substance or alcohol abuse. Participants with a discharge barrier were also excluded if they lived outside the greater metropolitan area (for practical reasons in conducting the interview).

Interview procedure

A semi-structured interview schedule developed by the project team consisted of open-ended questions to allow participants to express their experiences and perceptions of delay in their own words. Information was also sought to establish where the patient would be going after rehabilitation (home or care facility). Thereafter, the interview aimed to establish if and how the delay affected the participants emotionally by asking "How do you feel when thinking about the delay?" Throughout the interviews, more detailed information was elicited through the use of probing questions. Interviews ranged in duration from 30 to 60 minutes.

All interviews were digitally recorded and transcribed verbatim. To protect their privacy, participants were given a pseudonym.

Study size

Six patients took part in the study. Because of the relative homogeneity of participants in terms of ethnicity, residential location, and socioeconomic status, the small sample size was determined to be sufficient.²⁹⁻³¹ Informational redundancy (data saturation) was achieved as no new substantive

data were revealed in the latter interview texts.³² The narrow sample and focus of this project allowed us to demonstrate variance in emotional responses.

Data analysis

Data analysis followed Braun and Clarke's²⁹ 6-stage approach: (1) data familiarization occurred through transcription and repeated readings. This led to the (2) generation of initial codes, which were patterns repeated through the transcripts. Thereafter, (3) more systematic coding identified themes that represented participants' experiences. (4) The themes were reviewed and refined to ensure that they were relevant to the coded extracts. The last stages involved (5) defining and naming each theme and then (6) using representative quotations to illustrate each theme (see below). All coding was cross-checked by 2 or more authors; in the few instances where there was disagreement around the codes, discussion occurred and theme definitions were adjusted in order to ensure analytic rigor. Data analysis was managed through the use of NVivo software (NVivo qualitative data analysis software, 10th ed.; QSR International, Doncaster, Australia, 2012).

All applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed during the course of this research. Monash University and Alfred Health provided ethics approval for this project.

Results

Six patients experienced a delay in admission into ($n = 4$) or discharge ($n = 3$) from the SRU and participated in the project. One person experienced both admission and discharge delays. Eight potential participants with admission delays and 5 with discharge delays declined participation. Of these 11 patients (2 had both admission and discharge barriers), 7 mentioned to the recruiting doctor that the delay they experienced caused them such emotional distress that they did not wish to re-live it by discussing it in an interview.

Participants were from 46 to 85 years old (mean = 70.5, $SD = 14.8$) (see **Table 1**).

Table 1. Summary of participants' demographic and clinical details

Variable	n
Sex	
Male	4
Female	2
SCD cause	
Disc prolapse and other degenerative cord compression	3
Epidural abscess	2
Spinal cord ischemia	1
Level of injury	
Paraplegia	5
Tetraplegia	1
Completeness of injury	
Complete	0
Incomplete	6

Note: SCD = spinal cord damage.

Study findings highlighted the importance of communication between providers and participants in impacting patient outcomes.

Emotional responses to admission delays

Delays in admission to the SRU between 19 and 57 days (median = 41.5, interquartile range [IQR], 24.0-55.5) were experienced by 4 participants. While all perceived that limited bed availability was the primary reason for their delay, 3 were also aware of the impact of staffing issues following discussion with medical personnel in the acute hospital. This was related to health system factors: Julia received her acute care in a private hospital and learned that admission policies prioritizing public patients contributed to her delay: “[The doctors] also told me while I was waiting for the bed, if [a government] hospital needed a bed before me, they got priority.”

Frustrations arose during the delay period when participants were unable to access information about how long they would have to wait. Three also reported some anxiety and stress from not knowing how long the wait would be (see **Table 2**).

Extended acute hospital stays were perceived as potentially compromising participants' recovery, creating a sense of loss in terms of their progress. Care setting during this period shaped their perceptions of the delay, determining the type of support they received and directly affecting their ability to start the rehabilitation process.

Acute hospitals had limited staffing resources, and consequently 3 participants received little or fragmented therapy (**Table 2**).

Perceived compromises in recovery from delayed admission extended to bowel functioning: “I couldn't get into a routine because the staff were so busy... I couldn't get anything done at the same time each day” (Julia). Because incontinence has a major adverse impact following SCD, participants felt unable to move forward and start the rehabilitation process. Issues of continuity of care were also highlighted: variability in the nursing personnel occurred due to shift changes and rostering and limited participants' capacity to work on their continence, further contributing to feelings of compromised recovery.

In contrast, one participant who spent some of his delay in an interim rehabilitation setting felt that he was actively participating in recovery. James was transferred from the acute hospital to an interim rehabilitation unit where he received intense and beneficial therapy while waiting for transfer to the SRU (**Table 2**). Consequently, James did not perceive the delay as a problem. Similarly, Harry received medical treatment due his complex health status during the delay and reported his experience as appropriate. These examples suggest that negative feelings associated with delays can be managed or prevented, at least in part, through appropriate support and advice from health professionals, which may involve transfer to an interim rehabilitation facility.

Perceived health status also influenced experiences of delay. Participants who understood their general health as good, as in the case of Andrew, found the delay especially troubling. In contrast, because James was recovering from the infection that led to SCD and was undergoing medical treatment, getting well was his priority (**Table 2**).

These findings suggest that the emotional responses to delays into rehabilitation admission varied between participants based on 3 factors: length of delays, setting of care during the waiting period, and perceived health status. The 2 participants with longer waiting periods in acute hospitals and in good health perceived their delays as negative, leading to feelings of frustration, disappointment, and concern (**Table 2**). The

Table 2. Patient quotes regarding delays to admission

Theme	Exemplar quotes
Frustration, anxiety, and stress regarding not knowing how long the wait would be	<p>“[Clinicians] didn’t give a time forecast at all. They said that it... could be weeks, it could be months... They can’t really predict how long it takes... When they said that finally there would be a place, it was very last minute.” (James)</p> <p>“The wait to get into rehabilitation was more frustration as I knew that it was what I needed.” (Julia)</p> <p>“At the beginning, you may get a bit angry or whatever but you can’t do anything about it, you still have to wait.” (Andrew)</p>
Extended acute hospital stays perceived as potentially compromising recovery	<p>“[Just] 5 to 10 minutes a session and then maybe [only] every couple of days, they might get you out there. Limited resources, and limited people to do that.” (James)</p> <p>“I knew what should be being done, but I only had about 10 minutes physiotherapy each day and nothing else really... Everything depended on how busy [staff] were with other patients.” (Julia)</p> <p>“I wanted to get walking and doing something. [Being still] was the wasting away of what I could do before. I knew if I’m going to develop my muscles, I have to catch up with everything I’ve lost, and you lose a lot of muscle strength in a very short period.” (Andrew)</p>
Interim rehabilitation settings mitigated effects of delay on recovery	<p>“I had two sessions of rehabilitation every day... A [physiotherapist] would come to my bed and I’d do some leg movements and stuff, just bed-bound exercise. Then, in the afternoon, they put me into a chair and I go off into the [therapy] area.” (James)</p>
Delay influenced by perceived health status	<p>“I mean if you are well, you shouldn’t be in hospital. I was well. I am well now, except I can’t walk.” (Andrew, perceived general health as good)</p> <p>“I was getting intravenous [medicine] and I had to have that... 4 times a day, every 6 hours... That was my purpose in life at that time, to get control of the infection, and I didn’t feel ready... or feel the urgency to go into rehabilitation because other things were going on.” (James, recovering from infection)</p>
Interaction of multiple factors shaped emotional responses to delay	<p>“I really think that time was really too long a time to wait, when you know the physio[therapy] and all that would be helping so much.” (Julia, longer waiting period and good health)</p> <p>“[I was] very frustrated. [It was] the wasting away of what I could do before... You don’t want to be wasting away if you want to get on your feet.” (Andrew, longer waiting period and good health)</p>

sense of his recovery-focused goals being blocked left Andrew feeling disappointed. Julia was more fatalistic: “[I was] just concerned about it. I mean I couldn’t do anything about it, I just had to wait.” In contrast, because of their location and health, delays did not result in significant concerns or problems for Harry or James: “I wasn’t stressed because I was getting good [rehabilitation]” (James). These cases also highlight the potential role for information sharing by health professionals in shaping outcomes: Where patients had a sense of purpose and certainty around discharge, they reported better psychosocial outcomes.

Emotional responses to discharge delays

Three participants experienced delayed discharge from rehabilitation of between 14 and 102 days (median = 27.0), resulting from 2 barriers: equipment requirements and home modifications. Although John perceived medical issues as a reason for delayed discharge and interim discharge to residential care, this was not reflected

in his medical file; instead, his delay related to equipment availability. All participants required equipment such as wheelchair, commode, hospital beds, or hoist; Sarah and James also needed home modifications.

Funding issues and administrative or practical barriers were significant contributors to all delays, especially for one participant. Sarah required government funding for her wheelchair, ceiling hoist, commode, and hospital bed (**Table 3**). John and James avoided delay by accessing their equipment through different channels: John hired shower chairs, a walking frame, and wheelchair through the hospital, while James purchased the wheelchair, hoist, and commode himself in order to expedite discharge: “I used my own money. I was that desperate.” Participants’ ability to privately source equipment was also shaped by their degree of disability and financial resources; Sarah required more specialized and expensive equipment.

Exacerbating the equipment-related delays, home modifications were required to ensure participants could safely access and move around

the home environment: “[Clinicians] were quite firm, I was not allowed to go home unless they were satisfied with the facilities” (John). These included widening doorways, constructing ramps, or installing bathroom rails. The extent of the modifications depended on the patient’s mobility and the home itself, which further contributed to delay. Sarah’s home required extensive modifications whereas John’s modifications were “minimal...hand rails, modified the shower entries, and replaced the sliding glass door with a shower screen.” Although participants could choose to apply for funding or source funding privately, all opted for the latter in order to avoid longer delays in funding approvals, a not unreasonable course of action given that Sarah had already waited 10 weeks for equipment funding: “The funding delays, that is ridiculous. It works out about 6 months for ramps, 2 years for bathrooms.”

For the most part, the factors determining discharge were outside of participants’ control. This was especially the case for Sarah, who felt at the whims of “the [healthcare] system.” She felt imprisoned, “Like I am being punished for being paralysed... I am sure they won’t let me go home, they will keep me here forever.” The prolonged delay in her discharge exacerbated the severe emotional and psychological responses to SCD, including clinical depression (Table 3).

Communication issues further compounded these issues, leading to feelings of frustration. Sarah felt as though information was deliberately withheld: “They would say, ‘Two weeks, you got 2 weeks to go’. Then 2 weeks would come up, and I would ask again, and [get told] ‘another 2 weeks’ and so on.” This continual deferring of discharges was stressful. Sarah’s responses were shaped not

only by her extended rehabilitation stay but also by her concerns about the impact of SCD on her family: “My whole family is just about falling apart. [My daughter] was even crying to me last night on the phone, saying they are going to change your date again. We want you home.”

In contrast, John and James took steps to have some control over their situations, hiring the relevant equipment and engaging independent occupational therapists (in addition to the hospital therapist) to determine the necessary home modifications. James also opted to hire his own carer: “The [nurse] said, ‘You need to think about going home.’ I said, ‘How do I do that?’ ‘You can either go on the public system or you can arrange it yourself.’ I said, ‘I will arrange it myself’ ... so I got together a group of carers.” Neither reported any psychological responses to their delayed discharge from rehabilitation. James did not perceive that his discharge had been delayed and was therefore unaffected.

Participants’ perceptions of delay were also influenced by their inpatient experiences, whereby a positive experience appeared to buffer any adverse responses to a delay and vice versa. The social aspects of being an inpatient were important in this, as all participants were in shared rooms. Two participants saw this as providing opportunities for positive interactions (Table 3).

Discussion

Most participants experienced negative emotional responses from delays waiting for transfer into SRU or for discharge from SRU, including frustration, anxiety, and stress. They were concerned that prolonged waiting for transfer into SRU would compromise recovery. Patients’

Table 3. Patient quotes regarding delays to discharge

Theme	Exemplar quotes
Equipment needs contributed to delay	“I had to wait for funding to come through, then I had to wait many weeks for the equipment to be delivered to the house... I am not allowed to go home without the equipment.” (Sarah)
Emotional responses to prolonged delay	“A lot of crying, a lot of sleepless nights... I can’t handle it anymore... [The doctor] just said one day, she has got to get home, her mental health is deteriorating... I have had counselling and I have seen a psychiatrist twice... That was offered to me, because I was going downhill pretty quickly.” (Sarah)
Buffering effects of positive inpatient experiences	“We had some fun times when we were there. With all the incontinence problems, we always had something to laugh about.” (John)

experience of hospitalization influenced the effect of a delayed discharge on their psychosocial well-being, with participants who perceived their hospital stay in a more negative light experiencing more adverse emotional responses compared to the participants who perceived their stay more positively.

The emotional responses to a delayed discharge from rehabilitation may have been influenced by contextual factors, such as length of SRU stay, duration of delay, level of social support, locus of control, the patient's ability to manage these barriers, and the economic status of the patient. A prolonged barrier to discharge and limited means of managing this could negatively affect patients' emotional well-being. To reduce the negative psychological effect of a delayed discharge from rehabilitation, efforts should be made to identify barriers to discharge as early as possible and communicate openly with patients about these in addition to working with patients to explore options to overcome these barriers.

Participants' control over their circumstances appeared to play a role in the reported emotional responses to the delay. Where they were unable to change the situation, as was especially the case for those experiencing delayed admission, active avoidance of negative thoughts and feelings was one way of coping with the situation.³³ Improved communication – whereby patients felt part of the decision-making process – also offered a way to redress the psychosocial distress, but it was often not practiced; instead providers avoided prolonged or direct discussion about the delay and the reasons behind it. In examples where delayed discharge participants exerted some level of control over their arrangements, and thus could foreshorten the delay period, they felt better about the waiting period. These participants actually experienced significantly less delay than those who felt out of control. This supports existing research indicating that following the onset of SCD, people's evaluation of their ability to face the illness and to gain control over the situation influences coping.³⁴

These findings speak to the concept of locus of control (LoC),^{35,36} which refers to people's attribution of life events – internal (the person is important) and external (outside factors are important) – and the extent to which they believe

they have capacity to influence these events. People with a high internal LoC believe they contribute significantly to how things happen in their life, whereas people with a high external LoC believe that they are largely powerless and attribute events in their lives to forces outside their control. They therefore feel they cannot change their lives,³⁷ which can lead to feelings of helplessness and hopelessness and contribute significantly to depression.³⁸ Therefore, understanding patients' LoC can help health care providers comprehend their capacity to cope with the challenges related to the illness, such as procuring equipment, making home modifications, and managing the rehabilitation process. In addition, it can be used to plan interventions that promote positive behaviors and personal control. For instance, social support – of which effective communication is part – can reduce the impact of stressors and offer one way of facilitating coping.³⁴

One clear implication of this study is that health care providers should aim to optimize patient flow, not only for financial reasons but also to reduce the risk that vulnerable patients will experience adverse mental health effects due to delays to rehabilitation and subsequently returning to the community. There is considerable scope for providers to enhance their communication skills. Research in a range of rehabilitation settings has shown that when educational programs aimed at improving health care provider communication were implemented, it resulted in long-ranging benefits for patients.^{18-21,39}

An important strength of this study is that, to our knowledge, it is the first to explore the emotional responses to delays in SRU admission or discharge. This knowledge can be used by SRUs to help patients adjust and deal with the responses to a delay in admission or discharge. The findings highlight an opportunity for clinicians to improve their communication with patients and thus enhance emotional and psychological well-being. When pathways in and out of the SCU were clearly communicated, participants in the present study reported feeling in control, less uncertain, and more psychologically well than those who did not receive this information.

Our study findings are limited by the small sample size. It is worth noting, however, that a number of potentially eligible participants

declined participation because they did not want to re-live their delay-related emotional distress. We were unable to comment on the influence of age and gender on patient experiences due to the small sample. Our study design excluded patients referred and accepted but who were ultimately admitted to another rehabilitation unit because of lengthy delay, which occurred in 9% of patients referred to the SRU.¹² It is possible that this experience led to adverse emotional responses that were not captured by this study. We were unable to clearly document the psychological impacts of delay due to the small sample size. The research team was comprised of 1 clinician and 3 university researchers, which meant that while we had reduced access to potential participants, any preexisting researcher-based bias during analysis was minimized. Another potential limitation is that there may have been changes in barriers to admission or discharge since the study was conducted. However, ongoing monitoring of these problems indicates that they persist.

Despite these limitations, our study provides important insights. Delays to discharge were caused by home modifications, equipment, or carer requirements, hence they were largely due to financial constraints of the hospital system,

disability services, and the patient. This may be specific to the etiology of SCD. In the state where the study was conducted, people with a compensable traumatic spinal cord injury (motor vehicle-related or workers' compensation) are more readily able to access funding for necessary equipment, modifications, or carers, although delays persist in accessing these too. Future research into the challenges faced by people following SCD must take into account the added financial strain compared to those with traumatic spinal cord injury. Nonetheless, the emotional impact of these delays should not be minimized, and enhanced communication between providers and patients offers a way to alleviate some of these responses. Additional directions for future research include exploring the perspectives of health care providers, administrators, and families.

It is important to take steps to reduce the barriers to timely discharge from hospital for people with SCD. Assisting patients with strategies to optimize their emotional resilience to cope with the delays is critical to their well-being.

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