



ARTICLE

# Access to community support workers during hospital admission for people with spinal cord injury: a pilot study

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## Abstract

**Study design** A descriptive qualitative study.

**Objectives** To evaluate a pilot project enabling people with spinal cord injury (SCI) to have their support workers accompany them into a non-SCI specialist/public hospital (excluding ICU) to perform selected care.

**Setting** The study was conducted in New Zealand.

**Methods** Interviews and focus groups with people with SCI, support workers, care agency staff, and hospital staff who participated in the pilot project.

**Results** Twenty-five individuals participated in the study. Two themes captured participants' experiences of the pilot: 'Maintaining individualised care' and 'Role, tasks and responsibilities. Support workers were described as knowledgeable about SCI care needs and being better positioned to provide individualised care for people with SCI than general nursing staff. Participants with SCI felt less anxious having a support worker with them, and perceived less risk of acquiring secondary health complications during the hospital admission. Good communications is important to ensure there is a shared understanding of the role and responsibilities of having an unregistered support worker in the hospital environment.

**Conclusions** Having their regular support worker during admission to public hospital improved the SCI-specific care received. Support workers reduced the demand on hospital nursing staff who did not always have the time or specialist SCI knowledge to provide individualised care. People with SCI may be more likely to access medical assistance earlier and not defer hospital admissions if they can have support workers accompany them into hospital.

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## Introduction

People who experience a spinal cord injury (SCI) are likely to experience long term secondary health complications (SHCs) as a result of their injury [1]. A New Zealand study found the most prevalent self-reported SHCs at 6, 18, and 30 months post-injury were leg spasms, constipation, back pain, pain below the level of the SCI, and shoulder pain [2]. Secondary health complications remain prevalent many years after the SCI event, with people ≥10 years post-SCI reporting an average of four SHCs at any time point [3].

Secondary health complications, and particularly bladder, skin, and respiratory complications are the most frequent causes of re-hospitalisation for people with SCI [4, 5]. In an Australian study, Gabbe et al. [6] found 27% of people with a traumatic SCI visited an emergency department at least once within two years of injury, and 40% were re-admitted to hospital. Canadian research has found that people with SCI are re-hospitalised twice as often as the

general population [7], and they also have more extended hospital stays [8, 9].

People with SCI often have specific care needs especially related to bladder, bowel and skin care. Many rely on assistance to manage their care routines in the community. There are many terms used to describe this assistance, for example: carers, care or personal assistants, and support workers. In this paper, we will use the term support worker (SW). Good SWs may reduce hospital stays, poor personal hygiene, threats to safety and compounded effects of disability [10]. Having reliable and accessible SWs has been reported to reduce anxiety in those with SCI [10].

The effective management of SHCs for people with SCI requires access to appropriate health services, along with responsive and individualised care in hospital settings [11]. However, finding services with specialist SCI knowledge can be difficult. Because the incidence of SCI is relatively low, and rehabilitation for SCI is best managed in specialist centres, health professionals outside specialist settings generally have low exposure to people with SCI, limiting their ability to gain and retain knowledge and experience in this area [12, 13]. People with SCI report they receive less individualised time in hospital as nurses are busy with other clients [14]. Hospitalisation also alters a person's care routines. People with SCI can have a sense of vulnerability when their care routines are changed to meet the needs of ward staff and processes [15]. Disruption of daily care routines may put people with SCI at further risk of SHCs, including increasing the risk of pressure injuries and pressure ulcer development [16].

It has been highlighted that the complex needs of SCI are not always met while people with SCI are in hospital in NZ [17]. It has also been suggested that allowing people with SCI to continue to access their personal SWs while they are in a non-SCI specialist hospital could provide improved continuity of their care requirements and contribute to a lower rate of hospital-acquired SHCs. However, there are legal issues with patients having their own SWs delivering care in a hospital environment, including that SWs are not hospital employees and are generally not registered health professionals [18]. There is also additional cost involved if funders are paying for both hospital care and care from support workers.

The New Zealand National Spinal Cord Impairment Action Plan (2014-19) was implemented to optimise best possible health and wellbeing outcomes for people with SCI [19]. One of the Action Plan objectives was to develop a process where a person with SCI could use their existing SWs to provide essential personal support. This included individualised bowel and bladder management, and moving and handling with specialised equipment, e.g. hoist transfers, when they admitted to a public hospital outside of a specialist SCI service. Working collaboratively with hospitals and care

provider agencies in the Auckland area, The Accident Compensation Corporation (ACC) developed a pilot study to determine the feasibility of funding SW care for ACC clients with SCI (person with SCI) while they were in the hospital. ACC is New Zealand's no-fault national insurance scheme. ACC provides cover for anyone who sustains a traumatic or a 'treatment injury' (i.e., an adverse result of medical treatment). This includes medical care, rehabilitation, support services, home and vehicle modifications and income support for those in employment pre-injury.

This study aimed to evaluate the pilot providing SW to provide care for people with SCI while they were in the hospital, not including ICU care. The study focused on how the pilot project may have contributed to improved care for people with SCI when they were admitted to the hospital, and whether ongoing implementation was feasible. Findings were based on the experiences of the people with SCI, the support workers accompanying people with SCI into the hospital, hospital staff involved in the pilot, and care agency staff who completed the contingency plan.

## Methods

### Pilot process

ACC clients were eligible for inclusion in the attendant carers in public hospitals pilot if they had an SCI and received SW through approved care agencies; they might be admitted to a non-SCI specialist/public hospital (excluding ICU) in the pilot study catchment area over the study period, and were willing to provide feedback on their experience. The person with SCI had to be at risk of deterioration or avoidable SHCs. It also needed to be determined that a safe environment could not be reasonably provided for the person with SCI without an SW present, and their ability to maintain their dignity was at risk of compromise.

A total of 69 people with SCI who met these criteria consented to take part in the pilot study by their ACC case manager. Once consented, the person with SCI was required to have a contingency plan approved by ACC. The contingency plan was an agreed care plan developed by the person with SCI's care agency - determining care hours that would be required if they were admitted to hospital and confirmed the duties and tasks that were to be provided by a support worker while the ACC client was on the ward. ACC then approved the contingency plan. When the contingency plan had been approved, if a consented person with SCI was admitted to hospital either for an elective or emergency admission during the pilot, the person with SCI could have an SW with them in hospital for the hours approved on the contingency plan.

When the person with SCI was admitted to hospital, the approved contingency plan was shared with ward staff and filed in the notes of the person with SCI. The support worker or workers were given an orientation to the ward and a health and safety induction by the Charge Nurse on the ward.

## Evaluation methods

A qualitative approach using thematic analysis was undertaken to understand the experience of people involved in the pilot [20]. The pilot study was approved by the ACC ethics committee ACC#350. Interviews with hospital staff, support workers and care agency staff were undertaken to get the perspectives of all stakeholders involved in the pilot (approved by the ACC ethics committee ACC#415).

## Participant recruitment

People with SCI, SWs, hospital staff involved in the pilot, and care agency staff who completed the contingency plan were recruited.

Participants with an SCI were recruited to the pilot by their ACC case managers (as described above). Information was provided verbally, and via a study information and consent sheet. If a consented participant with SCI was admitted to hospital during the pilot (July 2018 to December 2019), they were eligible for inclusion in this evaluation of the pilot. Participant contact details were passed on to the research team once they had been discharged from hospital. Participants were then contacted by one of the research team to check they were happy to continue with the evaluation of their experience and to schedule an interview.

Hospital staff involved in the pilot, SWs and care agency staff were recruited through key hospital and care agency staff, identified through ACC staff leading the pilot project. These key contacts were asked to send information and consent forms to their staff members who had been involved in the pilot. The research team followed up with interested staff. Once participants had consented, an interview time was scheduled.

**Data collection** Data was collected pragmatically to suit the needs of the participants using semi-structured in-depth interviews, in person or via Zoom/telephone, and from two focus groups. Interviews took place at each participant's home or place of work. Interviews lasted between 20 and 80 min, and they were recorded and transcribed.

A distinct interview schedule was devised for each of the four participant groups (Supplementary Information). Questions were developed by ACC, then reviewed by the research team and through the Burwood Academy Consultation Network (people with the lived experience of SCI

[21, 22]. A lived experience advisor with SCI who was familiar with working with support workers provided input to all stages of the evaluation design, implementation and analysis process.

**Data analysis** A thematic analysis approach was used, following the six-stage analysis process described by Braun and Clarke [23]. After data familiarisation and noting ideas, initial coding of all data was completed by one author (JN). To ensure validity, secondary coding was completed by two authors (MA and JB). The initial themes determined by (JN) were then reviewed and finalised through discussion (JN, MA, JB, RM). In addition, the lived experience advisor (IS) reviewed the initial codes and contributed to the final theme discussion. To ensure anonymity, any potentially identifiable information was removed from quotes. Explanation of any omitted material is noted in square parentheses. Three consecutive ellipses denote words removed to improve readability. Each quote finishes with an identifier of participant role: person with an SCI (SCI), support worker (SW), a family member who also has a support work role (SW/family), care agency staff (CA), or hospital staff (HS).

## Results

Data from a total of 25 people were collected: twelve participants with an SCI; three support workers; two care agency staff; and three hospital staff were interviewed. Two focus groups were completed with four support workers and one care agency staff member. We considered this to be an appropriate number for an exploratory qualitative study of this nature [23].

The majority of the SCI participants were male (Table 1), while all the non-SCI participants were female (Table 2).

**Table 1** SCI participants demographics.

Characteristic	<i>N</i> (%)
<i>Age (years)</i>	
<29	0 (0)
30–39	3 (25)
40–49	3 (25)
50–59	3 (25)
60+	3 (25)
<i>Gender</i>	
Male	8 (67)
Female	4 (33)
<i>Ethnicity</i>	
NZ European	5 (42)
Māori	3 (25)
Pacific/Asian/Other	4 (33)

**Table 2** Non-SCI participant demographics.

Characteristic	N (%)
<i>Age (years)</i>	
20–29	1 (8)
30–39	3 (23)
40–49	6 (46)
50–59	0 (0)
60–69	1 (8)
70–79	1 (8)
Unknown	1 (8)
<i>Gender</i>	
Male	0 (0)
Female	13 (100)
<i>Ethnicity</i>	
NZ European	5 (38)
Māori	0 (0)
Asian	3 (23)
Pacific	2 (15)
Middle Eastern/Latin-American/African	1 (8)
Other	1 (8)
Unknown	1 (8)
<i>Role</i>	
Care agency staff	4 (31)
Hospital staff	3 (23)
Support worker	6 (46)

There was a range of ethnicity and ages across all groups. Demographics of the participants are shown as groups and not individually to maintain anonymity. Further details for the SCI participants are not included as this would risk identification. All of the participants with SCI had experienced hospital admissions before the pilot, so were able to reflect on the differences between hospital admissions with and without an SW present.

Two key themes were identified from the analysis: *Maintaining individualised care* and *Role, tasks and responsibilities*.

### Maintaining individualised care

The participants with SCI felt when they had their own support worker in the hospital, they were confident their SCI specific cares were performed not just by someone who had the skills to do them, but by someone who knew them and their individual needs. Participant 4 (SCI) described their support worker as “highly skilled” but felt, more importantly, they “understand my individual needs” and cared about them as a person, which made a significant difference. Participants with SCI felt this level of individualised care did not occur with the general ward staff:

“Yeah, the nurses you know, they know how to turn someone, things like that. But then, in terms of positioning, they didn’t really know what they’re doing. And I guess that’s because it’s personalised to me. I need it done a certain way and want to be in a certain position, and even after explaining that (in the middle of the night, they come in and turn me, and then I wake up and I’m completely in the wrong position.” Participant 1 (SCI). The SWs also provided an advocacy role and mental support within the ward environment. This was especially important when the person with SCI had existing communication problems, such as English being their second language or if they felt too ill to communicate.

“I am unable to talk when I’m in pain, the support worker is my voice. If you can’t communicate the support worker is person who knows you best. They know your medical history and needs, more so than family” Participant 8 (SCI)

Participant 9 (SCI) described their SW as a “mouth-piece”. They explained their SW could offer input and advice in decisions around medications, with the nursing staff, as they were more familiar with client’s needs. Knowing their care needs were being met by their own SW reduced the anxiety and made the experience “less stressful” Participant 9 (SCI).

### Little can be huge

Participants with SCI expressed their concern that seemingly inconsequential aspects of their care needs could have significant downstream effects: “Nursing staff often dismissed the importance of what they regarded as small things, but could turn into big issues for me.” Participant 4 (SCI). He explained that given his inability to drink independently, being supported to drink water regularly was really important for his bladder. Other small changes, such as introducing or changing laxatives, resulted in significant changes in his bowel pattern.

Hospital staff also acknowledged the lack of SCI expertise of staff working in general hospital wards.

“The majority of these SCI patients do not get admitted to wards that have any idea of managing patients with an SCI.” Participant 27 (HS)

For example, participants with SCI described that hospital staff were unable to change catheters and did not know how to do bowel cares. Participant 8 (SCI) recalled having to get their daughter to come in and do bowel cares

for them. Participants with SCI felt that nursing staff lacked knowledge, which put them at risk of getting SHC's. Indeed, due to previous bad experiences participants agreed that people with SCI actively avoided hospital, and that this could be different if they were able to have their SW in hospital with them:

“For all clients, they'll wait until it's the last option [going into hospital] and then they'll go in. I do feel that if they knew they could take their support worker with them, a lot of the stays wouldn't have to be that long. Because it's the last option, it's reached a point where it's really critical, and that causes the amount of stay that they need in hospital. But if they knew that they could do it earlier, go and sort it out with a support worker, it could be even shorter” Participant 19 (CA)

### Same level of care

Participants with SCI felt that they should be able to have the same level of care while they were in hospital that they did in their own home.

“We're not looking for a 5-star hotel; we just want the basics. The same level of care that is provided at home should be provided in hospital. Currently care in hospital [without an SW present] is less than care at home” Participant 4 (SW/FM)

Participants 5, 6, and 8 (SCI) felt they were considered as a “normal patient” when they were in hospital but, in fact, they had increased requirements because of their SCI. They identified that their care needs placed a high demand on limited nursing resources in a non-specialist SCI setting. All participants with SCI felt staffing levels in hospital were inadequate, leaving nursing staff too busy to provide the care they needed. Having an SW relieved the pressure for the hours they were there. The hospital staff also had a positive repose to the SW presence on the ward:

“Yes, there are things you don't do because you don't have the time or lack awareness of dealing with patients with a spinal cord injury. And that's where we need the caregivers.” Participant 26 (HS)

“The feedback [from the charge nurses] that I got was quite positive that they appreciated the support on the wards and someone who was familiar with the client” Participant 15 (HS)

The different participant groups did not all agree on the level of SW needed to support a person with SCI in hospital. The participants with SCI felt the minimum level of support would be two hours a day to cover their morning routine, including bowel cares.

“Two hours is adequate on most days. On extended-care days, two hours is tight. Also depends on circumstances around admission ... [it would be] better if care support hours in hospital are tailored specifically [rather than set for everyone]”. Participant 3 (SCI)

Care agency staff, who determined support levels through the contingency plans, described the need to “balance what the person wanted and needed” Participant 19 (CA). They explained that many of the tasks support workers did in the home environment were not necessary in hospital, e.g. laundry and vacuuming.

### Acknowledging the SCI expertise from lived experience

One issue that participants with SCI encountered was the lack of willingness of hospital staff to listen to and acknowledge the SCI expertise they had from lived experience. The shift patterns of nursing staff in the hospital situation meant a constant turnover of staff. When participants with SCI didn't have their SW with them, they felt they were constantly explaining to ward staff how to do their cares. They expressed frustration that information was not always passed over between shifts. In the worst-case scenario, participants with SCI felt ward staff did not listen to them and did not appreciate their lived expertise in SCI. “I was able to communicate [my care needs]. It's just whether they're [nursing staff] able to receive it.” Participant 1 (SCI). This lack of listening/appreciation of the person's own expertise in living with SCI affected the level of care they received. In some cases, participants with SCI felt nurses ignored important issues such as autonomic dysreflexia.

“A lot of the times they [person with SCI] struggle with making their voices heard. And that even if they tell their concerns [to ward staff], it's not often listened to, because the acute wards, their main aim is to address the issue [they were admitted with] and get them out the door.” Participant 27 (HS)

Role, tasks and responsibilities. A further key theme identified concerned who was responsible for what and when. For example, when asked, none of the SW participants knew about or were involved in, the development



of the contingency plans, which were intended to document the roles and responsibility of SW. A number of the SCI participants also reported they were unaware of how the hours of SW they received in hospital was determined. Although care agency staff felt the role boundaries for the SW were clear, they acknowledged there were differences in the roles the SW were able to do in the hospital setting.

“Having said that [their roles are clear], being out in the community and being in the hospital is completely different for the support worker. So, at home they do the PEG feed, in the hospital, they don’t OK. So, it’s the nurses who do it. However, they could say ‘he prefers it being done this way etc’. But it’s still the nurses who do it” Participant 18 (CA)

Hospital staff participants described confusion at times over what was the SW responsibility, and what was the nurse’s role (e.g., turning the patient). However, they felt this was down to “poor communication [about the contingency plans] rather than the quality of the contingency plans, which were clear enough” Participant 15 (HS). A consequence of poor communication was described by Participant 23 (HS) who commented: “At times the ward processes would take over and the cares could be done before the carer arrived in the morning”. Hospital staff felt the biggest concern of support workers being on the ward was:

“The health and safety aspects of having external people coming into hospital, thus needed to have orientation process, making sure ward staff knew who they were, what the carers were able to do” Participant 23 (HW)

It was intended that each SW would have an orientation to the ward their client was admitted on, but this didn’t always happen. “There was no orientation when I started on the ward, no health and safety, and I wasn’t shown how to use any of the equipment” Participant 16 (SW).

High turnover of staff on the wards during the pilot period, alongside low and infrequent admissions of people with SCI on the pilot onto individual wards, was blamed for some of the processes being overlooked:

“We set up an orientation checklist for wards, and this was sent out early on in the pilot, but the end I think everyone had forgotten it existed or there had been new people [Charge Nurses] on board who hadn’t heard about it” Participant 23 (HW)

## Managing changes for support workers

When their client was in hospital, SWs had changes to both the hours they worked with the client and the location of their work. The impact of these changes on SWs appeared to be related to the hours worked with the individual client; the total hours worked for the agency; the contract they were on; the policies of the agency they worked for; and their personal preferences. The ways that changes to hours and location of work were addressed differed across agencies. In some cases, SWs were allocated to other clients to make up their hours. Other strategies were to get SWs to do additional training while they had reduced client contact. Some SWs did not want to work for other clients. In one case, an SW worked part-time and had changed agencies to stay with a client, so had to manage with a reduced income while their client was in hospital. The care agency staff reported there was more complexity when family were employed as SWs:

“... especially if [the] SW is a parent or partner where they often stay 24 h with their client [family member]. But this may not be [covered] on the contingency plan. They’re still delivering services, but this extra service hasn’t been approved. Our agency will pay them for this, but we can’t invoice ACC for it.” Participant 25 (CA)

In addition, family members working as SWs often did not want to be given alternative work with other clients. Participant 25 (CA) identified there was a particular issue when SWs worked overnight on the pilot:

“When [the SW is] on a sleepover they’re paid minimum wage... they might be asleep all night because the client provides a bedroom and bed, they might have to wake up twice during the night to turn somebody, but they’re fit enough to work the next day. ... But in hospital, it’s a massive problem because they don’t sleep. All they get is a chair... therefore, they’re getting paid the minimum wage and then they’re not fit for a shift the next day at their top rate.” Participant 24 (CA)

Participants with an SCI were acutely aware of the increased burden on their SWs when they were travelling to the hospital to look after them, and the financial implications for SWs if they had to reduce their hours.

“The only thing is, I used to feel terribly guilty, ... because (one carer) was having to catch a bus way over from [the other side of city], so it was taking her like an hour, hour-and-a-half to get to work. And,

**Table 3** The advantages and disadvantages by participant group.

Participant	Advantage	Disadvantages
Persons with SCI	Met SCI-related needs Ensured same level of care Advocated with staff Less stress Felt safe Easier to bring own equipment with them	Risk of hospital staff directing questions toward support worker rather than person with SCI Risk of nursing staff leaving cares completely up to support worker.
Support workers	Stayed with their client Didn't have to find as many alternative hours to address reduction in income while person with SCI in hospital	Lack of role clarity in hospital - possibly due to lack of introduction Additional burden due to longer travel times Reduced income Reimbursements varied dependent on the individual agency
Hospital staff	Freed hospital staff to concentrate on reason for admission, not SCI-specific cares Reduced burden on overstretched resources particularly staffing levels Additional person to help with turns and moving patient	Roles of support worker not clear if contingency plan had not been shared Dealing with multiple support workers Difficult communicating health information due to confidentiality issues - support worker not staff or family member. Unclear on knowledge experience of support worker
Care agency staff	Agency staff felt the pilot process was simple and uncomplicated. Did not have to find as many alternative hours for support workers	Unclear inclusion criteria for allowing support workers to accompany client into hospital, with a process for appeal. Health and safety risk for agency if incident on ward as they were responsible - support workers were employed by care agencies.

you know, what carers get paid ...she actually got really sick at the beginning...and so I was really worried about her.” Participant 12 (SCI)

All participants overwhelmingly endorsed the introduction of SW in hospital to support people with SCI. However, the advantages and disadvantages were different for the different participant groups. This data is summarised in Table 3.

## Discussion

This study looked at the experiences of people involved in a pilot project where individuals with SCI could have their SWs providing selected cares for them during an elective or emergency admission into public hospital/non-specialist ward. The results indicate it is feasible for SW to accompany people with SCI into hospital. Furthermore, when the SW had appropriate hours and their responsibilities were clearly defined and understood by all stakeholders, it seemed to optimise the experiences of care for the person with SCI, and improve health outcomes.

All the participants felt there was benefit from SWs accompanying people with SCI into a public hospital. People with SCI described reduced anxiety as a result of receiving individualised care from SW who had SCI knowledge, and were more aware of possible secondary health conditions and what was needed to avoid them. Support workers also offered emotional support and

advocacy. This was especially relevant when the person with SCI had difficulty advocating for themselves because they were unwell or had communication impairments.

The presence of an SW took the pressure off busy ward staff, who did not have the time, resources or specialist knowledge to manage the SCI-specific care needs of the patient. With an SW taking care of the person's routine care needs (e.g., bowel, bladder and skincare) hospital staff could concentrate on treating the health condition that had led to the admission. Previous studies have also shown a lack of SCI specialist knowledge from health professionals [13, 24, 25] and identified that people with SCI perceive a reduced quality of care in hospital when nurses are unfamiliar with their individualised routines and knowledge to provide their care needs [18].

A number of potential issues to the widespread adoption of the pilot were identified. Although no adverse events were described as a result of non-healthcare registered SWs working in a hospital setting, hospital and care agency participants did identify potential legislative and health and safety issues. In the current study, all the SWs were employed by a care agency which was responsible for the health and safety of the SW. However, the hospital often had different equipment and health and safety policies and procedures. In some countries, such as Australia, SWs may not be legally permitted to perform care unless they are hospital employees, or registered health professionals [18]. Therefore, policy changes may be required in order to permit SWs accompanying people with SCI into hospital. This may be more complicated where legislative differences

occur at national and regional level, in addition to individual hospital policies. In this study, the SWs were all employed by an agency registered with the funding organisation. The agency was responsible for the competence level of the SW and for training, including background police checks. If SW are employed directly by the person with SCI, or family members provide care, there may be a need for other ways of ensuring the competence of the support workers.

This pilot took place at a limited number of hospitals and involved a detailed set up procedure. Health and safety requirements were managed through ward orientations and familiarisation with equipment. Contingency plans were used to detail the roles and responsibilities of SWs. Support workers had restrictions placed on their roles and responsibilities caring for a person with an SCI in the hospital setting. However, the result of the study indicated that consistency in the implementation of these processes was difficult to achieve in practice, and structured communication processes are needed to ensure the all parties were clear on the roles and responsibilities of the SW while they were on the ward.

This study also highlighted the difficulties of information sharing between hospital staff and the SW within the hospital environment. As SWs were not hospital staff or registered health professionals, they were unable to access the medical notes or be part of the usual staff handovers. Hospital staff felt unable to share patient information with the SW because of patient privacy regulations.

Often funding agencies will not resource SWs when a person with SCI is in hospital, as it is expected that their care requirements will be met by hospital staff. Participants in this study identified improved care and reduced risk of SHCs when an SW was present, compared to previous admissions without an SW. Secondary health complications, particularly pressure injuries, are costly in SCI [26]. The additional cost of funding SWs to perform selected SCI-specific, individualised care tasks in hospitals may be offset by cost savings achieved by preventing SHCs occurring and by people with SCI being more willing to access hospital services in a timely manner.

There are a number of factors that should be considered if individuals with SCI are able to have SWs providing selected cares in hospital. Prior to admission clear inclusion criteria for allowing support workers to accompany client into hospital are needed. The person with SCI should be assessed to determine the SW hours and tasks required during hospital admission. On admission, the SW accompanying the person with SCI should have a formal orientation to the ward where they will be working which includes familiarisation to the equipment and health and safety policies. Ideally this should be documented and completed prior to the SW starting work. During admission clear reporting lines and methods of communication

are required. Shared documentation is important to outline the roles and responsibilities of the SW, and as a method of communication between SW and hospital staff. This may need to be separate from the medical notes. A specific policy for each hospital site is recommended.

A number of factors should be considered when interpreting the results of this study. First, this pilot applied to people with ACC funding. ACC funded clients receive the care they need in the community. Many people with SCI rely on informal carers [27], and those who do not receive compensation may have to rationalise their care hours [28]. Further research is needed to look at the feasibility of unpaid SWs assisting people with SCI in hospital. Second, there was a delay between the hospital admission and interview for a number of the participants with SCI and this may have limited their recall. Third, we recruited care agency staff and hospital staff through key informants. However, when interviewed, it was apparent that the participants had variable involvement in the pilot. Further work is needed to consider the views of other health care professionals. Lastly, this pilot took place in an urban setting in New Zealand and didn't consider specific issues for rural or remote patients who would need to travel to different cities for hospital care.

## Conclusions

Having their regular support worker to do selected tasks during an admission to public hospital improved the level of SCI-specific care received by people with an SCI. This reduced the demand on nursing staff who were not resourced to manage the extra demands of caring for a person with SCI and often lacked specialist SCI knowledge. Support workers were generally not inconvenienced by accompanying their client into hospital. There was a perceived reduction in SHCs and anxiety for the person with SCI when their support worker is present. People with SCI may be more likely to access medical assistance earlier and not defer hospital admissions if they can have support workers accompany them into hospital.

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## Compliance with ethical standards

**Conflict of interest** The authors declare that they have no conflict of interest.

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