

# Interventions, stakeholders, and organisation related to pressure ulcer prevention for individuals with spinal cord injuries in transition from hospital to home - A scoping review

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## ABSTRACT

*Study design:* Scoping review.

*Aim of the study:* To obtain an overview of initiatives, organisational components, and stakeholders' perspectives on PU prevention in transitional care.

*Methods:* Scoping review searching the databases: MEDLINE, EMBASE, CINAHL, Cochrane Library, Web of Science, and SCOPUS in May 2022. Inclusion of English-written research on pressure ulcer prevention in adult people with spinal cord injury in transition from hospital or rehabilitation centre to the home care environment.

*Results:* Fifteen studies of different types are included in this study: six qualitative studies, four randomized controlled trials, three cohort studies, one cross-sectional study and an interventional study. The included studies are relatively low-level evidence but of acceptable quality.

*Conclusion:* Continuous tailored education and information about PU prevention and follow-up services are essential components in preventing PUs and rehabilitating people with SCI. The complexity of SCI requires adaptations, equipment and access to specialist care and treatment after discharge. However, there is a discrepancy between the international recommendations, the perceived needs, and the delivered healthcare services. The consequences are a lower quality of life and a higher risk of PUs for people with SCI.

## 1. Introduction

Pressure ulcers<sup>1</sup> (PUs) are a common secondary complication following spinal cord injury<sup>2</sup> (SCI) and one of the most frequent causes of hospitalization in this population. Up to 45–95% of people with SCI experience a pressure ulcer (PU) during their lifetime [1–3], and the annual self-reported prevalence of PUs (grade 2 or higher) in The United States varies from 25% to almost 40% [4]. PUs are defined as 'localized damage to the skin and/or underlying tissue, as a result of pressure or pressure in combination with shear. Pressure injuries usually occur over

a bony prominence but may also be associated with a medical device or another object' [2].

People with SCI have a lifelong increased risk of developing PU due to affected or lost sensory perception combined with immobility. Prevention should be initiated from the acute phase throughout the rehabilitation phase and into the home care environment in collaboration with people with SCI. They have to take responsibility for their PU prevention. People with SCI have altered pathophysiology and several secondary: problems with temperature regulation, hydration, incontinence and bowel issues [1,5,6]. Therefore, PUs in people suffering from

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<sup>1</sup> PU: Pressure ulcer.

<sup>2</sup> SCI: Spinal cord injury.

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SCI is a complex task that should focus on local wound treatment and secondary prevention, including repositioning and relieving the area with wound, minimizing shear, use of support surface, care and observation of the skin and sufficient nutrition [1,2,6–8].

Many of the PUs in this population become deep wounds with prolonged healing depending on the patient's active role as they have to observe the function and quality of supporting surfaces, position and take care of their skin [8–10].

An SCI is defined as 'damage to any part of the spinal cord or nerves at the end of the spinal canal (cauda equina) - often causes permanent changes in strength, sensation and other body functions below the site of the injury' [11]. The principles for rehabilitation after an SCI are structured rehabilitation based on the individual's active participation. The aim is to achieve the highest level of function and skills to secure independence, social integration, and the best possible quality of life<sup>3</sup> (QOL). Self-management is a core concept, and people with SCI must learn how to cope with their new life situation and handle secondary conditions and complications. The rehabilitation centres carefully plan the discharge and offer lifelong follow-up services [5].

Rehabilitation has received more attention in recent years as it supports the individuals' QOL and has socio-economic benefits [5,8]. Transitional care is critical in complex, long-term patient care involving different healthcare providers across sectors [12]. WHO defines transitional care: 'a set of actions designed to ensure the coordination and continuity of healthcare as patients transfer between different locations or different levels of care within the same location' [13]. Loss of information is known to cause adverse events in patients' transitions between healthcare services [12]. To date, no reviews on PU prevention in transition are performed. Knowledge from this review may contribute to planning and performing PU prevention for people with SCI.

### 1.1. Objective

The objective of this scoping review is to obtain an overview of research on PU prevention in people with SCI with a focus on transitional care. From injury to homecare environment, many healthcare providers are involved. We wanted to identify studies with descriptions of interventions, organisational aspects or stakeholders' perspectives (patients, caregivers, and staff) of PU prevention in transitional care.

### 1.2. Research questions

- Which interventions of PU prevention in transitional care of adults with SCI are reported in studies?
- What are the stakeholders' perspectives on PU prevention in the transitional care of adults with SCI?
- How is PU prevention organised for adults with SCI after discharge from the hospital to the home care setting?

## 2. Methods

A protocol for this scoping review was published before the start of the study [14]. The PRISMA ScR checklist was used [15].

### 2.1. Information sources

Databases searched: MEDLINE (Ovid), EMBASE (Ovid), CINAHL (Ebsco), Cochrane Library, Web of Science and SCOPUS. Time limit from the year 2000 to the current. We conducted the searches May 5, 2022.

### 2.2. Search terms

The search strategy was inspired by previous literature studies and

international guidelines related to PUs [16,17] and a proposed gold standard for literature search of non-traumatic injuries [18]. We consulted an academic librarian when planning the search process to achieve appropriate sensitivity and precision.

### 2.3. Search strategy

A short version of the search strategy is presented in Table 1. For the full search strategy, see Table 1A in the supplementary material.

### 2.4. Selection of sources

This review included English-written primary research describing initiatives, organisational components, or stakeholders' perspectives on PU prevention in transitional care of adult people with SCI. We did not include conference papers, reviews, protocols, editorials, or opinions.

### 2.5. Population, concept, and context

Studies of adults with SCI at any degree and severity (diagnosed according to all accepted diagnostic criteria) were included. Studies of PU prevention in people with SCI in transitional care from hospital and rehabilitation centres to home care settings were included, focusing on organisational components, prevention initiatives or perspectives of the patients and their caregivers. We included studies from all healthcare settings: Hospitals, acute care settings, rehabilitation facilities and primary care services.

## 3. Results

### 3.1. Study selection

The authors KS and MS screened all papers independently by titles and abstracts, followed by full-text assessment (Fig. 1). In case of disagreement, a consensus was reached through discussions. Endnote X9 was the software used for handling references and COVIDENCE for the review.

### 3.2. Critical appraisal of the included studies

We included different types of studies and could not use a single tool for quality assessment. We used Joanna Briggs's critical appraisal tools [19] to assess all included studies individually (blinded) by the two reviewers to ensure acceptable quality before the inclusion of studies. In case of disagreement, we discussed until consensus. The sample sizes of the included studies are relatively small and represent study types traditionally placed low in the evidence hierarchy. The included studies were all of acceptable quality, judged by the reviewing authors KS and MS.

We included fifteen studies (Table 2): Six qualitative studies, four randomized controlled trials, three cohort studies, a cross-sectional study and one interventional study.

All studies were thoroughly read to extract relevant information to our research questions. Data extraction was mainly done by (KS), followed by mutual discussions with the co-reviewer (MS). All studies are

**Table 1**  
Short version of search strategy.

Search	Search terms
1	Pressure ulcer OR pressure injury OR bedsore OR decubitus OR secondary condition OR secondary complication
2	Spinal cord injury OR spinal cord compression OR spinal cord contusion OR spinal cord lesion
3	Transition OR transfer OR discharge OR aftercare OR patient handoff OR discharge process or care coordination
4	#1 AND #2 AND #3

<sup>3</sup> QOL: Quality of life.

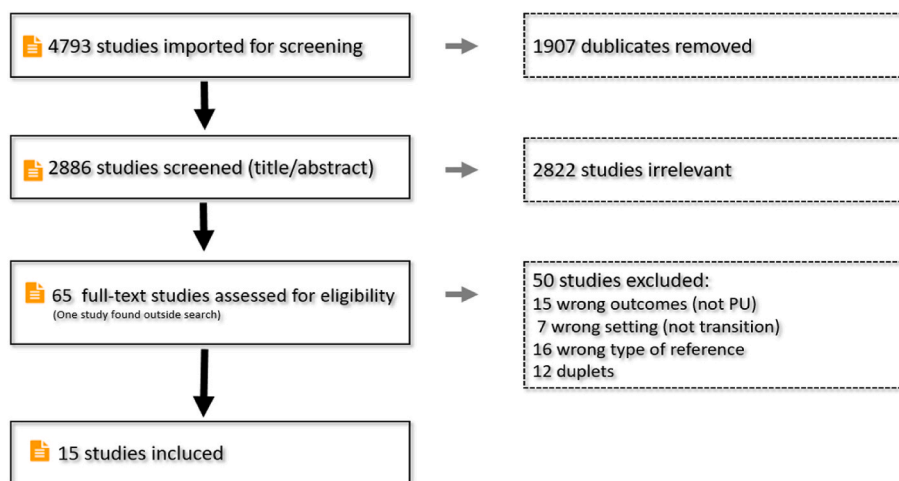


Fig. 1. PRISMA diagram.

initiated in rehabilitation facilities, and 13 out of 15 are from developed countries. All studies focus on different angles of PU prevention, and the relevant elements are presented and narratively described in the following section and Table 2.

### 3.3. Initiatives for pressure ulcer prevention in transition

Cahow et al. [20] tested a therapeutic recreation initiative with educational sessions and physical and leisure activities, including community outings in the SCIRehab project, in an American prospective cohort study with 1376 participants with traumatic SCI. They implemented the initiative in six different rehabilitation facilities in the USA. They registered multiple participant characteristics, time spent in therapeutic recreational activities and outcome measures at discharge and one year after the injury. The study found positive associations between hours spent on leisure skills and less rehospitalisation (odds ratio 0.926,  $p = 0.003$ ) and hours in community outings and less reporting of PU after one year (odds ratio 0.949,  $p = 0.003$ ). According to the authors, more time spent with education and practice in the community, assisted by physiotherapists and occupational therapists, caused the results. They found the therapeutic recreation and patient characteristics to be weak predictors for life satisfaction and mood state.

An American 5-years follow-up study of the SCIRehab project included 792 participants from five facilities [21], and they found an overall consistency within the 1- and 5-year data. The association between participation in therapeutic recreation and outcomes held less after five years, and they did not identify common predictors among the therapeutic recreational activities. The authors further concluded that access to enhanced experienced clinicians is essential.

Twenty people with SCI participated in a patient education program initiated and evaluated in a French interventional study by Robineau et al. [22]. They measured clinical and demographic data, knowledge and self-esteem, and QOL. After finishing the patient education programme, participants' knowledge increased and was sustained when measured after 12 months using the Skin Management Needs Assessment Checklist (revised SMnac score). Knowledge increased from an initial median SMnac score of 38.5 [34.4–44.2] to 46.9 ( $p < 0.0001$ ) measured three months after the education activities, and 47.2 [ $p < 0.0001$ ] measured after 12 months. The study showed an effect on QOL but no significant change in PU occurrence or in the participants' belief in their ability to prevent PUs.

Four randomized controlled trials (RCT) [23–26] organised post-discharge telehealth interventions with close contact with people with SCI after discharge, initiated from the rehabilitation unit and reached out into the home care environment.

Houlihan et al. [23] investigated the effect of telehealth in an American pilot RCT with 142 participants with SCI. The intervention was weekly CareCalls focusing on skincare and healthcare utilization and the possibility for participants to call the CareCall at any time.

Measurement of PUs for men before intervention: 18% (controls) and 19% (intervention), and after the intervention: 18% (controls) and 12% (intervention). For women before the intervention: 19% (controls) and 21% (intervention), and after the intervention 18% (controls) and 0% (intervention). The pilot study did not have an overall significant impact on PU. However, the one-side test indicates a positive effect for women as no PU's occurred in the intervention group ( $p = 0.04$ ).

Dallolio et al. [24] included 137 patients with SCI in their RCT conducted in four European rehabilitation centres: two from the UK, one from Belgium and one from Italy. The intervention was online sessions with structured interviews focusing on symptoms and physiological and psychological problems. They found no significant difference in frequencies of complications or PU after discharge (Table 3), but a significantly higher satisfaction with care in the intervention group and a higher functional score in the Italian centre.

Li et al. [25] included 78 participants with traumatic SCI in a Chinese pilot RCT measuring the effect of an online follow-up service via a WeChat platform. They found significant lower PU incidence after the intervention as two (5.13%) patients from the intervention group developed a PU, whereas nine (23.08%) in the control group ( $p = 0.023$ ). Furthermore, they measured an increased healthy lifestyle and family function in the intervention group 3- and 6 months post-discharge.

Hossain et al. [26] performed an RCT with 410 participants with SCI from the Centre for the Rehabilitation of the Paralysed in Bangladesh to determine if a community-based follow-up intervention with phone-based support and visits by healthcare professionals could prevent severe complications and death post-discharge. Participants in the intervention group received two calls a month the first year and one call a month the second year. The healthcare professionals visited the participants at home: twice during the first year and once during the second year. Participants were screened for complications, advised if necessary, and encouraged to do PU prevention. The study shows no effect on the risk of PU (risk ratio = 0.92, 0.56 to 1.53), nor did the survival data show any effect: mortality after two years was 7.4% in the intervention group and 7.8% in the control group, and a similar Kaplan-Meier survival curve both groups.

### 3.4. Stakeholders' perspectives on pressure ulcer prevention in transition

Lennox et al. [27] conducted a qualitative study with semi-structured

**Table 2**  
**Presentation of included studies.**

#	Author year	Country	Type of study	Objective of the study	Study population	Sector transition	Inclusion criteria	A) Organisation B) Intervention C) Stakeholders perspectives	Findings	Registration of pressure ulcers	Spinal cord injury Type, level and severity
1	Cahow 2012 [20]	USA	Prospective observational study (cohort)	Association between patient characteristics and therapeutic recreative interventions with QOL and functional outcomes.	Patients: Total: n = 1376 Intervention: 1032 Validation: 344 Male: n = 81%	From rehabilitation centre to home care setting	Patients ≥12 years admitted to one of six rehabilitation facilities from fall 2007 to Dec 2009	A) Change of inpatient recreation B) Therapeutic recreation activities and community activities and leisure activities during rehabilitation. C) Not investigated.	Community activities is associated with less reported PU 1-year post injury. Therapeutic rehab. and patient characteristics is a weak predictor for depressive symptoms.	Based on interviews, no information of PU details (category, number, duration etc)	TSCI High tetra plegia (cervical level C1–4): 294 Low tetraplegia (cervical level C5–8): 204 Paraplegia (T1 and below): 373
2	Dallolio 2008 [24]	Europe: UK, Belgium and Italy	Multicenter randomized controlled trial.  4 different centres: 2 in UK, 1 in Belgium and 1 in Italy.	Compare telerehabilitation intervention to standard care for SCI population from discharge to 6 month post discharge using FIM and SCIMII, registration of complications, and patient satisfaction.	Total: n = 137 (recruited from 4 centres): Intervention: n = 53 Control: n = 61	From spinal cord unit to home care setting or nonspecialised hospital care.	Nonprogressive compl. or incompl. SCI with lesions at C4-L2, living within range of SCI centre (or willing to travel) ≥18 years of age having suitable home facilities.	A) Organising telemedicine sessions post discharge B) 1 telemedicine session per week during 2 months. Followed by 9 bimonthly telemedicine sessions. Telemedicine sessions: Type 1: Structured interviews focusing on signs and symptoms held by medical doctor and nurse Type 2: Structured interviews focusing on mobility and functional parameters and skills held by physiotherapist and/or occupational therapist C) Patient satisfaction were monitored.	<ul style="list-style-type: none"> <li>No significant differences in occurrence of clinical complications between intervention and control group</li> <li>Higher functional score was found in 1 (Italy) of 4 centres.</li> <li>Higher satisfaction with care in telemedicine groups across all sites</li> </ul>	Complications were assessed at 2 months and 6 months by physicians from SCI units not involved in care of the patients, supplemented by patient and caregivers diaries.	Nonprogressive complete or incompl. SCI with lesions at C4-L2
3	de Laat 2016 [33]	Netherlands	Cross sectional	Description of behaviour to prevent PU's and association btw. behaviour and pt. characteristics (Health activation and self-management behaviour).	n = 162 Age: 56.9 ± 13.6 Male/ Female:107/55	After discharge for the first time from the spinal cord unit to homecare environment from two rehab centres in Netherlands	Participants from two rehabilitation centres TSCI or NonTSCI ≥18 years of age	A) None B) None C) Cross-sectional survey to investigate differences in patient activation score btw. SCI with PU and SCI without PU in two different rehab. centres.	<ul style="list-style-type: none"> <li>Low mean PAM score indicates low level of health activation</li> <li>Statistic significant association btw. health activation and 1. Level of education and 2. degree of paraplegia</li> <li>No significant difference in health activation btw. Pt.s</li> </ul>	PU history based on pt. reporting (questionnaire). No information of stage, but information about treatment is reported in categories: <ul style="list-style-type: none"> <li>No treatment</li> <li>Only dressings</li> <li>Bedrest</li> <li>Hospital stay (no surgery)</li> </ul>	TSCI/nonTSCI: 98/56 Complete/incomplete: 68/84 Level of SCI: Up to C4: 29 C5–C8: 38 T1-T6: 36 T7-L3: 14 Cauda equina: 14

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Table 2 (continued)

#	Author year	Country	Type of study	Objective of the study	Study population	Sector transition	Inclusion criteria	A) Organisation B) Intervention C) Stakeholders perspectives	Findings	Registration of pressure ulcers	Spinal cord injury Type, level and severity
4	Hossain, 2021 [26]	Bangladesh	Randomized controlled trial	Investigate effectiveness of follow-up service (combined phone-based with home visits)	SCI:410  Intervention group: Age: 33.4 (25.7–45.0) Male: 89%  Control group:	Home care setting after discharge from rehab. centre	SCI ≥15 years of age Wheelchair dependent at discharge Sustained SCI within 2 years	A) Organisation follow-up post-discharge phone based combined with visits B) Phonecalls (two per months the first year, one per months the second year) and home care visits (two visits the first year, one visit the second year). C) Not investigated	with history and no history of PU •Discrepancy between intended and actual PU prevention behaviour No statistical significant difference in intervention and control in PU or death after two years.	•Surgery  Based on participants assessment/pictures (phone), and health care professionals (home visits) (No information of PU details (category, number, duration etc)	Intervention: TSCI: 94% Time since injury: 5.9 months (4.6–8.1) Control: TSCI: 96%
5	Houlihan 2013 [23]	USA	Randomized controlled trial	Evaluation of telehealth intervention (CareCall) vs. Standard care in preventing PU and decrease depression.	n = 142 Mean age: 48,2 (13.3) Female: 55 (38.7%)	Home care setting after discharge from rehab. centres or from community disability organisations	People with SCD (SCI or Multiple Sclerosis) using wheelchair at least 6 h a day ≥18 years of age	A) Organising CareCall post discharge (telemedicine) B) Carecall weekly calls for six months vs. Standard care. C) Not investigated	No statistical significant difference in intervention and control. Sub group analysis indicates effect on women in group with one or more PU's.	Patient reported PU, no information of PU details (category, number, duration etc).	People suffering from spinal cord diseases: SCI: n = 106, MS: n = 36. Paraplegia incompl: 30 Paraplegia, compl.: 24 Tetraplegia, incompl.:28 Tetraplegia, compl.: 18
6	Kennedy 2010 [29]	United Kingdom	Multi-centre single cohort study.	To assess needs, barriers (environmental), level of participation and psychological function of spinal cord injured the first 18 months after discharge	n = 80 Mean age: 50,27 Men/women ratio: 2:1	At home 3–18 months after transition from rehabilitation	Participants from three centres. ≥18 years of age	A) None B) None C) Investigation of SCI perspectives post-discharge: • Perceived needs •Environmental barriers •Participation level •Individuals with SCI post discharge	•Community needs generally well addressed •Discrepancy of the amount of physical and psychosocial needs that are met •Delays in accordance to equipment, accommodation and adaptations •Secondary conditions and pain impacts independence and activity	Not reported	Participants: Tetraplegia compl.: 8 (10%) Tetraplegia incompl.: 23 (29%) Paraplegia compl: 17 (21%) Paraplegia incompl: 23 (29%) Injury type unknown: 9 (11%)

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Table 2 (continued)

#	Author year	Country	Type of study	Objective of the study	Study population	Sector transition	Inclusion criteria	A) Organisation B) Intervention C) Stakeholders perspectives	Findings	Registration of pressure ulcers	Spinal cord injury Type, level and severity
7	Le Fort 2020 [31]	France	Qualitative study: Semi-structured individual interviews	To explore function of social support and other potential factors that supports prevention of secondary conditions (incl. PU's) and long term skin prevention	n = 32 Mean age: 50 Male/female: 27/5	At home minimum one year after finishing rehab. program	SCI of any etiology finished rehab. in France ≥1 year ago ≥18 years of age	A) None B) None C) Investigation of SCI perspectives: 1. Knowledge: A foundation for social support (for patients and relatives) 2. Attitudes: Pt. attitudes and motivation for prevention found in family/spouse 3. Beliefs: Social support from related/spouse specialist 4. Practices: Social support in prevention routines	•Sexual life is dissatisfaction and needs not addressed Family (parents and partners) play an important role in social support and skin prevention. The support is dynamic and a reciprocal phenomenon and evolves over time.	Patient reported. No information of details of wounds (only used in demographic data, no PU results)	Cause of SCI: TSCI: 28 Ischemia: 2 Spinal cord compression: 2  AIS: A: 28 B: 3 C: 1
8	Lennox 2018 [27]	Australia	Qualitative study: Semi-structured individual interviews.	Describe the experiences with navigating and managing information in the community of people living with SCI	Patients Total: n = 22 Male: n = 16 (73%) Age >50: n = 15 (68%)	Home care setting after discharge from rehab. centres or clinics	≥18 years of age, English-speaking, experience with secondary conditions following SCI, received most health care services within the state of Victoria, Australia	A : None B) None C) Investigation of experiences and perspectives of information in community: • Multiple sources of information •Difficult access to information •Lack of information causes missed opportunities •Uncertainty surrounding SCI •Feeling isolated	•Greater support is required to navigate information sources •Rehabilitation is an opportune time to educate about information •Improved access to health providers with SCI knowledge is required	Not reported	Tetraplegic: n = 15 Paraplegic: n = 7 Transport related injuries: n = 11 (50%) Time since injury: >15 years: n = 12 (55%)
9	Li 2021 [25]	China	Randomized controlled trial	Analyse the effect of continuous care via telehealth (WeChat) vs standard care Measured by complication rates, health behaviour and family assessment score	n = 78 Men/woman: 40/38 Mean age: 47.12 (±10.90)	From discharge to home (intervention = 6 months)	Confirmed SCI sensorimotor dysfunction and reduced muscle strength (ASIA classified) Internal fixated stable disease Educational level: minimum primary school	A) Organising continuous care post discharge using telehealth (WeChat) B) One-to-one sessions for patients and primary caregivers focusing on: prevention and care of complications, rehabilitation exercises, dietary management, family	•Statistic significant lower incidence of PU (and other complications) in the intervention group (intervention: 5.13% control: 23.08%) •Health promoting lifestyle score increased significantly 3 and 6 months after	No information about if PU's are measured by patient or staff. No information of PU details (category, number, duration etc).	Complete SCI: 25 Incomplete SCI: 53  Cervical SCI: 10 Thoracic SCI: 32 Lumbar SCI:36 No significant differences between the two groups.

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Table 2 (continued)

#	Author year	Country	Type of study	Objective of the study	Study population	Sector transition	Inclusion criteria	A) Organisation B) Intervention C) Stakeholders perspectives	Findings	Registration of pressure ulcers	Spinal cord injury Type, level and severity
									and social support, psychological adjustment, self-care management		
								C) Not investigated	discharge in intervention group •Family function increased significantly 3 and 6 months after discharge in intervention group		
10	Manns 2007 [28]	Canada	Qualitative study: Questionnaire and open-ended focus group interviews	Explore patients (SCI) and caregivers perceptions of information needs and service delivery options	SCI: n = 35 Sex:23 males Age 39.0 ± 12.1 years  Caregivers: 23 Parents: 3 sets. mother: 1, spouses: 8. others: Siblings, daughter, aunt, grandmother, friends.	At home after hospital/ rehabilitation (participants from three different urban centres)	SCI: Able to provide their perceptions about the topic and SCI of < and >5 years duration. Duration of injury 8.5 ± 7.0 years. Caregivers (not paid)	A) None B) None C) Investigation of information needs perceived by SCI and caregivers: • Readiness • Information pathways, mentoring and family • Community health care • Health promotion, advocacy and relationships  Contextual factors: Individualization and collaboration	•Identification of important factors to reduce or prevent secondary conditions. •Readiness for information •Information pathways •Ongoing need for information about community healthcare •Contextual factors and barriers	Not reported	Paraplegic (members of Canadian Paraplegic Association). Duration of injury 8.5 ± 7.0 years. Tetraplegia: 19 Paraplegia: 16 Complete SCI: 33 Incomplete SCI: 2
11	Monden* 2021 [21]	USA	Prospective observational study	5-year outcome on the SCIR rehab project on relationship btw. patient characteristics and rehabilitation	Patients: Total: n = 792  Validation: 344 Male: n = 81%	At home care setting (follow-up data 5 years after discharge)	Patients ≥12 years from SCIR rehab project discharged from one of five rehabilitation facilities from fall 2007 to Dec 2009	A)Change of inpatient recreation B) Therapeutic recreation activities and community activities and leisure activities during rehabilitation. C) Not investigated.	Based on interviews, PU reported as dichotom parameter, therefore no information of PU details (category, number, duration etc)		TSCI High tetra plegia (cervical level C1–4): 212 Low tetraplegia (cervical level C5–8): 165 Paraplegia (T1 and below): 302
12	Munce 2016 [34]	Canada	Descriptive qualitative study Semi-structured interviews (telephone)	To explore the meaning of self-management from the perspectives of the traumatic SCI and their caregivers.	Total n = 45  SCI: n = 26 Sex: 6 male, 1 female. Age: 39–68. Time since injury: 2–25 years,  Caregivers: 7 (5 female spouses, 1 male sibling, 1 female	Home care setting after discharge from rehab. centres or clinics	≥18 years of age ≥12 months since injury Fluent english speaking Experienced a traumatic SCI Had formal og informal caregiver willing to participate	A)None B) None C) Investigate stakeholders meaning of self-management (see findings)	Identification of important elements of self-management.  Themes and subtjemes of self-management:  Internal responsibility attribution: Wellness awareness Monitoring for secondary complications	Not reported	TSCI: 7 Paraplegia: 5 Quadriplegia: 2

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Table 2 (continued)

#	Author year	Country	Type of study	Objective of the study	Study population	Sector transition	Inclusion criteria	A) Organisation B) Intervention C) Stakeholders perspectives	Findings	Registration of pressure ulcers	Spinal cord injury Type, level and severity
					personal support worker). Age: 39–65 years.  Acute care/ rehabilitation managers: 12 female managers. Age: 36–62 years.				Independence-dependence conflict Directing someone else to provide your care  External responsibility attribution: Established chronic disease self-management programs Importance of caregiver skill set		
13	Robineau 2019 [22]	France	Single-centre, prospective, interventional study without control group	Assess impact of patient education on PU prevention in people with SCI	n = 20, Sex: 14 men. Mean age 52.2 ± 9.8	At home after contact to rehab. Centre	≥18 years of age referred to rehab. Centre for hospitalization or consultation Mini Mental Test score ≥27 Understanding French	A) Patient education program B) Two educational group workshops to improve knowledge • involve participants (debate/discussions and peer to peer education) • contextually strategies to facilitate transfer of knowledge to everyday life. C) Not investigated	• Significant impact from education on skin management ability at all times during study and maintained over time • No link between level of change in knowledge and development of PU • Significant impact on quality of life after education • No impact on psychological score • Significant impact on knowledge from education	30% developed PU during the study (stage 1 or 2). Scale not mentioned and not precise description of PU was assessed by patients or clinicians. Location not reported	TSCI: 16 Non-TSCI: 4. Duration of injury median 234 months (14–684).  Paraplegia: 11 Tetraplegia: 9 Functional Independence Measure (FIM) median score 103.5 (59–116.2)
14	Sleight, 2019 [32]	USA	Qualitative study: Secondary analysis of treatment notes on patients in treatment arm without PU from a RCT (single site, single-blinded)	Identify possible protecting factors (pressure ulcer prevention)	n = 50 Age: 41.3 (12:5)	Home care setting after discharge from rehab. centres or clinics	Treatment notes from patients in treatment arm without PU from a RCT (single site, single-blinded)	A) None B) Lifestyle intervention (PU prevention program), 8 themes identified (see findings) C) Not investigated	8 protective factors identified: 1. Meaningful activity 2. Motivation to prevent negative health outcomes 3. Stability/resources 4. Equipment 5. Communication & self-advocacy skills 6. Behaviors/activities 7. Personal traits 8. Physical factors	Not reported	Not reported.
15	Zanini, 2020 [30]	Switzerland	Qualitative study:	Examine SCI and providers	SCI: 20 Female: 7	Home care setting after	SCI ≥18 years of age of any	A) None B) None	Recommendations: 1. Clarification of	Not reported	TSCI/nonTSCI: Not reported.

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Table 2 (continued)

#	Author year	Country	Type of study	Objective of the study	Study population	Sector transition	Inclusion criteria	A) Organisation B) Intervention C) Stakeholders perspectives	Findings	Registration of pressure ulcers	Spinal cord injury Type, level and severity
			Individual semistructured interviews.	experiences with outpatient and community care (PU prevention)	(35%) Family caregivers: 5 Health professionals: 22	discharge from rehab. centres or clinics	etiology lived in community >5 year and their caregivers. HP's involved in SCI care	C) Experiences with community services: •Users preference for expertise in SCI •Need of adequate community services	capacity of each involved partner 2. Collaboration btw. specialised and non-specialised services 3. Reinforcement of SCI-specialised nursing		Paraplegia: 9 (45%) Tetraplegia: 11 (55%)

Abbreviations: AIS = Score after the American Spinal Injury Association Impairment Scale FIM=Functional Independence Measure HP= Health Professional PU= Pressure ulcer RCT = Randomized Controlled Trial SCIM II= Spinal Cord Independence Measure IISCD= Spinal cord disease SCI= Spinal Cord Injury TSCI = Traumatic spinal cord injury NonTSCI = Non-traumatic spinal cord injury QOL = Quality of life.  
Abbreviations: AIS = Score after the American Spinal Injury Association Impairment Scale FIM=Functional Independence Measure HP= Health Professional PU= Pressure ulcer SCIM II= Spinal Cord Independence Measure IISCD= Spinal cord disease SCI= Spinal Cord Injury TSCI = Traumatic spinal cord injury NonTSCI = Non-traumatic spinal cord injury QOL = Quality of life.

Table 3  
Pressure ulcers after discharge [24].

Pressure ulcers after discharge	2 months n = 127		P	6 months n = 127		P
	Control n = 65	Telehealth n = 62		Control n = 65	Telehealth n = 62	
Yes (%)	7 (13.5)	9 (18.0)	0.53	6 (14.3)	8 (16.7)	0.76
No (%)	45 (86.5)	41 (82)		36 (85.7)	40 (83.3)	
Missing	13	12		23	14	

interviews with 22 people with SCI about the management and navigation of information in the community in Australia. They revealed limited access to health professionals with SCI knowledge and that participants felt on their own trying to use their knowledge and information in the transition from rehabilitation to home care environment. The authors see the rehabilitation period as an opportune time to educate about information sources and argue for a model of care that supports ongoing and long-term access to information about complications and conditions.

In a qualitative study, Manns et al. [28] performed focus group interviews with 35 Canadian people with SCI and 23 caregivers. The authors highlight the importance of patient education and information availability in preventing secondary conditions and maintaining and improving long-term health. The need for information and support from peers and family is ongoing but changes over time. 'Readiness' is considered a key concept for the individual ability to seek and take in new information. There is a dilemma between the value of learning with peers and individual needs: joining mutual sessions and learning from others is beneficial. However, the patient might not be ready to take in the information if they do not perceive the topics as relevant. Education and information pathways for people with SCI and their caregivers must be considered when organising and planning community services.

In a cohort study performed in the UK by Kennedy et al. [29], almost half of the 80 participants experienced challenging transitions to home care environments due to a lack of necessary accommodation, adaptations, and equipment delays. A follow-up close to discharge explained the surprisingly low impact of secondary conditions (including PU's).

Zanini et al. [30] explored experiences of community services in the Swiss healthcare system by interviewing 20 service users with SCI, five family caregivers and 22 healthcare professionals. They identified weaknesses in community services due to the lack of SCI expertise, inflexible working hours, and high staff turnover. The study suggests improvements in the organisation of healthcare services, expansion of inter-professional collaboration and reinforcement of SCI-specialised nursing services.

The French qualitative study by Le Fort [31] aimed to investigate social support in preventing skin complications among 32 people with SCI. Social support is dynamic and evolving and can be a strength. Participants describe how the family can be supportive in preventing skin complications. Family can motivate preventive actions, as the patients wants to stay healthy and participate in family life. According to the authors, social support should be considered in educational programs for patients and relatives.

In an American qualitative study, Sleight et al. [32] performed a secondary analysis of intervention treatment notes from 50 patients with SCI was performed by Sleight et al. They studied participants who did not develop severe PU's to identify possible protective factors. They identified eight themes with a potential protective impact to consider in organising support for the SCI population: Meaningful activity, motivation to prevent adverse health outcomes, stability/resources, equipment, communication and self-advocacy skills, behaviours/activities (proactive response, health promotion, knowledge & skills), personal traits and physical factors [32].

The cross-sectional study from the Netherlands by de Laat et al. [33] aimed to describe self-management behaviour to prevent PUs and the

association to patient characteristics to find differences between people with and without a PU history. They included 162 individuals and used the patient-reported Patient Activation Measure, focusing on self-management knowledge, skills and confidence. The study found a low mean health activation score, but most participants (94.4%) found themselves responsible for PU prevention. They found a significant positive association between high health activation and two patient characteristics: Educational level (odds ratio = 2.2,  $p = 0,017$ ) and level of SCI (odds ratio = 2.8,  $p = 0.036$ ). They found no significant differences between participants with and without a PU history.

A Canadian qualitative interview study by Munce et al. [34] describes the meaning of self-management from the perspectives of 26 people with SCI and seven caregivers versus 12 healthcare managers from acute care and rehabilitation centres. The study identifies several themes in two groups: 1. internal responsibility covers wellness awareness, monitoring secondary complications, independence-dependence conflict, and empowerment in managing own care. 2. external responsibility covers establishing self-management programs and the importance of caregiver skills. The authors recommend the involvement of stakeholders in the development of self-management programs due to the different perspectives identified in the study.

### 3.5. The organisation of pressure ulcer prevention in transition

Fourteen out of fifteen studies describe organisational elements of importance to PU prevention in transition with initiatives to supplement rehabilitation with community outings [20,21] or a telehealth solution to support people with SCI in transition [23–26]. New patient educational initiatives are other examples of organisational changes [22] to support PU prevention. The studies of stakeholders' perspectives describe different organisational elements. It can be barriers and perceived needs such as the need for information pathways, social support or health activation and self-management, and lack of equipment and access to specialised healthcare professionals [27–29,31] [30, 32].

## 4. Discussion

### 4.1. Summary of evidence

The included studies focus on challenges, factors relevant to rehabilitation and the prerequisites to manage secondary conditions and complications. They all lie within the complex field of rehabilitation of people with SCI and addressing issues of management of SCI and PU prevention in this population [1,2,5,6,8].

A fundamental in rehabilitating people with SCI is the ability to live a life as close as possible to the desired, and goals for rehabilitation are individual. Independence is considered valuable, and self-management is described as a core concept and depends on ongoing education, information, and community services. People with SCI need support from relatives, peers, and healthcare professionals during rehabilitation and after discharge to a home care environment. The studies identified several challenges in transitional care, such as lack of accommodation, aids, continuity in community services, and difficult access to SCI skilled staff.

### 4.2. Initiatives, stakeholders' perspectives, and organisation

Education and information are crucial for the individuals' independence, self-management, health activation, and ability to take care of their situation and handle PU risk. Life situation changes from the acute phase to the life after initial rehabilitation [5,20,21,27,28,32], and ongoing education and information are recommended [5,8,27,28]. Education about PU prevention increases the QOL and self-esteem, and the increased level of knowledge is sustained [22], which supports the value of educational activities in rehabilitation as recommended in guidelines

[1,2,5,6,8].

Rehabilitation and educational programs can lead to higher social integration and mobility. Including leisure activities and community outings in rehabilitation increases the individuals' skills and support a healthy lifestyle and seems to have a positive preventive effect on the occurrence of PUs and less rehospitalisation [20,21].

Patients' 'readiness' to seek and adapt information is a key element that supports an ongoing need for education and information [28]. Learning with peers can be challenging, as the topics are generic and focus on issues that may not seem relevant to all participants. Therefore, securing sufficient knowledge and support can be difficult as the need is individual and developing over time. The individual's self-care capacity and life situation impact the ability to prevent PUs, and several protective factors are identified: Educational level, support from relatives, personal traits, motivation, self-advocacy skills, behaviour, activity, physical factors, level and severity of the injury, equipment, and communication [28,31–33]. The prerequisites for people with SCI are very different, which argues for an individual approach to rehabilitation and follow-up.

Four of the included studies describe online telehealth follow-up [23–26] as a possible solution for ongoing education, information, and support post-discharge. These online sessions focus on issues relevant for the individual, which increases the 'readiness' to adapt information [28]. With visits to patients' homes, the follow-up intervention offers individual support related to the situation at home [26]. Relatives can motivate and support people with SCI to stay healthy and prevent PUs and should be involved in educational activities [28,31].

Transitioning to a home care environment is challenging with a lack of accommodations, adaptations and equipment [29]. People with SCI feel alone in transition, and they experience limited access to staff with SCI expertise in the community, inflexible working hours, and a lack of continuity in care [14,15,27,29,30]. Expanding the collaboration, knowledge transfer, and reinforcement of SCI-specialised nursing services is needed [30]. Establishing home visits from an SCI-specialised nurse and online services could bring the specialist closer to the people with SCI.

Organisational elements are described in almost all the included studies [20,22–24,27–32] and the guidelines in this field [1,2,5,6,8]. The recommendation is to involve existing knowledge and patients' and relatives' perspectives in the organisation of PU prevention. However, the included studies are from different countries and continents: Canada (2), USA (4), Australia (1), Asia (2), and Europe (6). Most of the studies are from developed countries with different models of healthcare financing and different possibilities and cultural differences. These factors affect the access to healthcare services, equipment and aids, the use of online services and access to rehabilitation and specialised health care.

## 5. Conclusions

The objective was to identify studies with initiatives, organisational components, and stakeholders' perspectives on PU prevention in transitional care of adults with SCI. Rehabilitation must focus on continuous tailored education and follow-up services to support the individual to live a life as close as possible to the desired, which can increase the QOL, level of social integration, mobility, self-esteem, and health activation. Furthermore, it can decrease the occurrence of PUs and rehospitalisation rate. The involvement of relatives in educational activities is essential as relatives can motivate and support people with SCI.

Several protective factors for PUs are identified: Educational level, support from relatives, personal traits, motivation, self-advocacy skills, behaviour, activity, physical factors, level and severity of the injury, equipment, and communication. These factors must be considered when organising rehabilitation and educational activities. The need for information and patient education varies over time, and it is individual and ongoing, like the ability or 'readiness' to take in information.

People with SCI require specialist treatment and care, but access to specialised healthcare after discharge is limited, and knowledge of SCI in the community is lacking. The needed accommodations, adaptations and equipment are lacking in transition, which causes challenging transitions from rehabilitation to the home care environment, and people with SCI feel on their own.

There is a discrepancy between the need identified in guidelines and studies of stakeholders' perspectives and the delivered healthcare services. The consequence is a missed opportunity for individuals with SCI to live an optimal life with the highest possible QOL and the lowest possible impact from secondary complications such as PUs. There is a development potential, which may decrease the occurrence of PUs and increase knowledge and self-management and the QOL and health of people with SCI.

### 5.1. Limitations

The evidence and quality of the included studies are relatively low since the sample sizes of the randomized controlled trials are small, and the other study types are traditionally placed low in the evidence hierarchy. However, the included studies were all judged to be of acceptable quality. The included studies are from various countries, and the results represent different types of healthcare systems, cultures and financing models. People with SCI and researchers' perspectives and expectation of the healthcare system and their role in rehabilitation vary from country to country.

### 5.2. Perspectives

PU prevention in people with SCI is described in international guidelines and the studies included in this review. The knowledge is not implemented in clinical practice, which would improve the quality of care and prevention.

Developing and implementing patient education programs with community outings and leisure activities could improve the individuals' skills. Establishing a closer collaboration between SCI specialised units and an online teleservice to the specialist unit for patients and their caregivers could improve healthcare services after the transition. An outreach service with SCI specialist staff could improve PU prevention in the community and support inter- and intra-professional collaboration. Prevention and treatment of PUs in people with SCI is a complex task. Prioritising this could improve the QOL and save lives and many expenses of treating PUs in the healthcare system.

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### Declaration of competing interest

**Declarations of interest:** None.

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### Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.jtv.2023.02.005>.

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