



HAL
open science

“What pressure ulcers mean to me?” Representations of pressure ulcer in persons with spinal cord injury: A qualitative study

Mathieu Gourlan, Alessandra Pellechia, Sandrine Robineau, Bernard Foulon, Dominique Gault, Marc Lefort, David Goossens, Sarah Mathieu, Isabelle Laffont, Arnaud Dupeyron, et al.

► To cite this version:

Mathieu Gourlan, Alessandra Pellechia, Sandrine Robineau, Bernard Foulon, Dominique Gault, et al.. “What pressure ulcers mean to me?” Representations of pressure ulcer in persons with spinal cord injury: A qualitative study. *Journal of Tissue Viability*, 2020, 29 (4), pp.324-330. 10.1016/j.jtv.2020.07.002 . hal-03340248

HAL Id: hal-03340248

<https://hal.umontpellier.fr/hal-03340248>

Submitted on 21 Nov 2022

HAL is a multi-disciplinary open access archive for the deposit and dissemination of scientific research documents, whether they are published or not. The documents may come from teaching and research institutions in France or abroad, or from public or private research centers.

L’archive ouverte pluridisciplinaire **HAL**, est destinée au dépôt et à la diffusion de documents scientifiques de niveau recherche, publiés ou non, émanant des établissements d’enseignement et de recherche français ou étrangers, des laboratoires publics ou privés.



Distributed under a Creative Commons Attribution| 4.0 International License

Title: “What pressure ulcers mean to me?” Representations of pressure ulcer in persons with spinal cord injury: a qualitative study.

Running title: PU representations in persons with spinal cord injury

GOURLAN Mathieu, PhD¹, PELLECHIA Alessandra, PhD², ROBINEAU Sandrine, MD³, FOULON Bernard⁴, GAULT Dominique, MD⁵, LEFORT Marc, MD⁶, GOOSSENS David, MD⁷, MATHIEU Sarah, MD⁸, LAFFONT Isabelle, MD, PhD⁹, DUPEYRON Arnaud, MD, PhD¹⁰, NINOT Grégory PhDs¹, GELIS Anthony MD, PhD^{1,9,11}

(1) Laboratoire Epsilon EA 4556, Université de Montpellier, University, Rue Henri Serre, Montpellier, France

(2) Unité transversale d'éducation du patient (UTEP), CHU Montpellier, Hôpital la Colombière, 39 avenue Charles Flahault, 34295 Montpellier cedex 5.

(3) Pôle de Médecine Physique et de Réadaptation Saint Helier, 54 rue Saint Helier, Rennes, France

(4) Association des paralysés de France, 1620 rue de Saint Priest, 34090 Montpellier, France

(5) Centre de rééducation Clemenceau, 45 Boulevard Clemenceau, 67000 Strasbourg, France

(6) Département de Médecine Physique et de Réadaptation, CHU Saint Jacques, 85 Rue Saint-Jacques, 44093 Nantes, France

(7) Centre de rééducation de la Tour de Gassies, 33520 Bruges, France

(8) Centre de Rééducation Fonctionnelle de Kerpape, Ploemeur, 92 Rue de l'Anse du Stole, 56270 France

(9) Département de Médecine Physique et de Réadaptation, CHU Lapeyronie, 371 avenue du Doyen Gaston GIRAUD, Montpellier, France

(10) Département de Médecine Physique et de Réadaptation, CHU Caremeau, 4 rue du Pr Debré, Nîmes, France

(11) Centre Mutualiste Neurologique PROPARA, 263 rue du Caducée, Montpellier, France

Corresponding authors and reprint request sent to:

Anthony Gélis, MD, PhD

Centre Mutualiste Neurologique PROPARA, Parc EuroMédecine, 263 Rue du Caducée, 34 090 Montpellier.

Phone : + 33 467 046 704

Mail : a.gelis@propara.fr

Conflicts of interests: authors report no conflicts of interests

Financial disclosure: This work was a part of REFESCAR project, funded by the Fondation Paul Bennetot (SPPR-09-003).

Acknowledgements

The authors would like to thank the medical teams of the different participating centers (Centre Saint Helier in Rennes, PM&R unit of the CHU de Nantes, Institut universitaire de réadaptation Clemenceau in Strasbourg, Rehabilitation Center of La tour de Gassies in Bruges, Centre mutualiste neurologique Propara in Montpellier, Centre de Kerpape in Ploemeur), the Fondation Paul Bennetot for its financial support, as well as Ms. Benedicte Clement for her help with the translation.

Title: “What pressure ulcers mean to me?” Representations of pressure ulcer in persons with spinal cord injury: a qualitative study.

Running title: PU representations in persons with spinal cord injury

Word count (article): 3332

Word count (abstract): 217

Figures : 1

Tables : 2

Appendix : 2

References : 37

Title: “What pressure ulcers mean to me?” Representations of pressure ulcer in persons with spinal cord injury: a qualitative study.

Running title: PU representations in persons with spinal cord injury

Abstract

Objectives: Explore the perceptions and beliefs related to pressure ulcers (PU), their prevention and treatment strategies, in order to discuss potential learning objectives for PU-related therapeutic education in persons with spinal cord injury (SCI).

Design: Qualitative study, using grounded theory for the analysis of data collected via a questionnaire.

Setting: Nine SCI referral centers, inpatient care

Participants: 131 persons with SCI were included. 76% were male, and 65% presented with paraplegia. The median age was 48 years (33.5; 58) and median time since injury was 11 years (3; 24.5). 70% had experience with PU.

Interventions: None

Main outcome measures: Data collection via an open-ended questionnaire on the representation of PU, its prevention and life experience of having a PU.

Results: Six categories were identified: (1) identifying what might become problematic, (2) daily preventive actions, (3) detecting the early signs, (4) managing the early signs, (5) need for care, (6) experience with PU and being bedridden. Pressure ulcers have dramatic consequences on psychosocial health. Prevention and treatment require self-management skills, such as self-risk assessment abilities, self-detection skills and problem-solving strategies, to optimise daily PU prevention in persons with SCI.

Conclusion: PU prevention tackled by persons with SCI bears some specificities that the physician must take into account in the construction of a self-management program in this high-risk population.

Keywords: Pressure ulcer, spinal cord injury, prevention, self-management, qualitative study.

1 **Title:** “What pressure ulcers mean to me?” Representations of pressure ulcer in persons with
2 spinal cord injury: a qualitative study.

3 **1. Introduction**

4 Pressure ulcer (PU) is the most common complication in persons with spinal cord
5 injury (SCI), representing the second cause of re-hospitalization after SCI [1,2]. There are
6 major PU-related economic consequences in this population [3]. In fact, in persons with SCI,
7 the presence of a pressure ulcer was related to a fourfold increase in the annual cost of care
8 over a one-year period [4].

9 In specialized SCI units, PU prevention includes both a mechanical dimension with the
10 evaluation of the seating position, and a behavioral dimension, with the development of
11 skincare management skills on a daily basis. In this population, a recent systematic review of
12 the literature on the efficacy of interventions related to skin care self-management showed
13 promising results, especially following postoperative flap surgery [5]. However, there is a
14 great heterogeneity in the proposed approaches and underlying theoretical frameworks [6],
15 reflecting the difficulties in apprehending skin self-care management in this population.

16 Several qualitative studies have explored PU-related beliefs and perceptions in persons
17 with SCI and their potential involvement in the development of PUs. In a sample of 14
18 persons with SCI, Jackson et al [7] tried to identify how life habits could influence the
19 development of PUs. Several characteristics emerged from the semi-directed interviews, such
20 as change in daily routine, alteration of preventive behaviors over time or compromising
21 between PU risk and activities of daily living. More recently, Florindez et al [8] conducted a
22 qualitative study with a similar objective in 25 persons with SCI. Data were extracted from
23 clinical observations and the main factors reported were: lack of rudimentary wound care
24 knowledge; equipment and supply issues; comorbidities; non-adherence to prescribed bed
25 rest; and inactivity. Conversely, Sleight et al [9] conducted a qualitative study on 50 persons

1 with SCI who presented with PUs, they identified eight types of potentially protective factors:
2 meaningful activity, motivation to prevent negative health outcomes, stability/resources,
3 equipment, communication and self-advocacy skills, personality traits, physical factors, and
4 behaviors/activities. King et al [10] described beliefs related to PU prevention on a sample of
5 22 persons with SCI and identified 4 types of representations classified according to PU
6 prevention approach: taking vigilant care, taking charge of care, maintaining health and
7 passing up care.

8 These studies refined the development of PU by identifying protective or at-risk
9 behaviors. Down the line, they could help categorize individuals according to their presumed
10 behavioral risk, but these studies bear a limited relevance in terms of identifying learning
11 objectives to better structure and enhance the efficacy of existing educational programs (e.g.
12 [11]). Furthermore, previous results based on data from medical charts must be consolidated
13 [8,9], and few studies have constructed their interview on the basis of a theoretical model
14 [7,10].

15 Explicit use of theory in health research has several benefits, including the
16 identification of key concepts related to behavior adoption[12]. Numerous theories exist in the
17 literature [13]. These notably include the Health Belief Model (HBM) [14], the theory of
18 planned behavior [15], the social cognitive theory [16] or the transtheoretical model [17]. The
19 HBM [14] appears to be the most used conceptual framework in health behavior research
20 [18]. According to this model, behaviors can be predicted based on several beliefs relying on
21 the perception of (1) the susceptibility of having a disease or developing a pathology (e.g.
22 probability of developing a PU in the future), (2) the severity of the disease or pathology (e.g.
23 a PU has major consequences on one's health), (3) the barriers associated with adopting the
24 required behavior (e.g. performing skin check and skin care takes time), (4) the benefits
25 associated with adopting the required behavior (e.g. performing skin check and required skin

1 care helps maintaining a healthy status) and (5) the cue that an action is required (e.g. redness
2 on pressure points) [14]. HBM relevance to explain health behaviors adoption was reported
3 elsewhere [18,19]. This model can notably serve as a conceptual basis to better understand the
4 subjective experience of patients with PU and refine some of the factors implied in the
5 process of health behaviors' adoption among this population [20].

6 The main objective of this work was to explore perceptions and beliefs related to PUs
7 their prevention and treatment in a SCI population, in order to discuss potential learning
8 objectives for PU-related therapeutic education in persons with SCI.

9

10 **2. Methods**

11 **2.1. Study design**

12 This was a qualitative cross-sectional study, based on an open-ended questionnaire and
13 conducted from December 2012 to February 2013. Study design was approved by the local
14 ethics committee (IRB 19-09-07). A signed consent form was obtained from all participants.
15 This protocol follows the consolidated criteria for reporting qualitative research (COREQ)
16 [22].

17 **2.2. Participants and procedure**

18 Inclusion criteria were: (1) being over the age of 18, (2) presence of SCI, (3) ability to
19 read and write in French and (4) having signed the consent form. Participants were recruited
20 in 9 SCI units distributed across France. Eligible participants were first identified by the study
21 physicians and then invited to take part in the study.

22 **2.3. Data collection**

23 Each SCI unit made available a room fitted with a computer with adapted keyboard
24 interface, if necessary. The questionnaire was completed online on the web platform
25 Epsyline®v6 (www.epsylab.fr). Mean time to fill out the questionnaire was 20 minutes. This

1 platform the French data protection agency (CNIL), and was especially designed for online
2 data storage of scientific research protocols within the Ekilia Compagny. The questionnaire
3 designed by the workgroup (MG, AP, AG) (Appendix 1) included 6 open questions. The
4 HBM was used as a framework for the study questions to identify perceptions and
5 experiences of persons with SCI. The formulation of each question was based on the
6 definition of each concept of this model [18]. There was no word limit for answers and
7 participants were encouraged to freely express their opinions, experiences, or feelings.

8 **2.4. Data Analysis**

9 We used the grounded theory to structure our analytic approach[23].

10 Open coding: The work group (MG, AP, AG) analyzed each questionnaire to formulate in
11 codes the relevant elements of the questionnaire. A definition was proposed by the working
12 group for each code and all coding discrepancies were discussed. Each member of the work
13 group had the possibility to include memos when reading the questionnaires, in order to note a
14 hypothesis, a code property, similarities between codes, potential categories or relationships
15 between the codes. These codes were treated with the RQDA software (RStudio software,
16 version 0.2-8, 2016). Saturation was reached when no new code appeared after a full
17 comprehensive questionnaire.

18 Selective coding: the work group organized open codes into themes and then categories,
19 which are more conceptual codes. Each category was a component of the general
20 phenomenon i.e. perceptions and beliefs related to PUs. They were precisely described and
21 defined.

22 Theoretical coding represents the identification of relationships between these categories (e.g.,
23 causal, dependence). To establish relationships between categories we used the notes or
24 memos written by responders and the workgroup discussed these relationships on a
25 conceptual level. The comprehensive framework was built using the different categories and

1 their relationships. In order to assess the appropriateness of the framework, questionnaires
2 that were not coded were studied to see if codes and categories found were present in the
3 comprehensive framework.

4

5 **3. Results**

6 131 participants were included in the study. Their main characteristics are in Table 1.
7 Code saturation was obtained after 62 questionnaires. Based on the 71 codes retained
8 (Appendix 2), the research team formulated 11 themes, grouped into 6 categories. The
9 appropriateness of the model was evaluated in the remaining questionnaires. The framework
10 of PU representations (Figure 1) has 6 categories, which can be grouped in two areas:
11 according to the person's environment (home or medical setting) and skin status (presence or
12 absence of PU). Table 2 groups quotes illustrating categories.

13 **3.1. Category 1: Identifying what might become problematic**

14 This category groups 2 themes for patients' perceptions of PU risk.

15 *3.1.1. Theoretical knowledge on the risk of PU*

16 This theme reflects the general knowledge on PU formation and its underlying mechanism.
17 Most often mechanical factors are reported (seating time, muscle atrophy, skin aging).

18 *3.1.2. My own susceptibility to develop a PU.*

19 PU risk factors identified by patients in their life experience. They can be physical factors
20 (e.g. prominent ischial bone), psychological or behavioral factors (lack of vigilance,
21 depression) or environmental factors (e.g. hospital stay, airplane trip).

22

23 **3.2. Category 2: Daily preventive action**

24 Daily skin care strategies implemented by patients included 4 themes, reflecting the
25 dimensions in which these strategies can become problematic.

1 3.2.1. *Involvement of a caregiver*

2 Persons with SCI regularly depend on a third person for monitoring at-risk areas, or
3 nursing care to decrease immobility or bad positioning or more generally body hygiene. Some
4 individuals experience their dependence on a third party as difficult: frustration at not being
5 able to do things alone, difficult interpersonal relationship with the third party, trust issues
6 with the third party when the latter is a newcomer. The life partner acting as a care provider
7 can also become problematic for patients.

8 3.2.2. *The place of equipment*

9 For some patients, specialized equipment can offer an absolute protection against PU and take
10 away the worry of PU emergence. This equipment can also lead to functional limitations such
11 as ability to perform transfers. Patients can also think that the equipment is responsible for the
12 PU when it is defective, improperly used or outdated.

13 3.2.3. *Body care*

14 This covers daily skin care actions. Some actions are related to a healthy lifestyle (e.g.
15 balanced diet, proper hydration) and some others are skin-specific, including skin care (e.g.
16 monitoring pressure points, skin cleanliness or hydration) and physical measures (e.g.
17 massaging pressure points, regular movements, changing position). The importance given to
18 these three dimension (healthy lifestyle, skin care and physical measures) can vary greatly
19 from one person to the next.

20 3.2.4. *Daily management.*

21 Individuals describe their perception of integrating preventive strategies in their daily life.
22 Ideally, they are experienced as usual tasks that are not difficult to implement. However, in
23 practice, they can be seen as constraining for various reasons: the need to think about doing
24 them, the time needed to execute them, the need to rely on a third party, and sometimes

1 limiting activities to avoid PU occurrence. The need for regularity in preventive actions is
2 regularly mentioned as a barrier.

3 **3.3. Category 3: detecting the early signs**

4 Patients report several skills to screen for skin lesions: sensation that there is the beginning of
5 a lesion (pain, vegetative signs, spasticity), and/or direct visualization of the early lesion (with
6 a mirror mostly). Strategies can be implemented to use these two modalities in a gradual
7 manner: for example, sensation of an early lesion is followed by the patient inspecting it and
8 then asking confirmation to a third party.

9 Multiple difficulties were reported by patients: perception of being unable to visualize the
10 skin areas, skin anesthesia rendering them numb to the pain caused by the wound. They could
11 also present with vegetative symptoms without linking these symptoms to a potential skin
12 issue.

13 **3.4. Category 4: Managing the early signs**

14 Two themes can be differentiated in the management of early-stage PU:

15 *3.4.1. Interpretation of the issue*

16 Individuals described their interpretation of the pressure ulcer's development, i.e. the intrinsic
17 or extrinsic factor that, in their opinion, led to the skin issue. The pressure ulcer can be
18 accidental, or caused by an abnormally long seating time. Some persons did not have a precise
19 idea and could bring up fate as a reason for the development of a PU.

20 *3.4.2. Acting at the beginning of the issue*

21 Some persons mentioned a list of necessary actions to manage this, e.g. relieving pressure
22 from the area concerned, reducing seating time, verification of the pneumatic cushion,
23 increasing vigilance level and monitoring. Some developed a coherent, efficient problem-
24 solving strategy adapted to their own personal situation once the beginning of a PU was
25 evidenced. For others, this strategy can be inadequate or nonexistent.

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24

3.5. Category 5: Need for care

In the presence of PU, it can be difficult for patients to rebuild a trusting relationship with new healthcare professionals. For some the need for care can bring up the notion of time (time to achieve complete wound healing), notion of burden of care or the feeling of being powerless faced with the wound evolution. Finally, there is the negative experience of returning to the hospital where they stayed for their initial SCI management post injury.

3.6. Category 6: Experience with PU and being bedridden

3.6.1. On mood and anxiety

PU can be the source of worries or anxiety. Some patients avoid thinking about the consequences of bed rest and PU. The boredom generated by being bedridden can be hard to overcome. Symptoms of depression can be experienced consequently to this boredom and bed confinement.

3.6.2. On social life

The bed rest needed to treat the PU is experienced at best as uncomfortable and at worst as cutting social ties. Patients report a withdrawal from social activities and isolation related to being bedridden, which reduces their mobility and activities of daily living. Life projects and, more generally, enjoyable life moments (family dinners, going to a movie) are forbidden.

3.6.3. On health

Some reported being aware of medical risks related to the presence of PU (infection, malnutrition). However, health consequences were rarely brought up compared to psychological and social consequences, i.e. few persons reported the risk of sepsis for their health, and were more inclined to speak about their social or psychological experiences.

1 4. Discussion

2 The qualitative study assessed PU perceptions and beliefs in 131 persons with SCI. The six
3 emergent categories describe daily strategies deployed to prevent PU (categories 1 & 2), to
4 manage early signs (categories 3 & 4) and the main bio-psycho-social difficulties related to the
5 presence of PU (categories 5 & 6). Furthermore, the first 4 categories cover the experience of
6 persons with SCI in their home environment, whereas the late two categories deal with the
7 medical setting experience.

8 The breakdown proposed in this study can help physicians target preventive therapeutic
9 education actions in this at-risk population related to the different categories highlighted, in
10 order to develop PU prevention competency, composed of several skills.

11 A first skill was the ability to evaluate one's personal risk to develop PU, also described by
12 Schubart [24]. It combines theoretical knowledge on PU pathophysiology and experience-
13 based knowledge, acquired over time by exchanging with healthcare professionals, peers or
14 previous PU self-experience. The construction of perceptions and beliefs in persons with
15 chronic diseases is based on these two types of knowledge and was brought forward as a
16 concept by Borkman [25], and constitutes one of the key points of the educational approach.
17 In persons with SCI, time since injury, but also access to information are determinants in
18 health-related knowledge [26]. It is likely that the sharing of experiential knowledge regularly
19 put into perspective with professional knowledge progressively helps build a more realistic
20 representation of PU risks.

21 The second skill pertains to screening for the beginning of skin complications. It can involve,
22 and often combines, the direct vision of the skin and wound experience (vegetative signs,
23 spasticity or neurological pain). If education on skin monitoring showed its effectiveness in
24 being a protective factor in this population [27–29], there has yet to be a study evaluating the
25 place of physical symptoms in the screening of skin disorders. During the course of SCI, early

1 signs of PU are generally poorly understood by patients, who often spend years interpreting
2 these new physical symptoms [30]. On a physiological level, autonomic dysreflexia and
3 neuropathic pain induce a type of neo-sensitivity [31], which can be useful to detect physical
4 problems such as the beginning of a PU. Patients need professional support to create a
5 personalized self-screening procedure for beginning PUs, using these two pathways and the
6 intervention of a third person if necessary.

7 Problem-solving abilities represent the third main skill underlined in this study. According to
8 D’Zurilla and Nezu [32], social problem-solving skills encompass cognitive attitudes and
9 instrumental skills necessary for coping effectively with daily life events. Elliott et al [33]
10 followed a cohort of 188 persons with SCI during the first 3 years post injury, in order to
11 evaluate the risk factors of developing a PU. After a multivariate analysis, predictive risk
12 factors were: being male, complete SCI and low problem-solving abilities. May et al [34]
13 reported a significant improvement of skin-related problem-solving strategies after an
14 educational intervention in a study without a group control and low statistical power (N=27).
15 To date, no one has measured the impact of an intervention centered on PU-related problem-
16 solving abilities in a population of persons with SCI.

17 The negative experience of the PU is mainly related to the necessity to receive
18 intensive care (i.e. Category 5) and to the psychosocial consequences of being bedridden (i.e.
19 category 6), which generates social isolation, boredom and can lead to symptoms of
20 depression, and may partly explain the difficulties with adherence to bed rest regime [8]. In
21 our experience, some people with SCI are able to develop efficient adaptation strategies to
22 fight boredom and the feeling of isolation. More precisely, it may be possible that these
23 patients have succeeded in building their character strength [35] to cope with the experience
24 of being bedridden. For instance, character strength of zest (i.e., approaching life with
25 excitement and energy) and self-regulation (i.e., regulating what one feels and does) were

1 notably associated with a lower level of disability and a higher level of physical health in
2 patients with traumatic brain injury [36]. In this context, future research could specifically
3 explore the living experience as well as the character strength that bedridden patients with
4 PUs succeed (or fail) to develop.

5 Several recommendations can be made to clinicians in light of this study, specifically in the
6 design of educational programs and the personalization of patient support. It is important to focus
7 on how the patient perceives his or her own likelihood to develop a PU, on how prevention is
8 organized daily, on the quality of the relationship with third parties involved, and finally on
9 the mental burden related to this prevention of top of the actions themselves. It is essential to
10 define modalities for detecting these wounds right from the beginning, as well as problem-
11 solving strategies for managing these wounds. The issue of consulting a healthcare
12 professional is also important. When there is a PU, the prescription of bed rest must be
13 carefully evaluated by the physician, especially in light of the patient's experience and
14 tolerance, and it might be essential to provide support to help the patient develop strategies to
15 fight boredom.

16 This study highlights the need of a scale in order to score skin-related prevention strategies in
17 this population. This could be helpful to clinicians to better analyze the development of a PU,
18 including behavioral components of PU prevention. It would be interesting to explore
19 strategies implemented to fight boredom and social isolation secondary to bed confinement.
20 The last perspective relates to the impact of educational programs, targeting teaching
21 objectives developed in this study, and especially promoting problem-solving strategies.

22 Limits:

23 The choice of designing an online questionnaire rather than conducting individual semi-
24 directed interviews could be discussed. Online surveys have been used for many years in
25 health psychology [37]. This data-collection technique bears the advantage of including an

1 important number of patients, vs. one-on-one interviews. Fewer elements are collected per
2 participant but it is counter balanced by the number of inclusions. In this study, we were able
3 to reach the coding saturation with 62 questionnaires. The main biases were controlled by the
4 precision of the recruitment and the quality of the questionnaire's design.

5
6 To conclude, this study describes the construct process of PU-related prevention strategies for
7 persons with SCI. Specifically, the construct of the perception of PU risk, modalities of self-
8 detection of skin wounds, and the role of problem-solving abilities. It also highlights the
9 negative experience on a psycho-social level of the prescribed bed rest for PU wound healing.
10 Taking into accounts these elements should allow the clinician to provide an individualized
11 support to patients, in prevention as well as management of the PU.

12

13

14 **References**

- 15 [1] DeJong G, Tian W, Hsieh C-H, Junn C, Karam C, Ballard PH, et al. Rehospitalization in
16 the first year of traumatic spinal cord injury after discharge from medical rehabilitation.
17 *Arch Phys Med Rehabil* 2013;94:S87-97. <https://doi.org/10.1016/j.apmr.2012.10.037>.
- 18 [2] Cardenas DD, Hoffman JM, Kirshblum S, McKinley W. Etiology and incidence of
19 rehospitalization after traumatic spinal cord injury: a multicenter analysis. *Arch Phys Med*
20 *Rehabil* 2004;85:1757-63.
- 21 [3] Krause JS, Murday D, Corley EH, DiPiro ND. Concentration of Costs Among High
22 Utilizers of Health Care Services Over the First 10 Years After Spinal Cord Injury
23 Rehabilitation: A Population-based Study. *Arch Phys Med Rehabil* 2019;100:938-44.
24 <https://doi.org/10.1016/j.apmr.2018.10.020>.
- 25 [4] Stroupe K, Manheim L, Evans C, Guihan M, Ho C, Li K, et al. Cost of Treating Pressure
26 Ulcers for Veterans with Spinal Cord Injury. *Top Spinal Cord Inj Rehabil* 2011;16:62-73.
27 <https://doi.org/10.1310/sci1604-62>.
- 28 [5] Baron JS, Sullivan KJ, Swaine JM, Aspinall A, Jaglal S, Presseau J, et al. Self-
29 management interventions for skin care in people with a spinal cord injury: part 1—a
30 systematic review of intervention content and effectiveness. *Spinal Cord* 2018;56:823-36.
31 <https://doi.org/10.1038/s41393-018-0138-3>.
- 32 [6] Baron JS, Sullivan KJ, Swaine JM, Aspinall A, Jaglal S, Presseau J, et al. Self-
33 management interventions for skin care in people with a spinal cord injury: part 2-a
34 systematic review of use of theory and quality of intervention reporting. *Spinal Cord*
35 2018;56:837-46. <https://doi.org/10.1038/s41393-018-0136-5>.

- 1 [7] Jackson J, Carlson M, Rubayi S, Scott MD, Atkins MS, Blanche EI, et al. Qualitative
2 study of principles pertaining to lifestyle and pressure ulcer risk in adults with spinal cord
3 injury. *Disabil Rehabil* 2010;32:567–78. <https://doi.org/10.3109/09638280903183829>.
- 4 [8] Floríndez LI, Carlson ME, Pyatak E, Blanchard J, Cogan AM, Sleight AG, et al. A
5 qualitative analysis of pressure injury development among medically underserved adults
6 with spinal cord injury. *Disabil Rehabil* 2019;1–7.
7 <https://doi.org/10.1080/09638288.2018.1552328>.
- 8 [9] Sleight AG, Cogan AM, Hill VA, Pyatak EA, Díaz J, Floríndez LI, et al. Factors
9 Protecting Against Pressure Injuries in Medically Underserved Adults With Spinal Cord
10 Injury: A Qualitative Study. *Top Spinal Cord Inj Rehabil* 2019;25:31–40.
11 <https://doi.org/10.1310/sci2501-31>.
- 12 [10] King RB, Porter SL, Vertiz KB. Preventive skin care beliefs of people with spinal cord
13 injury. *Rehabil Nurs Off J Assoc Rehabil Nurses* 2008;33:154–62.
- 14 [11] Robineau S, Nicolas B, Mathieu L, Duruflé A, Leblong E, Fraudet B, et al. Assessing
15 the impact of a patient education programme on pressure ulcer prevention in patients with
16 spinal cord injuries. *J Tissue Viability* 2019;28:167–72.
17 <https://doi.org/10.1016/j.jtv.2019.06.001>.
- 18 [12] Michie S, Prestwich A. Are interventions theory-based? Development of a theory
19 coding scheme. *Health Psychol* 2010;29:1–8. <https://doi.org/10.1037/a0016939>.
- 20 [13] Michie S. ABC of behaviour change theories: [an essential resource for researchers,
21 policy makers and practitioners : 83 theories. 2014.
- 22 [14] Rosenstock IM. Historical Origins of the Health Belief Model. *Health Educ Monogr*
23 1974;2:328–35. <https://doi.org/10.1177/109019817400200403>.
- 24 [15] Ajzen I. The theory of planned behaviour: Reactions and reflections. *Psychol Health*
25 2011;26:1113–27. <https://doi.org/10.1080/08870446.2011.613995>.
- 26 [16] Bandura A. Self-efficacy: the exercise of control. 13. printing. New York, NY:
27 Freeman; 2012.
- 28 [17] Prochaska JO, DiClemente CC. Stages and processes of self-change of smoking:
29 toward an integrative model of change. *J Consult Clin Psychol* 1983;51:390–5.
30 <https://doi.org/10.1037//0022-006x.51.3.390>.
- 31 [18] Champion VL, Skinner CS. The health belief model. *Health Behav. Health Educ. Res.*
32 *Pract.*, San Francisco, CA, US: Jossey-Bass; 2008, p. 45–65.
- 33 [19] Sulat JS, Prabandari YS, Sanusi R, Hapsari ED, Santoso B. The validity of health
34 belief model variables in predicting behavioral change: A scoping review. *Health Educ*
35 2018;118:499–512. <https://doi.org/10.1108/HE-05-2018-0027>.
- 36 [20] Wu H-L, Volker DL. The use of theory in qualitative approaches to research:
37 application in end-of-life studies. *J Adv Nurs* 2009;65:2719–32.
38 <https://doi.org/10.1111/j.1365-2648.2009.05157.x>.
- 39 [21] Sheppard R, Kennedy P, Mackey CA. Theory of Planned Behaviour, Skin Care and
40 Pressure Sores Following Spinal Cord Injury. *J Clin Psychol Med Settings* 2006;13:358–
41 66. <https://doi.org/10.1007/s10880-006-9048-1>.
- 42 [22] Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research
43 (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*
44 2007;19:349–57. <https://doi.org/10.1093/intqhc/mzm042>.
- 45 [23] Strauss AL, Corbin JM. Basics of qualitative research: grounded theory procedures
46 and techniques. 3. printing. Newbury Park, Calif.: Sage; 1991.
- 47 [24] Schubart JR, Hilgart M, Lyder C. Pressure ulcer prevention and management in spinal
48 cord-injured adults: analysis of educational needs. *Adv Skin Wound Care* 2008;21:322–
49 329.

- 1 [25] Borkman T. Experiential Knowledge: A New Concept for the Analysis of Self-Help
2 Groups. *Soc Serv Rev* 1976;50:445–56. <https://doi.org/10.1086/643401>.
- 3 [26] Tederko P, Krasuski T, Krasuski M, Długołęcka A, Tarnacka B. Determinants of
4 health knowledge and health perceptions from the perspective of health-related education
5 of patients with spinal cord injury: a systematic review. *Int J Rehabil Res Int Z Rehabil*
6 *Rev Int Rech Readaptation* 2017;40:97–106.
7 <https://doi.org/10.1097/MRR.0000000000000215>.
- 8 [27] Garber SL, Rintala DH, Hart KA, Fuhrer MJ. Pressure ulcer risk in spinal cord injury:
9 predictors of ulcer status over 3 years. *Arch Phys Med Rehabil* 2000;81:465–71.
10 <https://doi.org/10.1053/mr.2000.3889>.
- 11 [28] Raghavan P, Raza WA, Ahmed YS, Chamberlain MA. Prevalence of pressure sores in
12 a community sample of spinal injury patients. *Clin Rehabil* 2003;17:879–84.
13 <https://doi.org/10.1191/0269215503cr692oa>.
- 14 [29] Gélis A, Dupeyron A, Legros P, Benaïm C, Pelissier J, Fattal C. Pressure ulcer risk
15 factors in persons with spinal cord injury Part 2: the chronic stage. *Spinal Cord*
16 2009;47:651–61. <https://doi.org/10.1038/sc.2009.32>.
- 17 [30] Bhimani RH, McAlpine CP, Henly SJ. Understanding spasticity from patients’
18 perspectives over time: *Understanding spasticity*. *J Adv Nurs* 2012;68:2504–14.
19 <https://doi.org/10.1111/j.1365-2648.2012.05949.x>.
- 20 [31] Walters ET. How is chronic pain related to sympathetic dysfunction and autonomic
21 dysreflexia following spinal cord injury? *Auton Neurosci Basic Clin* 2018;209:79–89.
22 <https://doi.org/10.1016/j.autneu.2017.01.006>.
- 23 [32] D’Zurilla TJ. Problem-solving therapy: a social competence approach to clinical
24 intervention. New York: Springer; 1986.
- 25 [33] Elliott TR, Bush BA, Chen Y. Social problem-solving abilities predict pressure sore
26 occurrence in the first 3 years of spinal cord injury. *Rehabil Psychol* 2006;51:69–77.
27 <https://doi.org/10.1037/0090-5550.51.1.69>.
- 28 [34] May L, Day R, Warren S. Evaluation of patient education in spinal cord injury
29 rehabilitation: knowledge, problem-solving and perceived importance. *Disabil Rehabil*
30 2006;28:405–13. <https://doi.org/10.1080/09638280500192439>.
- 31 [35] Peterson C, Seligman MEP. Character strengths and virtues: a handbook and
32 classification. Oxford: Oxford Univ. Press; 2004.
- 33 [36] Hanks RA, Rapport LJ, Waldron-Perrine B, Millis SR. Role of Character Strengths in
34 Outcome After Mild Complicated to Severe Traumatic Brain Injury: A Positive
35 Psychology Study. *Arch Phys Med Rehabil* 2014;95:2096–102.
36 <https://doi.org/10.1016/j.apmr.2014.06.017>.
- 37 [37] Kaye BK, Johnson TJ. Research Methodology: Taming the Cyber Frontier:
38 Techniques for Improving Online Surveys. *Soc Sci Comput Rev* 1999;17:323–37.
39 <https://doi.org/10.1177/089443939901700307>.
- 40
- 41
- 42

Figure 1: Model of PU representations in persons with SCI

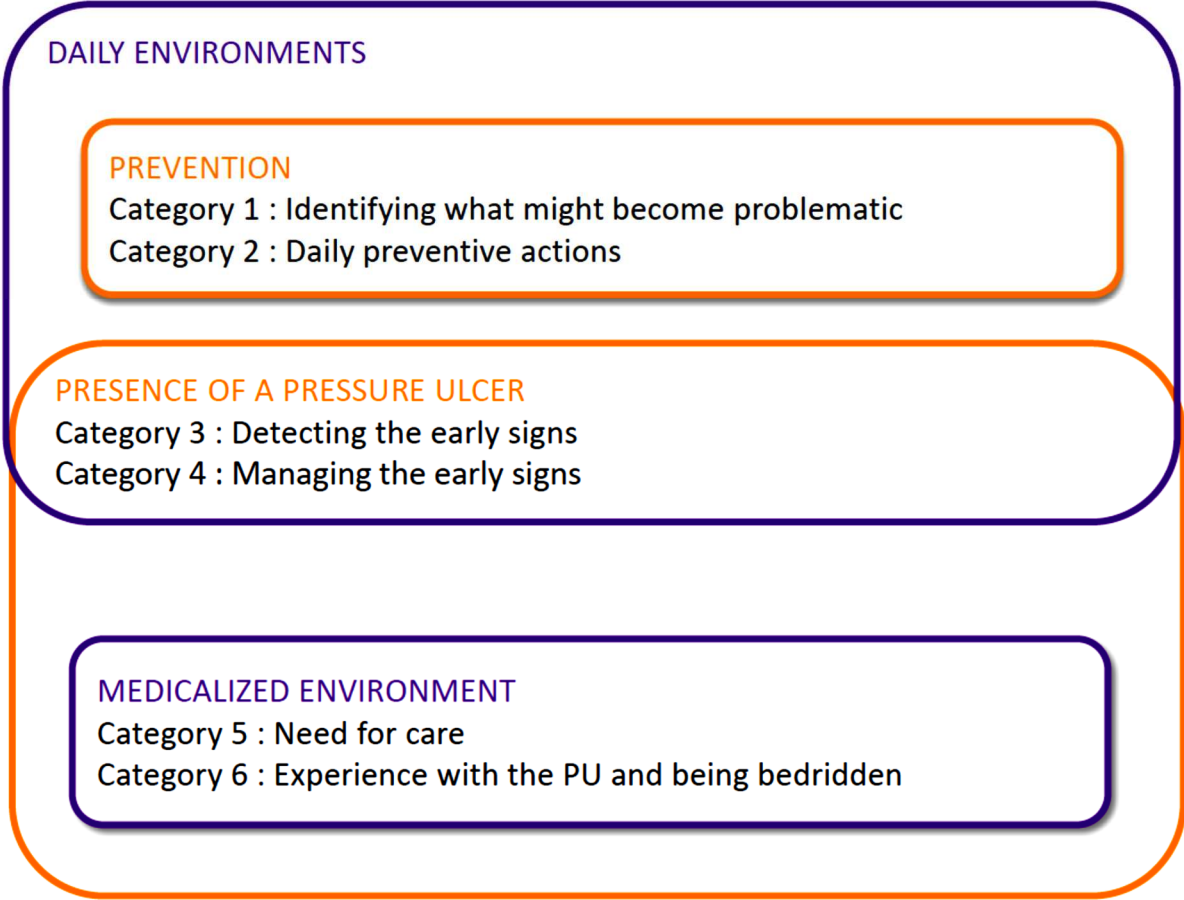


Table 1: characteristic of the studied population

Characteristics	N=131
Sociodemographics	
Age (years) median (Q1-Q3)	48 (33.5-58)
Sex	
Male	100 (76)
Living partner	80 (61)
Spinal Cord Injury	
Time since injury (years) median (Q1-Q3)	11 (3-24.5)
Etiology of the SCI	
Traumatic	107 (82)
Medical	24 (18)
Level of injury	
Quadriplegia	46 (35)
Paraplegia	85 (65)
Grade AIS	
A	83 (63)
B	26 (20)
C	22 (17)
Pressure ulcer experience	
Yes	92 (70)
No	39 (30)

Data are n (%) unless indicated. SCI: Spinal Cord injury; AIS: American Spinal Cord Injury Association Impairment Scale

Table 2:

Quotes extracted from the questionnaire, according to the categories

Category	Quotes
<p>Identifying what might become problematic</p>	<p>I must have a medium risk, because to date the only time I developed a pressure ulcer was during my hip surgery. I was bedridden for a month in 1989. Since then, I have never had a PU. The fact that I can reposition myself in my wheelchair must protect me. (Mr. R., 35 years old, neonatal paraplegia. Presented with one pressure ulcer)</p> <p>I believe I am at high risk because as I get older I will lose my strength, my skin will become more fragile, I will have more difficulties with my transfers and the risks are greater for me to touch the wheel of my wheelchair with my buttocks (Mr. J, 48 year old, quadriplegic following a motor-vehicle accident, at the age of 19. He has had several pressure ulcers)</p>
<p>Daily preventive actions</p>	<p>I do not have any specific difficulties. I trust my wife and my nurse who take care of me daily (Mr. R, 48 years old, quadriplegic for the past 35 years, he had had several pressure ulcers)</p> <p>Not being able to check the skin under my buttocks really bothers me. It is also difficult to instruct new caregivers on the importance of this verification and teach them how to do it. (Mr. F., 58 years old, quadriplegic for the past 39 years following a motor-vehicle accident. He already presented with a pressure ulcer).</p> <p>Assessing the best positioning support for my wheelchair air cushion is problematic. Because it is a cushion with 4 differentiated pressure areas, it can be difficult to know if each area is over-inflated or under-inflated (Mr. C., 41 years old. Traumatic paraplegia 7 years ago. He already presented with several pressure ulcers)</p> <p>I really do not do much, except for good life hygiene, no alcohol, no smoking and I watch what I eat because nutrition is an important factor. (Mr. C, 48 years old, traumatic paraplegia 12 years ago.)</p> <p>I do not do anything. I massage my skin, especially in locations where I already presented with a pressure ulcer (Mme V., 38 years old, paraplegic for the past 24 years. Already had several pressure ulcers)</p> <p>I make sure to reposition frequently in a 24-hour cycle to ensure partial or complete relief of load-bearing pressure points. Generally I get up at 7am. I place myself in a pressure-relieving position from 9:30 am to 11:00am. I get back into my wheelchair from 11am to 2pm. I go back to bed from 2 to 3:30pm. I resume my activities until 6pm in the winter and 9pm in the summer (Mr. L., 50 years old. Paraplegic for the past 19 years following a motor-vehicle accident. He had several pressure ulcers)</p>

	<p>One of the main difficulties is to adapt one’s life schedule to prevention and nursing care; without being a burden at work, keeping one’s performances intact and one’s abilities to adapt. It is difficult to be disciplined every day and repeat the same preventive gestures all the time (Mr. L., 50 years old. Paraplegic for the past 19 years following a motor-vehicle accident. He had several pressure ulcers)</p> <p>While taking care of my skin I can enjoy life, go outside with my electric wheelchair and enjoy the nice days and sun to play pétanque with my friends (Mr. D., 81 years old. Became paraplegic 26 years ago following a motor-vehicle accident. Already presented with several pressure ulcers)</p>
<p>Detecting the early signs</p>	<p>I don’t feel anything, I don’t see anything, but the nurses who care for me in the morning can see it since my quadriplegia is complete. (Mr. G., 40 years old. Paraplegia occurred 13 years ago after a motor-vehicle accident. Presented with one pressure ulcer)</p> <p>I have no sensations. To detect the early signs, visual screening is the only solution to protect myself (Mr. F., 44 years old, quadriplegia one year ago, had one pressure ulcer)</p> <p>I know that a problem is underlying when I have chills and sweats or if my skin becomes pink. (Mrs. T., 52 years old, quadriplegic for the past 13 years following a motor-vehicle accident. Never presented with a pressure ulcer)</p>
<p>Managing the early signs</p>	<p>Right from the onset of redness one must act to avoid a more serious problem. (Mrs. T., 52 years old, quadriplegic for the past 13 years following a motor-vehicle accident. Never presented with a pressure ulcer).</p> <p>Sweats and goose bumps in the upper body, where I can still experience sensations. Sometimes sudden muscle spasm. When it occurs at night it is a reminder to turn around. During the daytime it is a sign that can point to other causes. I proceed by elimination until I have a visual confirmation (Mr. F., 58 years old, quadriplegia 39 years ago following an accident. One previous pressure ulcer)</p> <p>When I see it is red and that the skin doesn’t become white when pressing on it, it is a sign that the pressure ulcer is imminent. At first I massage the area, but when it becomes red I must stay in bed. As soon as the redness sets in, one needs to stay in bed until it heals (Mrs. V., 38 years old, paraplegic for 24 years. Presented with several pressure ulcers)</p>
<p>Need for care</p>	<p>The most bothersome thing is being bedridden with hospitalization and surgery if needed. It is not a good moment to experience (Mr. F., 47 years old. Became paraplegic after a motor-vehicle accident 26 years ago. He experienced several pressure ulcers)</p> <p>It has a major impact on our life, because of the dressings that need to be done daily. If we soil ourselves everything needs to be done again. It poisons our life. It acts on our mood and behavior (Mr. J, 48 years old, quadriplegia)</p>

	<p>19 years ago following a motor-vehicle accident. He has had several pressure ulcers)</p> <p>When there is a pressure ulcer, what a drag! I would rather stay at home than go to the hospital. I am getting older and I am scared of the hospital, which is not adapted for people who are autonomous with their wheelchair (Mr. B., 57 years old, traumatic paraplegia 18 years ago, never had a pressure ulcer)</p>
<p>Experience with a PU and being bedridden</p>	<p>It puts your life on hold because any action that was started or anything we usually do in our daily routine is stopped. Since we are already limited with our mobility and everything that comes with it: work, family life...everything. (Mr. T., 24 years old, paraplegic after a motor-vehicle accident a year ago. Has already experienced one pressure ulcer)</p> <p>Bedridden and staying only on one side is very difficult. Eating in bed not with one's family at the table. Being bedridden halts any ongoing project. It prevents from spending good times, one is bored, gets depressed. Having to get cleaned in bed rather than taking a good shower, passing bowel movements in bed also is rather uncomfortable. The smell of the pressure ulcer can also be problematic (Mrs. C., 43 years old, paraplegia occurred 23 years ago after a motor-vehicle accident. She has already experienced several pressure ulcers)</p> <p>It is the most important freedom that is affected. A pressure ulcer, regardless of the location, alienates completely a person in her activities of daily living. Not being able to shower for example, limited autonomy, and dressings are time consuming (Mrs. T., 63 years old, paraplegic following a motor-vehicle accident 45 years ago. She has already experienced several pressure ulcers)</p>