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Lessons learned from patients with spinal cord injury in managing pressure ulcers: a qualitative study

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ABSTRACT

Objectives: To explore how individuals with spinal cord injury self-manage the prevention and treatment of pressure ulcers and to provide insight into experiences with self-management support.

Design: Qualitative study using semi-structured interview and a deductive thematic analysis.

Setting: Community.

Participants: Twelve of the 14 participating adults with a spinal cord injury had experience with pressure ulcers, and eight of these had a current pressure ulcer.

Results: Respondents suggested to tailor treatment of pressure ulcers to patients' individual wishes and capabilities of patients. Patients and caregivers need to be aware of the importance of determining the cause of pressure ulcers to prevent deterioration. Patients often depend on informal caregivers for follow-up and prevention, and healthcare professionals in non-SCI specialties often lack the knowledge needed to manage pressure ulcers in this specific patient group. Tailored education and peer support are important for patients to set boundaries, be assertive, and cultivate a positive attitude when dealing with pressure ulcers. It is difficult to combine treatment of severe pressure ulcers and preventive measures with work roles. Managing the social impact of pressure ulcers requires more coordination with caregivers.

Conclusions: To support self-management of pressure ulcers in patients with a spinal cord injury, they must find out which preventive measures and treatments suit them best. Healthcare professionals play an important role in the self-management of pressure ulcers and can help patients deal with the emotional and social impact of pressure ulcers. To know patient's needs and tailor their education, healthcare professionals of non SCI organizations need to have knowledge of pressure ulcers management of this specific patient group.

1. Introduction

Patients with a spinal cord injury (SCI) are at risk of developing pressure ulcers because they sit for prolonged periods and have impaired mobility with loss of sensation [1–5]. The prevalence of pressure ulcers varies between 9.6% and 47.4% in individuals with SCI [6–9]. Pressure ulcers affect physical and social abilities [10] and can have detrimental psychological [11,12] and financial consequences [13–16]. Therefore, preventing pressure ulcers is important in individuals with SCI [17] and these individuals need to be able to self-manage the prevention and treatment of their pressure ulcers. Self-management behaviour of patients with SCI, e.g. daily skin inspection, material use, pressure relief and lifestyle measures [18] can prevent pressure ulcers [17,19].

Self-management is 'the individual's ability to manage the symptoms, treatment, physical consequences, psychological consequences and lifestyle changes inherent in living with a chronic condition' [20]. The patient has three roles in the self-management of their chronic disease: 1) managing the medical disease, 2) performing normal (social) roles and activities, and 3) managing the emotional impact of the condition [21].

Individuals with an SCI need support from healthcare professionals and programmes to self-manage pressure ulcers. There is no generic selfmanagement programme for every patient and self-management support must be tailored to each individual's needs [22,23]. Healthcare professionals need to understand these needs to provide the right kind of support to help patients prevent pressure ulcers and cope with treatment regimes. The objective of this study was to explore the experience of managing the prevention and/or treatment of pressure ulcers in patients with SCI and to provide insight into their self-management support experiences.

2 Methods

2.1 Study design

The qualitative study was conducted between March and May 2018. To recruit participants, we collaborated with the Dutch Spinal Cord Injury Association.

2.2. Participants

Community-dwelling adults with SCIs were invited to participate in the study by the Dutch Spinal Cord Injury Association via their website and a newsletter. Those who were interested contacted the first researcher and received written information about the purpose and procedure of this study. Subsequently, those who still wanted to participate were assessed for the following inclusion criteria: aged 18 years or over, at least two years wheelchair-dependent, and available for an interview in May 2018. Patients who were not able to understand or speak Dutch or who had a mild or severe cognitive disability were excluded. Patients who met the inclusion criteria received an invitation to participate.

It was estimated that 12–16 patients were needed to reach data saturation. Therefore, we made a list of the first 20 patients who contacted the first researcher. The interviews started with the first patient on the list until we reached saturation on the three roles of selfmanagement described below.

2.3. Data collection

The data was collected by semi-structured interviews using an interview guide. The purpose of the interview was explained in the introduction after which the three roles of self-management were discussed in relation to prevention and treatment of pressure ulcers. These three roles were managing medical tasks, managing emotional impact, and managing social life. All interviews were audio-recorded.

Interviews lasted 1 h and were held at the home of the participant or another convenient place. Two research assistants conducted the interviews, of which one asked the questions and the other made notes and made sure that all interview topics were covered during the interview.

In total, four research assistants were trained by the senior researcher (BVG) through a pilot interview with a non-participant. The pilot interviews were audio-recorded, and the research assistants received feedback on their role as an interviewer and the questions they asked. Data from these pilot interviews was not collected for this study.

The interview process was iterative. After the second interview, the content of both interviews was evaluated and adapted where needed by the research assistants and the senior researcher. After the fourth and sixth interviews, the interviewers discussed the content of the interviews and whether data saturation had been reached.

2.4. Data analysis

Participant data was processed anonymously. Each audio-recorded interview was transcribed verbatim and transferred to Excel (Version Microsoft Office 365). For the analysis, a deductive thematic analysis [24] was used by the senior researcher who supervised the research assistants. The research assistants worked in pairs, read the verbatim text and marked the relevant parts before generating initial codes. They searched for the three themes managing medical tasks, emotions and social life taken into account prevention and/or treatment followed by generating subthemes within each theme. This process of coding and searching for subthemes was an iterative process performed by the research assistants and supported by the senior researcher (BVG).

3. Ethical issues

All participants gave written informed consent to participate and permission for the interview to be audio-recorded. Assessment of this study by the Dutch Central Committee on Research Involving Human Subjects was not deemed necessary. The principles of the declaration of Helsinki [25] and the European General Data Protection Regulation [26] were adhered to.

4. Results

4.1. Participants

A total of 29 people indicated that they wanted to participate. Eleven did not meet the inclusion criteria, leaving 18 people who were invited to an interview. Of these, three participants withdrew and one did not respond, leaving 14 interviewees. Twelve were men and two were women, aged between 41 and 71 years old. Seven interviews were held at the participant's home address, two at a central place with good wheelchair access chosen by the respondents, and five interviews were held by telephone. All respondents had an SCI ($n = 14$) and most SCIs were caused by a traffic or sport accident ($n = 12$). One participant had a vertebral infarction and one had spina bifida. In total, 12 of the 14 respondents had experience with pressure ulcers, eight of which had a pressure ulcer at the time of interview.

The participants' responses are described below according to the three interview themes.

4.2. Managing the medical tasks of prevention or treatment of pressure ulcers

4.2.1. Managing preventing pressure ulcers

All respondents, including those who never experienced a pressure ulcer, were aware that daily preventive measures (e.g. daily inspection of the skin and pressure release) are needed to avoid pressure ulcers. Respondents also mentioned the importance of technical aids. To perform these preventive measures, respondents depended on help from others. Often, this daily care is combined with the support of informal caregivers.

However, according to respondents, healthcare professionals in the community do not know how to prevent pressure ulcers in patients with SCIs. This can lead to misunderstandings when the patient stands up for themselves.

“The home care nurses are all good and friendly. I have a very good team. But they are not experts at it. And yes, a spinal cord injury and pressure ulcers are different from a pressure ulcer in someone who can still move ...

... People do really risky things. I send people home if they have long nails, give them a choice to either cut them off or go home” (respondent 11).

Respondents mentioned how important it is for them to stand up for themselves and to be assertive – to communicate clearly what is and is not required and to ensure that caregivers take them seriously. Sometimes the partner, who cares for the patient at home, continues to provide this care when the patient is admitted to hospital.

“In the hospital, my wife took care of me. Because people who don’t know about it [taking care of a wound in patients with a spinal cord injury] shouldn’t be allowed to treat my wounds” (respondent 5).

At the same time, being in control is often misunderstood by the authorities with whom the care has to be arranged, and patients with SCI who claim to be in control sometimes do not receive sufficient care.

“If you tell the authority [the indication bureau] that you are in charge of your own household, they cancel care hours. Because you are in control. I am in charge, but I can’t do it. I arrange my care, my finances, I arrange it all myself. I can control my computer via the sticker on my head. But when people talk to me on the phone, they don’t hear what’s wrong with me” (respondent 11).

4.2.2. Managing various types of support

Respondents who have lived with their SCI for many years indicated that rehabilitation has changed. Nowadays, much more is known about the prevention of pressure ulcers.

“When I was in rehabilitation in 1974, I received practically no advice on pressure ulcers. I later learned this myself with other fellows” (respondent 7).

For some participants, a refresher rehabilitation course on how to improve their physical condition helped to prevent and treat pressure ulcers.

“Keep your condition up and train well. I had descended so much that breathing was bad and everything went wrong. After 6 weeks there [in a revalidation centre] I was back to my old self again. When you see what exists nowadays in rehabilitation. The knowledge has increased

enormously. During that time [in the revalidation centre], the wound also healed faster” (respondent 5).

Respondents also acknowledged that a healthy lifestyle with regular exercise and healthy food is important for preventing pressure ulcers. Respondents played different sports, including hand-biking, wheelchair tennis, fitness, gardening, swimming and sailing.

“I also work out in the rehabilitation centre and I have a special chair in which I sit down and then my legs are fixed and then I am lifted up and then I have a platform near my chest that I lean against with a cushion and then I can do cross training, move a rope up and down, play boxing and lift weights” (respondent 3).

To promote a healthy diet, respondents also consulted dieticians to provide insight into their daily eating patterns and their body’s energy consumption.

“I have also been consulting a dietician for a few weeks now to find out what I eat and how I eat it. Also, to monitor my weight. It seems that a person with a spinal cord injury gains on average 2 kg a year. If it’s not going my way, in 10 years’ time I’ll be 20 kg heavier and that’s what I’m trying to avoid” (respondent 3).

Respondents use various support aids, such as seating cushions or special mattresses. They know how to use these materials but may still decide to not use them.

“He [rehabilitation specialist] recommended the antidecubitus cushion to me. I have had it for a year now. The wound is again a bit open now, but that is because I do not sit on that cushion all day. If you move around the garden on a stool, you are not going to use your cushion, or in the evening in front of the TV. In the bathroom I am sitting on a stone plate. So, then you sit on hard surfaces again. Then the pressure ulcer cushion doesn’t work because you don’t always use it” (respondent 1).

Respondents felt that, to prevent pressure ulcers, much more attention should be paid to using technological aids. Healthcare professionals can help with this, but respondents claimed that they rarely offer this help. Instead, information on technological aids is often disseminated by peers.

“Well, for example, I use a bladder stimulator. This is a fantastic tool that also helps prevent pressure ulcers. Every time, this tool [bladder stimulator] also stimulates the buttock and leg muscles ... through peers. I mentioned this to the medical doctor myself and this operation was simply reimbursed by the health insurance company” (respondent 2).

4.2.3. Managing treatment pressure ulcers

The respondents had received varying levels of treatment for their pressure ulcers in the past. Some respondents had been admitted to a hospital or rehabilitation centre for years and some had undergone several operations to treat the pressure ulcer. Others did not require surgery and were treated at home.

All respondents felt it was important to participate in the treatment they received and realized that some treatments are unavoidable.

“And when I hear him [nurse] tell me that he is going to involve a surgeon, then everything starts to happen in my head and I can already see the whole trajectory ahead of me, and of course I start

to rebel, but I can rebel if I want to, but if it's necessary, it's necessary, so far as that participation" (respondent 8).

Surgical reconstruction of a pressure ulcer is an intensive but sometimes necessary treatment and was the only solution to heal the wound for some participants. Although the treatment team may advise to perform surgery as soon as possible, this treatment must be tailored to the patient's preferences. One respondent chose to postpone the operation and go home, contrary the usual treatment, after being hospitalized for almost 2.5 years and undergoing several operations. This respondent told the healthcare professional that he desired a better quality of life, which did not include hospitalization and spending 24 h a day lying in bed. The respondent would rather sit in a wheelchair, and managed well at home.

"Last year, we [the respondent and the nurse practitioner] decided to also look at the quality of life" (respondent 9).

4.2.4. Managing high risk full situations

In addition to treatment, respondents said that knowing the cause of the pressure ulcer was important to prevent them from deteriorating and recurring. Pressure ulcers can be caused by actions or movements the individual is not aware of, such as medication changes, wheelchair adjustments, or physical changes. Participants explained that they sometimes did not realise the causes immediately and that it is important to check all activities and movements if a pressure ulcer occurs.

"Then the pressure ulcer at my sit bone was healed within 2 weeks. Then I used the shower chair, I went back to bed and it was damaged again. And this went on and on. So one day, after about six months, I was washing myself underneath like I do every morning, I felt my sit bone. My sit bone went through the cushion of the shower chair onto the wooden support of the cushion" (respondent 10).

Other respondents also experienced that pressure ulcers were caused by situations they were not aware of, for example sitting on a wooden stool while singing in the choir or sitting on a defective seat cushion while driving a car. The respondents feel no pain in these situations but they can lead to severe pressure ulcers. Ulcers can even occur after a simple initial abrasion, such as when using a patient transfer lift.

4.3. Managing the emotional impact of preventing and treating pressure ulcers

Participants indicated that they are and feel dependent on others to inspect their skin, get dressed, or get in and out of bed. Many respondents felt that they were not taken seriously.

Respondents were stressed, anxious and losing control about preventing pressure ulcers if they did not have a good relationship with their home care professionals.

"I have had 3 home care organizations and we clash greatly. I feel like they don't understand me. They come and make me feel like I am losing control. This is so difficult for me. Especially with the skin control. I feel that they don't understand. They do not understand why I am so concerned about my skin control. I am constantly discussing this with them" (respondent 4).

Respondents also said that being hospitalized for a long time with pressure ulcers can be hard. They mentioned how lonely it can be with nothing to do all day.

“The 2nd time or the 3rd time I just didn’t want to go to the hospital anymore. I wanted to do it at home because I had that negative experience from the last time. And then they started to send me to all kinds of therapies with games and a psychologist and I think that because it was the first time, I let it come over me too much and was not assertive enough” (respondent 8).

Respondents also talked about how peers or healthcare professionals teach them to deal with their emotions. According to respondent 8, there are phases that you have to go through, from being very ill, angry, and sad to dealing with your feelings and getting on with life. Peers can be role models and can help put things into perspective. For example, respondent 12 said that having a toe amputated was nothing compared with another patient, who had their leg amputated because of a pressure ulcer.

Respondents also emphasized how important it is for others to be honest. They talked about how good it feels when a nurse is sincere and gives them space to cry.

“Yes, that kick in the butt is not sometimes necessary, it’s always necessary. But also, uhm, when you’re having a hard time, they [the nurse] sit with you and offers you a shoulder and you can cry on it. So it’s both” (respondent 8).

4.4. Managing the prevention and treatment of pressure ulcers in one’s social, everyday life

4.4.1. Managing family life

According to the participants, preventing and treating pressure ulcers while participating in social and family life, maintaining contacts with friends, or going to work requires coordination with caregivers and the care organizations. For example, families often want to sit together at dinner time. Being in the chair around dinner time and being able to go back to bed not long afterwards requires coordination with home care nurses.

“The difficult thing, of course, is that I have to coordinate with the home care what the possibilities are for getting in and out of bed. Especially because you also want to combine it with your own family life. I still have two children living at home. So yes, it’s nice to be able to sit in the chair for a while, especially during dinner. Then I get out of the chair at 3 p.m. and go back to bed between 7 and 8 p.m., because that’s when everyone is home and I’ve had most of the day with the children” (respondent 13).

Being able to participate in family life during hospitalization requires more than coordination. It requires understanding of the healthcare professionals in the hospital that the patient needs to be with their family. Sometimes it is possible to fulfil that need.

“My girlfriend and little daughter were allowed to come and sleep over every weekend. You know, we still had a bit of a family bond” (respondent 9).

To cope with an intensive operation and subsequent rehabilitation, one respondent planned extra quality time with his family, knowing that the period afterwards would be difficult.

“Hmm, doing nice things with my family, because I know that September will be a difficult time. We just got back from holiday and in three weeks we are going again and in July and August we are going to Spain. We just have a lot of fun things planned. And after that, I just expect to be busy with rehabilitation for the rest of the year” (respondent 9).

Respondents stated that they were at home more than they wanted to be because preventive measures cannot always be planned in advance. This causes uncertainty and makes respondents reluctant to participate in social activities.

“Yes, negative. I am at home more because I have to take my bottom into account. And if my bottom is bothering me, I have to leave immediately. And because I have a stoma, I have to undress completely, otherwise I can’t lie on my stomach without the stoma getting in the way, so it takes time. It’s no big deal but I do notice that it has a big impact on my life compared to before I had it” (respondent 8).

4.4.2. Managing work and hobbies

Participants also reported that preventive measures, such as changing positions and not sitting in the wheelchair all day, are difficult to apply at work. Respondents with a busy schedule stated that do not have always have the opportunity to change their position regularly.

“When I worked 60 hours a week, I did not have the opportunity to lie down for a while” (respondent 6).

Even with a pressure ulcer on the buttocks, respondents could not always alternate between sitting in the wheelchair and lying down for a few hours during the day. Staying at home was also not an option because participants were worried to lose their job if they were absent too often.

“The pressure ulcer occurred a long time ago. I think about 18 years ago. It is only now actually healed. That is because I have never laid down on my bed to relieve it. I work my whole life and you can’t lie on your bed because then you would lose your job” (respondent 5).

Respondents were aware that it is important to not sit down continuously while working to avoid pressure ulcers. One respondent indicated that they were more likely to develop pressure ulcers at work and that they inspected their skin every morning before work. The respondent would not go to work if the skin was red, so the vulnerable spot can be relieved by not sitting in the wheelchair all day.

“3 days a week, these are also my risk days ... if the home care nurse finds a red spot in the morning, I will cancel my appointments and try to stand up [by using a stand-up chair] as much as possible and be out of the wheelchair” (respondent 4).

Respondents reported that people often do not understand why it is important to stay in bed and relieve a specific part of the body. It is difficult to understand why you can be out of bed one day and must stay in bed the next. They also found it difficult to explain why it takes so long for a wound to heal.

Respondents also reported having to adjust different materials to be able to do sport or go to work, such as using suitable seat cushions or making safe transfers. They also talked about how they learn from their experiences and mistakes.

“The second time I had surgery, I was home for about 3 weeks and then I started singing. I sing in two choirs and then I sat down on a wooden stool, over again” (respondent 8).

5. Discussion

In this study, we explore how patients with SCIs self-manage their pressure ulcers and how they handle strategies to prevent and treat their pressure ulcers. A key finding was that the cause of pressure ulcers in patients with spinal cord injury needs to be determined as the patient and healthcare professional may not be aware of it. Respondents often depend on (informal) caregivers for follow-up and prevention, and healthcare professionals often lack the knowledge needed to manage pressure among patients with SCI and the impact it has on social life. Tailored education and peer support are important for patients to set boundaries, be assertive, and cultivate a positive attitude when dealing with pressure ulcers. It is difficult to combine treatment of severe pressure ulcers and preventive measures being at work. Managing the social impact of pressure ulcers requires more coordination with caregivers.

This study shows that individuals with SCIs are able and eager to self-manage the prevention of pressure ulcers. In agreement with others, our study has shown that it is important to tailor these measures to the individual [22,27,28], but proper tailoring is not easy. Healthcare professionals are often aware of general preventive measures, which are based on guidelines, but lack the knowledge to tailor these measures to individuals.

It has long been recommended to involve the patient and consider their life context when administering care [29]. This requires healthcare professionals to come together with the patient to make an informed decision about care. However, this can be difficult because healthcare professionals often believe that patients do not have the competence to participate in decision-making [30]. This attitude was also revealed in our study, where respondents felt that they were not taken seriously by their healthcare provider. Our participants reported that, while healthcare professionals understand how to prevent and treat their pressure ulcers, they were less aware of their physical vulnerability and that one careless moment can lead to a pressure ulcer.

Individuals with SCIs need preventive measures that are appropriate to their situation to be able to self-manage their pressure ulcers. Here, healthcare professionals need to discuss with the patient which preventive measures are best suited and how they can be integrated into daily life. Self-management programmes [31] aim to help patients learn how to manage the treatment, emotions, and social impact associated with pressure ulcers and therefore should consist of several components [22,32]. Self-management support consists of providing information and encouraging the individual to maintain control by understanding their condition, so they are able to monitor their condition and act accordingly [33].

Gourland and colleagues (2020) [27] studied which educational topics and skills are needed to manage daily preventive measures [27]. While [27] nicely summarized the recommended measures for preventing pressure ulcers, our study shows the impact that these measures have on the daily life of individuals with SCIs. We showed that patients feel that healthcare professionals need to better adapt these general recommendations to their individual situation [18]. Patients want to find out how they can be part of their family and have a social life and how they can be themselves – essentially, how they can balance between following the recommendations and living their own life.

In agreement with others, we showed that peers also play an important role in managing patient's daily life, by serving as role models [34]. We also showed that individuals with SCI want to be able to cope with the measures they have to take to prevent pressure ulcers. Therefore, individuals need to know their boundaries and how to set boundaries to be able to work together with healthcare professionals and caregivers. Healthcare professionals and peers can help individuals with SCIs to set boundaries by asking them how the preventive measures can be integrated into their daily life. Trust and mutual respect are an essential part of this process and patients must learn to be assertive.

5.1. Strengths and limitations

Every interview was conducted by two research assistants, which ensured that all interview topics were covered during the interview and no information was missed. The research assistants were supervised by the senior researcher. Another strength of the study was the thematic analysis, which clustered the data according to predefined themes. Care was taken not to analyse the experience and impact of the SCI itself.

There may have been some recruitment bias in this study because participants were recruited via the Dutch Spinal Cord Injury Association, and only those patients who were willing to talk about the research topic agreed to participate. At the same time, inviting these individuals to share their perspectives has given us an insight into how preventing and treating pressure ulcers affects their daily life.

6. Conclusion

Patients with SCI may need some time to find out which measures are best for preventing and treating pressure ulcers. Healthcare professionals play an important role in helping the patient with SCI to self-manage the treatment, emotions, and social impact of their condition and to adapt measures to the individual situation. Respondent's experiences could play a role in future decisions and help to tailor self-management support to the individual's wishes and capabilities. Healthcare professionals who care for patients with SCI need to acquire more and adequate knowledge about pressure ulcer management in SCI to be able to better anticipate the needs of these patients.

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Declaration of competing interest

Authors report no conflicts of interests.

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