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# Factors affecting adherence to behaviours appropriate for the prevention of pressure injuries in people with spinal cord injury from Malaysia: a qualitative study

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## Abstract

**Study design** Focus group qualitative study.

**Objectives** To explore factors affecting adherence to behaviours appropriate for the prevention of pressure injuries (PIs) in people with spinal cord injury (SCI) in Malaysia.

**Setting** University Hospital, Malaysia

**Methods** Four sets of focus group interviews were conducted, each with 5–10 participants, totalling 30 people with SCI. A trained interviewer used structured interviews designed to explore participants' experiences of complying with recommended behaviours for the prevention of PIs. All interviews were digitally recorded, transcribed, and analysed utilising thematic analysis.

**Results** The factors that affected participants' adherence are classified into four main themes: (a) educational aspects, (b) internal drive, (c) social and environmental factors, and (d) post-SCI physiological changes.

**Conclusions** This qualitative study provides initial exploratory evidence regarding the thoughts, experience, and opinions pertaining to PI preventive behaviours within the Malaysian SCI population. The emerging themes contribute to an in-depth understanding of the competency of the Malaysian healthcare system in PI prevention, personal and societal factors influenced by the socio-demographic backgrounds, and disease-related factors that influence the adherence to such preventive interventions.

## Introduction

Pressure injuries (PIs) are a debilitating post-SCI complication which are known to affect a person's general health condition, psychological status, and function and community integration. Furthermore, they may be the cause of

mortality due to the development of sepsis from infected ulcers [1, 2]. PIs are common complications [3, 4] following SCI. They constitute one of the most common causes of recurrent hospitalisation [5], thereby resulting in financial burden due to hospital costs and resulting unemployment [5, 6]. The prevalence of PIs in SCI populations across low and middle-income countries is highly variable, ranging from 26% to 46% [4]. As many as 95% of people with SCI will experience a PI during their lifetime [7]. The prevalence of such was 8% after 1 year, increasing to 9% after 2 years and 32% at 20 years post-SCI [8]. However, accurate measurement was difficult in such countries due to lack of reliable reporting as a result of health infrastructure constraints, difficulty in detecting stage 1 PIs and inability to capture data on mortality secondary to SCI-related complications [4, 9].

Various studies have been conducted to investigate the risks of PIs [2, 10]. Demographic risk factors including age, education level, ethnicity, economic status, and social-background have been identified as increasing the risk of

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developing PIs [10, 11]. Lower levels of adherence to PIs have been shown to contribute to a higher risk of PI occurrence [10, 12]. Differing demographic backgrounds, lifestyles, and personal values are also significant factors in determining adherence levels to PI preventive behaviours [12]. Further risks of occurrence include SCI related factors (level of injury, functional level, traumatic vs non-traumatic, previous history of PIs, autonomic dysreflexia, spasticity, contracture and incontinence), accessibility to healthcare systems and psychological factors [2, 10]. Identification of these risk factors has allowed us to understand the fundamental knowledge of PI formation and hence develop pro-active preventive interventions [2, 10]. However, these findings may not be generalizable; therefore, an in-depth understanding of the risks in different socio-economic backgrounds is necessary [13]. Malaysia is a multi-ethnic country with a marked diversity of culture, lifestyles, personal values and healthcare systems. To prevent PIs among people with SCI in Malaysia, there must first be an understanding of the local degree of PI knowledge, the competency of healthcare staff and infrastructure in preventing and managing PIs, and the individualized risk profiles and socio-environmental factors which might play significant roles in PI preventive interventions. An in-depth understanding of these factors will allow the development and implementation of effective PI preventive interventions specifically for the Malaysian SCI population.

Given the lack of prior research demonstrating adherence levels among the local SCI population and the uniqueness of Malaysia's heterogeneous population, it is appropriate to deploy qualitative research as an initial exploratory tool. This will enable us to uncover the beliefs, opinions and experiences within the local SCI population, and explore the factors influencing adherence to PI preventive behaviours, thereby allowing relevant conclusions to be developed.

## Methods

This study used a qualitative methodology to provide an accurate description and interpretation of experiences and factors affecting adherence during PI preventive behaviours.

### Participants

Convenience sampling was used to select a total of thirty participants with SCI who were undergoing inpatient rehabilitation or attended the outpatient SCI rehabilitation clinic in the University Malaya Medical Centre, and who satisfied the inclusion and exclusion criteria. The inclusion criteria was as follows: (1) aged 18 years and above; (2) inability to walk except for therapeutic purposes; (3) traumatic and non-traumatic etiologies of SCI; (4) ability to manage skin

regimen independently—as determined by a Spinal Cord Independence Measure (SCIM) score of 6 in the domain of mobility in bed and action; (5) proficiency in either Bahasa Melayu or English, and (6) at least three months post-injury. The exclusion criteria were: (1) concomitant brain injury with cognitive impairment as determined by the Mini Mental State Examination (MMSE) score of 24 or lower; (2) complete dependence on caregiver; (3) residence in nursing home; (4) non-traumatic etiology of SCI progressing in nature, such as metastatic diseases or HIV-associated myelopathy, and (5) signs and symptoms of depression based on Patient Health Questionnaire-9 with a score of 5 or above.

### Data collection

Four focus group of 5–10 participants were conducted by one researcher (NMH). Demographic data regarding participants' age, duration of SCI since onset (sub-acute or chronic) and years of experience in dealing with PIs were collected. The duration of each session ranged from 60 to 75 min. The demographic data and participants' characteristics relevant to this study were gathered through a checklist-type questionnaire given to participants. The trained interviewer asked predetermined, open-ended questions pertaining to the experiences and factors that affected adherence to PI preventive behaviours. The development of the interview guide was based on the author's experience in working with people who have SCI (see Supplementary Appendix 1 for interview guide). The questions were structured to cover the following: (1) level of knowledge pertaining to PIs; (2) adherence level to PI preventive behaviours; (3) factors that hindered PI preventive behaviours; (4) facilitating factors towards PI preventive behaviours, and (5) perceptions of PI preventive behaviour. Interviews were conducted until data saturation was reached, i.e., the point at which no new themes or issues arose within a category of data. The participants could freely discuss and exchange opinions on the topic with other participants. Group sessions were audiotaped and subsequently transcribed verbatim in the original language used in the interview (Bahasa Melayu).

### Data analysis

A thematic analysis approach, as outlined by Braun and Clarke (2006), was employed to organise the data from the focus group discussion sessions [14]. Transcripts were read and re-read by two researchers (NMH and ANMY) to allow familiarisation with the data and identify emerging concepts and codes. The analysis focused on the factors, reasons and limitations that influenced adherence to PI preventive behaviours. Two researchers (NMH and ANMY) coded the data independently using an inductive

**Table 1** Demographics characteristics of the participants.

Characteristics	Frequency	Percentage %
<b>Age</b>		
<20	1	3.3
21–30	7	23.3
31–40	13	43.3
41–50	5	16.7
51–60	3	10.0
>61	1	3.3
Total	30	100%
<b>Ethnicity</b>		
Malay	21	70.0
Chinese	4	13.3
Indian	5	16.7
Total	30	100.0
<b>Type</b>		
Outpatient	27	90%
Inpatient	3	10%
Total	30	100%
<b>Marital status</b>		
Single	14	46.7
Married	12	40.0
Divorcee	4	13.3
Total	30	100.0
<b>Education level</b>		
Primary	2	6.7
Secondary	16	53.3
Tertiary	12	40
Total	30	100
<b>Level of injury</b>		
Paraplegia	28	93.3
Tetraplegia	2	6.7
Total	30	100
<b>History of PI Formal Education by HCP</b>		
Yes	20	66.7
No	10	33.3
Total	30	100
<b>History of PI since the latest onset to the time of interview</b>		
<6 months	7	23.3
≥6 months to 1 year	5	16.7
>1 year	12	40
Nil	6	20
Total	30	100
<b>Duration of SCI since the onset</b>		
≥3 months to 1 year	4	13.3
>1 year to 10 years	10	33.3
>10 years	16	53.3
Total	30	100

approach and later reviewed the codes together, until sub-themes were formed based on commonality. The third researcher (JPE), an expert in qualitative research, reviewed the sub-themes to confirm interpretations and assist in their development. Further discussion between two researchers (NMH and JPE) were conducted to finalise the developed themes. Data interpretation and analysis were conducted in the original language used in the discussion. The verbatim transcripts were translated into English language only for publication purposes.

### Data trustworthiness

To ensure data trustworthiness several steps, described by Shenton et al. (2004), were adopted [15]. NMH is a rehabilitation physician with 5 years' experience in managing patients with SCI and is a novice qualitative researcher. JPE is a rehabilitation physician with a special interest in the field of spinal cord rehabilitation and is an experienced qualitative researcher. ANMY is a medical ethics expert with experience in qualitative research and data analysis. Steps were undertaken to ensure data validity; i.e., prolonged engagement with the participants by utilising informal ice-breaking sessions and a 30-min question and answer session regarding PIs care before the actual interview. These sessions enabled the researchers to gain the participants' acquaintance and trust and provided a better understanding of the research field. Data triangulation was adopted by holding four focus group discussion sessions with different participants at different times. Data triangulation was achieved by two researchers analysing the verbatim independently, and later reviewing the same together to confirm interpretation, codes and themes. The researchers involved in the initial data analysis included one researcher with a SCI rehabilitation background and one without an SCI background to reduce potential bias during data interpretation. Further interpretation confirmation was conducted by an experienced qualitative researcher with a long-standing SCI rehabilitation background. The researchers also kept records of all analysis and reflexive notes and maintained the verbatim quotations throughout all stages of analysis.

### Results

The demographic characteristics of the participants are presented in Table 1. Four broad categories were identified: educational aspects, internal drive, social and environmental factors, and post-SCI physiological changes. These themes reflect what and how these factors influence the level of adherence towards PI preventive behaviours among people

**Table 2** Themes and sub-themes on the factors influencing the level of adherence towards PI preventive behaviour.

Themes	Sub-themes
Educational aspects	Source of information Self-management
Internal drive	Responsibility toward family Attitude Pressure injury experience Mood
Social and environmental factors	Social and ethical inappropriateness Physical and situational threats Family support Societal attitude
Post- SCI physiological changes	Pathological factors as facilitators Pathological factors as barriers

**Table 3** Illustrative quotes for source of information.

*“During the earlier time when I first got the injury, in Hospital XY, they were not that good in educating the patients. They were cold and unfriendly. After some months of post-injury, I met Dr. T (Rehabilitation Physician) at another centre. She emphasised and reinforced both turning and pressure relief techniques. I was scared to perform turning, as I was not trained or educated on that technique”.*

(S1\_F3)

*“Before I was discharged, the doctors and nurses did inform me to buy ROHO cushion and ripple mattress. However, they never taught anything about PI. No one told me that if I sit for too long, I may get PI. No one mentioned that. He said (the doctor), “As long as you have ROHO cushion and ripple mattress, you will be fine.””.*

(S3\_M1)

*“I did not really care about PI until the doctor requested someone with a similar situation like me. He talked to me and eventually, I can accept. If the advice came from a doctor who did not suffer the way we suffer, it would be difficult to accept”.*

(S2\_L1)

living with SCI. The four broad categories are presented in Table 2. Each of the themes are discussed below. Illustrative quotes to support the themes are presented in Tables 3–14.

## Educational aspects

Educational aspects refers to issues encountered during knowledge delivery pertaining to PI preventive interventions among people with SCI. This theme consists of two sub-themes, as depicted in Tables 3 and 4 with supportive quotes relevant to the sub-themes.

**Table 4** Illustrative quote for self- management.

*“I didn’t know the correct way of pumping air into ROHO cushion until I spoilt 2–3 of them. Then, I learnt the appropriate amount of air used when we sit, in which our buttocks should be buried comfortably into the cushion by not touching the base”.*

(S1-L1)

**Table 5** Illustrative quote for responsibility toward family.

*“I have to manage 3 children; I am a single father and I have to do all things alone. I have to be 99% - 100% fit and I must take care of my health very closely”.*

(S3-A1)

**Table 6** Illustrative quotes for attitude.

*“At the beginning of the injury, I was disciplined and diligent doing push-up and checking my buttocks. However after sometimes I’ve become lazy and didn’t continue performing the behaviour”.*

(S4\_F3)

*“It is not because of insufficient knowledge. We know the risks and consequences as we witness our counterparts, but I find the bad attitude of not doing preventive measure is hard to change”.*

(S3\_R1)

*“It is not difficult to be consistent, disciplined, and to have the attitude to take good care of ourselves”.*

(S2-L1)

**Table 7** Illustrative quotes for pressure injury experience.

*“I didn’t really care because I was new to the injury, and subsequently, I developed PI for real, from redness and it later worsened to the size of 5-cent coin (wound), whereby in 2–3 months, it started to have some discharge. Then, I knew that the skin can be really sensitive and I started to take steps of pressure relief diligently”.*

(S2\_R3)

*“I’ve seen my friend passed away due to pressure sores. I learnt from it and advised my other counterpart regarding the hazardous cause. It serves as a constant reminder”.*

(S3\_L2)

*“At first, I was diligent in following the measures. But after some time, I found by doing or not doing the steps, it doesn’t cause me anything and nothing really happened. So, I resorted to not doing anything”.*

(S1\_R1)

**Table 8** Illustrative quote for mood.

*“Before this, I didn’t know how to perform preventive care. Partly because I felt down due to the injury. I really didn’t want to think and I had no interest about it”.*

(S3\_K4)

**Table 9** Illustrative quotes for social and ethical inappropriateness.

"I did pass flatus unintentionally and unpredictably in one occasion as I was doing some movement for my pressure relief when I was sitting beside someone. Then I realised that this could happen anytime. It affected me in a way because I felt embarrassed. It gave me such an impact that I need to be careful next time".

(S2\_S1)

"Because of the dressing for PI, of course you will find it is more difficult to do push up because the soaked dressing will have unappealing smell".

(S3\_K1)

"During meeting in the midst of discussion, suddenly it is time for you to do pressure relief; this will give rise to some awkward looks and situations".

(S3\_A2)

**Table 10** Illustrative quotes for physical & situational threats.

"In my circumstance, it took me 30 minutes to ride back home on my motorcycle. If it is raining, it will take me another 1 hour..."

(S4\_Z1)

"Working time starts at 9, and there is only one sick bay to accommodate 60–70 people with disabilities. We have to struggle to be able to use it".

(S2\_L2)

"I didn't know the toilet bowl has a crack on it and later developed a pressure sore whilst transferring on it".

(S4\_C1)

**Table 11** Illustrative quote for family support.

"Family support is important. If the family didn't know what the ongoing issue was, they would not give reminders, such as, 'Have you performed regular push up as there is redness appearing on the skin?' Families must be educated with similar knowledge".

(S2\_S1)

**Table 12** Illustrative quotes societal attitude.

"Just imagine, I have to take some time off to do dressing (for PI) every day on working days. I consume a lot of my working time to do the dressing. So, your boss will perceive you as problematic. They will feel that hiring a spinal cord injured employee is actually a burden to the organisation. It (preventive measures) disturbs our efficiency at work. Since we are wheelchair-bound, we have to show them (employer) that we are also credible".

(S3-H1)

"In terms of the level of care, it depends on one's perception of how they want to do it. I do not take too much care about my preventive measures, as it is a hindrance factor to many other activities".

(S2\_R1)

## Source of information

Credibility, expertise and trustworthiness are important characteristics of an efficient knowledge provider. Most

**Table 13** Illustrative quote for pathological factor as facilitators.

"I can feel pain or burning sensation over my buttocks, and it subsequently developed into spasm over the lower limb. Then, I knew that something was not right and I changed my position. I don't have to do it frequently".

(S4\_Z2)

participants were exposed to PI information during their initial encounter with the healthcare providers (HCPs) following their SCI. The effectiveness of education was highly dependent upon the HCPs' efficiency in conveying the information. Participants stated that the information was usually superficial, insufficient and sometimes incorrect. Some participants also stated that HCPs were incompetent in detecting PIs, hence less emphasis was placed on the preventive method. Flaws in the education given led to poor understanding of PI risks, which led to incompetency in performing the preventive behaviour. The education was most effective when given by a multi-disciplinary team of HCPs specialising in the care of SCI patients, as opposed to HCPs with less experience and specialisation in SCI and its complications, particularly in centres lacking specialty in rehabilitation medicine.

The participants also gained access to information from the internet and their peers. They reported that they could better digest, value and relate to the information conveyed by peers sharing similar conditions, than that from HCPs using existing guidelines, who were perceived as different and unable to understand the participants' situations.

## Self-management

The participants were also able to empower themselves with problem-solving skills and knowledge to manage problems or challenges encountered whilst practising PI preventive measures. These measures were tailored to their individual needs and ever-changing lifestyles and may not be addressed in the standard guidelines of PI preventive behaviours. This self-empowerment skill is one of the most crucial attributes in improving self-efficacy in performing PI preventive behaviours, hence maintaining and enhancing the adherence level. However, without proper guidance from the HCP, incorrect information regarding preventive measures may be accessed or improper behaviour adopted that may not align with medical recommendations.

## Internal drive

Internal drive refers to inherent personal factors which influence preventive behaviours among SCI persons. This consists of four sub-themes, as depicted in Tables 5–8 with supportive quotes relevant to the sub-themes.

## Responsibility toward family

Fulfilling duties towards family serves as an internal push or facilitator for adherence to the preventive behaviours. The participants feel that they need to stay healthy to fulfil their responsibilities as the head of the family or breadwinner or in managing the household. Thus, they were more ready to commit to preventive behaviours to avoid burdening their family with severe complications of PIs, which could affect family relationships, finances and the psychological state of the family.

## Attitude

Negative or positive attitudes influence levels of adherence. Participants possessing apathetic or ‘couldn’t-care-less’ attitudes risk being ignorant of and losing interest in continuing preventive measures. Participants who were very diligent after SCI may become less diligent over time, perceiving the behaviours as troublesome. However, several participants who were consistent and disciplined, gradually became used to the routine and successfully developed good preventive habits. Most agreed that self-discipline and positive attitudes were crucial to maintaining adherence.

## Experience of pressure injury

Several participants disclosed that their experience with PIs served as encouragement in adhering to preventive behaviours. Having first-hand experience of PIs or observing their peers struggling with the serious complications increased their understanding of the hazardous effect of taking the preventive matters lightly. The more severe PIs complication suffered, the more likely they were to adhere to the preventive acts. In contrast, a few participants perceived that the preventive measures had less beneficial effect; hence, they resorted to not performing them at all. This belief was driven by having little or no experience of PIs during the disease, as well as non-adherence to the preventive acts.

## Mood

Motivation is influenced by the psychological status of those suffering from SCI. Downheartedness or low mood as a result of SCI, can lower a person’s motivation to perform the preventive behaviours as they are still in denial and more concerned about the chances of recovery following SCI. They have little or no interest in learning about skin care, despite previous education regarding the disease.

## Social and environmental factors

The third theme concerning “Social and Environmental Factors” describes external factors which influence adherence levels. Four main sub-themes were identified, as depicted in Tables 9–12 with relevant supportive quotes.

### Social and ethical inappropriateness

Strict adherence to ensure the effectiveness of PI preventive measures requires people with SCI to perform these measures in all situations. This may result in humiliating situations occurring whilst performing pressure relief in public, such as passing flatus or unappealing smells arising from soaked PI dressings. Such scenarios deterred individuals from performing pressure relief. Society may perceive pressure relief as a peculiar act, mainly stemming from lack of understanding regarding the SCI impairment.

### Physical & situational threat

A non-conducive environmental condition can hamper SCI sufferers from utilising preventive acts. Factors contributing to such difficulties included lack of facilities in workplaces, e.g., sick bays to accommodate employees with SCI. Poorly maintained amenities, such as cracked toilet bowls, may be hazardous to persons performing preventive measures. Other factors, including being trapped in unfavourable and unpredictable situations (e.g., stuck in traffic whilst riding a tricycle) also contributes to such problems. These situations not only hinder adherence but also increase the chances of further developing PIs.

### Family support

Families play an important role as facilitators in preventive care. They provide support by offering assistance and affirmation, which serve as a constant reminder and help to fill any knowledge gaps and inefficiency in performing the preventive measures.

### Societal attitude

Some participants reported that they perceived the preventive behaviours as a burden, which interfered with their daily lives. Being overly occupied with daily work, house chores and tasks tends to cause negligence towards self-care, which adversely affects adherence to preventive methods. It was also believed that by performing some preventive acts, they may be perceived as ineffective, inefficient, less-productive employees. It was deemed

**Table 14** Illustrative quotes for pathological factors as barriers.

*"I developed spasm over my truncal area while I was doing my push up, which caused my body to stiffen. Immediately, I fell backwards with my wheelchair".*

(S4\_F3)

*"I had a fracture on my collar bone. If I had to do pressure relieve every 2 hours, I don't think I can do it. It causes severe pain".*

(S2\_A2)

important for them to display a high-credibility appearance despite their disabilities, in order to keep their jobs.

### Post- SCI physiological changes

Two sub-themes emerged regarding physiological changes following SCI, which influenced the adherence level (as depicted in Tables 13 and 14), with supportive quotes relevant to the sub-themes.

### Pathological factors as facilitators

The identified facilitative pathological factors were pain and spasm over lower limbs when a person with SCI sat for too long. This served as an alarm or signal that it was time to perform pressure reliefs and prevent total abandonment of such behaviours. Paradoxically, having such signals may reduce the appropriate frequency of performing pressure reliefs that are recommended in the guideline.

### Pathological factors as barriers

Pathological barriers towards preventive behaviours included truncal spasm, which usually occurs whilst performing pressure relief acts. This can be hazardous as it may cause falls, whereas orthostatic hypotension which occurs in acute SCI hinders one's ability to be upright or move to perform the preventive actions. Concomitant fracture of the upper limb together with SCI also caused a hindrance due to pain. The presence of these physical barriers had deleterious implications in regards to PI preventive acts, decreasing adherence. Keeping safe and avoiding other medical hazards were sufferers' utmost priority.

## Discussion

This study explored factors influencing the level of adherence towards PI preventive behaviours. Many quantitative and qualitative studies investigating the risks of developing PIs, have indicated that poor adherence towards the preventive behaviours plays a role in PI occurrence

[8–10, 16, 17]. This study allows an in-depth understanding of what and how those factors affect the adherence. Four broad themes emerged from this study: (1) Educational aspects; (2) Internal drive; (3) Social and environmental factors and, (4) Post-SCI Physiological changes. The results of this research overlapped with those of previous qualitative studies covering a range of behavioural components including motivation, education, psychological and biological aspects [13, 16, 18].

Education has been shown to be crucial to knowledge empowerment [2, 17]. To the best of our knowledge, limited or no prior research exists describing how PI education is conducted in our local setting. Hence, this study delves indirectly into the shortfalls of education intervention within our healthcare system. Based on our experience of managing SCI patients, education about PIs is often conducted at the bedside by the HCPs during the acute phase, usually taking place in the surgical ward or sometimes in a hospital without specialised rehabilitation medical services. The quality of this education very much depends on the competency of the HCPs, as shown in our study [19, 20]. Structured PI prevention programs often begin during the active inpatient rehabilitation admission, by specialised multi-disciplinary rehabilitation teams trained in post-SCI care, during the sub-acute phase. However, not all hospitals are fortunate enough to have this service. This education is usually confined to the recommendations in the basic manual to avoid information overload which may overwhelm the patient and takes place during the initial phase, emphasising the core principles of PI prevention methods regarding skin care, pressure reliefs, equipment and a healthy lifestyle. Peers are not usually involved in the formal education as they are not trained. Education is rarely extended to the community; if occurring at all it is held in isolation, is uncoordinated and with a lack of supervision. Hence, certain psychosocial aspects are poorly addressed, despite their evident importance as shown in this study.

Analysing the shortfalls in the education system assists us in determining how the education intervention should be improved. All HCPs dealing with SCI patients should be educated about the risks of PIs and preventive method steps, especially when dealing with patients during the acute phase [17, 20]. Knowledge evaluation should be conducted among HCPs from time to time to ensure that their competency is at a high level [21]. SCI patients' education should be structured as recommended in the evidence-based guidelines, especially in the early stages that address many dimensions of PI prevention [2, 22]. The content of the education should not only encompass traditional medical models, but also behavioural approaches which promote self-management [17, 22]. A systematic review which explored the content of skincare self-management intervention for people with SCI, utilised a Behaviour Change

Technique (BCT) components to code the intervention content. It had revealed that 65 out of 93 BCTs were not coded to any interventions, implying that many components of behavioural science remain unexplored despite their potential impact on skincare [22]. Our findings address this disparity by providing an in-depth understanding of factors that influence these BCT components, including credible source, behavioural practice, action planning, feedback on behaviour, social support, commitment, habit formation, prompt/cues, body changes and social and environmental consequences [22]. These findings may assist clinicians in developing relevant educational content and preventive methods which are appropriate to end-users. Other necessary elements are the experience and knowledge-sharing, which may be achieved by conducting group sharing sessions moderated by a trained HCP, enabling cross-over of knowledge and enhanced problem-solving skills. HCPs have a role as “gatekeeper” to ensure that the information shared is in line to the medical recommendations. This may also allow the HCPs to increase their understanding of issues which might arise once the participants return to their community. Hence, a more individualised approach to giving relatable recommendations beyond medical perspectives and standard guidelines is achieved. This also promotes self-management, assisting patients to learn, consistently apply and incorporate the recommendations into their daily lives effectively [2]. The education interventions should be effectively targeted and matched to different groups of needs and different phases of SCI [2, 23].

Peer influence has been shown to be a critical factor and should be integrated into the community outreach programme. This might provide more behavioural approaches outside the conventional medical framework [2, 17]. The Peer Information Network was an evaluation project of peer support conducted in America [24]. 24 peer advisors were trained, operating through community centres to promote independence for people living with disabilities. However, the project encountered multiple downfalls in implementation; low recruitment; high loss to follow-up of subjects, and lack of control over peer-advisor training [2]. Learning from these pitfalls we propose a peer-match buddy system, in which online profiles of a potential peers are outlined, from which the person with SCI can choose the peer deemed most compatible with their own clinical characteristics, lifestyle, personal values and personality traits. Thus, an opportunity is provided to develop a close, long-lasting mentorship bond and individualised guidance. Hence, loss of follow-up might be reduced and a role model of effective empowerment formed [25]. Ideally, this system should be initiated during the early rehabilitation phase, so that good attitudes can be instilled, and psychological aspects

supported. Regress or deviation of motivation or attitude can be detected earlier by peers and addressed. Peers should be trained to ensure the dissemination of correct information. This study provides additional information regarding the challenges and obstacles pertaining to preventive behaviours relevant to our community, which can be used to prepare the peers with strategies to tackle such problems.

In previous literature, pathological implications post SCI, such as pain, has been found to negatively affect mood, function and quality of life [26]. Moderate-to-severe pain impairs weight-shifting and mobility which leads to increased risk of PIs development [26]. Interestingly, several participants admitted that pain was a facilitative factor which served as a reminder or indicator that it was time to perform pressure relief acts. However, this behaviour deviates from the recommended standard practice [1, 2]. Further study is warranted to explore the effectiveness and implications of such practice [1, 2]. Strikingly, despite similarities with prior studies which focused on the complications of non-adherence towards preventive behaviour, a noteworthy implication of performing preventive behaviours was identified; passing flatus, unappealing smells and receiving awkward stares from people around whilst performing pressure relief are perceived as socially and ethically inappropriate. These acts, which may give rise to embarrassment, are rarely discussed and may lead to abandonment of the preventive practices. This indicates that shortfalls in certain preventive acts exist which may not be suitable in some circumstances.

This study also reveals that certain preventive steps are not well adapted to certain lifestyle or biological changes. Our local approach is very traditional and conventional. Perhaps we might start to incorporate technological advancement to local preventive methods, e.g., electrical stimulation [27], dynamic weight-shifting technology and power weight-lifting or tilting wheelchairs [28]. The expense of such equipment limits their usage in our preventive intervention. This study hopes to motivate local innovators to produce sophisticated versatile equipment that is affordable, and more importantly, able to solve pertinent issues of the preventive behaviours.

### Limitations of the study

The advantages of using focus group discussion allowed us to achieve maximal variation, provide a wider range of information and promote interactivity [29]. The recommendation that preventive behaviours should be initiated early post-injury [2] and the evidence indicating that SCIs possess different sets of PI risks at different stages, rationalises the combining of inpatient and outpatient participants during the discussion sessions. [30, 31].



It is worthwhile to note some limitations of this study in interpreting the results. This study may not represent all populations of SCI in the country, as the interview was more focused on those independent of skin care regimen. The results may be influenced by selective memory and inability to recall events. Nonetheless, the themes were identified repeatedly across the study sample, hence increasing the reliability of the study outcomes. Future research could focus on the education needs pertaining to PI preventive behaviours, utilising in-depth semi-structured interviews. The interviews should be conducted among HCPs (HCPs or peers), people with SCI and their care takers. This will expand the context and rigorous information pertaining to what is lacking from different perspectives of both providers and recipients of the education.

## Conclusion

This qualitative study provides an initial exploratory analysis regarding the thoughts, experience and opinion pertaining to PI prevention among the heterogeneous Malaysian SCI population. It contributes to an in-depth understanding of the competency of the Malaysian healthcare system in PI preventive management, personal and societal factors influenced by the socio-demographic backgrounds, and disease-related factors which affect adherence to preventive intervention. We believe that our study has provided the necessary evidence to urge that requisite actions or strategies be taken to improve current states of practice in our healthcare landscape.

## Data availability

The datasets generated and/or analysed during the current study are available from the corresponding author on reasonable request.

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**Author contributions** NMH is the corresponding author responsible for designing the review protocol, writing the protocol and report, conducting the search, screening potentially eligible studies, leading the process of extracting, coding, analysing data, interpreting results, updating reference lists and creating 'Summary of findings' tables. She is also responsible for summarising the whole research protocol,

findings and interpretation into a written manuscript with the assistance of the other co-authors. ANMY has experience in qualitative study and was actively involved in the verbatim transcription, coding and thematic analysis alongside the lead researcher. She was also involved in the data interpretation. She assisted the lead researcher with the reference list. JPE contributed and gave her expert advice in qualitative study protocol, assisting the data coding, thematic analyses and data interpretation together with the lead researcher. She also contributed to the re-structuring of the manuscript. NH contributed in advising on the focus of the study and the recruitment of participants. She also assisted in proofreading the manuscript.

## Compliance with ethical standards

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

**Ethics** This study was approved by the Institution's Medical Research Ethics Committee (20164–2377).

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