Title

Educational provision for patients following a spinal cord injury; a service evaluation

Short Title: Spinal cord injury patient education

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Abstract

Background

Approximately 40,000 people in the UK live with spinal cord injury.

Aim

To explore the views of patients and healthcare staff relating to the specialist education and information provided following a spinal cord injury (SCI).

Methods

A service evaluation consisting of questionnaire surveys distributed to patients and staff at the London Spinal Cord Injury Centre.

Results

98% of healthcare staff found giving education an enjoyable part of their role with most agreeing (45/48) it is the responsibility of all healthcare staff. The formal education programme was valued by patients, sessions were graded to inform future programme.

Face to face was the preferred delivery method for 80% of inpatients and 40% of outpatients with the 2nd most preferred method being an App/elearning for both patient groups.

Conclusion and implications for practice

Findings support the continued need for both formal and informal sessions, provided by all members of the healthcare team, with particular emphasis on issues such as bladder and bowel management and sexual function post discharge.

Keywords: spinal cord injury, information, education, service evaluation

Introduction

Approximately 40,000 people in the United Kingdom (UK) live with spinal cord injury (SCI) and 1,200 new injuries occur every year (Qin Liu et al., 2014). Secondary medical complications are common and include pressure ulcers, bladder and bowel dysfunction (Sezer et al., 2015), which are costly both for the individual with SCI and the healthcare service.

A vital element of rehabilitation is the provision of information and education. Patient education optimises patients’ participation in their own decision making and care process, and promotes concordance with agreed plans, reducing the risk of post injury complications, promoting independence and improving quality of life (Harvey & Davidson, 2011). Ultimately, information gives patients the skills needed to successfully reintegrate into the community and be as independent as possible. The challenge is to develop and implement methods that enable all patients to manage and process the information they need in the best way possible (Eloranta et al., 2016; Kesanen et al., 2013). Patients’ preferences and their ability to absorb information are, however, factors which need to be considered in choosing the right approach.

Specialist rehabilitation at the London Spinal Cord Injury Centre (LSCIC) includes an intensive programme of formal and informal education to help patients understand how the SCI has affected their body and how to care for themselves. Peer support workers are an important part of this process and help individuals achieve the adjustments necessary for living with SCI (Haas et al., 2013). The current eight week formal inpatient programme has been in place for more than five years. It is run two days per week by a group of specialist staff and includes 10 one hour sessions (Table 1). Educational provision prior to 2013 was evaluated by a multi-disciplinary working party, which included representatives from ASPIRE (spinal cord injury charity) and peer support workers. This resulted in the development of the current format, which reflects an evidence based understanding of the lived experience of SCI and the key concepts shown to impact quality of life, as reported in the meta-synthesis by Whalley-Hammel (2007).

Table 1: Inpatient programme structure

|  |  |
| --- | --- |
| Health and fitness  | LSCIC physiotherapy team |
| Relaxed | Clinical psychologist |
| Help for you \* | Spinal cord injury charities |
| Life after hospital \* | Community Liaison CNS |
| Your Skin & Nutrition \* | LSCIC Nursing team |
| Spinal Injuries Association Vocational talk \* | Spinal Injuries Association |
| Managing your Bladder and bowel \* | LSCIC Nursing team |
| Coping & Independence | Clinical Psychologist |
| Money Matters \* | Aspire (SCI Charity) |
| Sexuality, sexual function and relationships | Sexual Function CNS |

\* Peer support worker in attendance

In addition, informal information and education is provided daily by healthcare professionals as they assist patients with their care and progress is monitored in individual two weekly goal planning meetings, attended by both patients and health care staff. A multiple-choice trouble shooting quiz, which the patient undertakes with a member of the health care team assesses patients’ knowledge levels prior to discharge. This enables the healthcare professional to determine any further information required and to make sure that they receive the information they need to live as independently as possible after discharge. Patients are also given a large A4 education folder to take home, which contains information on how SCI affects the body. To ensure staff have the necessary skills and knowledge, they all complete a comprehensive competency book as part of their induction.

Study aim

The aim of this study was to explore patients’ and healthcare staff (HCS) views about the information and education currently provided to people with a SCI at the LSCIC, Royal National Orthopaedic Hospital (RNOH).

Method

A service evaluation approach was taken to address the study aim. The local research and innovation centre approved the project and confirmed that ethical approval was not required.

Between September-November 2017 outpatients (up to 2 years post injury), inpatients on the LSCIC and healthcare staff actively involved in the rehabilitation of people with a SCI at the RNOH were invited to participate in a questionnaire survey. Healthcare staff were provided with study information via team meetings, inpatients during conversations with their peer support worker and outpatients (who had previously agreed with a specialist spinal cord injury charity to be contacted) via email. Participant consent was inferred by return of an attached questionnaire. Peer support workers assisted with survey completion where necessary.

Patient participants completed a locally designed paper or online questionnaire, which asked them to rate each of the 10 formal education sessions (Table 1) using a Likert scale of 1-5 and provided additional opportunity for free text comments. Health care professionals completed a paper questionnaire consisting of multiple choice questions regarding the informal education they give to patients and which also provided an opportunity for free text comments. Descriptive statistics (frequencies and percentages) were used to describe the sample and to report the quantitative data. Free text comments were collated under three main headings.

Results

A total of 90 people completed the survey, 48 HCS and 42 patients.

Patients

Of those approached (*n*=91), 10 inpatient and 31 outpatients agreed to participate- although only 23 completed the full questionnaire (Table2).

Table 2: Demographics of participating patients

|  |  |  |
| --- | --- | --- |
|  | Inpatients (*n*=10) | Outpatients (*n*=23) |
| Gender | Male *n*= 5 (50%) | Male *n*= 20 (64.52%) |
| Age | ≤ 30 years *n*= 2 (20%)31-64 years *n*= 7 (70%)≥ 65 years *n*= 1 (10%) | ≤ 30 years *n*= 4 (17.39%) 31-64 years *n*= 15 (65.22%)≥ 65 years *n*= 4 (17.39%)  |
| SCI level | Paraplegic *n*= 4 (40%)Tetraplegic *n*= 4 (40% | 14 (60.87%) paraplegic 3 (13.04%) tetraplegic6 (26.09%) Able to walk |
| Attended education sessions | Yes *n*= 9 (90%)  | 18 (78.26%) Yes5 (21.74%) No |

Formal education

The most highly rated sessions were ‘bladder and bowel management’, ‘skin and nutrition’ and ‘help for you’ (Table 3).

Table 3: Most popular sessions

|  |  |  |
| --- | --- | --- |
| Education session | No. of Inpatients rating session as 5 (most useful) | No. of Outpatients rating session as 5 (most useful) |
| Bladder and bowel management | 5/7 (71%) | 13/19 (68%) |
| Skin and nutrition | 4/7 (57%) | 12/18 (67%) |
| Help for you | 4/7 (57%) | 10/18 (56%) |

Most inpatient respondents (60%) stated they would not remove any topics but a few people suggested that topics on sex (*n*=3), equipment choice and demonstration (*n*=3) should be added.

Other inpatients commented that ‘I think all the talks were very helpful and the staff were helpful and friendly’. Eleven of the 15 outpatients (73%) also stated that they would not remove any sessions, although one person did not feel the need for the session on sexuality, sexual function and relationships and another stated they would remove the relax session. Additional comments made by outpatient respondents included: ‘wasn’t enough talk about sex and spinal injury’ ‘no help from RNOH after discharge’, ‘Often the talks just duplicate the things I had already learned on the ward’.

Post discharge needs

Thirteen respondents commented specifically on the information they needed to support the post discharge period (example comments in Table 4), whilst 15 out of 23 respondents (65%) reported using the post discharge education pack education pack. The most common complication experienced following discharge was bladder issues, including urinary tract infections and blocked urinary catheters (*n*=6). In addition, there were reports of skin issues (*n*=2), pain (*n*=1), autonomic dysreflexia (*n*=1) and spasms (*n*=1).

Table 4: Information needs after discharge

|  |  |
| --- | --- |
| Theme | Comments to support |
| Family and friends understanding of SCI | ‘family and friends understanding of SCI’, ‘Helping partners’ |
| Sex and relationships | ‘more about sex and relationships’ |
| Community assistance | ‘getting assistance from DWP and social services’  |
| Accessibility post discharge | ‘accessibility once discharged e.g. public transport, taxis, rail travel’ |

Session timings and structure

The majority of inpatient (80%, *n*= 8) and 29% (*n*=6) of outpatient respondents stated a preference for weekday sessions. Seventy-five per cent of inpatients (*n*=6) and 48% (*n*=10) of outpatients also stated a preference for afternoons sessions, although one respondent commented that ‘straight after lunch poor choice as everyone sleepy’. Face to face sessions were the most preferred delivery method for the majority of inpatients who responded (80%) and for 38% of outpatient respondents (*n*=17). An app/e-learning option was the 2nd most preferred method for both inpatient and outpatients. Respondents reported a ‘did not attend ‘(DNA) rate of between 20-30% for each session. Reasons for non-attendance were not ascertained.

Family attendance

Six of the inpatient respondents (60%) and five of the 21 (24%) outpatient respondents said they would like to attend sessions with family members. The topic areas which were seen to be important to invite family member to include: ‘sexual function, skin, coping and independence’, ‘life after hospital’, ‘Money matters’. However, patients generally did not want their family members at the ‘bladder and bowel’ session.

Staff

Health care staff who participated included rehabilitation consultants, qualified nurses and support workers, therapists; occupational and physiotherapists, case managers and rehabilitation practitioners.

Of the 48 HCS who responded, 89% (*n*=43) reported providing informal education to inpatients within the last week and 96% (*n*=46) within the last month, with 98% (*n*=47) expressing that it was an enjoyable part of their role. Most respondents (94%, *n*=45) agreed that information and education provision was everyone’s responsibility.

The most common barrier to information provision was reported as a lack of time (n=31), followed by inadequate staffing (*n*=13), poor knowledge (*n*=12) and a lack of patient concordance (*n*=11) (Table 5). A few respondents further commented that they did not feel confident in all topics; had other work commitments and/or would prefer to deliver timetabled rather than ad-hoc sessions.

Table 5: Problems related to information provision

|  |  |
| --- | --- |
| **Barriers** | **Responses** |
| Time | 31/67 |
| Knowledge | 12/67 |
| Inadequate staffing | 13/67 |
| Lack of patient compliance | 11/67 |

Thirty three (58%) respondents stated that they would ask patients questions to assess how well they had grasped the information received, but only 14 reported writing the results of the trouble shooting and reporting gaps in patients’ knowledge in the education folder, whilst even fewer (*n*=11) reported the provision of further education and retesting at a later date. During morning sessions of personal care was seen as the best opportunity to educate on bladder, bowel and skin.

Free text comments

Free text data from staff were collated under three headings (Table 6):

Table 6: Free text comments

|  |  |
| --- | --- |
| Heading | Example comments  |
| Communication(clear and accurate information, language, Joined up working) | “Lots of pictures and models, not too much medical jargon” “Good talking skills, good knowledge, good rapport with pts”“Ability to give the RIGHT and APPROPRIATE information”“Being careful on what is said to the patient- each pt is different and not all aspects of care are black and white”“All MDT must be consistent, need to find a way to communicate to each other”“Feedback at goal planning would be great”“Assessment of recall” |
| Barriers(understanding, compliance, provider knowledge, delivery/format of education, time, privacy and dignity) | “Time, concentration, education levels, background privacy, culture, time since injury”“Nurse knowledge, competence in delivery of education”“Readiness and reception of pt”“All staff has same understanding to ensure that the education provided is the same, staff knowledge should also be tested, staff to be familiar with education pack”“Very varied level of pt ability/retention, patients would benefit from some 1:1 teaching, teaching with different staff, to check all is retained/understood”“Allowing adequate time and making sure that time is protected for both staff and patient”“No interruptions, have time”  |
| Priorities (priority given to patient education) | “Education does not seem to be a priority for a lot of staff and pts” “Discuss on other occasions to check understanding”“Opportunities!”  |

Discussion

The aims of this study were to collate patients’ and HCS’ views about the information and education currently provided to people with a SCI at the LSCIC, RNOH and use these data to inform an evaluation of current provision. Whilst the results indicate that both inpatients and outpatients are generally happy with the formal education programme they receive, a number of barriers relating to its provision were identified. Addressing these barriers and making relevant changes to current provision should enable patients to be better supported throughout their rehabilitation trajectory.

Findings support the need for information throughout the in-hospital and post discharge period. Post injury complications are common after a SCI (Sezer et al., 2015) with findings from this study suggesting that information and education on bladder and bowel management is particularly important after discharge. Our findings support those of van-Wyk et al. (2015) that delivery of education should continue following discharge and reintegration into a community setting; with specialists working with community staff to facilitate this support. Sessions should also be provided in a number of different formats to create more engaging learning experiences for patients. Whilst face to face sessions were generally preferred by our participants, the use of e-learning/ mobile Apps was also viewed as a popular education delivery method, perhaps reflecting the needs of the younger group of patients, a finding also widely supported in the literature (Delparte, 2014; van-Wyk et al., 2015).

In terms of barriers, time was a primary staff concern, although it was unclear whether it is the amount of quality time spent with the patients or the amount of education/information that needed to be learnt by the patient during a short admission period, which was more of an issue. Ljungberg et al. (2011) concur that it is a challenge for rehabilitation professionals to provide health education in increasingly shorter time frames. Inadequate staffing is seen as a barrier to giving education and could link into why staff feel they have insufficient time to do this. The nursing workforce crisis has been widely documented and Twycross (2018) estimates that in England alone there are around 40,000 unfilled posts. However, van- Wyk et al. (2015) challenge the notion that HCS lack time, arguing instead that it depends on whether education is seen as a priority, a point also reflected in our study findings. A lack of perceived value might also explain why there was a 20-40% non-attendance rate for each session, thus it is imperative to foster an environment where education is valued.

The second identified barrier was HCS knowledge. Findings suggest that staff do not always feel they have the expertise and confidence to give education, which could lead to variability in the quality of information given. A study by Gupta et al. (2012) comparing nurses’ knowledge related to pressure ulcer care in people with a SCI showed a significant difference in management knowledge between nurses working in two different SCI units, highlighting knowledge variation. Nurses cannot be expected to provide effective education/information if they do not have enough expert knowledge. Another issue is that staff may have the knowledge but not the skills necessary to deliver patient education, making them less confident in this role. Petre et al. (2017) highlight the need for HCS to develop an educational relationship with patients rather than the more dominant advisory relationship, but staff often receive inadequate training on how to be a successful patient educator and may feel more secure in the position of expert (van-Wyk et al., 2013; Petre et al., 2017). van-Wyk et al. (2013) further highlight the importance of embracing adult learning principles, a point also supported by Delparte et al. (2014).

Our findings further identify a lack of patient concordance in some cases. This suggests that attention needs to be paid to patients’ readiness to learn after an intense physical and psychological life changing event (van-Wyk et al., 2013). Patients may not be motivated to learn different aspects of their care/injury until the need arises (Delparte, 2014; Whalley-Hammell, 2007). Information and education needs to be delivered at a time most relevant and meaningful to each patient and their family, thus highlighting the potential need for better assessment of individual needs during the inpatient period and at subsequent intervals post hospital discharge.

Recommendations for future research and practice

Education needs to be viewed as a priority element of all SCI rehabilitation programmes. Patients should be encouraged to attend formal education sessions and staff should optimise opportunities for informal education provision. Staff should also be provided with training to support their delivery of quality education. Specifically, more attention to the use of adult learning theory is needed to enable successful patient engagement and learning. The development of skill based competences such as coaching/motivational interviewing would also be beneficial.

Future research on the use of different information and education formats such as the use of an App is recommended. Additional investigation into how community based education can continue post discharge to improve quality of life and further reduce post injury complications is further suggested.

Limitations

This single site service evaluation is limited in scope and lacks generalisability. Recruitment and data collection from patient participants was affected by hospital volunteers and a peer support worker not having the capacity to assist with recruitment as originally envisaged and reasons for not attending the sessions were not ascertained. A formal process of thematic analysis was not possible due to the limited number of free text comments.

Conclusion

The aim of this study was to evaluate current information and education delivery from the perspective of both patients and staff. Findings support the continued need for both formal and informal sessions, provided by all members of the healthcare team, with particular emphasis on issues such as bladder and bowel management and sexual function post discharge. A high-quality patient education programme has the potential to reduce post injury complications, however, to optimise the chances of success, barriers to delivery such as time, prioritisation and staff knowledge and skills need to be addressed.

Key points

1. Appropriate patient education and information provided throughout the illness and rehabilitation is critical for people with long term conditions
2. Barriers to the delivery of information and education, including staff time, knowledge and skills need to be addressed
3. Different formats should be explored to optimise the delivery of information and education to all patient groups to help reduce post injury complications.

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