Evidence Table

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Author/Year | Design/Subject | Description of Intervention | Outcome Measures  | Results | Comments/ Limitations |
| Bernet (2019)1  | Longitudinal, Qualitative / Convenience sample of patients with spinal paralysis (n=10) | Patients attended nurse-guided patient education during rehab program; Followed by 2 (1 shortly after discharge and 1 5-6 months later) face-to-face interviews, recorded digitally and transcribed verbatim. | Researchers identified themes in qualitative responses (3 themes identified: self-management competences, internal and external factors for developing daily life competencies, transition to home)  | Patients were especially interested in information relating to the present situation.Relatives were more likely to read manual during stay, patients after d/c. Patients and relatives used the internet during rehab and at home for demonstrating transfers and getting dressed, for new solutions. Peer support for self-management competences in dealing with physical and mental challenges during and after rehab was helpful (“you will take someone who is also in a wheelchair more seriously.”) Improving patients’ ability to communicate well and transparently helped them gain confidence.Patients suggested more mental preparation for the transition to home.Strong relationships between patients and peers helped minimize complications and visits to the doctor. “An e-learning program would be an ideal supplement to the standard education program for SCI Patients. Helpful videos and links could support the patients in the learning process.” | This qualitative review identified areas of improvement that can be addressed to improve patient and caregiver education before or during the transition to home. Many of these topics are things we will be addressing with our product (i.e. video supplements to education, peer modeling and education, promoting good communication and strong relationships). This study gives the unique perspective of the patients pretty early into the transition period, reiterating many points from the needs assessment and justifying the need for this material we are producing.  |
| Chaffey (2017)2  | Systematic/Scoping Review / Individuals with acute and chronic SCI (n=137 across 8 studies) | Peer educators were the only source of education in 4 out of the 8 programs studied, with the peer educators as only part of the education program in the other 4. 3 studies focused on hospital-based programs, with peer education as a component of the patient education. 1 study conducted a peer education program that was available to participants after hospital discharge, the timing of this program focused on cognitive behavioral intervention to address patients’ personal goals or medical complications. 1 study examined a peer support program over the phone, with health education and discussion of personal experiences regarding topics chosen by the group (equipment, home renovations, relationships, self-care, physical activity, weight control, etc.). 1 study included a program with a home-based peer mentor personal trainer that focused on strength training, self-efficacy, and fitness-related behaviors. The final 2 studies examined the same program conducted in two different low-income countries. The program consisted of a 1 week course taught by peer educators with SCI regarding topics like wheelchair skills, transfers, bowel and bladder, skin care, sexuality and relationships, etc.) | Outcomes for these studies looked to measure data and constructs surrounding participant satisfaction with programs, perceived topics learned, self-efficacy, secondary complications, adjustment, and quality of life (QOL). Outcomes for the 8 studies included: Semi-structured individual interviews (3), Hospital admission data, Focus group qualitative data (2; 1 in person and 1 over telephone), Leisure Time Physical Activity Questionnaire for People with SCI, Self-reported participant satisfaction, Generalized Perceived Self-Efficacy Scale, Self-reported data to peer mentors (regarding medical complications, depression, anxiety, rehospitalizations, physician visits), Hope Scale and Herth Hope Scale, Positive and Negative Affect Scale, Life Satisfaction Survey, MOS SF-36 | The qualitative data from the studies reviewed found that participants reported positive experiences. A variety of outcome measures found positive changes regarding participant’s hope, adjustment, quality of life, and self-efficacy. The studies that examined medical complications found a decreased occurrence with peer education. Health outcomes improved after all peer education programs in the two studies that used this outcome, with reduced rates of medical complications and hospitalizations. All the included studies reported improvements with constructs surrounding self-confidence and self-belief for participants, improving health-related quality of life post-discharge.Peer mentors helped ease adjustment to new life circumstances, offered wisdom regarding past experiences, problem solved, and role modeled.   | **AMSTAR**: 5 pointsUse of a peer educator would reduce the use of medical terminology during education and would therefore likely also address the clinical question of using health-literacy-conscious education. The author notes relevant results from a few of the studies surrounding positive changes in self-efficacy, medical outcomes, and lack of hospital readmissions. These address the goal of patient education in the rehab setting: to address complications that occur after SCI, before they happen.Adding a peer education component to the education program, but not completely replacing the standard of care may be a good solution until more research is available on the use of peers for education in SCI. |
| Gassaway (2019)3  | Quasi Experimental Design (“multiple-baseline,” repeated baseline measures and staggered introduction of intervention across 3 behaviors) /Individuals with SCI admitted to IPR (n=81)  | Over 15 weeks, 33 classes conventional classes (nurse led, didactic class with presentation then Q & A) were replaced with peer-led, mixed-media class (a video of peer mentor introducing self-management challenge followed by discussion and a problem-solving activity). 14 conventional classes and 19 revised. | Positive engagement responses documented from video recordings of classes; Qualitative interviews with 37 patients who participated in both conventional and revised classes. | Statistically significant higher average of positive engagement responses observed during revised classes.Interviewees believed revised class strengthened understanding of topic; found topics delivered by peers to be more informative and engaging than standard class. | **Downs & Black:** 15/29**Limitations**: Downs and Black: Low quality study (level 4 evidence) with revised implementation to accommodate demand for new class structure (strength and weakness due to positive feedback on revised structure and poor methodology of study). Unvalidated outcome measuring engagement and data for 27% of classes conducted due to recording problems. **Comments**: Promising anecdotal results regarding peer education in IPR, but one should use caution generalizing data to wide populations when peer mentoring is highly based on the individual and the culture of the mentor program. |
| Hoffman (2011)4  | Qualitative study /2510 online video views and 422 in-person attendees at the SCI Forums with voluntary, self-selected survey participation. Participants included individuals with SCI, health care professionals, and others (caregivers, friends, family, students). While the target population was individuals with SCI (making up 42.4% online and 45.3% in-person), family/friends, students, and health care professionals made up the majority of participants.  | Experimental group: Online videos of the SCI Forums (described below) were posted to the Internet within 3 to 6 months of the in-person session. Frequency and duration are difficult to determine from the article; however, videos posted once per month. Control group: In-person SCI Forum sessions held at University of Washington represent the standard of care for community-based SCI education since 1987 for this Northwest Regional SCI System population. Educational treatment was provided by expert speakers including medical specialists and rehabilitation professionals, or community members with experiential knowledge, as coordinated by the NWRSCIS.  | The primary outcome measure was a brief participant survey based off of the Department of Education’s National Institute of Disability and Rehabilitation Research’s (NIDRR) recommendations. The survey evaluated the quality and effectiveness of the education format (both online and in-person) as voluntarily self-reported by participants based on their satisfaction and attitude changes. Open-ended comments section allowed for qualitative themes to be assessed. Google Analytics was used to assess video viewership data from April 1, 2009 to March 31, 2010.  | 91% of online participants favored the video format to written information, including 88% agreed or strongly agreed with learning new information, 52% changing their attitude, and 61% likely to change their behavior or take action as a result of the video. Themes from individuals with SCI include viewers (1) planning to use the videos in training sessions with new caregivers, (2) have a better understanding of information leading to increased confidence and more informed participation in care, and (3) discovered new ways to cope through videos of others living with SCI.  | **CASP Checklist:** 7 yes, 2 can’t tell, 1 no. **Limitations:** Self-selected sample preventing blinding, lack of methodological rigor of study design, and limited quantitative data for statistical analysis. The online video format is an effective education delivery method, as evidenced by the nearly six-time greater reach of the online format in just one third of the amount of time and wide geographic distribution of online audience reaching beyond solely the intended target population of individuals with SCI. Despite study design weaknesses, the results do validate this education delivery method as one that can be suggested to avoid barriers such as location, time, and convenience that are present with the in-person form of education as well as preference of video over written format.  |
| Jones (2019)5  | Interrupted time-series analysis /Individuals with SCI (n=1117) in inpatient rehabilitation with an anticipated discharge location of home  | Peer mentoring interventions including one-to-one mentoring and peer-led self-management classes  | Unplanned hospital readmissions (number of patients readmitted & number of days rehospitalized), General Self-Efficacy scale (GSE), and depressive symptoms via Patient Health Questionnaire (PHQ-8): all at 30, 90, and 180 days post dischargeSatisfaction with Life Scale (SWLS): 180 days post discharge Subjects were interviewed via phone call for the 30, 90, and 180 day follow-up outcome measures | Statistically significant decrease in level and slope of number of patients readmitted and decrease in level of number of days rehospitalized [Level refers to shorter length of stay and severity of condition requiring readmission] Number of one-to-one peer mentoring visits associated with reduction in number of patients and number of days readmitted as well as higher GSE, indicating this intervention improves self-efficacy and unplanned hospital readmissions rates for individuals with SCI post inpatient rehabilitation discharge  | This article supports the use of peer mentoring, especially in the form of one-to-one mentoring. Results indicate shorter lengths of stay and less severe conditions requiring readmission, which may be explained by improved self-efficacy leading to proper utilization of healthcare services. Self-management skills include ability to know when to seek healthcare services, which is evidenced by less time for resolution when identified early by the patient.  |
| May (2006)6  | One group, repeated measure design / Patients with SCI in rehab for first time (n=23 finished program)  | Standard patient education program consisting of 8 weeks of lecture classes twice per week.12 topics: function of SC, bladder and bowel care, medications, skin care, temp control, autonomic dysreflexia, circulation, sexuality, nutrition, wheelchair care, home accessibility, assistive technology. Data was collected within 2 weeks of admission to rehab, just prior to d/c and 6 months post discharge.  | No standardized tools to measure SCI education so measures were developed to evaluate topics discussed in this study. 29 item multiple choice questionnaire (MCQ) used to assess knowledge, with different versions of sexuality questions for males and females. Life Situation Scenarios (LSS) were developed for patients to “solve” and determine plan of action; performance checklist based on Holistic Critical Thinking Scoring Rubric used for problem solving ability. Likert scale to range perceived importance of education topics. | Changes over time between admission and post-d/c were statistically significant, with average score on MCQ increasing from 22.26/29 to 24.22/29. Content topics most frequently answered incorrectly were temperature/ autonomic dysreflexia, sexuality, skin care, functions of spinal cord, wheelchair care and bladder care. Life situation scenario results “approached significance” between admission and post-d/c. Bladder care, bowel care and skin care were assessed as important topics throughout all 3 data collections, no statistically significant changes.  | **Downs & Black:** 18/29This non-controlled study with a small sample size demonstrated results of standard patient education consisting of lecture-based classes but was evaluated based on principles of adult learning. None of the results demonstrated clinically significant changes between admission and 6-months post discharge. Although MCQ did meet standard of significance, the change in score was minimal. Potentially demonstrating ineffectiveness of standard patient education in rehab, but limited by poor study design. |
| Olinzock (2004)7  | Qualitative study (retrospective) / Individuals with SCI (n=30) with varying levels of injury including first-time admission paraplegia (n=13) and tetraplegia (n=13) as well as readmissions (n=4) to assess learning readiness between discharge and readmission  | Assessment of narrative nursing entries from documented progress notes Verification by nurses and nurse researchers of patients with SCI including discussion and evaluation by the nurses of the documented transcriptions to compare assessment of data  | Emergence of themes including initiative, motivation, and information seeking behaviors; problem-solving and thoughtful self-reflection; self-sufficiency, independence in self-care, and documentation of directing/instructing others in care needs; self-selecting behaviors such as adherence or compliance with instructions taught by nurse; and physiological and psychosocial responses  | The Rehabilitation Learning Readiness Model (RLRM) for SCI was developed including five learning readiness stages (dependent, involvement, engagement, self-initiation, and self-direction) and five corresponding instructional roles (authority, guide, motivator, mentor, consultant) Verification by nurses illustrated that orientation to the RLRM was minimal and significance for education and research purposes supported.  | While this model was developed for nurses, it can be applied to healthcare providers implementing patient education and working towards self-direction of care, which includes physical therapists. Previous research and as evidenced by the lack of documentation of the self-direction stage illustrates that not all learning readiness occurs within the time period of inpatient rehabilitation.Progression through the stages of the RLRM are unique to each individual, including time to adjust, severity of injury, and stress due to its challenges. **Limitation:** Self-direction stage was difficult to see evidence of due to retrospective nature of study with reliance on documented progress notes and realistic progression during inpatient rehabilitation.  |
| Schubart (2012)8  | Pre and post single group pilot test / Adults with SCI who had access to the internet and spoke English (n=15, n=14 completing pre and post questionnaires) | Interested patients who met inclusion criteria were invited to participate in an Interactive e-learning program on pressure sore prevention following d/c to home in outpatient clinics;  | Pre and follow-up questionnaires administered by nurse;Questions used from 3 related instruments to assess e-learning program; 1st part measuring constructs of convenience, engagement, enjoyment, layout, privacy, satisfaction and acceptability; 2nd part measuring knowledge acquired  | Most participants answered feedback questions on format positively reporting format was easy to use and understand information, it was useful and was a good method for delivery of education.Pre-score median was 96/120Post score was 107/120. | **Downs & Black:** 13/29Internet interventions were well received by participants and improved learning access to those who wouldn’t otherwise be able to receive it. Responses to questions regarding program’s impact and effectiveness were especially encouraging. As time in rehab is shortened, pts and families have less time to learn self-care information and need to have access to knowledge at home. **Limitations:** Small sample size limits generalizability to larger population and narrow education topics may limit generalizability to other subject matter. |
| Skeels (2017)9  | Qualitative analysis or “process evaluation” of a Randomized Controlled Trial of a research study called “My Care My Call” (MCMC) /Participants (n=84) included individuals with chronic (greater than 1 year) traumatic SCI, identification of a self-management need, and telephone access. Peer mentors (n=2) were trained individuals who have been living with SCI for 5 years or more. | The intervention group received a total of 14 calls (8 weekly calls, 4 bi-weekly calls, and 2 monthly calls) with their peer mentor (i.e. peer health coach) over the 6 month study. Subjects discussed during these calls included self-management, unmet healthcare needs, and peer chosen topics to initiate conversation. The peer mentors were trained by an SCI association on the above topics as well as effective storytelling of their own experience, motivational interviewing (MI), and Brief Action Planning (BAP), which is a health empowerment goal-setting tool to encourage self-management behaviors.  | The goal of the qualitative analysis was to define the principle roles and methods used by the peer mentors during the MCMC study. Peer mentor roles were classified by the communication tools (CT) and information delivery strategies (IDS) used to improve information exchange. The 7 CTs were: shared stories, identifying support systems, BAP, resource review (education and referral), affirmation statements, in-between call support, and reflective listening based on MI skills. The 5 IDSs were: relationship building, providing opinion, providing advice, post-call personal support package (fact sheets, websites, etc.), and action planning through problem-solving and decision-making.  | The peer mentor roles defined were role model (personal experiences, opinions, advice), supporter (reassuring encouragement), and advisor (education, strategy planning). As role models, reflective listening and shared stories were the primary CTs utilized while providing opinion and providing advice were the main IDSs used. As supporters, reflective listening, shared stories, in-between call support, identifying support systems, affirmation statements, and the IDS of relationship building were utilized. As advisors, reflective listening, shared stories, identifying support systems, BAP, resource review, and in-between call support were the CTs used while post-call support and action planning were the IDSs incorporated.  | Benefits of the peer mentor relationship include credibility, equitability, mutuality, acceptance, and normalization. Frequent coaching call topics include SCI and health, assistive technology/durable medical equipment, partnering with the doctor for quality care, and empowerment, which help to explain the positive influence on self-management and self-efficacy. **Limitations:** Small sample size (n=42) received the intervention. Limited generalizability due to specific, small geographic location (Greater Boston Area) and eligibility criteria of telephone access, which excluded lower socioeconomic status individuals by nature.  |
| Van Wyk (2015)10  | Literature review on evidence on SCI-related education; 14 articles chosen (7 quantitative, 3 qualitative, 4 mixed-method)  | 5 databases were searched using inclusion criteria of patients with SCI, education, and outcome of any kind. | Learning programs were evaluated by several measures, some SCI specific (SCIM) and others were more general (Social Problem Solving Inventory Revised [PSI-R]). Many studies highlighted the importance of tracking use of resources to determine relationship between information and the patients exposed.  | Barriers: lack of available quality information that is easily accessed, difficult to facilitate learning readiness, large amount of information that needs to be learned in a short amount of time, various healthcare and societal changes that have created organizational challenges (shorter LOS, increased patient:nurse ratios).Family and peer involvement in education is essential. Peer support specifically provides discussion, problem solving, sharing of experiences/concerns/support influencing knowledge acquisition, awareness of information needs, motivation and emotional support from peers. Video media was superior in increasing retention of knowledge compared to written or in-person information. | To improve SCI education during rehab, programs should maximize receptiveness of newly injured patients, optimize delivery of education and increase the number of opportunities for learning, promote and support lifelong learning and include patient and program evaluation. Additionally, the patient is not always ready to learn in rehab and would benefit from access to the information later. Increasing the number of opportunities for information is essential because individuals will be ready for learning at different times. |
| Whiteneck (2011)11  | Prospective observational longitudinal cohort design /Participants (n=493) included individuals with traumatic SCI who were participating in the SCIRehab Project (“5-year multicenter study investigating details of the SCI rehabilitation process … and relating them to first-year postinjury outcomes”). Eligibility included age of 12 years or older and inpatient rehabilitation admission to one of the six participating medical centers.  | N/A, as this study assessed intervention (the amount and type of therapy services) provided in inpatient and post-discharge settings during the first year post-SCI rather than analyzing the results of a particular type of intervention for individuals with SCI  | Number of hours of therapy services including physical therapy (PT), occupational therapy (OT), speech therapy, recreation therapy, psychology, social work/case management, and nursing (defined as direct patient education). Hours were recorded for inpatient (by the treating clinician) and post-discharge (self-report) services until the first anniversary of SCI.  | Post-discharge services accounted for 44% of total hours of therapy services. However, PT and OT post-discharge services accounted for the majority of their rehabilitation hours (56% and 52%, respectively). The interquartile range of post-discharge services was double that of inpatient services, indicating the amount of therapy services post-discharge is highly variable.  | It is well documented that there has been a reduction in length of stay in inpatient rehabilitation (98 days versus 37 days during 1973-1979 and 2005-2008, respectively). This increases the need for assistance and burden on the individual with SCI’s family. Of interesting note, the authors did not differentiate patient education from other interventions except for with nursing services, which decreased from a mean of 30.8 hours to 0.9 hours post-discharge. This suggests patient education could be an area affected by the reduced length of stay. **Limitations:** There is a discrepancy between method of collecting data for inpatient and post-discharge services (treating clinicians vs. self-report, respectively), indicating accuracy of hours could be over- or underestimated.  |
| Zanca (2017)12  | Qualitative study for the purpose of developing a tool (TEAM) to assess the ability of individuals with SCI to direct care and caregiving /Participants include 26 individuals with chronic tetraplegia due to SCI (> 1 year) with > 6 months experience directing care; 16 caregivers (information or hired) with > 6 months experience providing care; and 25 professionals who educate individuals with SCI and their caregivers during inpatient rehabilitation  | No treatment but rather assessment of direction of care skills and themes. Key focus groups included separate meetings with individuals with SCI, paid and unpaid caregivers, and rehabilitation professionals who work with individuals with SCI. In addition, follow-up conference calls during the tool drafting and revision phase of the TEAM development.  | Teaching Effective Assistance Management (TEAM) toolThemes identified through content analysis including within the categories of “Learning to Direct Care after SCI,” “Building Positive Working Relationships between People with SCI and Caregivers,” and “Direction of Care and Caregiver Training in Inpatient Rehabilitation.”  | \*See table below of themes extracted during the TEAM development process(Appendix A)  | Overall tips for successful direction of care for the individual with SCI: self-awareness of your body, communicate clearly and specifically, confidence to self-advocate, problem-solving skills, patience, and flexibility (“to a point”)Information presented for U.S. Army Medical Research and Materiel Command Fort Detrick as well as three previous poster presentations and one oral presentation at the Academy of SCI Professionals Educational Conference  |

Synthesis

Standard of care patient education in a lecture format during inpatient rehabilitation does not result in significant changes in knowledge, problem-solving ability, or critical thinking, which demonstrates its limited effectiveness.6 The available literature indicates adult learners need to be ready for learning in order to successfully implement new information;11 however, with the coping that is initially required after spinal cord injury (SCI), many are unable to learn when they have easy access to education before the transition to home.1,6,10 It is well documented that there has been a reduction in length of stay in inpatient rehabilitation post-SCI, decreasing the available time for learning and adjusting before the transition to home.1,8,10,11 This trend increases the need for assistance and burden on the individual with SCI’s family,11 which supports the need for continued focus on self-direction of care post discharge.7

 In contrast to other supportive relationships, benefits of the peer mentor relationship include credibility, equitability, mutuality, acceptance, and normalization.9 Peer mentors and modeling have been effective at increasing positive experiences, patients’ hope, adjustment, quality of life, and self-efficacy.2 Additional positive peer mentoring outcomes specific to one-to-one mentoring include statistically significant decrease in unplanned hospital readmissions, decrease in severity of condition requiring readmission, decrease in number of days re-hospitalized, and increase in self-efficacy.5 Peer mentor roles include role model, supporter, and advisor with sharing stories, opinions, advice, resources, and identifying support systems as commonly incorporated strategies.9 Use of a peer educator is also beneficial in its reduction of the use of medical terminology during patient education, addressing the need for incorporation of health-literacy-conscious education for increased effectiveness.2

Many of the peer education studies showed poor methodology with small sample sizes,4,9 no control group, and high risk of bias.1,3,6,8,10 It was difficult to measure the success of peer education programs, as measures used in the studies were unvalidated or did not measure learning directly.3,6,8 Outcomes that were used in the studies measured indirect concepts, such as classroom engagement, patient satisfaction with program, functional independence, quality of life, self-efficacy, and rate of hospital readmissions.2,3,5,10

 An e-learning program was often suggested as a solution.1,10 One study implemented an e-learning program post-discharge to prevent pressure wounds.8 More broadly, the online video format is an effective education delivery method, as evidenced by the nearly six-time greater reach of the online format in just one third of the amount of time with a wide geographic distribution.4 This is particularly relevant to individuals with SCI with a functional level including periscapular and shoulder mobility but lack of hand function/fine motor control, as they require assistance from caregivers to attend in-person education sessions. Although power and generalizability were limited by small sample size and lack of control, the studies illustrate improvement in patient learning using online formats with positive feedback from participants on the usefulness and ease of understanding of the information.4,8

Self-efficacy is suggested to influence self-management, and this relationship then affects other factors that impact quality of life for individuals with SCI including documented physical and psychological health impairments, such as secondary conditions and depression.2,5 For individuals with SCI with a functional ability level that requires assistance from caregivers for activities of daily living and self-care, direction of care is an essential component of self-management.12

Successful direction of care incorporates self-awareness of the body, clear and specific communication, confidence to self-advocate, problem-solving skills, patience, and flexibility.12 Additional themes surrounding direction of care are included in Appendix A.12 Successful direction of care is dependent on readiness to learn.7,12 The Rehabilitation Learning Readiness Model (RLRM) for SCI was developed including five learning readiness stages and five corresponding instructional roles.7 While this model was developed for nurses, it can be applied to healthcare providers implementing patient education and working towards self-direction of care goals, which includes physical therapists.7

Many of the outcomes used to assess peer mentoring, including unplanned hospital readmissions,5 self-efficacy,2,5 depressive symptoms,2,5 secondary complications,2 quality of life,2 are indirect evaluations of effective direction of care. Therefore, the development of an outcome measure to directly assess the ability of individuals with SCI to direct care and caregiving suggests that this is a growing topic of interest and importance in the SCI population.12

Despite the low quality of many of these studies, they did not demonstrate any negative impacts on the patients. In fact, many illustrated positive results that suggest standard of care patient education might be improved using peer mentors and online learning.1–4,6,8,10 While the results regarding the effectiveness of peer mentoring in patient education are promising, they require more research to validate. Many studies on the topics of peer mentoring and direction of care are qualitative due to the nature of the topics.1,4,7,9,10,12 This study design in combination with the small sample sizes reduces the ability to generalize the results to the SCI population at large. However, with the development of TEAM, direction of care via peer mentoring specifically can be studied quantitatively with larger sample sizes increasing the opportunity for rigorous statistical analysis and generalizability.12

Bibliography

1. Bernet M, Sommerhalder K, Mischke C, Hahn S, Wyss A. “theory does not get you from bed to wheelchair”: A qualitative study on patients’ views of an education program in spinal cord injury rehabilitation. *Rehabil. Nurs.* 2019;44(5):247-253. doi:10.1097/rnj.0000000000000175.

2. Chaffey L, Bigby C. Health Education by Peers with Spinal Cord Injury: a Scoping Review. *J Dev Phys Disabil* 2017;30(1):1-14. doi:10.1007/s10882-017-9569-6.

3. Gassaway J, Jones ML, Sweatman WM, Young T. Peer-led, transformative learning approaches increase classroom engagement in care self-management classes during inpatient rehabilitation of individuals with spinal cord injury. *J Spinal Cord Med* 2019;42(3):338-346. doi:10.1080/10790268.2017.1385992.

4. Hoffman J, Salzman C, Garbaccio C, Burns SP, Crane D, Bombardier C. Use of on-demand video to provide patient education on spinal cord injury. *J Spinal Cord Med* 2011;34(4):404-409. doi:10.1179/2045772311Y.0000000015.

5. Jones ML, Gassaway J, Sweatman WM. Peer mentoring reduces unplanned readmissions and improves self-efficacy following inpatient rehabilitation for individuals with spinal cord injury. *J Spinal Cord Med* 2019:1-9. doi:10.1080/10790268.2019.1645407.

6. May L, Day R, Warren S. Evaluation of patient education in spinal cord injury rehabilitation: knowledge, problem-solving and perceived importance. *Disabil. Rehabil.* 2006;28(7):405-413. doi:10.1080/09638280500192439.

7. Olinzock BJ. A model for assessing learning readiness for self-direction of care in individuals with spinal cord injuries: a qualitative study. *SCI Nurs.* 2004;21(2):69-74.

8. Schubart J. An e-learning program to prevent pressure ulcers in adults with spinal cord injury: a pre- and post- pilot test among rehabilitation patients following discharge to home. *Ostomy. Wound. Manage.* 2012;58(10):38-49.

9. Skeels SE, Pernigotti D, Houlihan BV, et al. SCI peer health coach influence on self-management with peers: a qualitative analysis. *Spinal Cord* 2017;55(11):1016-1022. doi:10.1038/sc.2017.104.

10. van Wyk K, Backwell A, Townson A. A narrative literature review to direct spinal cord injury patient education programming. *Top. Spinal Cord Inj. Rehabil.* 2015;21(1):49-60. doi:10.1310/sci2101-49.

11. Whiteneck GG, Gassaway J, Dijkers MP, et al. Inpatient and postdischarge rehabilitation services provided in the first year after spinal cord injury: findings from the SCIRehab Study. *Arch. Phys. Med. Rehabil.* 2011;92(3):361-368. doi:10.1016/j.apmr.2010.07.241.

12. Zanca JM. Systematic Assessment of Caregiving Skill Performance by Individuals with Tetraplegia and Their Caregivers. *Kessler Foundation.* 2017.

Appendix A12

|  |  |  |
| --- | --- | --- |
| **“Learning to Direct Care after SCI”****(Themes of challenges encountered)**  | **“Building Positive Working Relationships between People with SCI and Caregivers” (Key suggestions)**  | **“Direction of Care and Caregiver Training in Inpatient Rehabilitation” (Topics discussed in inpatient rehabilitation)**  |
| Difficulty with or denial of direction of care training during inpatient rehabilitation due to difficulty with acceptance  | Set clear expectations early and involve both the individual with SCI and caregiver in the establishment of expectations  | Self-care |
| Overwhelming volume of information in short period of time  | Explain the why behind the task to avoid the perception of being “picky”  | Activities of daily living  |
| Difficulty with transfer of skills from the hospital setting to “the real world”  | Respect each other’s expertise of their role in the caregiver/care recipient relationship  | Equipment use  |
| Lack of understanding of their post-SCI capabilities  | Identify solutions early, which requires self-advocacy when something does not feel right  | Management and prevention of secondary conditions  |
| Feeling vulnerable in terms of dependence on caregivers and fear of “nitpicking”  | Develop new solutions by being flexible and collaborative  | Emergency preparedness  |
| Limited caregivers who are informed about SCI specifically  | Re-assess the “big picture” regularly to identify areas for improvement  | Management of medical conditions  |
|  | Treat one another as you would like to be treated  |  |