

**Original citation:**

Mostafa, M.A., Plastow, N. and Savin-Baden, Maggi (2019) *The Effectiveness of Spinal Cord Injury ADL Inpatient Education on Rehabilitation Outcomes: a Systematic Review and Meta-analysis*. The British Journal of Occupational Therapy. ISSN Print: 0308-0226 Online: 1477-6006 (In Press)

<https://doi.org/10.1177/0308022619879019>

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# **The Effectiveness of spinal cord injury ADL inpatient education on rehabilitation outcomes: a systematic review and meta-analysis**

## **The Effectiveness of spinal cord injury ADL inpatient education**

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### **Abstract**

**Introduction:** Occupational therapy patient education is an acknowledged intervention, which may enable clients with spinal cord injury to improve performance of activities of daily living. Many spinal cord injury individuals return to the community with inadequate activities of daily living skills due to short length of stay in inpatient rehabilitation. This systematic review evaluates the effect of activities of daily living education on rehabilitation outcomes following spinal cord injury.

**Method:** A systematic review and meta-analysis of activities of daily living clinical trials for spinal cord injury was conducted using the PRISMA guidelines.

**Findings:** Three educational interventions were identified: Clinical Practice Guidelines for Preservation of Upper Limb function following spinal cord injury; Peer Mentoring Education; and Needs Assessment Checklist. The educational programmes improved performance in activities of daily living, patient awareness, and health and well-being (P: 0.0001-0.755). Intermediate and long-term rehabilitation outcomes including self-efficacy, pain, and participation did not improve (P>0.05). The overall random effect of the Clinical Practice Guidelines programme was ineffective (Heterogeneity: P=0.00001, I<sup>2</sup>=97%).

**Conclusion:** There was mixed evidence for the effectiveness of activities of daily living education following spinal cord injury. Further research on occupational therapy patient education during spinal cord injury rehabilitation to improve outcomes is needed.

## Keywords

Spinal cord injury (SCI), activities of daily living (ADL), inpatient rehabilitation education, rehabilitation outcome measures

## Introduction

A spinal cord injury (SCI) is defined as the damage to the spinal cord resulting from trauma, disease or degeneration. Symptoms of SCI involve partial or complete impairment of sensory function and/or motor function below the level of injury. An injury at or above T1 segment results in 'tetraplegia' while 'paraplegia' is the result of injury below the T1 segment. The most severe SCI leads to impairment of the systems that are critical to the control of bowel or bladder functions, blood pressure, breathing, and heart rate. Around 250-500 thousand people annually around the world experience SCIs. While the prevalence of SCI in many countries is not well known, the annual global incidence is estimated at 40-80 people/million. The average age at which patients sustain SCI is around 40 years (CDC, 2014; World Health Organization, 2014).

While spinal cord injuries have a significant impact on all areas of occupational performance, restoring the skills and routines needed for independence in activities of daily living (ADL) is often a primary focus for occupational therapy. These ADLs include the activities persons perform to take care of their own body and include feeding, dressing, bathing/showering, personal hygiene, grooming and toilet hygiene, bowel and bladder management and functional mobility (transfers and wheelchair ambulation). Occupational therapists use education and training to facilitate goal setting, and improve the knowledge and skills of their clients (American Occupational Therapy Association, 2014). Education is different to training. While training focuses on practical skills to maximise independence in daily life activities (American Occupational Therapy Association, 2014; Shotwell, 2014; May et al., 2006), education helps individuals to acquire knowledge, think creatively and develop their collaborative skills (UNESCO, 2014). Occupational therapy patient education is an acknowledged intervention widely used by occupational therapists to enable the client to acquire positive and healthy behaviours and routines in their daily activities, and prevent secondary complications. Therefore, it focuses on information about occupation such as ADL (how to dress, suitable assistive devices in feeding,

proper wheelchair use, and sexuality issues); home adaptation; disease or infection prevention; well-being (spasticity management, healthy nutrition, obesity prevention, and fitness); employment; aging with SCI; and participation in social life. Occupational therapists use lectures, videos, leaflets, workshops, and discussions formats (Wyk et al., 2015; Ljungberg et al., 2011; May et al., 2006).

Patient education generally has been used as an effective intervention in healthcare across different settings. Many studies demonstrate its effectiveness in reducing the negative consequences of diabetes and breast cancer (Gibbons et al., 2009; Austin et al., 2006), and in pressure ulcer prevention and management (Brace and Schubart, 2010). We therefore expect that it should also contribute to improvement in occupational performance, participation, health and wellness, and quality of life in individuals with SCIs.

The optimum goal of SCI rehabilitation is to improve the overall functional status. Specific outcome measures are critical for the assessment of functional recovery. The Spinal Cord Injury Measure (SCIM) is a widely used functional outcome measure to evaluate the performance and progress in ADL specifically for SCI. As a valid, reliable and effective outcome measure, it can be used to guide assessment and planning for SCI occupational therapy education (Glass, et al. 2009).

Decreased length of stay in inpatient rehabilitation settings and a lack of resources allocated for rehabilitation are the main concerns in ensuring effective rehabilitation for individuals with a SCI, especially in low- and middle-income countries. The result is that many patients with inadequate skills in ADL, mobility, and prevention of medical complications are discharged from inpatient rehabilitation. These individuals are expected to continue skills training during outpatient care, but then face difficulties in transportation accessibility, caregiver availability, and healthcare insurance coverage. Maintaining health and well-being after SCIs requires a lifelong commitment to routines and engagement in meaningful activities. Patient education forms an integral part of SCI rehabilitation, is low cost, and widely accessible to many individuals (Emerich et al., 2012).

Optimising occupational therapy SCI patient education is likely to improve rehabilitation outcomes for SCI individuals (Tederko et al., 2017). This suggests the need to evaluate current interventions to establish best practice in occupational therapy SCI patient education. To our knowledge, there have been no systematic reviews of clinical trials that evaluate the impact of occupational therapy SCI patient education. The purpose of this study was to explore the state of the art of ADL education with adult inpatients following SCI and assess its impact on rehabilitation outcomes.

## Method

The research question guiding this review was ‘What is the effect of ADL education on rehabilitation outcomes in SCI adult patients treated in an inpatient rehabilitation setting?’ Our aim was to determine the characteristics (including outcome measures used) and assess the effect of ADL education on rehabilitation outcomes in SCI adult patients treated in an inpatient rehabilitation setting.

## *Design*

We conducted a systematic review and meta-analysis. The independent variable was Adult SCI ADL educational programme in an inpatient rehabilitation setting. Any rehabilitation outcomes were included as dependent variables.

The objectives of the review were to:

- Determine the characteristics (including outcome measures used) of adult SCI ADL inpatient rehabilitation education, including the type of educational programmes, duration, educators, and theoretical framework employed;
- Identify the rehabilitation outcome measures used;
- Perform a quantitative meta-analysis to determine the effect of adult SCI ADL inpatient education;
- Identify barriers and facilitators to educational interventions in this setting.

## *Search methods for identification of studies*

This systematic review followed the 27-items set of PRISMA (Preferred Reporting Items for Systematic Review and Meta-Analysis) which provides guidelines on how to report research methods and findings (Moher et al., 2009).

## *Electronic search*

The searches were conducted by the first author in January and February 2018 after obtaining necessary ethical approval from Stellenbosch University. The searches included all eligible studies before February 2018 using Cochrane Library, MEDLINE, EMBASE, CINAHL and PsychINFO databases. The parameters used for the review included: population (adults patients with SCI), intervention (ADL education), setting (inpatient rehabilitation), and any outcome. The search strategy was devised to find papers about ‘spinal cord injury’ or ‘paraplegia’ or ‘quadriplegia’ or ‘tetraplegia’ in

combination with terms for 'activities of daily living' or 'ADL' and 'education' (see supplemental material online for detailed search strategy).

Titles of the articles obtained were reviewed and excluded if not relevant to SCI ADL education. Searched abstracts were reviewed and excluded because they were not reported in English (5), not clinical trials (6), or not an inpatient rehabilitation setting (4). One abstract was excluded because there was no full text and its author was contacted by email for confirmation. Finally, four full texts were reviewed in depth. In one article it was not clear if the intervention involved ADL education. Despite many attempts to contact the author, no answer was received. A web search was done and the intervention was found to involve wheelchair transfer education in addition to complications prevention education and the article was considered eligible. No article was excluded based on the quality appraisal of study. The principal author used the PRISMA process to review titles, abstracts, and full texts, and select articles for inclusion in the review. Each step was reviewed by the other two co-authors. Discussion between the three authors and consensus were used for decision making. The process of studies selection was documented in a PRISMA flow diagram (Figure 1).

### *Criteria for considering studies for this review*

The following criteria were considered for eligibility:

- Clinical trials (published English full report, of any time, involving human participants) investigating the effectiveness of SCI ADL education on rehabilitation outcomes.
- Intervention with sufficient description to allow a clear decision that it is a programme or format of SCI ADL inpatient rehabilitation education.
- No restriction was applied based on the type of SCI ADL patient education, formats, duration, the phase of inpatient rehabilitation, rehabilitation outcome tools, and educator.
- Any number of individual adults, the age of 16 years and above, with spinal cord injury of any cause, either male or female, of any ethnic groups, and from any geographic location.

The following criteria were considered for ineligibility:

- Studies included interventions not focusing on SCI ADL education.
- Studies that did not include outcome measure tool(s).
- Studies that included only qualitative data.

- Studies that included other disabilities besides SCI or individuals under 16 years.

### ***Data extraction and management***

The eligible articles were analysed and the numerical data (means, standard deviations and P values) were used to perform meta-analyses. Eligible studies were examined for any withdrawal, additional information or results, important missing or unpublished information, and bias. A data extraction tool (modified from the EPOC data collection checklist) was used to perform data extraction which included:

1. Characteristics of participants: sample size, participants, withdrawals, intervention group, control group, age, gender, and any other relevant available or attainable data.
2. Characteristics of interventions: number, main components of interventions, types, duration, frequency, and materials.
3. Methods: study design, time limits and duration, intakes, type of setting, location, and educators.
4. Outcomes measure tools.
5. Results: tables summarising results.

### ***Data analysis and synthesis of findings***

Quantitative data of included studies were reported descriptively using text and tables while a narrative approach was used to synthesise qualitative data. Included studies in the review were aggregated according to clinical importance (impact), methodological characteristics (design, setting, and intervention), participants, and outcomes. Data collected across the studies were used to perform meta-analysis as follows:

1. Summary statistics for each study to describe the observed intervention.
2. Summary (pooled data) intervention effect estimated in the individual studies (P values).
3. Dichotomous data were used to perform the RevMan test for heterogeneity and estimate the effect size of the intervention.

Meta-analysis is greater than a comparison between two interventions in one group of subjects to find common or total effects size. It is also about estimating the overall effect of consistent multiple outcomes. It may also be used to find different outcome effects between studies, and to interpret the reason for the variation. Narrative review is largely

subjective because different experts can come to different conclusions, especially when few studies are included in the review. Meta-analysis, by contrast, applies objective formulas and can be used with any number of studies (Deeks, et al., 2008).

### *Risk of bias in systematic review*

The search process started after obtaining necessary approval of the study proposal, which included the research question, strict inclusion and exclusion criteria, and clear methods. The authors adhered to the study protocol all through the study. In order to reduce bias in this review, five large databases and a sufficient range of terms without any filters were used to search eligible articles. Eligible articles were read in-depth to extract data that was directly relevant to the review question. All data collected was used in the interpretation of findings. The review conclusions were supported by the evidence and included consideration of the relevance of included studies. This review could have a selection bias in terms of language (English articles only included) and searched databases, which may exclude articles of other languages or databases not searched. Moreover, only four articles were included. However, the quality and risk of bias in included studies were assessed using Downs and Black's (1998) checklist. The risk of bias in this review was also assessed using the ROBIS tool (Whiting, et al., 2016). Eligibility evaluation, risk of bias in included studies, Downs and Black's (1998) checklist, and the ROBIS tools were performed by the principal researcher and double reviewed by the other two co-authors. Therefore, the findings of the review are likely to be reliable.

## **Results**

Only four quantitative studies were identified within the scope of SCI ADL education (Table 1). There was mixed evidence for the effectiveness of these programmes.

The four studies included three patient educational programmes that were different in terms of their structure, planning, and implementation. Both Rice et al. (2014) and Rice et al. (2013) were included in meta-analysis as they were randomised clinical trials that involved intervention and control groups. These employed as an intervention the "Clinical Practice Guidelines for Preservation of Upper Limb function Following SCI" (CPG). The other two studies were quasi-experimental clinical trials and involved only intervention groups. One of them employed the Peer Mentoring Education programme (Ljungberg et al., 2011) and the other employed the Needs Assessment Checklist (Kennedy and Hamilton,

1999). As these two studies were quasi-experimental studies, they were not included in meta-analysis. The total number of participant patients across all studies was 226 individuals with SCI (range: 37-82 individuals). The age of the participants ranged from 16 to 110 years; where stated, more men (166: 73.5%) participated than women (60: 26.5%), and more patients were paraplegic (128: 56.6%) than quadriplegic (98: 43.4%).

### *The effect of ADL education*

Rice et al. (2014) and Rice et al.'s (2013) CPG intervention included multiple outcome effects, where we assumed independence, group by outcome, and test difference. Our meta-analysis evaluated common or total random effects of these outcomes. Missing standard deviation values were not substituted, and therefore, some outcomes appeared in the forest plot without being considered in meta-analysis.

The CPG programme had an insignificant effect, when results were subject to meta-analysis using the RevMan random test for clinical trials. In Rice et al. (2014) and Rice et al. (2013) studies, the clinical heterogeneity was insignificant; however, the RevMan random test showed substantial statistical heterogeneity ( $P < 0.00001$ ;  $I^2 = 97\%$ ). The P value for the overall effect was 0.003 ( $< 0.05$ , CI:95%); however, the diamond was on the right of the centre line, indicating the insignificant effect (Figure 2). This can be attributed to bias introduced to the two individual studies included in meta-analysis, decreased consistency between outcome effects, and low statistical power of effects (P values). A statistical analysis bias was introduced to this review due to decreased consistency or real difference between outcome effects; however, this result couldn't have been reached without performing meta-analysis.

Ljungberg et al. (2011) and Kennedy and Hamilton (1999) had clear clinical heterogeneity and their results varied in significance. ADL education had a positive effect on wheelchair ambulation on tile and on ramp, prevention of SCI secondary complications, decreasing doctor visits, neuropathic pain intensity awareness, improving performance in ADL, and the quality of assisted and dependent transfers ( $P < .05$ ). There was a positive impact on enhancing self-efficacy and increased provision of an ultralight wheelchair, but results did not reach significance ( $P > .05$ ). No significant difference was found in transfer quality, pain, wheelchair propulsion on carpet, wheelchair setup and selection decision, satisfaction with life, and participation ( $P > .05$ ). Sociodemographic factors including age, gender, marital status, aetiology of injury, level of SCI, and pre-injury employment status were insignificant.

## *Educational programmes used for ADL patient education*

The CPG used by Rice et al. (2014) and Rice et al. (2013) is an ADL educational programme that focused on wheelchair ambulation and transfers. It involved two separate forms, one of each for therapist and patient. The patient form was designed to be accessible, appropriate for novice adult without previous medical background, and organised into modules. In order to meet different learners' styles and preferences, different education formats were utilised, including interactive discussions, printed hand-outs, pictures, and videos illustrating wheelchair propulsion and transfer skills to take home after discharge. The educators reviewed the CPG material with the intervention group patients during therapy sessions and throughout their stay in inpatient rehabilitation setting (40.1-41.7 days).

Ljungberg et al.'s (2011) study used the Peer Mentoring Programme. The educators 'peer mentors' saw their mentees in person or by phone during daily life scenarios within the first week of admission to active inpatient rehabilitation. The mentors monitored the health status of their mentees using the Medical Complications Tracking Form (MCTF), provided education, and initiated referrals to healthcare professionals if needed. The educational programme lasted one year where contacts between mentors and mentees were gradually decreased to allow a successful transition of mentees to the community. The first three months' contacts took place weekly, followed by three months of biweekly contacts, and six months of a monthly contact.

The Needs Assessment and Goal Planning Programme (NAGPP) is a comprehensive rehabilitation tool for everyday clinical use and it was used as an ADL educational programme by Kennedy and Hamilton (1999). The Needs Assessment Checklist (NAC) is a part of the NAGPP used to evaluate and compare rehabilitation needs and outcomes. Therefore, the NAC reflects patient perception of their needs, choices, and priorities. The NAC was administered twice by a key worker who had the responsibility of coordinating the Rehabilitation and Goal Planning Programme; the first after beginning the active rehabilitation programme and the second on admission to the pre-discharge rehabilitation ward. The keyworker had the responsibility of coordinating the goal planning system with other members of the multi-disciplinary team, and the patient was responsible for establishing and identifying needs, clarifying goals and specifying targets.

Participants in SCI ADL education had newly acquired SCI with neurological deficits and were admitted to an inpatient rehabilitation setting for active rehabilitation management. They were free of mental and cognitive deficits, able to communicate, and learn. Participant patients in Rice et al.'s (2014) and Rice et al.'s (2013) studies were expected

to be full-time wheelchair users, while in Ljungberg et al.'s (2011) and Kennedy and Hamilton's (1999) studies it was unclear.

The educational programmes in this review were delivered by healthcare and non-healthcare staff. In order to decrease differences in backgrounds among the educators, they received adequate training in SCI patient education and proper supervision on different roles according to each educational programme. The CPG was delivered by an experienced occupational therapist and physical therapist on various motor-learning theories related to the CPG programme and supervised by the research team (Rice et al., 2014; Rice et al., 2013). The Peer Mentoring Programme was delivered by five patients with SCI (four peer mentors and one supervisor mentor) who passed a successful inpatient rehabilitation programme and had an average experience of 11.8 years being SCI patients. In addition, peer mentors received a standardised training manual (Gilmore et al., 2008) and one day of training. They also received individual supervision by the peer mentor coordinator and participated in a weekly group meeting with professional staff at the hospital led by an experienced clinical psychologist (Ljungberg et al., 2011).

Compared with the CPG and NAGPP, the NAC was delivered by a keyworker responsible for coordinating the goal planning system with other members of the multi-disciplinary team and the patient. As a theoretical framework, the process of transformation from input to outcome was used and that involved problems definition for a specific population and specified solution(s): the critical input; the important steps to produce the desired effects; the mode of delivery; and the expected outcome. The NAGPP consists of three conceptual levels: the need statement; the goal; and the behavioural target (Kennedy and Hamilton, 1999).

All educators participated in research activities such as obtaining consents and data collection. Besides that, some of them provided knowledge, and discussed and demonstrated proper methods of daily life skills practicing (Rice et al., 2014; Rice et al., 2013; Ljungberg et al., 2011). In Kennedy and Hamilton's (1999) study, educators participated in identifying patient's needs and priorities, and discussion of these goals with the rehabilitation team. Only in Ljungberg et al.'s (2011) study did educators carry out referrals for further medical management when needed.

Contact with SCI patients was determined by the role of each educator, being either on a daily basis (Rice et al., 2014; Rice et al., 2013), or twice daily in Kennedy and Hamilton's (1999) study. Only Ljungberg et al. (2011) followed a gradual decrease of contacts, starting with a weekly contact and ending with a monthly contact to provide an opportunity for practicing daily life activities as independently as possible, and allowing a smooth discontinuation of educational intervention. Rice et al.'s (2014) and Rice et al.'s (2013) educational sessions took place during physiotherapy and occupational therapy sessions (3-4 hours/day). The time of educational sessions in both Ljungberg et al.'s (2011) study and Kennedy and Hamilton's (1999) study was unclear.

The special educational context used in this review was supportive of SCI ADL inpatient education. It enhanced the involvement, participation, and partnership of educators and SCI patients. Adequate availability of both educators and patients within inpatient rehabilitation allowed mutual commitment, easy contact, sufficient communication, and adequate concern during planning and implementation of educational programmes. In addition, consistency between the patient's ability to learn, formats, and resources of education was addressed with sufficient concern. The amount and type of information, learning strategies, and materials used appealed to different patients of SCIs and resulted in high levels of commitment to the educational programmes. Withdrawal from studies were related to causes such as secondary complications post-SCI and change in functional status.

On the other hand, some barriers were encountered during planning and implementation of three ADL educational programmes. The studies of Rice et al. (2014) and Rice et al. (2013) limited the ADL interventions to wheelchair ambulation and transfers. Moreover, in Ljungberg et al.'s (2011) and Kennedy and Hamilton's (1999) studies the ADL domains were unclear. Patient's perspective, priorities, preferences, needs (meet or unmet), the roles of the family and caregiver, and phase of inpatient rehabilitation, which are important determinants of occupational therapy patient education, were not addressed in the four articles. On the other hand, Rice et al. (2014) and Rice et al. (2013) were the only authors who highlighted clearly the role of an occupational therapist in inpatient education. Time is an education determinant but was not clear or not justified in the articles. Besides that, the educational strategies used lacked the variety of educational formats, such as lectures and conferences, while the theoretical approach did not consider adult education.

### ***Rehabilitation outcome measure tools***

Thirteen different SCI ADL education rehabilitation outcome tools were identified in this review which can be categorised into seven groups according to their domains (Table 2). Both Rice et al. (2014) and Ljungberg et al. (2011) used multiple rehabilitation outcome tools, while Rice et al. (2013) and Kennedy and Hamilton (1999) used only one rehabilitation outcome tool each. Most of the outcome tools used are standardised and had acceptable/excellent validity and reliability. Diversity was clear in data intakes which followed different timetables according to each study's employed method. Data collection time varied among eligible studies (1-5.67 years). The measurement tools were objective such as Transfer Assessment Instrument, subjective such as Numeric Rating Scale, and mixed such as Wheelchair selection. The General Self-Efficacy Scale was self-administered while the other measure tools were administered by either research assistant, rehabilitation worker, or peer mentors. All the tools were generic; however,

three used occupational therapy outcomes: Transfer Assessment Instrument, Satisfaction With Life Scale, and Craig Handicap Assessment and Reporting Techniques.

### ***Bias in included studies***

The studies used in the review included risks of sampling (4/4), measurement (3/4), contamination(4/4), maturation (2/4), and exposure bias (4/4). The authors of the articles took some measures to counteract and reduce possible sources of bias such as randomisation (2/4), matching of participants in terms of SCI diagnosis (4/4), and following strict educational protocols (3/4). Blinding of participants (0/4) was not possible due to the nature of health education programmes and long length of stay of SCI in inpatient. Due to the familiarity of health professionals with interventions taking place in their settings, it was considered impossible to conceal the CPG intervention from the educators. There are other factors besides educational programmes intervening with treatment that explain the risks of maturation and exposure biases. The inclusion criteria were wide and allowed unmatched individuals to enrol in studies such as paraplegia and tetraplegia, men and women, complete and incomplete neurological deficits, and the wide age range (16-110 years). Sample attrition was substantial given that the response rate was 25%-64.9% and withdrawal rate was 35.1%-40.5%. The withdrawal was related to common challenges individuals face in the first year after SCI, for example, change in functional status, medical complications, and transportation difficulty.

### ***Quality of included studies***

Downs and Black's (1998) checklist was used to measure the quality of included studies. This quality appraisal tool has 27 questions divided into seven subsets: Reporting (1-10), External validity (11-13), Internal validity/bias (14-20), Internal validity (21-26), and Power (27). Rice et al. (2014) and Rice et al. (2013) had good rating scores (23/28), while Ljungberg et al. (2011) had a fair rating score (15/28), and Kennedy and Hamilton (1999) had poor rating scores (7/28). Because of the nature of educational interventions, study subjects were not blinded to the intervention (question 14) and it was not possible to conceal interventions from both patients and healthcare staff (question 24). Moreover, the recruitment of participants took place over a long time (in years) due to the undetermined occurrence of SCI (question 22). Loss of patients to follow-up studies because of substantial withdrawals was not taken into account (question 26)

which resulted in sample attrition and insufficient statistical power of studies' findings (question 27). These five questions had zero score in the four eligible studies.

## Discussion

The mixed review findings demonstrate that SCI ADL inpatient education is an effective intervention used to acquire skills and healthy behaviours and routines in ADLs, and increase awareness. These study findings concur with the American Occupational Therapy Association (2014), Shotwell (2014) and May et al. (2006) studies. Other than acquiring good ADL routine and practice, SCI ADL inpatient education proved to be an effective intervention in the prevention of secondary complications such as pressure ulcers and urinary tract infection after SCI, similar to other conditions in diabetes and breast cancer (Brace and Schubart, 2010; Gibbons et al., 2009; Austine et al., 2006). Therefore, occupational therapy SCI inpatient education is likely to improve rehabilitation outcomes, which is consistent with Tederko et al.'s (2017) viewpoint. Insignificant results of the meta-analysis in this review could be attributed to decreased patient motivation to learn, inadequate time and resources, and lack of the variety of education formats and programmes. In addition, while Deeks, et al. (2008) state that meta-analysis can be conducted on any sample size, it is important to note that a meta-analysis with small sample sizes lessens the power of the pooled effect. This leads to limitations in interpretation of results. The small number of studies found emphasizes the need for occupational therapists to conduct clinical trials in this area to demonstrate the efficacy of interventions with inpatients with SCI.

Based on Wyk et al. (2015) and May et al. (2006), the SCI ADL educational interventions must have clear scope by owning comprehensive process, specific tools, and clear ADL domains. The American Occupational Therapy Association (2014) explained that the domains of the ADL include many activities such as grooming, dressing, and toileting. Though, Rice et al. (2014), Rice et al. (2013), and Ljungberg et al. (2011) limited their ADL educational interventions to wheelchair ambulation and transfers. While in Kennedy and Hamilton's (1999) study the domains of ADL were not listed. Limited and/or unclear ADL domains decreases the importance and use of the educational programme. None of the used educational interventions was occupation-focused. An occupation-focused approach is defined as bringing the person's immediate attention to occupation (Fisher, 2013). Therefore, SCI ADL educational interventions must focus on occupational therapy outcomes such as occupational performance, participation, role competence, and occupational justice.

ADL educational intervention had a wide range of outcomes relevant to ADLs, behaviour, attitudes, prevention, medical status, satisfaction, and participation. The review identified 13 different rehabilitation outcome tools but none

was specific to ADL. Wyk et al. (2015) highlighted the importance of evaluation of an SCI educational programme as a method to determine the impact of a programme on SCI individuals. They explained that occupational therapy education outcome evaluation can involve an informal assessment that can be used, for example, to measure knowledge increase relevant to ADL.

On the other hand, there are important aspects of occupational therapy patient education which were not included in the outcome evaluation in this review, such as patient's needs, preferences, learning styles, and resources. People with SCI were more likely to fruitfully engage in occupational therapy educational interventions that are closely related to occupational therapy outcomes. In contrast, occupational therapy education programmes that fell outside the scope of practice and that were irrelevant to participants' needs were more likely to be ineffective (Wyk et al., 2015; May et al., 2006).

Standardised rehabilitation outcome measures are increasingly used and recommended, such as Spinal Cord Independence Measure (SCIM-III). The SCIM-III is specific to ADL, a reliable ( $r: 0.49-0.84$ ) and valid (Cronbach's alpha:  $0.78-0.80$ ,  $P < 0.01$ ) rehabilitation outcome measure. It is widely used as a minimum data set and strongly recommended in both clinical practice and research in the United Kingdom (Glass, et al. 2009). However, the SCIM-III was not included as an outcome measure by any of the studies identified in this review.

The context of the ADL education was supportive relevant to inpatient setting, educators, patients, supervision provided, and time of admission to inpatient educational programme. However, these educational programmes phases were not addressed and time of education was unjustified. The inpatient rehabilitation setting facilitated availability, accessibility, communication, and adherence of the educators and patients. Possible barriers encountered by educational programmes such as transportation, workload, and allocated time for education were minimised. On the other hand, SCI patients had a suitable level of education to understand and gain information. The ADL information, learning strategies, and materials appealed to different patients of SCIs, as the withdrawals were related to other causes such as secondary complications post-SCI. During education, consistency between the patient ability to learn, formats, and resources of education was addressed with adequate concern, exemplified in the use of a CPG patient form.

This review's findings agree with May et al. (2006) that SCI ADL inpatient educators could be healthcare and non-healthcare staff. However, these educators require training and experience relevant to SCI rehabilitation and patient education. Healthcare educators such as occupational therapists, physiotherapists, and nurses are preferable due to their educational background and expertise. Non-health educators are criticised for limited type and depth of information provided to SCI patients. Nevertheless, supervision is necessary to guide the process and evaluate the outcomes of SCI ADL education (Wyk et al., 2015; Tederko et al., 2010).

The phases of occupational therapy patient education must link to each other, support the continuum of patient services, and be linked with post-discharge performance and needs (American Occupational Therapy Association, 2014). Therefore, occupational therapy SCI patient education must be linked and suit each phase of inpatient rehabilitation relevant to patient needs and the stage of management. For example, education starts bed-side and shifts to other formats like discussion, conference, and peer interaction. SCI patients will gradually take responsibility for themselves (Wyk et al., 2015; Tederko et al., 2017). Rice et al. (2014) and Rice et al. (2013) partially addressed these phases when providing SCI patients with hand-in materials to review later when they are more ready to learn. This strategy is recommended by Wyk et al. (2015) and Khazaeipour et al. (2014) to improve learning readiness. Moreover, Ljungberg et al.'s (2011) study made a clear link to living with an SCI after being discharged home.

Drake and de C. Williams (2017) highlighted the importance of temporal aspects for the successful implementation of a SCI patient education programme. All participant patients were enrolled in the ADL education programmes during the first week of admission to the active inpatient rehabilitation and, depending on the role of each educator, their contact with SCI patients was determined. However, the decision about the duration of educational programmes and time of each contact was not explained. Ljungberg et al.'s (2011) study was the only study that included a gradual decrease of sessions to allow opportunities for practice and exploring unmet needs, and smooth discharge from the ADL educational programme.

The international classification of functioning, disability, and health (ICF) is a global framework that illustrates the interrelationship between specific health conditions and activity, participation, and personal and contextual factors (Pettersson, et al., 2011). Reflecting on the ICF, SCI influences many body functions that leads to decreased activity and participation. However, improving environmental and personal factors may optimize performance in ADL and social participation. This review assumes that occupational therapy SCI patient education improves methods of performing ADL and participation in social life such as using a wheelchair in ambulation and engaging in sport activities. By means of prevention, body functions and structure are maintained such as using pressure relief techniques and adequate positioning to prevent pressure ulcers and maintain skin integrity. Environmental factors (making the home accessible) and personal factors (increased knowledge about methods of performing ADL and positive attitudes towards disability) can be improved by means of patient education. Occupational therapy SCI patient education within the framework of the ICF may improve activity and participation through improving and/or maintaining body functions, increasing competency in personal factors, and adapting environmental factors.

### *Implications for research and practice*

Although this review summarized and evaluated the practice of ADL education, it identified gaps in research relevant to SCI occupational therapy education. There are few studies testing the impact of occupational therapy inpatient education relevant to SCI. Moreover, these studies used only three ADL education programmes that have limited or unclear domains of ADL, and nonspecific ADL measuring tools. However, these study findings may inform the development and testing of a comprehensive, specific, occupation-focused, and clear ADL inpatient education programme that may optimise SCI rehabilitation outcomes. These study results can guide future research relevant to occupational therapy education. Theory on education should inform the design of interventions to achieve the proposed change in knowledge, behaviour, and skills of SCI patients. On the other hand, adopting the three educational protocols simultaneously in occupational therapy patient education could optimise SCI rehabilitation outcomes. There is a need to address staff education relevant to education theories such as Adult Learning Theory. There is a need to establish a resource centre that includes important resources of occupational therapy SCI patient education. Health educators, SCI patients, families, caregivers, students, and researchers need to be familiarised with these resources.

## Conclusion

Occupational therapists have an important role to play in patient education focussed on the core occupational concerns of inpatients with SCI. This systematic review found three ADL educational programmes used by inpatient SCI in rehabilitation settings. These educational programmes were evaluated from different perspectives using 13 rehabilitation outcome measures. In conclusion, the results were mixed. The CPG programme did not have an effect on rehabilitation outcomes. The short-term rehabilitation outcomes such as ADLs, some wheelchair and transfers skills, patient awareness, and prevention of secondary complications improved. The intermediate and long-term rehabilitation outcomes such as self-efficacy, pain, and participation were insignificant. This review's results cannot be generalised; however, the use of ADL education is suggested in practice to increase the effectiveness and improve the quality of inpatient rehabilitation following SCI. The study has many limitations, however, it establishes a basis for future endeavours such as the need for an occupational therapy SCI education resource centre and the development of a comprehensive and occupation-focused educational protocol.

### Key findings

- Four quantitative studies were identified within the scope of SCI occupational therapy inpatient education.

- Patient education improved short-term rehabilitation outcomes including ADL's, some wheelchair and transfers skills, patient awareness, and prevention of secondary complications.
- The Clinical Practice Guidelines for Preservation of Upper Limb function (CPG) following SCI did not improve rehabilitation outcomes.
- There is a substantial need for occupational therapists to conduct clinical trials of patient education interventions to develop the evidence base for this approach

#### **What the study has contributed**

This is the first review targeting occupational therapy SCI inpatient education. The study encourages the use, and addresses the gaps, of occupational therapy inpatient education relevant to SCI.

#### **Research ethics**

This research was approved by the Stellenbosch University Health Research Ethics Committee in 2017, Reference No: 1635.

#### **Consent**

Informed consent was not relevant as this is a systematic review and involves no participants.

#### **Declaration of conflicting interests**

The authors confirm that there is no conflict of interest with respect to the research, authorship, and/or publication of this article.

#### **Funding**

This research received no specific grant support from any funding agency in the public, commercial, or not-for-profit sectors.

#### **Contributorship**

The three authors have made a substantial contribution to the concept of the research, data collection and analysis, and interpretation of findings. They revised the article for important intellectual content; approved the version to be

published, and agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or the integrity of any part of the work are appropriately investigated and resolved.

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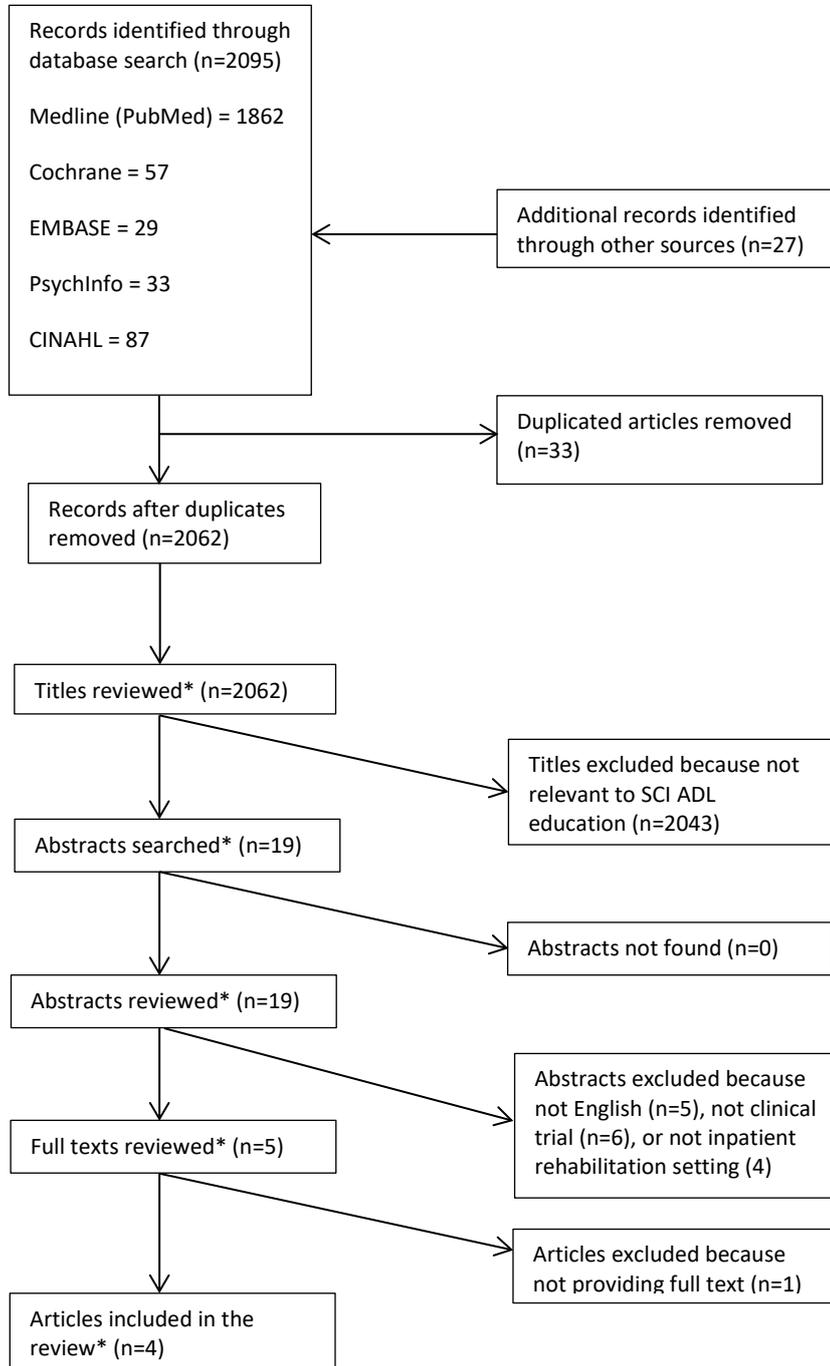
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Figure 1. PRISMA diagram articles selection process.



\* Screened by principal author and double reviewed by two co-authors

**Table 1.** Summary of the four papers included in the systematic review.

References	Scope	Design, participants and response rate	Setting and year of study	Intervention	Intervention time-scale	Intakes	Measures	Statistics	Results	Quality score (28) 1= poor, 28= high quality
Rice et al., 2014	ADL education: preservation of UL health in MWC users with SCI	Single blinded RCT, N=37 volunteers, Randomisation: IG (%):12(32.4), SCG (%):25(67.5), eligible first- time manual WH users with SCI, recruited from 93 candidates, Age: 38.3 (SD: 15.9) years, had a non- progressive SCI	Inpatient rehabilitation setting, March 2007- December 2011	IG: In addition to standard care, reviewed a WH education protocol (CPG, structured, multifaceted, and interactive education, Hand-outs, pictures, and videos), provided by 1 PT and 1 OT, CG: received standard care	Throughout stay in inpatient, 3-4 hours per day during PT and OT interventions	T1: at discharge from inpatient rehabilitation, T2: at 6 months post- discharge, T3: at 1 year post- discharge	WH setup, WH selection, WH propulsion biomechanics (Smart- Wheel), Pain using WUSPI and NRS, SWLS, CHART	Independent variable: Clinical practice guidelines for preservation of UL function, Dependent variables: WH setup, WH selection, Propulsion biomechanics (tiles, carpet and ramp), Pain, Satisfaction with life, and Participation. SPSS (V.19) and SAS Proc Mixed repeated- measures programme, Significance Priors:	IG: showed better skills on key WH propulsion biomechanics variables related to UL health (MWC propulsion on tile and ramp, positive impact on carpet but did not reach significance). MWC propulsion: (a) on the tile lower push frequency (p=.02), (IG: N=10, M±SE: .74±.16), (SCG: N=18, M±SE: .95±.24), (b) on the carpet a simple main effect trend, intervention group had lower push	23

with neurological deficits, were anticipated to be full-time WH users, and scored >17/25 on a modified Mini-Mental State Examination.

P=.05, Trends: P=.10, frequency (p=.10), (IG: Tests: Shapiro-Wilk test N=9, M±SE: .80±.14), for normality of (SCG: N=17, M±SE: distribution, Mixed-.95±.20), (c) on the ramp model analysis of difference was significant variance, Chi- (p=.03), (IG: N=12, M±SE: square/Fisher exact 65.40°±22.99), (SCG: analysis. N=17, M±SE: 50.12°±24.00). No significant difference was seen in WH setup (p>.05: 0.295-0.898), WH selection (p>.05: 0.130-0.755), pain, satisfaction with life, and participation (p>.05).

Rice et al., 2013	ADL education: Transfer quality in new full-time WH users with SCI	Single blinded, RCT, N=70 volunteers, Randomisation: IG (%):32(45.7), SCG (%):38(54.3), eligible first-	Inpatient rehabilitation setting, University of Pittsburgh Medical Center Rehabilitation	IG: In addition to standard care, reviewed a transfer education protocol (CPG, Clinical practice guidelines for	Throughout stay in inpatient injury, T1: at discharge from inpatient rehabilitation, T2: at 6 weeks	Four times during the first year after injury, T1: at discharge from inpatient rehabilitation,	TAI	Independent variable: Clinical practice guidelines for preservation of UL function, Dependent variables: WH transfer (TAI).	Transfer quality across all times did not reach significance IG (M±SE: 8.73±.6) compared with SCG (M±SE: 8.35±.14), P=.075, assisted sitting pivot transfer was higher quality in IG (M±SE:	23
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time WH users with SCI, recruited from 280 candidates, Age: 46.5 (SD: 16.7) years, had a non-progressive SCI with neurological deficits, were anticipated to be full-time WH users, and scored >17/25 on a modified Mini-Mental State Examination.

Institute in Pittsburgh, Pennsylvania, March 2007-December 2012

preservation of upper limb function), provided by 1 PT and 1 OT, CG: received standard care

post-discharge, T3: at 6 months post-discharge, and T4: at 1 year post-discharge

SPSS (V.19) and SAS Proc Mixed repeated-measures programme, Significance: P=.05, Tests: Shapiro-Wilk test for normality of distribution, Mixed-model analysis of variance, Chi-square/Fisher exact analysis.

9.43±.55) compared with SCG (M±SE: 7.81±.46), P=.026, dependent transfer was higher quality in IG (M±SE: 9.14±.34) compared with SCG (M±SE: 8.09±.29), P=.019

Ljungberg et al., 2011

Impact of SCI education (involving ADL

Quasi-experimental, non-random, uncontrolled pre-test/post-

NRH in Washington DC

A one-year peer mentoring programme led by 5 mentors (four peer

Weekly contacts take place for three months, followed by

T1: on entering the programme participants completed

GSEF, MCTF, Neuropathic Pain Intensity Rating Scale, and, Exit

Independent variable: Peer mentoring programme, Dependent variables: Self-efficacy (GSEF) and Secondary

GSEF: 0-6 month: 67% of the subjects increased their GSEF score, but the result did not reach significance, Mann–

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education)	test,	mentors and	three months	the GSEF in	interview	medical complications	Whitney U-test was
on self-	Participants:	one supervisor	of biweekly	addition to	with mentees	(MCTF).	significant (z=-2.5,
efficacy and	newly acquired	mentor, two	contacts and	biographical		SPSS (V.15), Non-	p=.013) with education
prevention	SCI resulted in	mentors were	six months of	data, T2: six		parametric statistics,	9th grade and higher.
of medical	moderate to	more than 10	monthly	months after		Tests: Difference in	Results for other
complicatio	severe	years post-	contact (total	enrolment		GSEF at zero and 6	subgroups were
ns	neurological	injury). The	of one year	participants		months: Mann-Whitney	insignificant, Pain
	deficits, N=24	programme	contact). For	completed		U test, Rates of	(Neuropathic Pain
	(out of 37	includes	the first three	the GSEF and		secondary	Intensity Rating Scale,
	enrolled in the	education on	months,	an exit		complications/MCTF	NPS): Wilcoxon test was
	study, 13	WH transfers	newly	interview,		(two periods: 0-6	significant (P=.001).
	dropout mainly	during inpatient	enrolled	MCTF was		months, 7-12 months):	Medical complications
	due to	care and on	mentees met	completed		Wilcoxon test, Pain	(MCTF): doctor visits and
	disconnected	discharge the	with their	and compared		(Neuropathic Pain	medical complications
	phone	aim was	mentor	every contact.		Intensity Rating Scale,	decreased between 0-6
	numbers),	tracking	weekly in			NPS): Wilcoxon test,	months and 7-12
	Eligibility:	medical	person at the			Significance value was	months, P: .001 - .046.
	minimum age	complications	hospital or			not reported.	Mentees were satisfied
	18 years,	and assisting SCI	over the				and perceived the
	admitted to	individuals with	phone. After				mentors as very
	NRH within one	adjusting to life	discharge				knowledgeable about
	year of SCI,	after SCI.	mentors				how to successfully live
	motivation to		contact				with SCI and secondary
	regularly		mentees by				complications after SCI.

interact with their peer mentor, ability to communicate in English. Patients with cancer-related SCI were ineligible, Age: 35.38 (19-69) years, Level of education: 6th-11th grade 10(27%), H.S diploma or GED 19(51%), Bachelor 5(14%), Master 3(8%).

phone or meet in person if needed.

Mentees provided an average rate of 4.22 on five-point Likert scale, with five being 'excellent'. Suggestions: on how to improve the programme included more extensive in person contact and community outings such as riding the metro and visiting a restaurant.

Kennedy and Hamilton, 1999	Impact of the Needs Assessment Goal Planning	Quasi-experimental, non-random, uncontrolled pre-test/post-	Inpatient rehabilitation setting (National spinal injuries	The Needs Assessment Programme	The mean time from admission to the first Needs	T1: within 2 weeks of patient being mobilised to active	NAC	Independent variable: Needs Assessment and Goal Planning Programme, Dependent variables: nine domains	At the time of the second Needs Assessment independence was significantly greater and needs were significantly	7
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Programme	test, 82 adults	centre in the	Assessment	inpatient	of Needs Assessment	lower after rehabilitation
on	diagnosed with	United	was 92.5 days	rehabilitation,	Checklist including 216	in all 9 domains,
independen	SCI, mean age	Kingdom),	(range 6 ± 245	T2: upon	indicators, Non-	Wilcoxon test for nine
ce in ADL	of participants	between July	days), and the	patient	parametric statistics,	domains of NAC P<.0001.
	41 years (range:	1994 and	mean time	transfer to	Tests: difference	
	16 and 74)	December	between the	the pre-	between means of two	
		1997	first and the	discharge	intakes of NAC:	
			second Needs	ward	Wilcoxon test,	
			Assessment		Significance was not	
			was 95 days		reported.	
			(range 17 ±			
			235 days).			

PT: Physiotherapist, OT: Occupational therapist, ADL: Activities of Daily Living, WH: Wheelchair, UL: Upper limb, MWC: Manual wheelchair, CPG=Clinical Practice Guidelines, IG= Intervention group, SCG=Standard care group, WUSPI=Wheelchair Users Shoulder Pain Index, NRS=Numeric Rating Scale, TAI=Transfer Assessment Instrument, NAC=Needs assessment checklist, WUSPI=Wheelchair Users Shoulder Pain Index, SWLS=Satisfaction With Life Scale, CHART=Craig Handicap Assessment and Reporting Techniques, NRH= National Rehabilitation Hospital, GSEF= The General Self-Efficacy Scale, MCTF= Medical Complications Tracking Form, GED=General Educational Development

Figure 2. Forest plot of comparison effect size of ADL education on rehabilitation outcomes.

**Table 2. Categories and psychometric properties of the measures.**

Categories of rehabilitation outcomes	Rehabilitation outcome tools	Validity and reliability	
<b>Manual wheelchair propulsion and transfer</b>	Wheelchair biomechanics (ambulation on tile, carpet, ramp) <sup>1, *</sup>	High/excellent	Interrater and intrarater: r=.70-.99
	Transfer Assessment Instrument <sup>2, *</sup>	Moderate/high	Spearman rank correlation coefficients=.192-.690, Interrater: r=.64, intrarater: r=.35-.89
<b>Pain</b>	Wheelchair Users Shoulder Pain Index <sup>1, **</sup>	High/excellent	Has internal consistency, Intrarater r=.99
	Numeric Rating Scale <sup>1, **</sup>	Acceptable/moderate	Adequate evidence of construct validity, r=.59-.93
	Neuropathic Pain Intensity Rating Scale <sup>3, **</sup>	Acceptable	Test-retest reliability .45-.78
<b>Self-efficacy, Satisfaction, and Participation</b>	The General Self-Efficacy Scale <sup>3, **</sup>	Moderate/high	Cronbach's alphas: .76 to .90
	Satisfaction With Life Scale <sup>1, **</sup>	Acceptable/moderate	r=.44-.64, a=.84
	Craig Handicap Assessment and Reporting Techniques <sup>1, *</sup>	Acceptable	r=.57-1.00
<b>Prevention of Secondary Complications</b>	Medical Complications Tracking Form <sup>3, *</sup>		
<b>Needs Assessment</b>	Needs Assessment Checklist (ADL domain) <sup>4, **</sup>		
<b>Decision making</b>	Wheelchair setup <sup>1, **</sup>		Not reported
	Wheelchair selection <sup>1, ***</sup>		
<b>Interview</b>	A qualitative in-depth exit interview <sup>3, **</sup>		

<sup>1</sup>Rice et al., 2014; <sup>2</sup>Rice et al., 2013; <sup>3</sup>Ljungberg et al., 2011; <sup>4</sup>Kennedy and Hamilton, 1999

\* Objective measure, \*\* Subjective measure, \*\*\* Objective and subjective measure