Health Sector Transition and Recovery Programme

Caretakers Programme for 100 Caretakers Completed

Payment Deliverable: SIRC 5

Spinal Injury Rehabilitation Centre

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स्पाइनल इन्जरी पुनर्स्थापना केन्द्र
Spinal Injury Rehabilitation Centre
A Project of Spinal Injury Sangh Nepal

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This document addresses the requirements of the Spinal Injury Rehabilitation Centre's (SIRC's) payment deliverable 5 under the Health Sector Transition and Recovery Programme: 'Report on Caretaker Training Programme'.

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1 BACKGROUND

The 7.8 magnitude earthquake that hit Nepal on 25 April, and the multiple aftershocks that followed claimed more than 9,000 lives, left more than 23,000 people injured and destroyed over half a million homes. Fourteen districts were most severely affected.

The DFID funded Nepal Health Sector Support Programme (NHSSP) has been providing technical assistance (TA) to the Ministry of Health (MoH) and Department of Health Services (DoHS) since 2010 to help implement the second National Health Sector Programme (2010-2015). In the aftermath of the earthquakes, DFID contracted Options to build on its existing programme of TA support and provide further TA to support a Health Sector Recovery and Transition Programme. This twelve month programme runs until July 2016 and aims to restore essential health services, including obstetric care, family planning, physical rehabilitation and psychosocial support, across the 14 most affected districts with a particular focus on Ramechhap, Dolakha and Sindupalchowk districts.

2 SPECIFIC BACKGROUND

Caring for a loved one can be an emotionally and physically trying experience although it is also extremely rewarding. Being a caregiver involves many responsibilities that may be new to someone who has just become a caregiver of an injured person. It can be demanding and stressful, especially when caregivers are often unsure what they are doing. Hence, it is empowering and valuable for caregivers to be trained.

The Spinal Injury Rehabilitation Centre is located in Sanga, Kabhre, Nepal. SIRC acknowledges that caregivers — the men and women who care for family members and loved ones — deserve to be recognised and supported for the vital role they play in the lives of individuals with spinal cord injuries.

SIRC provides caregiver training for caregivers and families of patient to equip them to better care for the physical and socio-emotional needs of persons with spinal cord injury.

3 RATIONALE

The impact of a spinal cord injury is not isolated to the injured individual but also affects their families circle and communities. Given the rural context in which many SIRC patients live, it is important to support the instrumental role of family members in the continuum of care given to patients. Critical to this therefore, is developing their understanding of the needs and fears of their injured family member as they transition from SIRC back to their communities. SIRC is therefore providing a comprehensive carer training programme to increase carers' knowledge, skill and confidence to support and manage the rehabilitation of their injured relative. Greater awareness of different elements of their relative's injuries condition will help the carer to better understand their role. It is hoped this type of training provides opportunities to solve problems, to reduce stress and empower both carers and the persons they look after. The emphasis on practical knowledge in the trainings is intended to assist carers to build core skills on managing the health of spinal cord injury patients and to prevent complications arising.

The caretaker training is aimed at persons who are responsible for the day-to-day care of their injured relative. SIRC aims to provide practical information in its tailored training programme to o equip carers with the knowledge, skill and confidence to manage the rehabilitation of their loved one. The intention is to build the capacity of family members to manage and prevent spinal cord injury complications. Carers' understanding of pertinent issues and the implementation of appropriate responses are addressed in the training programme. The recognition and acknowledgment of the key role played by family caregivers has led to the creation and delivery of the caregiver programme.

4 PURPOSE AND OBJECTIVES OF THE ASSIGNMENT

The overall objective of the assignment under the under the Health Sector Transition and Recovery Programme was to provide caretaker training to 100 caretakers of SIRC patients to help them learn techniques and provide tips on how to provide safe, healthy and supportive environments for spinal cord injury care patients.

Other objectives were as follows:

- Educating family and caregiver about preventing spinal cord injuries.
- Identifying complications, means of preventing complication and ways of managing spinal cord injuries.
- Helping to build a better relationship between patient and their families.
- Learning patient care techniques, including proper bathing techniques and lift-and-carry techniques.
- Recognizing early signs of health issues and illnesses, how to check for basic vital signs and how to manage chronic illnesses.
- How to meet the physical and nutritional needs of patients.
- To raise awareness about emotional support and wellness issues.
- To help caregivers maintaining their own health and wellbeing.

5 ACTIVITIES

- Five caregiver training courses were run between September 2015 and May 2016 attended by 107 participants. The caretaker training programme was five days long for two and a half hours per day, from 13.30-16.00 hrs, totalling twelve and a half hours. This was the first structured caretaker training programme delivered at the centre, although caretaker training has been a feature of the work completed by members of the multidisciplinary team who were involved in the current training.
- The training was provided by a multi-disciplinary team of nurses, physiotherapists, a psychologist, peer counsellors, a wheelchair technician, a dietician, a vocational trainer, and occupational therapists. Each department at SIRC — medical, physiotherapy, psychological and occupational therapy — facilitates the 2.5 hours training for five days to provide holistic knowledge of the essential care of patients.
- SIRC used active learning methods for caregivers to assess the 'distance travelled' between the start and end of the training programme.
- The training used active learning methods to assess the knowledge, skill and confidence of caregivers in providing appropriate care to their family member with a spinal cord injury.

- SIRC documented lessons learning for facilitators of training in order to arrive at an optimal service design for caregiver training.

6 INTENDED OUTCOMES

The main objectives of the training were to educate families and caregivers about the prevention of spinal cord injury, to identify complications, preventions and management of spinal cord injury and to help building and develop a better relationship between patient and his/her family.

The focus was therefore on improving the knowledge of caregivers about the health of spinal cord injury patients and actions needed to manage and prevent complications, thereby reducing morbidity and mortality in this vulnerable group.

Another intended outcome was to build the capacity of SIRC to deliver training to caregivers as caregivers are a key support mechanism for spinal cord injury patients both during in-patient times and after discharge.

7 TRAINING PROGRAMME CONTENT AND STRUCTURE

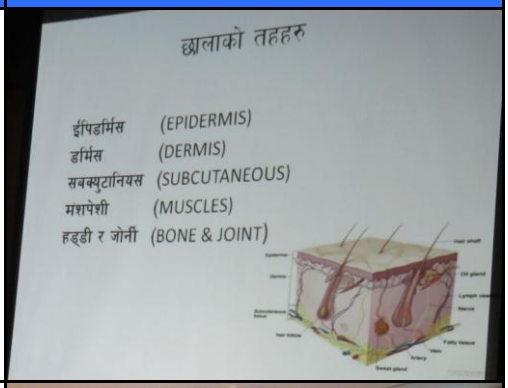
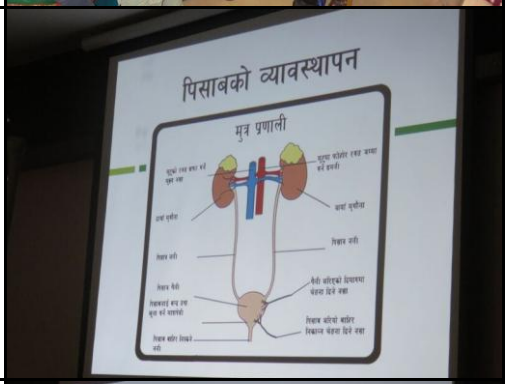
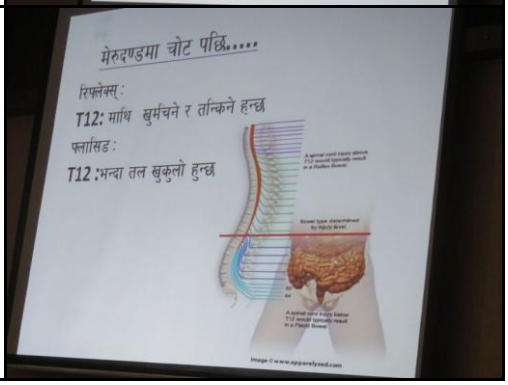
The 14 areas listed in Table 1 were covered in the caregiver training programmes. There were intentionally mapped onto the rehabilitative pathway of spinal cord injury patients and reflect the multi-disciplinary approach practised at SIRC. Caregiver education encompassed the medical, social, psychological and vocational aspects of a patient's life, which caregivers and family members are involved in supporting on a daily basis.

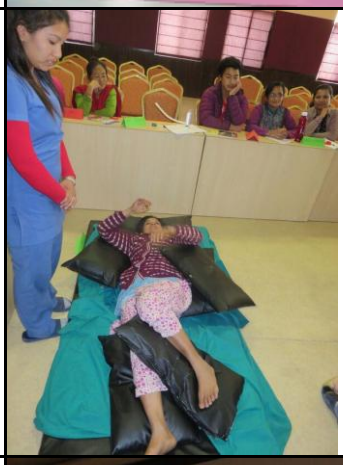
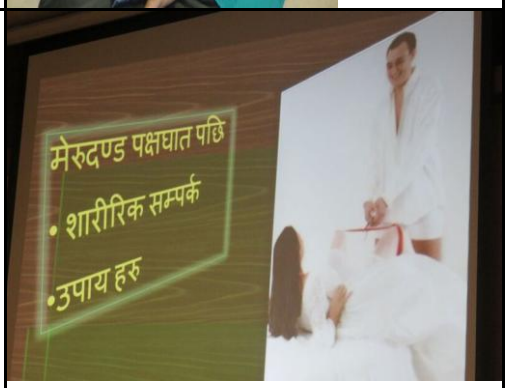
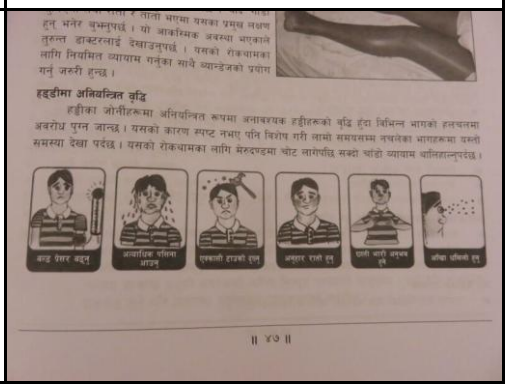
Staff from relevant departments within SIRC led the sessions based on their expertise, profession and experience. They worked alongside the SIRC training coordinator and the DFID-funded international training consultant to develop, review and refine programme content and delivery to respond to the needs of caregivers who took part in the training.

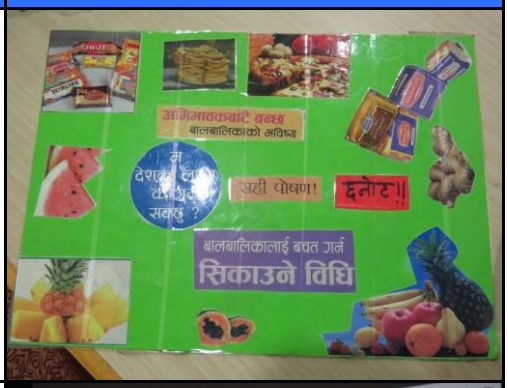
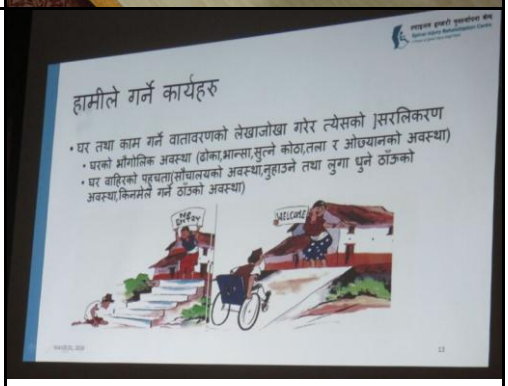
A detailed account of course content and photographic evidence of delivery which provides a visual account of materials and lesson activities is given in Table 1. Table 2 summarises the final timetable followed by the trainers who delivered the course. These two tables highlight the comprehensive approach taken by SIRC to offer a holistic view of caring for a spinal cord injury patient, informed by evidence-based multi-disciplinary practices.

Table 1: Overview of course content and photographic evidence of delivery

Topic	Details	Photographs taken during training programmes
1. Spinal cord injury overview and complications	What are spinal cord injuries, functions of the spine, major causes of spinal cord injury in Nepal, complications	

Topic	Details	Photographs taken during training programmes
2. Skin management	Pressure ulcer causes and relief techniques; daily skin care; most appropriate positioning in bed, on wheelchair or chairs, working area; correct and incorrect positioning	
3. Respiratory management	Coughing, relaxation and huffing technique. Spirometry and positioning	
4. Bladder management	Functions of the bladder; differences in types of bladder issues; causes, prevention and treatment of urinary tract infections	
5. Bowel management	Anatomy of the bowel, neurogenic bowel dysfunction and its management and video demonstration of digital rectal stimulation	

Topic	Details	Photographs taken during training programmes
6. Aids to daily living (ADL) assistive devices	Individual assessments, types of ADLs and their functions, application of ADLs for different patient needs, role of ADLs in daily activities	
7. Pain and spasticity in spinal cord injuries	Causes, symptoms, treatment, trigger points and demonstration of positioning	
8. Sexual activity of spinal cord injury patients	How sexual activity is considered in the context of Nepal, cultural attitudes, effects of spinal cord injury on marriage and sexual relationships, aids that can improve sexual functioning and relationships, implications for fertility, importance of pleasure in human beings	
9. Psychological impact and coping skill	Importance of not ignoring psychological impact of spinal cord injuries as this plays a vital role in the quality of life and degree of independence, coping skills, signs and symptoms of depression, vocational and social activities and opportunities	

Topic	Details	Photographs taken during training programmes
10. Nutrition	The types of nutritious food for patients	
11. Accessibility, home care and modifications	Means of accessibility, importance of modifications to home and other infrastructure and role they play in quality of life of individual with spinal cord injuries. How modifications can be made to kitchens, bathrooms, bedrooms and yard areas. What other modifications can be made to improve independence and mobility	
12. Vocational training	Importance of vocational training for wheelchair users, process of training assessments in SIRC, types of training provided, challenges for training	
13. Transfer onto wheelchairs and basic wheelchair issues	Types of transfer to wheelchairs and techniques, types of wheelchairs, maintaining wheelchairs, practical demonstration of wheelchair skills (basic and advanced), price and availability of wheelchairs	

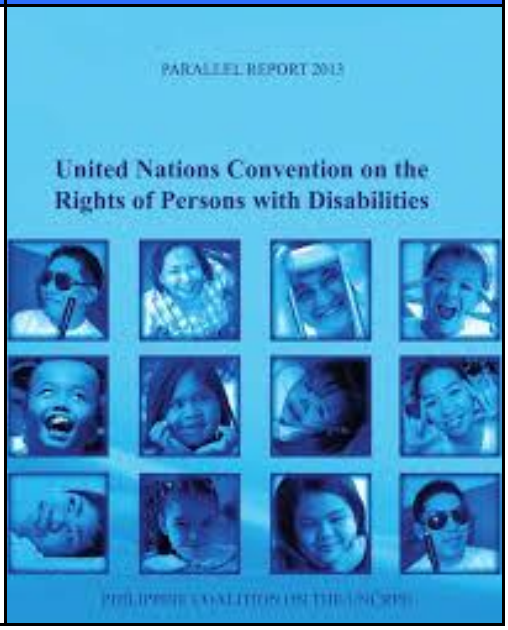
Topic	Details	Photographs taken during training programmes
14. Disability rights (Convention on the Rights of Persons with Disabilities, UNCRPD)	Policy in Nepal, types of disability cards and allowances, how and when tax relief applies to persons with a disability, procedures for claiming tax rebates and entitlements, availability of legal aid, travelling rights abroad, key components of UNCRPD	

Table 2: Training timetable

Day/time	1:00 – 1:15	1:15- 2:00	2:00- 3:00	3:00-3:20	3 :20– 4:00
Day 1	Introduction & pre-test (MDT team)	Spinal cord injury overview	Skin management	Tea break	Bladder management
Day 2	Ice breaker	Respiratory management	Bowel management	Tea break	Psychological support
Day 3	Ice breaker	Pain and spasticity in spinal cord injury	Sexuality	Tea break	ADL and assistive devices
Day 4	Ice breaker	Nutrition	Accessibility , home care & modification	Tea break	Transfer and basic wheelchair and its maintenance
Day 5	Ice breaker	Vocational training	Disability rights	Tea break	Course feedback and post-test

The training programme was delivered through presentation slides, visual demonstration of techniques and methods for patient care and active learning exercises to support knowledge transfer to caregivers.

The following methods were used for training delivery;

- PowerPoint presentations in Nepali with pictures to help participants understand clearly.

- Theoretical knowledge to increase knowledge of participants and practical demonstrations to help them apply the theoretical knowledge in practice.
- Practical demonstration was done on respiratory management, positioning, transfer and wheelchair maintenance.
- Videos were used wherever possible
- Materials used for patients were shown including assistive devices, catheters, spirometers, medicines and materials.
- Interactive sessions involving role plays, active learning methods, question and answer sessions and engagement in demonstrations.

Seventeen SIRC staff (Table 3) from all departments contributed to the training course by preparing educational materials to be delivered during sessions. The staff subsequently facilitated sessions and supported carer participants to develop their understanding of spinal cord injury care and management.

As part of ongoing quality assurance and reflective practice, an audit of each training programme was conducted by the international training consultant. This facilitated a review of each programme through reflective discussions and agreement on an action plan for the next caregiver training course. The revisions were directly informed by both caregiver feedback and responsiveness to the sessions and trainer reflections through a 'what worked' process of learning. Photographic documentation of the training also contributed to discussions during this process.

Table 3: Trainers involved in caregiver training courses

Department	Trainer's role
Management	Head of rehabilitation services International training consultant Training coordinator
Nursing	Head of department Staff nurses
Physiotherapy	Head of Department Physiotherapists
Occupational therapy	Head of department Occupational therapists
Social	Psychologist Social worker Peer counsellors Nutritionist
Vocational	Head of department
Wheelchair maintenance	Wheelchair technician

The lessons learned led to changes in programme content, structure, delivery style and materials used. Figure 1 displays the final caregiver training content and structure which emerged from the

cycle of learning. The development process and details of the changes that resulted from lessons learning across the five different training courses are outlined in Section 13 below.

8 TIMELINE OF DELIVERY

Five caregiver training courses were run between September 2015 and May 2016 (Table 4) for 107 caretakers.

Caregivers were encouraged by the training coordinator who explained to them about the course, and what it offered. The coordinator was supported by members of the multi-disciplinary team to communicate the benefits of caregiver education in their roles as designate family members and carers. Details of the content and structure of the training and learning outcomes were discussed with caregivers. They were then encouraged to attend the training and supported throughout the experience to ensure that their knowledge of spinal cord injuries and their role as caretakers was developed.

Table 4: Project training schedule

Training number	Date of training	Number of caretaker participants
1	20-22 September 2015	20
2	3-6 November 2015	30
3	25-28 January 2016	25
4	28 March- 1 April 2016	17
5	4-10 May 2016	15
Total		107

9 MONITORING AND EVALUATION METHODOLOGY

A multi-layered monitoring and evaluation design was employed when capturing the outputs and outcomes of delivering training to the more than 100 caregivers of patients treated at SIRC. A process approach to evidencing the project deliverable enabled the training development process to be documented while simultaneously measuring knowledge transfer to caregivers in terms of spinal cord injury patient rehabilitation for designated family members. It was necessary in the design to take account of the educational profile of caregiver participants to assess the feasibility of using written and/or verbal methods. A key learning by the end of the training courses was that most caregivers preferred verbal methods of feedback because of their limited literacy. However, where literacy capabilities were weak but not absent, support from SIRC staff helped caregivers complete written pre- and post-training assessments designed for measuring their progress.

This report contains findings from verbal and written methods used during the training courses. The use of pre and post training surveys provided evidence of knowledge and understanding with regards to spinal cord injury, its management and rehabilitation. (Annex 1) The quantitative analysis of the pre and post surveys is also presented in this report.

10 LEARNING OUTCOMES

A total of 107 caregivers participated in the five training courses between September 2015 and May 2016. Figure 1 shows that overall 55% of participants were male and 45% female. A predominance of male attendees was observed at four out of the five courses.

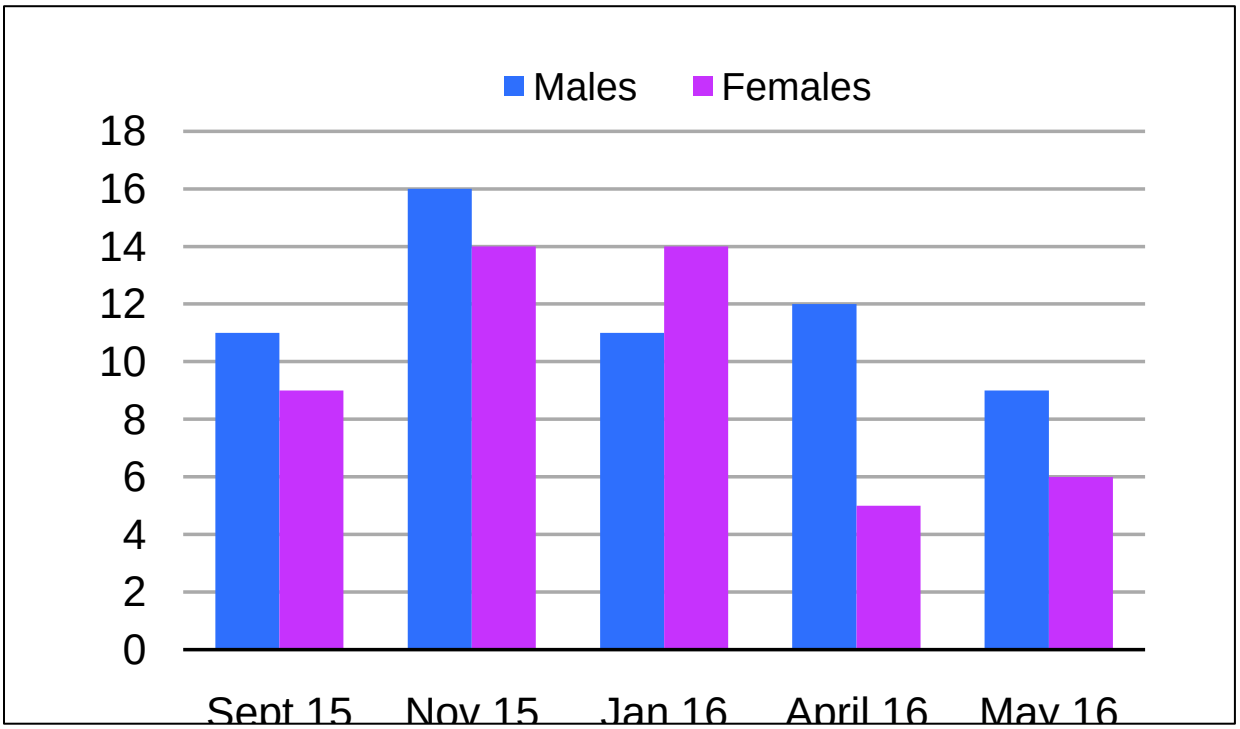


Figure 1: Gender breakdown of participants at the five caregiver training courses

10.1 Knowledge Exchange

Based on the literacy capabilities of the participants, 28% of them were able to complete written pre and post training surveys. These surveys were designed to assess their level of understanding and knowledge about spinal cord injury rehabilitation prior to the course and after completion of all the training sessions. The questions were mapped directly to the teaching areas of the programme. The changes in caregivers' levels of awareness and understanding was used as an indicator of knowledge transfer during the training.

Detailed discussions were held at the end of each course where the coordinator solicited verbal feedback based on questions put to caregivers about the learning they had acquired. All (100%) of participants provided feedback. Further support was given to caregivers who required clarifications around topics covered in the training courses. This often took the form of one-to-one guidance to address queries, or direct demonstrations of key caregiver skills.

10.2 Quantitative Findings

The pre- and post-responses of caregivers were aggregated across all five training courses to facilitate the analysis of knowledge at the start and end of the courses. Fifteen questions were included in the surveys. Using a repeated measures protocol, participants completed the same survey at the designated measurement points. Their initials were used to ensure that a matched

pairs analysis of responses could be carried out to improve robustness and reliability of the results.

Pre training knowledge

Participants were given multiple choice options in the pre-training survey. The number of correct answers per question was calculated and analysis of individual questions conducted in addition to a cumulative examination of responses to the pre-training questions. It emerged that the highest level of existing knowledge among caregivers was about:

- position changing times during sleep (85%)
- coping with mental tension (81%)
- home modification requirements (78%).

In contrast the lowest levels of knowledge were in relation to:

- number of types of spinal cord injury (33%)
- symptoms of urinary tract infection after spinal cord injury (44%)
- advantages of home modifications (44%).

An interesting observation to note between the levels of knowledge in these areas is the finding that while a large percentage of caregivers were able to identify the requirements of a house for a spinal cord injury patient in, the advantages or reasons behind doing related modifications was poorly understood. It seems that the caregivers were aware of what needed to be done but did not clearly understand how or why it would benefit the life of a spinal cord injury patient.

The overall mean score of caregiver knowledge (based on correct responses to questions) at the pre training point was 53%.

Post-training knowledge

Using the same set of questions and a multiple choice format, participants were asked to complete the post-training survey. Following test correction checks, the highest level of positive response was noted for:

- position changing times during sleep (96%)
- symptoms of urinary tract infection after spinal cord injury (88%)
- best method of managing bladder problems (88%).

The questions which received the lowest number of correct responses were:

- number of types of spinal cord injury (37%)
- normal bowel habits for a spinal cord injury patient (70%)
- ways to prevent pressure sores (74%).

However, knowledge was relatively good on the latter two questions at post training stage (70-74%) showing increases of between 6% and 11% from the pre-training situation. In addition, the overall mean score of caregiver knowledge (based on correct response to questions) at the post training point improved to 87%.

Distance travelled

The 'distance travelled' part of the analysis focused on the changes observed in caretaker knowledge after completion of the training course. Based solely on the assessment form findings, there was a 34% average improvement in the level of knowledge among caretakers who responded to these questions. Figure 2 illustrates the shift across the measurement intervals.

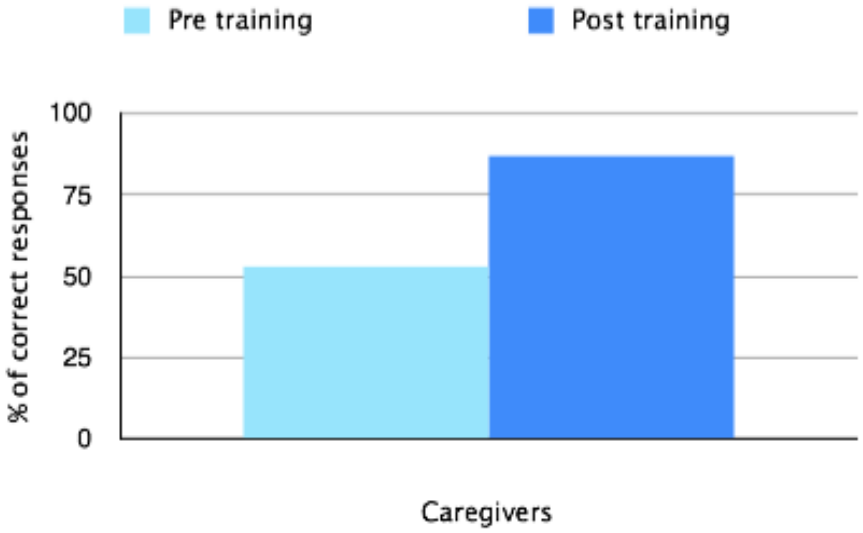


Figure 2: Level of caretaker knowledge at pre and post training points

The greatest improvement in before and after knowledge occurred on:

- symptoms of urinary tract infection after spinal cord injury (+50%)
- advantages of home modifications (+37%)
- types of patient transfer (+34%).

The comparison of pre and post-training knowledge suggests that the areas where caregivers exhibited the lowest level of understanding (symptoms of urinary tract infection after spinal cord injury and advantages of home modifications) had resulted in the greatest improvement in knowledge. This points to a significant learning outcome among caregivers and supports the active listening and reflective approach taken by the SIRC training team. Through discussions with caregivers and during the learning activities employed as part of the course, trainers directed the knowledge transfer to give additional attention to the areas of learning that needed the most support. Awareness among trainers that the lowest level of knowledge was in understanding the symptoms of urinary tract infection after spinal cord injury or by creating awareness among caregivers about the contribution home modifications can make to a spinal cord injury patient's quality of life, the training course was likely to have had a critical effect on their loved one's health, rehabilitation at home and on the prevention and management of complications.

10.3 Qualitative Findings

Verbal feedback from discussions about knowledge improvement and review of training experiences by caregivers corroborated the pattern of results from the pre and post training surveys. It was evident from the caregiver participants' views that they benefited by improving their self-awareness, understanding and knowledge about spinal cord injury healthcare, management and complication prevention. The holistic nature of the training, which encompassed the medical, social, psychological needs of their loved ones, was informed by a

rights-based approach to health and social care. Combining knowledge around medical issues that affect the individual's daily living experience with an understanding about their right to a full and equal life as a person with a disability was acknowledged by caregivers in their feedback. Examples of feedback ate given below:

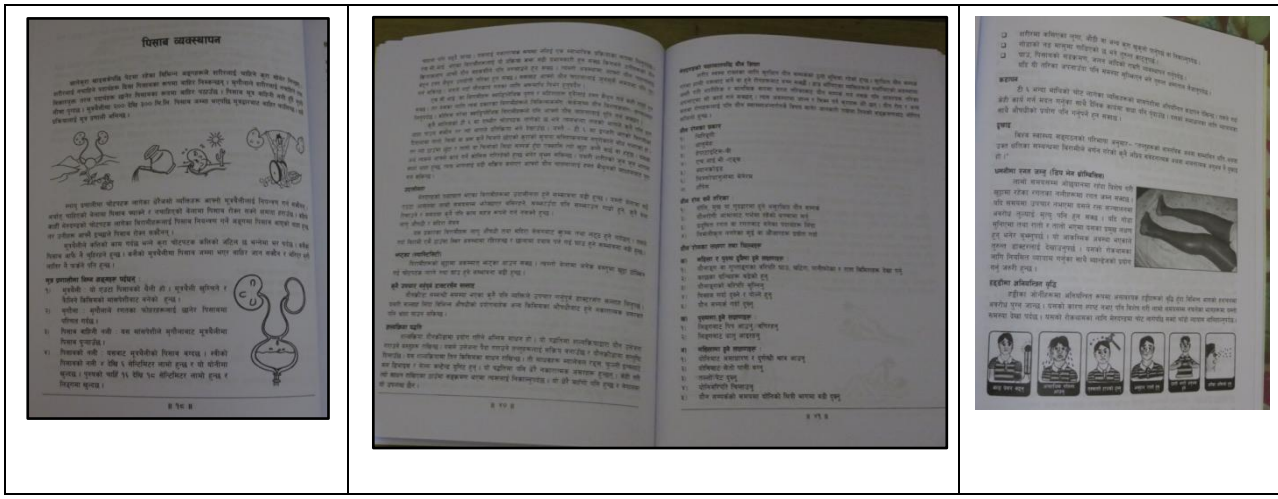
> *"I liked the training session very much. What I especially liked was I got to know how to care for patients, how to do therapy and how to make patients' minds fresh."*
>
> "The training was helpful to increase our level of knowledge on skin care, mobility of patient, clean intermittent catheterisation and clean intermittent self-catheterisation (CIC\CISC) and its impact on infection"
>
> ***"****The training was fruitful but it would have been more effective if they could deliver additional teaching on how to do house management, bathroom management and free mobility on public places by patient themselves."*
>
> ***"****The training was effective to have increased understanding on rights of injured people or people with disabilities."*
>
> *"The training helped to provide good care to spinal cord injury people and motivate them accordingly. We became aware about different complications arising from spinal cord injury."*
>
> *"The training cleared most of my doubts regarding spinal cord injury."*
>
> *"I learnt that spinal cord injury people can do so many things to be self-independent."*
>
> *"I learnt so much from this training."*

11 DEVELOPMENT OF CARETAKER MANUAL

An A5 booklet containing 78 pages of written and visual material was redrafted before the start of the training programmes. Review of the booklet led to additional materials being included with a greater emphasis on graphics and diagrams to inform readers [caretakers] about key messages. The areas which required development included:

- sexual function
- physiotherapy
- occupational therapy
- complications.

Written in Nepali, each section gave an overview of the pertinent learning points needed by caretakers to firstly understand the health condition of the 'patient', secondly to manage day-to-day activities and thirdly to prevent complications such as chest infections, pressure ulcers, urinary tract infections and faecal incontinence —all of which can profound impact the morbidity of people with spinal cord injuries. See Figure 3 for some pages from the manual.



12 FIGURE 3: PAGES OF THE CARETAKER MANUALTRAINERS' REFLECTIONS AND FEEDBACK

12.1 Role of International Training Consultant

The international training consultant played the role of mentor in the development process and auditor of the quality of the training (quality assurance cycle).

The international training consultant acted as a mentor by:

- helping in caretaker programme planning meetings by selecting appropriate subjects for the training, including bladder, bowel and skin management;
- helping design the caretaker programme taking into consideration the correct pitch to ensure participant learning needs were met (Annex 1);
- assisting with the selection of trainers for the programme and outlining the related requirements (Annex 2);
- providing guidance and support to the SIRC training coordinator relating to the training package including time management and communication with staff to enhance timely planning and coordination;
- acting on feedback from the caretakers during the training programmes. for example the nutritional requirements of patients to assist with bowel management;
- providing advice regarding the management of patients whilst caretakers were involved in the training programme;
- supporting the heads of departments in the assessment of trainers (Annex 3); and
- training on 'root cause analysis', related to identified risks, with implications on training (Annex 4).

The international training consultant acted as auditor for quality assurance by carrying out audits of the March and May 2016 training courses. The findings of both audits were fed back to the training team verbally and in written form. The audits provided commentaries on each topic along with feedback and suggestions to improve the delivery of future programmes (Annex 5). Note that these were the fourth and fifth such training courses under programme, and therefore it was an appropriate time to assess the programme for learning and development purposes as well as for quality assurance.

Reflections

A planning meeting was held by the training coordinator and head of departments prior to the caretaker training courses beginning. It was agreed that the courses should be more practical than theoretical. The preferred number of participants was agreed as 15 per course as larger groups were found to be unmanageable. The international training consultant in collaboration with the rehabilitation manager ensures that all caretakers of SIRC patients receive training before discharge home. By supporting carers' knowledge about the risks of spinal cord injury, it was fully recognised that associated morbidity and mortality rates are likely to decrease. In general participants were focused, able to ask questions, and interacted well with the trainers (and vice-versa), which indicated that the training provided was pitched at a level which carers responded to.

During implementation of the training programme, it became apparent to the training consultant that the female caretakers needed support with childcare arrangements to enable them to fully engage in the sessions. In response, participants' young children were taken to the supervised child friendly space within SIRC and cared for during the courses. This was replicated without prompting in the second audited training, which demonstrated consideration for the children and participants.

It was unusual to see caretakers leave the classrooms, which reflected the organisation of patients on the ward to ensure the caretakers could attend the training without having to worry about the care of their patients. Learning gathered through summative reflection sessions following each training programme highlighted that a formal approach to caretaker courses was necessary to facilitate the active and meaningful participation of carers. An essential driving force for the success of the courses was the allocation of staff to look after patients on the wards to oversee patients whilst the caretakers were away at the courses.

Most of the suggestions in the audits were subsequently addressed which demonstrated the trainers' openness to make changes or adjustments including:

- making sessions more practical-based
- changing English words into Nepali, for example on presentation slides
- greater use of Nepali videos to enhance understanding and reflect a more realistic culture that viewers can relate to
- staff being made available to assist participants unable to read and write during the pre and post testing as previous courses had resulted in verbal testing only.

There was a noticeable improvement in the ability of junior staff to facilitate a learning environment in the second audited taker training, which demonstrated their increasing levels of experience in teaching others. Their confidence in their subject was more visible and this is a credit to them.

During the second audited programme in May 2016, (following suggestion by the international training consultant), the rehabilitation in charge and lead nurse carried out trainer assessments, which they agreed were beneficial for them as heads of departments. This demonstrated openness to change and the progress of the training department in providing continuing professional development opportunities for the head of departments, their staff, as well as

providing evidence of in-house monitoring and evaluation. Figure 4 shows how the caretaker training programme developed over time through positive feedback.

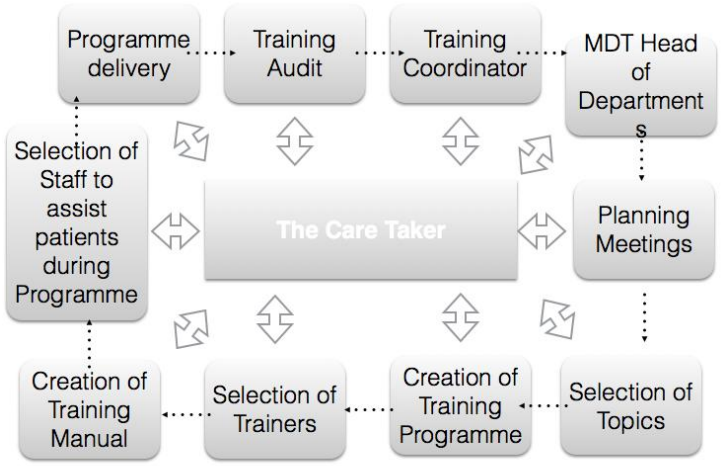


Figure 4: Caretaker training development cycle

Through the consultant's advisory and mentoring role, which included formal audits and root cause analysis sessions, there was an observed development in the learning and skills capacity of staff. Particular improvements were noted in the areas of communication, information sharing and support with carers, which staff acknowledged would enhance patient outcomes, potentially reducing morbidity and mortality rates.

Key outcomes

The international consultant observed the following three major outcomes:

- The head of SIRC's departments committed to providing monthly caretaker training programmes as a result of the observed improved knowledge and skills on spinal cord injury care of carers after the training courses. SIRC staff demonstrated their belief in the importance of caretakers having and needing the opportunity to learn about the specific needs of people who have sustained a spinal cord injury.
- The improved willingness of SIRC staff to learn and improve practices.
- SIRC staff's improved listening to carers' voices and responding to the needs of patients and caretakers.

12.2 SIRC Trainer Reflections

The international training consultant encouraged and supported staff with continued professional development through the use of reflective practices in their roles as trainers. Opportunities were taken to review delivery style, participant responsiveness and learning outcomes at each course the international consultant supported capacity improvement across

the multidisciplinary team on reflective practice. A structured format guided the learning cycle and informed ongoing revisions of the programme to improve delivery style and carer response to the sessions. The goal was to increase learning outcomes by providing carers with a sustained level of knowledge and understanding that would underpin the development of skills and confidence in their roles as carers for spinal cord injury patients. The framework of questions followed by trainers is given in Annex 6.

Using the reflection framework, there was clear agreement between the trainers that participants responded best to practical, demonstrated sessions where practices and techniques could be visually communicated supported by clinical knowledge. According to the trainers the essence of knowledge transfer was being able to engage and interact with carers to encourage ownership of their roles as a carer for their family member with a spinal cord injury. As one trainer stated; “The participants must be more involved with more practical than theoretical learning as this can be more easily applied”. The use of videos, role plays and practical demonstrations involving carers was viewed by trainers as effective training techniques which carers responded well to. Linking the information to the condition of the patient they were caring for was also recognised as critical for knowledge transfer as this embedded the information in the context of their own situation.

By creating a learning environment conducive to open and active participation, trainers reflected on how this was a mediating factor in carer and trainer interaction in the sessions. It was described as cooperative, two-way, and engaging. Trainers commented on how interested, curious and interactive carers were in the programme. The level of interaction and style of delivery by the trainer created an atmosphere where trainers were able to respond to queries, clarify issues and support carers with individually specific requests about caring for their loved one based on their medical status and level of injury. The identification and discussion of problems during the training sessions were viewed by trainers as a positive process leading to beneficial outcomes for the carers and ultimately the patients they care for.

The trainers consistently agreed that they had a professionally rewarding experience which enhanced their capacity as trainers and offered them insight about the role of carers in the lives of individuals with spinal cord injuries. The SIRC trainers who contributed to the caregiver training programme were keen to acknowledge their pleasure at being able to provide information and support that would be valuable to carers and their family members. The longer term implications of leaving SIRC with a knowledge base to support carers was also recognised by the trainers.

13 LESSONS LEARNED

Taking account of process and interval data gathered across the five carer training programmes, a set of lessons have been drawn to inform future SIRC caretaker training programmes. These may also offer identifiable actions or considerations which need to be taken in developing or delivery a caretaker programme for spinal cord injury patients in other settings. The following points are driving or restraining forces in caretaker training programmes:

1. Taking account of the family system approach to care it is necessary to provide assisted childcare for female caregivers attending trainings. It became apparent at the first training

programme that childcare would give female caregivers in particular the opportunity to dedicate their time to learning.

2. Reliance on written teaching material was not a viable mode of delivery for caregiver training given the low literacy levels of many participants coupled with the need to transfer practical skills linked to patient care. Through a cycle of reflection and review between trainers, and with the support and mentorship of the international training consultant, multiple delivery modes were introduced and developed. These were refined and sustained across all five training courses.
3. Recognition that verbal and practical communication is best suited to caregiver learning meant focusing on the use of verbal feedback to document learner outcomes. On reflection and through the development process, it became apparent that this type of data could not on its own provide a robust measurement of impact and knowledge transfer. As a result, written pre and post-training surveys were introduced at the last two training programmes (March and May 2016). Support was offered to carers in completing the surveys where literacy was a barrier. Quantitative observations allowed comparisons in participants' knowledge and understanding. Verbal feedback was gathered to offer a more individualised account of the learning experience of the caretaker participants.
4. The training course was accompanied by a training manual, which was distributed to all participants. This can be used to reinforce the learning and practice messages delivered in the sessions and to remind carers of information received in the programmes.
5. Key ingredients in running a programme which ensured caretaker responsiveness were trainers' listening openly and responding actively to the learning needs of carers and paying specific attention to the injury status and caring needs of their family member.
6. The combined roles of mentoring and quality assurance of the international training consultant were critical to the delivery of a training programme that was responsive to carer needs, informed by the inclusion of appropriate and relevant material for spinal cord injury care and delivered through using training tools that embrace a multi-media approach to active learning. The consultant's understanding and experience of educational pedagogies in low resource settings was reinforced by his/her level of expertise in clinical knowledge and practice. His/her contribution to capacity building within SIRC by supporting the training teams as they developed and delivered the caretakers' training programmes was a driving force in the overall process.

14 RECOMMENDATIONS

The following recommendations are made based on a cumulative review of feedback and proposed suggestions put forward by both carers and trainers:

1. Caretakers should be given an induction session upon the admission of their family member to SIRC and also in the early stages of rehabilitation to clarify their role and responsibilities while remaining at SIRC.
2. Given the reliance on carers to support their family member during the rehabilitation process, it may be necessary to consider the delivery approach to caregiver training to incorporate 'onward' practice sessions and observation of techniques to accompany structured learning held to date through a more traditional classroom based approach. This

could then be followed up with tailored advice to carers based on the level of injury and needs of their family members during the rehabilitation stay at the centre.

3. A mixed methods approach, incorporating a matched pairs design where pre and post measures are used to support open ended feedback on carer's learning experiences should be sustained. Dedicated staff time should be included at the first and last sessions to help carers, where required, to complete the documents.
4. Continued professional development of SIRC staff as trainers needs to be sustained to ensure that experience acquired by delivering the caregiver courses is further supported to strengthen existing capabilities and promote their potential as trainers or trainers within their own departments. This would contribute to the overall strategy to help SIRC become a centre of excellence in training related to spinal cord injuries for patients, family caregivers and health care professionals.
5. SIRC are currently developing their next five year strategic plan. Given the importance and relevance of carer and patient education programmes it is important that carer and patient education is embedded in the new plan. This will help ensure that these services become an integral element of SIRC's institutional and community based rehabilitation programme.

Annex 4: Root Cause Analysis Examples

No:	Root Cause	Plan of Action	Responsibility	Date due
1	*****Patient Education ****Most **cost effective** action and most **effective**	Visual flip charts, individual feedback, ensure patient can teach someone else to do their care if they are sick or if caretaker not available. All SIRC staff should know how to teach	Chanda All MDT	From now
2	Care taker education	Visual flip charts, individual feedback. All SIRC staff should know how to teach	Chanda All MDT	From now
3	Accessibility, assistive devices	Continue patient/carer education re modifications. Need modification before discharge Coordinate with local	Keshab/Suresh	From now
	Follow up telephone calls	5 calls per day = 100 per month. Report concern to HOD. Telephone follow up policy	Shiva/Suresh	from now
5	Essential equipment	Telephone, Mattress, Cushion, Mobility	Sassy	from now
6	CBR follow up	As per need. Every 6 months	Prajwal	March 2016
7	Re-admission to SIRC	Admit as required with no delay	Mandira	from now
8	Peer Support	Create consumer network through PGT	Shiva, Sonika	June 2016
9	Local Organisations	Network with DPO's, health Centres, NGO, INGO	Suresh	from now

Ask why?	What happened?	What was done? corrective, preventable action	Will this prevent the problem from happening in the
Problem	A patient developed a pressure sore within 4 weeks		
Why?	Not enough Patient knowledge	Patient training - and assess knowledge	Yes
Why?	Not enough Care taker knowledge	PU graphic education (photos) in nepali	Yes
Why?	No Home assessment	Half way home/transitional care ward	Yes
Why?	Air Mattress with load shedding of 18 hrs	Non electric Mattress	Yes
Why?	Frequent changes or no care taker	Assistive devices, electric wheelchair to reduce burden	Yes

Annex 5: Reflection of Trainers Form

CPD* Reflections of the Trainer*

Reflections from the training

Reflection should be used to underpin and consolidate learning in all areas of professional work. Considering what happened in a particular situation and what could be improved is probably the most important activity available to enhance learning. Reflection is recognised as an essential skill for life long learning. (Boore & Deeny 2012) "Reflection operates through s careful re-examination and evaluation of experience, beliefs and knowledge". (Kember 2001). "Reflection most commonly involves looking back or reviewing past actions, though competent professionals can develop the ability to reflect while carrying out their practice". (Kember 2001)

A Structure for Trainer Reflection

Structure	Reflection
Situation or experience	Describe what happened and the sequence of events that occurred
Causation	What were the factors that caused the experience?
Background	What background factors influenced the situation?
Reflection	What was I trying to achieve and why did I intervene as I did? What were the consequences of my actions for: myself, the patient/family, for the people I work with? How did I feel about this experience when it was happening? How did the patient/student respond and feel about it, and what did he/she say? What factors and/or knowledge influenced my decisions and actions?
Alternative Actions	What other approaches were possible choices? What would results of those other choices have been?
Learning	Now, how do I feel about this experience? Could I have dealt better with the situation? What have I learned from this experience? What can I identify that I need to learn?

*Continuing Professional Development "CPD"

Title of Reflective Practice: _____

Please write your reflective practice below (and continue over the page):

Name Signature Date

14.0 Other Annexes (available on request)

Annex 1 - Caretaker programmes

Annex 2 - Criteria for selection of trainers

Annex 3 - Support to head of departments in assessing trainers

Annex 4 - Root cause analysis training

Annex 6 - Audit assessment tool