



MONASH University

**The lived experiences of adult students with a
spinal cord injury (SCI) returning to study in
Bangladesh**

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BSc in Occupational Therapy

A thesis submitted for the degree of Master of Philosophy at

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Abstract

Introduction

The Centre for the Rehabilitation of the Paralysed (CRP) is a hospital-based, non-government organisation in Bangladesh. It is the only service provider that, for the last 40 years, has been delivering rehabilitation services to people with spinal cord injury (SCI). Over the years, research has been conducted based on the organisation's data on epidemiology, activity limitations and participation, mortality rates, work participation and vocational outcomes. Many students report being a "student" of different level of education as a pre-injury occupation. However, this area has been relatively underexplored, to date. This research, therefore, aimed to explore the lived experiences of adult students with SCI returning to study in Bangladesh.

Methods

A narrative enquiry approach in a qualitative research design was chosen as a methodological framework. Purposive sampling was used to select 15 adult participants, who had experienced an injury between 15 to 18 years of age, from the database of the CRP in Dhaka, Bangladesh. In-depth, semi-structured interviews were conducted, using the Occupational Performance History Interview-II, based on the Model of Human Occupation guiding framework. Additional self-developed questions, regarding the physical environment of the school, were included. Field notes and a reflective journal were used as the other sources of data. The average length of the interviews was 60 to 90 minutes. Interviews were conducted in Bengali, the first language of the participants and the researcher. The interviews were audio-recorded, transcribed verbatim in Bengali, and then translated into English. Braun and Clarke's (2013) six steps of thematic analysis were used to analyse the data.

Results

Seven themes were identified. These were: 1) Accident as a critical life event; 2) Value and benefits of returning to study; 3) Influence of the academic environment on student participation; 4) Meaningful relationships at the academic institute; 5) Finding other productive roles; 6) Accessing home and community living; and 7) Impact of the social environment. The findings demonstrate the significance of achieving an education, as well as the importance of meaningful relationships with friends and teachers and family support, in facilitating students to achieve their goals. The findings also illuminate the substantial environmental barriers in the academic institute, their homes and in the community that students with SCI experience, as well the challenges of feeling different and experiencing negative responses towards disability in their everyday lives.

Conclusions

These results highlight gaps in current rehabilitation and educational practices in Bangladesh that impact the academic participation of students with SCI. Occupational therapists should facilitate meaningful participation at the academic institute by maximising advocacy at different levels, among students, teachers, community and policymakers, to enable equitable participation for non-SCI students. Developing a peer mentoring service, by including successful students with SCI as peer counsellors, would strengthen the rehabilitation services. Since this research drew mainly on the experiences of students, a more comprehensive understanding of these issues and their implications for academic institutes could be gained by investigating the perspectives of other groups of people, such as teachers, families, friends and peers of students with SCI.

Declaration

This thesis is an original work of my research and contains no material which has been accepted for the award of any other degree or diploma at any university or equivalent institution and that, to the best of my knowledge and belief, this thesis contains no material previously published or written by another person, except where due reference is made in the text of the thesis.

Signature:

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Conference presentations during candidature

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Definition of Keywords

Spinal cord injury (SCI): SCI refers to damage to any part of the spinal cord or nerves at the end of the spinal canal. It can cause permanent changes in sensory and motor capacity of a person with SCI.

Tetraplegia: Tetraplegia is a term used to describe the inability to voluntarily move the all four limbs.

Paraplegia: Paraplegia refers to the inability to voluntarily move the lower half of the body.

Student with SCI: Student with SCI refers to the person with SCI who described himself or herself as a student pre-injury. The literature review considers research related to students with SCI from any level of study, such as school level, secondary level and tertiary level. However, the current study aimed to explore the lived experience of adult students with SCI which means they were typically studying at post-secondary level.

Return to study: This refers to the person with SCI whose pre-injury occupational role was as a student and who had started studying again after the rehabilitation from the CRP.

Education participation: This refers to the student being actively engaged in the classroom, participating in co-curricular activities at the academic institute and belonging to the student community. Education participation can be at school level, post-secondary level or tertiary level.

Adult: Person with SCI above the age of 18 years old.

Chapter One

Introduction

This research aimed to explore the lived experiences of adult students with spinal cord injury (SCI) returning to study in Bangladesh. The adult students refer here are those who are over 18 years of old and have had the SCI between 15-18 years of old. The participants over 18 years of old were able to consent by themselves and the 15- to 18-year-old age range covers the period when students finish two important milestones, school and college education, in Bangladesh. This chapter provides background information about education system in general and access to education of a person with disability including SCI in Bangladesh, SCI rehabilitation in Bangladesh and the context of this research. The chapter also discusses the significance and provides an overview of the research.

1.1 Education system in Bangladesh

Education in Bangladesh is overseen by the Ministry of Education of the Government of Bangladesh. The Ministry of Education runs the educational activities through Secondary and Higher Education Division and Technical and Madrasa Education Division. The Secondary and Higher Education Division is responsible for formulating laws, rules and regulations for the management and administration of primary, secondary and higher education sector. On the other hand, the Technical and Madrasa Education Division is responsible for religious Muslim schools or madrasahs, as well as for development of curricula and administration of graduate examinations in technical and vocational education (Ministry of Education, 2020).

Primary education is a 5-year cycle between Grade 1-5, secondary education is a 7-year cycle with three sub-stages: junior secondary between Grade 6-8, secondary education between grade 9-10 and higher secondary between grade 11-12. The junior, secondary and higher

stages are designed for age groups 11-13, 14-15 and 16-17 years. Higher education or tertiary education is followed by graduate level (Secondary and Higher Education Division, 2020).

Primary and secondary education is financed by the state and free of charge for all students at public schools. However, though private schools charge a small amount of fee for male students, women education is free of charge up to grade 12. The literacy rate in Bangladesh is 73.91% for 15 years or more (Ministry of Education, 2020).

Education is one of the five basic human needs in Bangladesh. It is the fundamental responsibility of the state to provide necessities including food, clothing, shelter, education and medical care (Government of the People's Republic of Bangladesh, 2019). Yet, ensuring the education participation of person with disabilities, including SCIs, is still a work on progress. This current research explored the lived experiences of adult students with SCI returning to study in Bangladesh, and so a detail description of education of a person with disabilities including SCI in Bangladesh context is discussed next.

1.2 Education of a person with disabilities in the Bangladesh context

In Bangladesh, it is estimated that 10% of its entire population is suffering from some form of disability, either physical or cognitive (WHO, 2011). Additionally, a situational analysis of the disability pattern in Bangladesh revealed that the prevalence of disability in children under 18 years is 6% and above 18 years is 14% (Khan & Anisuzzaman, 2011). There is no specific information, however, on the overall population of people with SCI or the prevalence of students with SCI participating in education. The Bangladesh Bureau of Statistics generated a population monograph in 2015 and investigated the relationship between disability and highest level of educational attainment (Bangladesh Bureau of Statistics, 2015). They found that the highest level of education varied, depending on gender and disability status. A total of 49.4% of males with some disabilities and two-thirds (66.28%) of males

with severe disabilities have had no formal education. In contrast, 68.09% of women with some disabilities and 80.4% of women with severe disabilities have had no formal education. Only 15.46% of males with severe disabilities and 07.04% of women with severe disabilities were found to be completing school. The educational attainment of people with disabilities was generally lower for non-disabled people. Therefore, it is apparent that disability is a barrier in receiving education in Bangladesh (Bangladesh Bureau of Statistics, 2015). Nevertheless, a systematic search of Bangladesh government reports was performed and there was no evidence found, particularly, regarding the participation in education of people with SCI.

Access to education for a person with disabilities in Bangladesh

Khan and Anisuzzaman (2011) conducted a situational analysis on the status of education of children with disabilities in Bangladesh. They described three educational set-ups in Bangladesh:

- i. Special education: Children with particular disabilities, such as cerebral palsy, autism, and attention-deficit hyperactivity disorder (ADHD), enrolls in a specialised setting.
- ii. Integrated education: This approach provides the opportunity for students with disabilities to participate in a mainstream educational system. Skilled teachers provide education to facilitate the students' education and provide specialised materials for them.
- iii. Mainstream education: This approach includes students with disabilities by creating an accessible environment to facilitate the equal participation of both types of students, those with a disability and those non-disabled students.

Besides these educational set-ups, home-based education is also provided, in the case of the unavailability of these setups. Children with disabilities are mostly seen in home-based education provided by parents and family members.

Khan and Anisuzzaman (2011) described different barriers to education experienced by people with disabilities in Bangladesh, such as inaccessible environments, negative attitudes, a lack of trained teachers, inaccessible curricula, suitability of the educational methods and a lack of national commitment in addressing the education of children with disabilities. As a result, these people are usually left out of education.

The student researcher took some photos of the home environments of research participants in this study, and the educational institutes in rural areas of Bangladesh. These photos are presented below, in particular to assist that the non-Bangladeshi reader of this thesis to visualise the life of a person with disability living in the rural areas of Bangladesh.



Photo: An inaccessible home in a rural area of Bangladesh

Photo: An attempt to modify the environment with local resources



There are rehabilitation centres for children or adult with neurodevelopmental disabilities and people suffering from non-communicable diseases throughout the country, delivered by government and non-government services. However, there is only one rehabilitation centre providing rehabilitation services to people with SCI in Bangladesh. This centre is known as the Centre for the Rehabilitation of the Paralysed (CRP) (Quadir et al., 2017). The CRP is a

non-government and not for profit organisation, which provides physical, psychological and economic rehabilitation services, involving the doctors, nurses Physiotherapists (PTs), Occupational Therapists (OTs), counsellors and social workers, with an interdisciplinary team (IDT) approach (Ahmed, Quadir, Rahman, & Alamgir, 2018). Islam et al. (2011) explored the clinical and sociodemographic characteristics of 115 patients with SCI admitted at the CRP, Dhaka, Bangladesh from January to June 2009. These authors found five main reasons of traumatic SCI, which are fall from height (50.5%), fall while carrying heavy load on head (15.2%), fall of heavy object on neck (5.1%), fall of heavy object on back (12.1%) and road traffic accident (RTA) (11.1%). Additionally, TB spine (62.5%) and transverse myelitis (37.5) were found as the reason for non-traumatic SCI. A recent study, on the demographical distribution of people with SCI in Bangladesh, reported that 87.6% were male and 12.4% were female, with an age range of 11 to 80 years, and that 56.5% had traumatic paraplegia, 29.2% had traumatic tetraplegia and 14.3%, the rest, had non-traumatic paraplegia (Quadir et al., 2017). The authors extended their findings that, most of the participants were in their third decade (31-40 years of old) which consisted 28.6%, followed by 27.4% in between 21-30 years and 26.8% in between 41-50. These findings show that, most of the person with SCI are in working age and unable to support their family financially after having the injury.

Quadir et al. (2017) also described the standard rehabilitation process as taking three months at CRP. It may also be extended, depending on secondary complications, such as pressure ulcers. The CRP emphasises successful community reintegration, focusing on occupational or productive participation by providing vocational training, and continues regular community follow-up, with home visits by outreach teams comprising IDT members (CRP, 2018a).

Over the years, a number of studies based on CRP data have been conducted. These studies have described the epidemiology of SCI, characterisation of SCI, demographic characteristics of people with SCI, health status, quality of life and socioeconomic status after discharge, and survival rate after discharge (Hoque, Grangeon, & Reed, 1999; Hossain et al., 2019; Islam, Hafez, & Akter, 2011; Quadir et al., 2017; Rahman et al., 2017) and life expectancy (Hossain, Rahman, Herbert, et al., 2015; Razzak, Helal, & Nuri, 2011).

Additionally, studies about community life and community care have identified the significance of community-based care following discharge, community integration and life satisfaction, and occupational participation in the community (Ahmed et al., 2018; Alve, Bontje, & Begum, 2019; Hossain et al., 2017; Hossain et al., 2016). A few other studies have identified the significance of the loss of work-related income, barriers and facilitators to socioeconomic inclusion for women with disability, vocational reintegration and assessment for return to work (Hansen, Mahmud, & Bhuiyan, 2007; Hossain et al., 2019; Quinn et al., 2016; Ullah, Sarker, & Chowdhury, 2015). The lack of studies focused on education, however, means there is a clear evidence gap regarding the academic participation of students with SCI in Bangladesh. One recent exploratory study surveyed 103 Bangladeshi students with SCI, identified through the CRP database (Ema, Rahman, Ullah, Chowdhury, & Nayan, 2018). These authors identified that positive support from family was reported by 92.8% of the respondents as the most influential factor related to their return to study, and that financial hardship (28.6% respondents) and an inaccessible environment (19.0% respondents) at the academic institute were the two most common barriers (Ema et al., 2018). These results, therefore, suggest the importance of further exploring this area and, specifically, the need to better understand the lived experiences of students with SCI in Bangladesh.

1.4 Significance of the study

SCI rehabilitation focuses on facilitating social and occupational reintegration into the community (Kurtaran et al., 2009). To facilitate occupational reintegration, occupational therapy treatment is directed towards people with SCI, to help them become competent in student and work roles. In Bangladesh, CRP provides vocational training for persons with SCI, focused on different skills, such as computer skills, tailoring, and electronics, which can be undertaken as new professions after SCI. There is no structured work rehabilitation program at CRP, however, to facilitate return to previous education. A study that identified the vocational preferences of 183 persons with SCI showed that return to work is associated with gender, age, occupation before injury and area of residence (Ullah et al., 2015). This previous study found that 18% of persons with SCI were previously engaged in non-income generating activities (i.e., as students or housewives) and generally preferred to go back to their previous activities (Ullah et al., 2015). Another descriptive, cross-sectional study that was carried out among SCI patients at CRP identified the post rehabilitation job status of people with SCI in Bangladesh. The study involved 110 participants and showed that 14% of participants reported being a student as their pre-injury occupation and only 5% of them had returned to their previous studies after having utilised the rehabilitation service (Nayan, Miah, Moniruzzaman, Ema, & Hossain, 2016).

In Bangladesh, occupational therapists (OTs) play a significant role in the large number of patients undertaking work rehabilitation programs. Although there is no structured work rehabilitation program, OTs provide occupation-focused treatment and assess the vocational preferences of people with SCI; however, there has been less focus on how students with SCI fare in their further educational life following rehabilitation. This current study, therefore, sought to investigate the lived experiences of students with SCI, in order to provide new evidence to guide the field of SCI rehabilitation in Bangladesh. A better understanding of the

lived experiences of students with SCI will also help to strengthen the existing occupational therapy service and identify how community activities can be planned to facilitate a smooth reintegration of students with SCI back into academic life.

1.5 Structure of the thesis

This thesis includes a series of traditional chapters and conference presentations undertaken during the candidature.

Chapter One provides a brief introduction, a description of spinal cord injury (SCI) in Bangladesh, the significance of the study, the structure of the thesis and the overall research aim.

Chapter Two includes the literature review, particularly details of the search strategy, an introduction to education systems around the world, the benefits of education and the environmental barriers to education participation for students with disabilities, the impacts of relationships, and strategies for supporting reintegration into education. This is followed by a summary of key gaps in the literature and future recommendations.

Chapter Three describes the methodology of the thesis, including the research aim, objective and questions, the research design, ethical considerations and a description of the study setting. It also describes the methods of sampling and recruitment, data collection, data analysis, and strategies to ensure trustworthiness.

Chapter Four presents the results of this study, explaining the seven themes and subthemes identified through qualitative analysis of the interviews.

Chapter Five discusses each theme, the implications for practice, the strengths and limitations of the research, and recommendations for future research.

Chapter Six presents the conclusions, by highlighting the key messages of the research.

Chapter Two

Literature Review

2.1 Introduction

Returning to previous education after SCI is a primary goal of rehabilitation for the students with an SCI. The rehabilitation research of developed countries is now focusing on community reintegration after rehabilitation (Shem, Medel, Wright, Kolakowsky-Hayner, & Duong, 2011). Adult rehabilitation, therefore, is more focused on the return to income-generating activities whereas, for a school-aged child with SCI, the focus is on the return to school. Environmental accessibility in and outside of school, relationships with peer groups and teachers, and social and family supports play very important roles in achieving this goal. Students with SCI studying in any level of education need different services. There is some evidence on the educational participation of children or adolescents with disabilities, however, there is limited information on the further education of adult students with SCI after rehabilitation (World Health Organization [WHO] & International Spinal Cord Society [ISCoS], 2011). This chapter will provide an overview of the existing literature on this topic. The literature review includes all forms of disability, level of education according to different age in different countries. Therefore, the literatures included in the review shows the variances of education participation of students with different disabilities or disorder and informs the gap in the evidence and how it is related to this current research.

2.2 Search strategy

A thorough electronic search of the literature was performed in the related databases, including PubMed, OVID Medline, and CINAHL. The key search terms were based on the research topic sentence and question. Searches were made for Spinal Cord Injury* OR Tetraplegia* OR Paraplegia* AND Return to Study, Students, Education Participation,

Academic Reintegration and School Re-entry. The truncated keywords included the broader terms of the keywords. In addition to the database searches, additional steps included citation tracking and key author searches, using Google Scholar, to find specific articles and grey literature, such as reports and policies of government and non-government organisations.

Peer-reviewed articles, regarding the educational participation of people with SCI and other disabilities, published in English between 1990 and 2019, were included in the literature review. The initial search did not show any more recent articles as this topic is not a fast-paced one. Therefore, including the articles in the last 30 years highlighted the gap in the evidence and directed to many new of potential research work. The initial search strategy identified 568 articles, which were exported to the Endnote Bibliographic software. The student researcher screened the titles, keywords and abstracts and reviewed the articles in the subsequent phases. A data-charting form was developed to summarise the articles, recording the following key characteristics: authors, year of publication, study location, study population, aim of study, methods, results and limitations identified in the study. The student researcher met regularly with her supervisors to discuss new findings in literature and data charting, as well as to clarify the confusion and queries with the supervisors.

The data-charting form was used to organise the literature findings. The similar findings were organised in the same topic. The findings from the literature were organised into the following topics: the benefits of education; environmental barriers to educational participation for students with disabilities; the importance of relationships for participation in education; and, strategies for supporting reintegration into education. This literature review was focused on the return to study of students with SCI. Studies involving participants with different diagnosis, different age groups and levels of education internationally were included to assist in identifying gaps within this specific field. Given these studies were undertaken in

different parts of the world where the education systems vary, it is important to highlight the diversity in the education systems.

2.3 Education system

Different countries define level of education and years of age in a wide range of ways.

Throughout this chapter, the level of studies is defined depending on the perspectives of different countries and, although the naming of the levels is somewhat similar, the definition is not the same. The following table portrays this diversity:

Table 1. 1

Education systems throughout the world

Country name	Level of education	Age group
The United States of America (USA)	Primary education (elementary school)	6-11 years of age
	Middle school	11-14 years of age
	High school	14-18 years of age
	Tertiary education (Undergraduate, master, professional program and doctoral degree)	Above 18 years of age
Australia	Primary level (Grades 1-7)	5 – 12 years of age
	Secondary level (Grades 7 -12)	12 -19 years of age
	Tertiary level (University or technical college)	Above 19 years of age

Sweden	Primary level	7 -16 years of age
	Secondary level	16 -19 years of age
	Tertiary level	Above 19 years of age
United Kingdom (UK)	Primary education	5 – 11 years of age
		Key stage 1: 5-7 years of age
		Key stage 2: 8-11 years of age
	Secondary education (Key stage 3)	12 – 14 years of age
	Key stage 4	15 -16 years of age
	Key stage 5	17-18 years of age
	Tertiary education	Above 18 years of age
Canada	Primary level (Grade 1-6)	6-12 years of age
	Secondary level (Grade 7 - 12)	12- 18 years of age
	Tertiary level	Above 18 years of age
South Africa	Primary education (Grade 1 - 7)	7 – 15 years of age
	Secondary education	15 – 20 years of age
	Tertiary education	Above 20 years of age
Bangladesh	Primary education (Grade 1 -5)	6 - 10 years of age

Secondary education (Grade 6 - 10)	11 – 15 years of age
Higher secondary education/ College education (Grade 11 - 12)	16 – 18 years of age
Tertiary education (university)	Above 18 years of age

Sources: (Australian Government, 2018; Classbase, 2012a, 2012b, 2012c, 2012d, 2012e; International Student, 2018)

The education systems across the countries have some similarities and dissimilarities, regarding levels of study and age group. Additionally, vocational education is also available in many countries, for achieving hands-on job skills. This research focuses on studying in the educational system in Bangladesh. It outlines three different categories of education, general, Madrasa (religious) and technical education, and includes four levels, as there are in other countries (Classbase, 2012a).

2.4 Benefits of education

There are different aspects of the benefits of education, which have been discussed in the literature. The focus of rehabilitation is on facilitating the return to income-generating activities for adults and, for the school-going patient, the reintegration is more focused on the return to study (Sandford, Falk-Palec, & Spears, 1999). Another author conducted a qualitative study by interviewing two undergraduate and four postgraduate wheelchair-user students in post-secondary education with different types of disabilities, including SCI, who were living in the USA (Paul, 1999). The author found that post-secondary education influenced adults' sense of personal achievements, recognition and respect in society, reducing misconceptions about their disability (Paul, 1999). The participants highlighted that

the lack of respect and underestimation of them within society had made them more motivated to seek higher education, to secure employment (Paul, 1999).

A number of other studies have found that having a higher education standard has a positive influence on obtaining work as an adult (Anderson & Vogel, 2002; Holmlund, Guidetti, Eriksson, & Asaba, 2017; Jang, Wang, & Wang, 2005; Lidal, Huynh, & Biering-Sørensen, 2007; World Health Organization [WHO] & International Spinal Cord Society [ISCoS], 2011). While determining the factors related to the employment of SCI adults who sustained SCI as children or adolescents living in the USA and Canada, Anderson and Vogel (2002) interviewed 195 subjects, who were 24 to 37 years old at the time of injury. The study results showed that education is one of the factors strongly associated with employment. The researchers found that persons with tetraplegia had higher levels of education than those with paraplegia and that more years of schooling was always associated with higher rates of employment, for both groups. Additionally, post-secondary education was more significantly associated with employment, for both types of paralysis (Anderson & Vogel, 2002). A cross-sectional study, based in Taiwan and including 169 people with SCI within the age range of 18 to 60 years at the time of interview, showed that those with high school education have a higher chance of returning to work than those without (Jang et al., 2005). Krause, Terza and Dismuke (2008) performed a secondary analysis of the cross-sectional data of 1,296 adults with traumatic SCI in the age range of 18 to 64 years and found variation between employment and level of education. The settings consisted of a Midwestern university hospital and a private hospital in the South-eastern United States. They also identified that education is significantly related to employment. The more educated person with SCI is more likely to be employed (Krause, Terza, & Dismuke, 2008). More recently, a qualitative follow-up study in Sweden, which included eight SCI adults, seven to 11 years after their initial injury, and aged 20 to 34 years at the time of the interview, showed that, although

continuing education in general is a challenge for them, it enhanced their competence in the job environment (Holmlund et al., 2017).

A recent report by WHO stated that, although there is not enough evidence in low- and middle-income countries, compared to higher income countries, education is still one of the important factors related to employment in low- and middle-income countries (WHO & ISCoS, 2011). The Committee on the Rights of Person with Disabilities (CRPD) report in Bangladesh shows that people with a disability are educated less often, which is the second most common reason, after an inaccessible environment, for unemployment and discrimination at work experienced by a person with a disability (CRPD Bangladesh, 2015).

2.5 Environmental barriers to education participation

2.5.1 Physical environment of school

Environmental barriers significantly restrict the return to study of students with disabilities. Swedish studies describe environmental accessibility features for students with disabilities as the “fit” between students and environments (Egilson & Hemmingsson, 2009; Egilson & Traustadottir, 2009; Prellwitz & Tamm, 2000). These accessibility issues differ from country to country and the challenges are somewhat different across Scandinavian countries than the other parts of the world. A comparative study included students in Sweden, aged nine to 17 years in Grades 4 to 12, with physical and psychosocial limitations regarding their school participation (Egilson & Hemmingsson, 2009). The participants included students with a physical disability such as spina bifida, cerebral palsy, neuromuscular and musculoskeletal disorders. While both groups needed the adapted environment, the school authority better met the needs of the physically disabled students than the students with psychosocial limitations. This previous study revealed that students with physical limitations mostly face difficulties in sports activities, writing and participation in classroom activities and field trips (Egilson &

Hemmingsson, 2009). Yet, the natural environment, especially when the winter season covered the playground with snow, hampered mobility in Icelandic schools (Egilson & Traustadottir, 2009; Prellwitz & Tamm, 2000).

A qualitative study in Sweden included five boys and five girls with a physical disability and not SCI, aged from 7 to 12 years, from junior and senior primary schools (Prellwitz & Tamm, 2000). The author conducted a semi-structured interview with the students, which consisted of a part of the Assessment of Adaptations in the School Environment, a new Swedish assessment developed using the theoretical framework of the Model of Human Occupation, with an emphasis on environmental descriptions (Taylor & Kielhofner, 2017). This study suggested that, generally, the classroom was considered to be a good physical environment because the students were pleased with the use of technical aids and there were no major challenges in transferring activities. There was minimal space for propelling the wheelchair, and the uneven height of shelves for books and blackboards was sometimes found to be a difficulty in the classroom. The school library was accessible for the students and the lift was considered to be only for the use by students with restricted mobility. The toilets were comparatively small but created no difficulty, since school had adapted the toilets, too (Prellwitz & Tamm, 2000).

While these Swedish studies identified the “fit” between environment and student in a more positive way, other studies from different countries provide additional insights into the environmental barriers to participation in education.

Mulcahey (1992) conducted a qualitative study in Philadelphia by interviewing four adolescents with SCI, aged between 15 and 17 years, regarding their experiences of further education in the school environment after rehabilitation. The author found that accessibility was a common barrier, stated by all the participants. Most commonly found barriers were

small doorways, steps without a ramp, elevators, and small bathrooms, and a barrier that was specially mentioned by tetraplegic participants, was the unavailability of computers in the classroom (Mulcahey, 1992). One of the limitations of this study is that it was conducted over 25 years ago, and accessibility in school environments in the USA may have improved since then.

Sandford et al. (1999) determined the barriers of SCI, with a retrospective review. They selected 16 participants from 10 to 23 years of age who were wheelchair users who had been discharged from a regional centre in the USA and had returned to school. They included both students with tetraplegia and paraplegia caused by SCI. Architectural barriers were most frequently mentioned, with an emphasis on inaccessible toilets. Participants specified some barriers, such as drinking from the fountain, accessibility within the school environment, unavailability of lifts and extracurricular facilities (Sandford et al., 1999). In the same year, Paul (1999) conducted a study of six wheel-chair user students at an urban university. The author interviewed three students with SCI whereas three other students had different physical disabilities. Similar to the findings of the above-mentioned studies, inaccessibility features identified were the university buildings, classrooms, lifts, lavatories, desks, housing facilities, computer facilities, recreation facilities and the distance between buildings (Paul, 1999).

More recently, a study was conducted in Western Cape, South Africa, which explored the policy implementation for learners with disabilities in mainstream schools (Vosloo, 2009). The participants were 6- to 14-year-old children with paraplegia who were studying in a mainstream school. The age range of the participants was different from previous studies and their types of disorder were not specifically mentioned. Yet, most of them were wheelchair users and the rest either walked with a mobile device or an abnormal gait. The author found

that inaccessibility in the community, lack of implementation of government policies, unavailable social support, the design of the physical environment of the school, and the unavailability of assistive devices in school restrict the participation of disabled students in school. The author also stated that inaccessible public transport and roads make their participation challenging, as well (Vosloo, 2009). Losinsky, Levi, Saffey and Jelsma (2003) conducted a descriptive, cross-sectional study in South Africa, to measure the distances between five faculties in a higher education institute, with the aim to ease the mobility of wheelchair users. The author emphasises that the distance travelled by wheelchair using students within the educational institution plays a big role in participation. As such students require more time than non-wheelchair users for mobility, they don't get time for socialising with friends and peer groups, which limits their full integration into campus life (Losinsky, Levi, Saffey, & Jelsma, 2003).

Most of the studies discussed above were performed in developed countries. There has been minimal information regarding children with SCI returning to study in low-income or developing countries. The WHO and International Spinal Cord Society (ISCoS) (2011) state that it is difficult to accommodate children with SCI or other disabilities in education because of a lack of resources in low-income countries (WHO & ISCoS, 2011), and Bangladesh is one such country. Most of their educational institutes do not have an accessible entrance and toilet space. Over the last few years, however, under the state's primary education development program, the schools are being renovated with newly installed ramps, corridors, toilets and accessible classrooms. Yet, secondary and tertiary educational institutes are still not equipped with accessible designs to support the educational participation of students with disabilities (CRPD Bangladesh, 2015). Furthermore, there is no published work on the academic reintegration of students with SCI in Bangladesh. In summary, therefore, it is said

in the literature that the availability of an accessible environment is a factor restricting the participation of all levels of students in educational institutions all over the world.

2.5.2 Extracurricular activities

Restriction in participation in education involves barriers of the extracurricular environment, as well. Lightfoot, Wright and Sloper (1999) interviewed 33 mainstream, secondary school students with chronic illness or disability in the United Kingdom (UK). The study produced some positive results regarding participation in extracurricular activities, as the school used to adapt these activities, such as drama, music events and field trips, for the students, to enable their participation (Lightfoot, Wright, & Sloper, 1999). A Canadian study by Doubt and McColl (2003) also explored the experiences of teenagers with a physical disability regarding their social integration in a school community. The participants, who were 15 to 19 years of age with cerebral palsy and spina bifida, included wheelchair users and independent walkers. The study identified that students with disabilities could not attend extracurricular activities, such as sports, as it was not suitable for them. As a result of limited resources allocated to extracurricular activities, students with disabilities had limited participation (Doubt & McColl, 2003). Asbjørnslett and Asbjørnslett (2008) conducted a study in Norway with a similar aim to the previous study, although no SCI participants were included. The previous study found that the students considered themselves excluded when they could not perform extracurricular activities with their friends and peer groups. This highlights the importance of designing extracurricular activities to facilitate participation and foster better relations with classmates (Asbjørnslett & Hemmingsson, 2008).

2.6 Importance of relationships

2.6.1 Friendship and peer relationships

Relationships with peer groups have both positive and negative impacts on the return to study of students with SCI and other physical disabilities (Dockett, 2004; Doubt & McColl, 2003; Lightfoot et al., 1999; Sandford et al., 1999). McMaugh (2011) investigated the disability-related experiences of junior high school students in Australia. The author conducted three interviews with 24 young people with chronic illness or physical disability, with mean age 12.4 years. The children felt that they faced both positive and negative peer relationships. The negative relationships with peers derived from their traditional beliefs and attitudes about disability stigma. The children distinguished the classmates into two groups: friends and peer group. Around one-third of the children reported a positive relationship with friends, in terms of shared interests, academic goals, positive social support, and available cooperation during their absence from school. On the other hand, the other one-third of the children reported a negative relationship with their peer groups, by experiencing bullying and harassment (McMaugh, 2011).

Dockett (2004) interviewed 13 parents/guardians and 10 children with chronic illness, aged between five and 16 years, who were participating in the Ronald McDonald House Charities Learning Program. All the children attended the mainstream school, with no specific information on the time gap between chronic illness and schooling. They showed both excitement and nervousness to be back with friends at the academic institution. Meeting friends again, after the long absence from school, made them excited, however, being open about their disability in discussion with friends made them anxious and nervous, too, because they feared being teased in school about having different kinds of abilities (Dockett, 2004).

Both children and teenager students with disabilities attending academic institutes commonly experience ignorance from peers, being the subject of curiosity, and bullying and harassment (Lightfoot et al., 1999; McMaugh, 2011; Prellwitz & Tamm, 2000). Children with disabilities have stated that they hide their general health needs in order to avoid answering questions from their peers (Lightfoot et al., 1999). At worst, Prellwitz and Tamim (2000) found physical clash as well, with their assistive devices taken away by peers to play with. The negative experiences ultimately resulted, therefore, in loss of social contact with their peers. Peer relationships, however, were found to be a motivating factor, as well. While there was the negative peer group, there were always some friends to support and help them in difficult times (Prellwitz & Tamm, 2000; Sandford et al., 1999).

A phenomenological study investigated the perceptions and experiences of seven teenagers with cerebral palsy and spina bifida who were students of four regular secondary schools in Central Ontario, Canada. The authors highlighted that lack of awareness among non-disabled peers about their ability had a negative influence on the students with disabilities. Thus, educating the peer group of the students with a disability in different ways, such as disclosing their needs and writing in school magazines about their abilities, can play a key role in making a positive environment for all students (Doubt & McColl, 2003). Although little research has discussed the peer relationship experiences of students with SCI, other than positive friendships, at least one study suggested that SCI students lost their friends after returning to school (Sandford et al., 1999). Therefore, peer education is important to increase awareness of the non-disabled friends or classmates, so they can be welcoming.

2.6.2 Student-teacher relationships

Student-teacher relationships play a key role, in the educational institution, for students with disabilities. Vosloo (2009) emphasised that the attitudes of teachers and other school staff

play a key part in encouraging and managing the inclusive environment. The author highlighted that strategic planning and support could meaningfully and positively influence the attitudes of teachers who are teaching students with a disability. Teachers are more helpful towards students with physical disabilities than intellectual impairments. The physical education instructor, however, faces different challenges to integrating students with disabilities into mainstream education, in terms of educational plans, activity planning and safety considerations (WHO & ISCoS, 2011).

Sandford et al. (1999), in their study conducted with 16 students in the USA, found that, in their efforts to be helpful, teachers showed leniency towards students with disabilities because the teachers did not have enough knowledge about a student's capability and, thus, they accepted delays in classroom, homework or assignments. Additionally, the teachers were not well aware of students' health-related issues, which sometimes created difficult situations; for example, one student missed a medical/therapy appointment, of which the teacher was not aware (Sandford et al., 1999).

Paul (1999) added that students with disabilities considered the faculty, other students and non-teaching personnel as their university community. The positive experience, therefore, motivated them for education participation. Apart from the SCI students, other physically disabled students studying in Sweden emphasised that good relationships with teachers were important because teachers' positive reactions, knowledge, and attitudes facilitated their learning and boosted their confidence (Asbjørnslett & Hemmingsson, 2008; Lightfoot et al., 1999). The Swedish study by Asbjørnslett and Hemmingsson (2008) also reported that challenges for the teachers could be solved by arranging teacher-student meetings to facilitate plans for the better learning and physical participation of students with disabilities. Additionally, teachers should be provided with detailed information about SCI students

regarding their physical and psychosocial limitations and health conditions. The United Nations, Educational, Scientific and Cultural Organization (UNESCO) has published a toolkit, highlighting the issues of learning in an inclusive friendly environment, which contains specific information about SCI and can be used to develop understanding of how to create supportive, educational environments for students with SCI (UNESCO, 2009).

2.6.3 Support from school health staff

Comprehensive support from school health staff is also very important (Lightfoot et al., 1999). Lightfoot et al. (1999) is the only study that included a consideration of the influence of school health staff on a student's well-being at school. This previous study found schools have nurses for general health check-ups and doctors for treatment, equipment and adaptation support. The study found, however, that the school nurses were not always available, and the school doctors were not well versed in students' treatment and individual needs.

Consequently, the students stopped seeking help from the health professionals at school. As the school health professionals were general practitioners, without the specific knowledge of the health needs of students with disabilities, this study showed the importance of specialised health professionals in schools, as an effective way to bridge this gap (Lightfoot et al., 1999).

2.7 Strategies for integration

2.7.1 Peer mentoring

There is evidence that shows support from the peer groups of those who have faced similar challenges can play a key role in the recovery of a person with SCI, in terms of physical, emotional, academic and occupational status (Kolakowsky-Haynera, Wrighta, Shemb, Medela, & Duongb, 2012). These authors have investigated the effectiveness of a community-based mentoring program, known as 'Back on Track'. This mentoring program, in the USA, is a structured program, which aims to improve the ability of a person with SCI,

traumatic brain injury (TBI) or other neurological disorders to access and maximise their utilisation of programs and services available in the community. The mentors were from different backgrounds, including employees, students and retired workers. Among 121 trained mentors, 31% were persons with SCI, 29% were persons with TBI, 4% were persons with cerebral palsy and 7% were persons with other disabilities. Among 131 mentees, most mentees were with TBI (61.1%), 29.8% were with SCI and rest of them were other disabilities, such as stroke and cerebral palsy. SCI was the second most common group of participants. The age range of the mentees was 16 to 26 years. The program coordinator closely supervised the mentor-mentee relationship, and meetings and documentation were maintained properly, in the structured period. After two years of the comprehensive program, the peer-mentoring program was found to be effective for achieving further education and employment of youth and young adults with SCI. Although there were some challenges, such as student drop out and the different geographical locations of mentor and mentee, the structured mentoring program was, overall, beneficial for the mentee, with respect to achieving educational and employment goals, with better quality of life outcomes (Kolakowsky-Hayner et al., 2012; Shem et al., 2011).

In addition to this structured mentoring program in the USA, other spinal injury centres in different countries provide mentoring services for people with SCI. For example, the Back-up Trust in the UK, the Indian Spinal Injuries Centre in India and the CRP in Bangladesh. Nevertheless, none of these provides a service especially for students with SCI (Back-up Trust, 2018; CRP, 2018b; Indian Spinal Injuries Centre (ISIC), 2016).

2.7.2 Assistive devices

Students have identified that assistive devices are an important tool for better participation at school. Hemmingsson and Borell (2000) studied the need for physical and social

accommodations, in upper secondary schools, for students with severe physical disabilities. They defined accommodation as the substitution for accessibility and adaptation that is widely used in other countries. They assessed the accommodation needs of 48 wheel-chair user students from four Swedish schools. These students, with different physical disabilities, were participating both in a regular and a special classroom. The findings indicated that having a writing device facilitated independence in writing. The writing devices were special pencils, pencil holders and mobile arm supports. Apart from the writing devices, students frequently needed computer use, including an adaptive computer interface, headgear, mouth stick and special control devices, such as a joystick (Hemmingsson & Borell, 2000). Scandinavian schools provide adapted educational tools, which make school activities easier. Adapted chairs in schools help students to maintain a neutral posture, which is important for achieving best performance with full concentration and endurance (Egilson & Traustadottir, 2009).

In an audit conducted by Vosloo (2009), the availability of seating devices and adapted computers in classrooms of South Africa were shown to be important. In addition to these, another study identified the reality of inclusion of young people with physical disabilities in mainstream schools of Ireland. This previous qualitative study conducted interviews with 16 young people and revealed that Irish school students with disabilities benefitted from the use of a recorder in the exam hall, which was a very useful technique (Shevlin, Kenny, & McNeela, 2002).

2.7.3 Classroom assistants

There is now a focus, internationally, on including students with a disability in mainstream education (Giangreco, Doyle, & Suter, 2014). The teacher assistant concept has included a new dimension in supporting students with a disability in academic institutions. Teacher

assistants are known by a variety of names around the world, such as learning support assistant, classroom assistant, paraprofessionals, teacher's aides, etc. This group of people provides assistance, either to teachers in the classroom or to the learners, to facilitate their participation in class (Giangreco, Doyle, & Suter, 2014).

Giangreco et al. (2014) reviewed published works, from around the world, on the use of assistants in the classroom. They noted that there are different countries who utilise this concept, with various names, such as the USA, the UK, Sweden, Canada, Italy, Finland, Malta, New Zealand and Singapore. Although South Africa approaches this concept as “caregivers to assist learners” in school, the classroom assistants are funded by parents. The assistants are responsible for assisting the students to go to the toilet, playground and between classes (Giangreco et al., 2014; Vosloo, 2009).

In the Swedish school setting, the personal assistant was mostly found to provide support in classroom functioning (Asbjørnslett & Hemmingsson, 2008). These authors assert that the children with assistants have a higher degree of participation and structured learning than children without. However, the constant presence of an assistant appeared to have both positive impacts and drawbacks. Egilson and Traustadottir (2009) assert that, while the support of assistants is increasing student participation, their constant availability can restrict children using their own capabilities and can create unnecessary dependencies. A study conducted in the USA also revealed that the persistent presence of assistants sometimes hampers peer interaction and creates dependencies (Giangreco et al., 2014).

2.7.4 Legislation and policy

There is a range of federal and state legislation facilitating the right to education of people with disabilities around the world. The type of and such legislation and policies, and their implementation, varies within different countries. The United Nations Convention on Rights

of the Person with Disability (CRPD) (United Nations, 2018) highlighted the rights for every person with a disability, and education is one of them. It states that, to enable persons with disabilities to participate in an inclusive society, accessibility is one of the most important components in buildings, roads, transportation and other indoor and outdoor facilities, including schools, housing, medical facilities and workplaces (United Nations, 2018).

In 1965, the USA introduced its first legislation recognising the education of children with disabilities, named *The Elementary and Secondary Education Act 1965*. The continued failure to ensure the education participation of many children, however, led to the development of the *Education for All Handicapped Children Act 1975*, focusing on making individual education plans (IEPs) for all children, separately. In 1990, this act was modified, with several major provisions by amendment, and renamed the *Individuals with Disabilities Education Act 1990* (IDEA) (Murdick, Gartin, & Crabtree, 2007). IDEA segregated the special education service, depending on the age and type of injury. Additionally, Section 504 of the *Rehabilitation Act 1973* and the *No Child Left Behind Act (NCLB) 2002* protected IDEA. The purpose was to support the school reintegration of children with central nervous system (CNS) injury, to ensure special education instruction as well as related services, such as homebound instruction, transportation, physical, occupational and speech therapy, school nurse, assistive technology and counselling services (Carney & Porter, 2009).

Some other high-income countries, such as the United Kingdom, focused on anti-discrimination. They addressed the complaints of individual students regarding education exclusion, following the *Disability Discrimination Act 1995* (Organisation for Economic Cooperation Development, 2011). Denmark focuses on providing assistive devices or compensatory aids, through the Ministry of Education, to facilitate equal participation in academic activities (Organisation for Economic Cooperation Development, 2011). On the

other hand, France focuses more on adapting academic pathways, both physically and instrumentally (Organisation for Economic Cooperation Development, 2011). Australia introduced its *Disability Discrimination Act* in 1992 (Australian Human Rights Commission, 2018) and has set standards in relation to the education and training of students with disabilities. Specifically, the education provider must ensure the same participation of students with a disability as there is participation of their peers without disability, and provides a special focus on an accessible curriculum, learning materials, teaching strategy and equal participation in extra-curricular facilities, with reasonable adaptations (Australian Disability Clearinghouse on Education and Training, 2018).

The implementation of laws regarding disability education in low- and middle-income countries is different from developed countries. The UNESCO stated that the biggest barrier to implementing inclusive education in these countries is the failure to implement legislative and policy framework supporting inclusive education (UNESCO, 2009). For example, the government of South Africa started to identify the barriers to accessible education, however, the project made a little progress due to a lack of funding and the absence of legislation (Dube, 2005).

In South Asia, however, Sri Lankan children with disabilities have access to special education through mainstream classrooms in government schools, special education units in ordinary schools and special schools run by non-governmental organisations (NGO). They have made good progress, compared to other South Asian countries, through the special education branch of the Ministry of Education, without specific disability education-related laws and legislation (Reiser, 2008). India is following its government's *Right to Education Act 2009*, which provides free education to children with disabilities (Reiser, 2008). Similarly, the People's Republic of Bangladesh has introduced the *Special Education Act*

2009 (National Disability Development Foundation, 2009). Unlike other low- and middle-income countries, however, there are many barriers to its implementation in Bangladesh (CRPD Bangladesh, 2015). The last disability report of WHO (WHO & ISCoS, 2011) emphasised appropriate and workable educational policy. It suggested performing a survey to investigate the prevalence of students with a disability and the accessibility of the physical school environment. Additionally, WHO emphasised academic modes and trained educators, especially for low- and middle-income countries, acknowledging the need for a specialist field of education for educators teaching and supporting persons with disabilities (WHO & ISCoS, 2011).

2.8 Summary of key gaps and issues

- 1) **Age and level of education:** There is great variation in the published literature in the age groups studied. Thus, researchers have recognised the importance of educational participation of students with disability in primary, secondary and tertiary levels, depending on age. On the other hand, most studies have included students who are below or equal to 18 years of age, and the overall number of studies that have focused on tertiary level education is relatively lower than those that have focused on primary and secondary education. As a result, it is hard to compare the findings in terms of age at each level of education. Therefore, this current research is focused on exploring the lived experience of adult students with SCI only to portray the experiences in detail of this specific group of people.
- 2) **Types of disability:** Many studies have identified the experiences of returning to study for participants with different types of physical disability, chronic illness and psychosocial limitation, such as cerebral palsy, spina bifida, juvenile rheumatoid arthritis, polio, muscular disorders, traumatic brain injury, hemiparesis, congenital abnormalities, alternative communication disorders and spinal cord injuries. Some

articles, however, do not mention the diagnosis of participants. The Scandinavian countries have focused their work mostly on students with spina bifida and cerebral palsy. Students with spina bifida have a range of different difficulties, including cognitive disorders, whereas students with SCI largely face sensory and motor-related difficulties. So overall, there have been few studies conducted specifically with students with SCI. The current study focuses on the lived experience of students with an SCI, which is a field in which further evidence is needed.

- 3) **The decade of publication:** The time of publication shows that most of the studies regarding the academic participation of students with disabilities were conducted between 2000 and 2010, with some studies from Canada and the USA having been undertaken in the 1990s. Two more recent studies of the efficacy of a community-based mentoring program were conducted in 2011 and 2012, whereas research on the perceptions and experiences regarding return to study of students is relatively old, having been published in the 1990s. Therefore, the current study aims to add new evidence in this field to facilitate the updating of practice and policy.
- 4) Most published articles followed qualitative designs with small sample groups, which potentially restricts the transferability of results. Furthermore, the study findings from one culture or context may not be easily compared with the findings of a study from another context. As no literature was found in Bangladesh context regarding the lived experience of adult students with an SCI, the current study aims to add new knowledge in this field.
- 5) Scandinavian research shows that their academic institutions are comparatively more accessible for students with a physical disability than those with psychosocial limitation. Additionally, studies from other parts of the world discuss more the barriers to study, whereas the Swedish study findings emphasises the “fit” between

the students and their environment, which is a positive approach. They have more published work in the field, but only one study on participants with SCI.

- 6) The reviewed studies that focused on students with SCI included more participants from urban schools than rural ones. This showed different levels of participation, depending on geographic location. The current study includes the perspectives of participants from rural and urban areas to highlight the importance of geographic location.
- 7) Many studies discussed physical barriers to participation in education, whereas the psychosocial, social and occupational adjustment of the students is widely ignored. Therefore, this study current study sought to investigate environmental barriers and facilitators related to the continuing education of adult students with an SCI, attitudinal barriers, varied pre-injury and post-injury experience, meaningful relationship with friends, and the impact of social environments.

Recommendations

- 1) Given the identified gap in knowledge about the experiences of students with SCI, regarding their return to study, more research is required to strengthen the field of SCI rehabilitation research.
- 2) Apart from the findings related to physical barriers, it is important to address the wider range of barriers, in terms of the physical, psychosocial and occupational aspects of the students. Further study of the strategies adopted by students, their level of adjustment with occupational life and daily routines, and the barriers to participation will inform recommendations for occupational therapists, to improve rehabilitation plans.
- 3) The perspectives of students with disability may be different, depending on age, gender, type of disability and level of education. It is important, therefore, to study

these areas, discretely, to gain deeper insights. Hence, in this current study, the researcher aims to explore the lived experiences of adult students with SCI, who were injured between 15 to 18 years of age.

- 4) Every country has unique issues, so it is very important to conduct studies in different cultural contexts to better understand the particular variations in the issues facing students with SCI, and their implications for rehabilitation. This influenced the researcher to explore the lived experiences of adult students with SCI, injured between 15 to 18 years of age, returning to study in Bangladesh.

Chapter Summary

This chapter presented findings from literature all over the world in relation to students with disabilities, including details of the literature search strategy, the education systems in different parts of the world, the benefits of education, the environmental barriers to educational participation, the importance of relationships, strategies for integration, and a summary of key gaps and issues.

Chapter Three

Methodology

This chapter will outline the methods for this research, including the overall aim, the research questions, the rationale for the research design, the ethical considerations, the study setting, the approach to sampling and recruitment, the data collection procedures, the data analysis process, and the research rigour.

3.1 Research aim, objectives and questions

3.1.1 Overarching research question

What are the lived experiences of adult students with SCI returning to study in Bangladesh?

3.1.2 Research questions

- 1) What are the experiences of adult students with SCI, as they transition back to study and post-injury study participation?
- 2) What are the environmental barriers to and facilitators of study participation for adult students with SCI?
- 3) How did their occupational roles change in the pre- and post-injury periods?

3.1.3 Aim and objectives

Aim: To explore the lived experiences of adult students with SCI returning to study in Bangladesh.

Objectives:

- 1) To explore the personal experiences of transition and post-injury study participation of adult students with SCI, who were injured between 15 and 18 years of age.

- 2) To explore the environmental barriers and facilitators of returning to study for students with SCI.
- 3) To gain an understanding of the occupational roles of students, before and after SCI.

3.2 Research design

3.2.1 Qualitative methodology

A qualitative paradigm was chosen as the framework to guide this study, as the student researcher aimed to explore the lived experiences of human beings, which is a focus of qualitative methodology (Creswell, 2013). In qualitative research, researchers emphasise investigating the social contexts that influences the subjective experiences of human beings over time (Dew, 2007). Qualitative research prioritises people's words or stories, instead of the "science of numbers", as in quantitative studies (Liamputtong, 2013; Patton, 2015).

Four specific characteristics of qualitative methodology were used in this study, as follows: the naturalistic setting, inductive reasoning, data triangulation and narrative inquiry.

According to Creswell (2013), in qualitative research, the setting is an integral part of the phenomenon being studied. This is because the researcher talks to the participants, directly, and explores their behaviour in that context. The student researcher conducted the interviews in the homes of the participants, who live in various locations across the countryside of Bangladesh and in other dwelling places, such as university accommodation (for details, see section 3.4: Study setting), because these were the places where the participants experienced the issues being studied. Conducting the interview at students' homes helped the student researcher to have a close-up and personal connection with the participants, to accumulate in-depth data and to observe how the participants behaved in their unique contexts (Creswell & Poth, 2018).

One of the characteristics of qualitative research is that it is based on inductive reasoning. It starts with specific information and moves to the generalised conclusion (Braun & Clarke, 2013; Creswell & Poth, 2018; Liamputtong, 2013). The student researcher had no hypothesis before starting the study but, rather, collected data from participants, separately, which later led to the development of themes. The student researcher actively listened to participants, conducted observations during the interviews, took notes and, later, critically reflected on the findings.

As outlined in Creswell (2013) and Patton (2015), data triangulation refers to the use of multiple sources of data in qualitative research. So, along with the in-depth semi-structured interviews, multiple sources of data were collected, such as demographic information, field notes and reflective journals (for details, see section 3.6: Data collection). This approach helped to develop a comprehensive understanding of the phenomena being studied (Patton, 2015) and the approach is also regarded as a qualitative research strategy, designed to view the data from different sources and acquire a rich and detailed description of the study phenomena (Carter, Bryant-Lukosius, DiCenso, Blythe, & Neville, 2014).

Clandinin and Connelly (2000) also discuss the fact that participants may talk about their experiences in terms of past, present and future aspects, in a narrative inquiry (Clandinin & Connelly, 2000). In this study, there was a chronology of data; the participants described their occupational identity, competence and environment compared to past and present status, including the plan, and the researchers shaped the findings in the same way.

3.2.2 Approach

This study explored the lived experiences of adult students with SCI, who were injured between 15 to 18 years of age, regarding their transition and return to study in Bangladesh. The study aimed to describe the occupational lives of the participants, including details of

events in relation to their pre and post-injury occupational lives. In addition, the researcher explored how each student's experiences have been influenced and shaped by their peers, family and school environment. The narrative enquiry approach was, therefore, deemed appropriate for this study. As Liamputtong (2017) describes, narrative enquiry aims to understand the unique experiences of the individual and the way of representation of the experiences and their contexts, relationships and environments. Narrative enquiry focuses on storytelling, in terms of social, cultural, familial, linguistic and institutional perspectives, depending on the way an individual's experience has been shaped over time (Clandinin, 2013). It also describes the phenomena experienced by the individual in personal life, as influenced by social and environmental factors (Creswell & Poth, 2018; Haydon & Riet, 2017).

In narrative inquiry, people can tell their stories to reveal the way their lives are influenced by illness (Clandinin & Connelly, 2000). The Occupational Performance History Interview-II (OPHI-II) (discussed in section 3.6) was chosen because it is designed to enable interview respondents to tell their occupational life stories in the narrative form, including their circumstances, difficulties and relationships, from social and environmental perspectives.

3.3 Ethical considerations

Ethical clearance was obtained from the Monash University Human Research Ethics Committee (MUHREC). The project number was 17877 (see Appendix A for Ethics approval certificate from MUHREC). Additionally, ethics approval was obtained from the CRP (see Appendix B for Ethics approval certificate from CRP, Bangladesh) since the data belonged to CRP.

3.3.1 Informed consent

The National Health and Medical Research Council (NHMRC) states that, for participation to be voluntary, prior description and understanding of the research is necessary. The student researcher properly clarified the information, including the purpose, methods, demands, risks and potential benefit (NHMRC, 2018). So, following the guidelines, the Participant Explanatory Statement (see Appendix C for Participant Explanatory Statement) was provided to participants, containing clear information regarding what they were required to do if they consented to participate in the study. The student researcher translated the form into Bengali so that it was easily understandable to the participants. In addition, the student researcher clearly discussed that the decision of participation, decline or withdrawal from the study could be made by November 2019, and the individual responses provided in the interview would be kept confidential. This time frame was selected as the student researcher would start writing up the results after this date. Once the writing was undertaken, it would be difficult to separate withdrawn data from the analysis. Nonetheless, there was no participation withdrawal in this study. The student researcher was very much mindful of the confidentiality of information, so participation was not disclosed to the rehabilitation centre. This ensured that there was no situation that resulted in any harm to participants' ongoing or further rehabilitation at/through CRP (NHMRC, 2018). After clearly explaining the study to participants and reading the Participant Explanatory Statement, the student researcher rechecked participants' understanding by an overall discussion. The participants were given an opportunity to ask questions before starting the interview. Then, if the person chose to participate in the study, they were provided with a Consent Form (see Appendix D) to sign.

3.3.2 Unequal relationship

In accordance with chapter 4.3 of the NHMRC guidelines, it was appreciated that there was the potential for a pre-existing relationship with participants to exert influence on recruitment and participation in the study, as the student researcher had been employed at the CRP. So, to avoid the risk of participants experiencing coercion to participate in the study, the student researcher liaised with the CRP to hire a research assistant (RA). The student researcher discussed with the CRP about the ethical issues that needed to be considered by the RA, such as that the RA must not be in a power relationship with the participants and the importance of confidentiality issues. The CRP identified a suitable male RA employed through CRP to assist with this research. Following the CRP human resource guidelines, the RA was bound to follow the confidentiality issues regarding his all responsibilities in this current research. In this role, the RA was responsible for reviewing the participant list from the CRP databases and contacting potential participants for scheduling interviews and transcription work. The RA was responsible for the recruitment process, to minimise the potential bias due to a possible pre-existing relationship with the student researcher (Braun & Clarke, 2013; NHMRC, 2018). Then, the RA recruited the study participants over the phone, to seek their verbal consent and schedule interviews. The RA approached potential participants, to minimise the possibility of coercion, which could potentially exist if the student researcher was a former therapist of a participant. Additionally, no participants were known to be a direct patient of the student researcher during her tenure, so there was no impact on participation relating to a pre-existing relationship (NHMRC, 2018). In addition, to ensure safety, the RA accompanied the student researcher when travelling to interviews.

3.3.3 Risk and beneficence

Risk to the participants

According to the NHMRC, the risks and benefits of research are one of the most important aspects to consider in human research. The risk includes the likelihood of harm and the consequences (NHMRC, 2018). Low risk, as defined by the NHMRC, is when the participant experiences only discomfort as a result of research participation. In terms of this study, the potential risks to the participants included psychological discomfort and inconvenience of time involved.

During data collection, two incidents arose. The student researcher travelled to the home of one of the participants and found that, just before her arrival, the grandfather of the participant had passed away. Since the situation was emotionally overwhelming for the participant, the student researcher discontinued the interview and left. The participant lived around 300 km from Dhaka, where the student researcher lived during the data collection period. Considering the distance, therefore, the RA did not re-schedule the interview with that person on a different date and, rather, selected a new participant. Another participant became emotional while describing her difficulties. The student researcher offered a break from the interview for a few minutes and provided support by changing the topic. The participant was ready after approximately ten minutes to recontinue the interview. Once the interview was completed, the student researcher checked with the participant to see if she was still emotional, and the participant claimed that she was alright.

Risk to researcher

The student researcher travelled to the residences of the participants, such as homes and university residential accommodations. In this instance, the NHMRC (2008) also emphasises the safety of the researcher in the research situation. To manage the safety of the student researcher, she was accompanied by the same adult male RA during visits to the homes of participants that exceeded 50 km distance from her area of residence. In Bangladesh, some

people do not allow a woman to interview a man or vice versa, and do not allow women to be on their own in the presence of men whom they do not know. In this current study, the student researcher did not encounter any such incidents. The RA explained the flow of data collection to the participants over the phone during recruitment and this cultural context did not present issues in the current study.

The student researcher provided the Head, Occupational Therapy Department, CRP, with the telephone number, travel itineraries, details of the addresses of the participants' homes and the expected times of interviews, as the first-hand emergency contact. After each interview, it was confirmed that the student researcher safely returned home. The student researcher kept the Head informed to minimise the risk. Additionally, in terms of long-distance travel exceeding 300 km, the student researcher needed to stay overnight, in some instances, in the local area. For example, to undertake interviews in rural areas of Bangladesh, the student researcher and the RA needed to travel by local transport, using, for example, rickshaws, auto-rickshaws, speedboats, and vans to reach villages and rural areas where some of the participants lived. In these cases, the RA travelled with the researcher, and safety was the top priority for selecting hotels. The student researcher had weekly zoom meetings with the supervisors after the interviews, to debrief and discuss any upsetting or challenging experiences that occurred during data collection and to obtain appropriate advice.

3.4 Study setting

Before describing the study setting, the following is a brief description of the overall situation of the education of persons with disabilities in the context of Bangladesh, where the study was conducted. This information is included to assist the reader to understand the context of the study, to facilitate their understanding of the situation.

3.4.1 Data collection setting

Data were collected in three settings: a) the CRP; b) participants' homes; and c) the university residential service.

a) CRP

CRP is a non-government organisation involved in providing specialised rehabilitation for a person with SCI in Bangladesh. The organisation has been working for the past 39 years as a 100-bed, hospital-based facility and community-based program, including continuous follow-up. It is the largest rehabilitation centre in the country, which operates using a multi-disciplinary team approach. The team includes doctors, nurses, occupational therapists, physiotherapists, psychological counsellors, spiritual counsellors, vocational trainers and social workers. The team approach focuses care in terms of physical, psychological and economic issues, and emphasises successful reintegration after rehabilitation (CRP, 2018a; Quadir et al., 2017).

The CRP accepts referral of SCI patients at any level of injury and type of paralysis, age, gender and race. There is a combination, therefore, of age, gender, types of paralysis, and a variety of employment and educational backgrounds. As part of rehabilitation, the CRP strongly emphasises employment after SCI. Thus, the organisation has a vocational training centre with different training facilities, such as shopkeeping, computer, electronic, and tailoring (Hansen et al., 2007). During their inpatient stay, occupational therapists assess patients' vocational needs and, following the findings, patients are advised to take part in training (Ullah et al., 2015). Generally, patients start vocational training after getting discharged from the hospital. One of the selected participants was undertaking vocational training and living at the CRP. He returned to study after the discharge, completed one of his educational milestones and recently started to take vocational training, along with continuing

the study. Another participant was residing in the CRP area. The interviews were conducted at the CRP, for both participants.

The CRP offered the student researcher an office room to conduct the research work. The facilities included the workstation and locked filing cabinet. The office room was used for all of the research activities, such as selecting participants, performing the interviews, storing the data and undertaking transcription and translation of data, to ensure confidentiality.

Particularly, consent forms and handwritten notes were stored in the locked filing cabinet and audio recordings were immediately transferred from the phone to the password-protected, personal laptop of the student researcher, after the interviews. The interviews were then uploaded to Monash University's Lab Archives research storage system. The quiet room was used to conduct the interviews with these two participants. The office room was selected to minimise environmental distractions and for the privacy of the participant.

b) Participant's home

The patients usually go back to their home after their discharge from the CRP, and participants living in their own communities preferred the interviews to be at their homes. The student researcher travelled to the homes of ten participants, following the prescheduled date and time. As the participants were living with another family member, the student researcher clearly discussed the purpose and significance of the study with the family members, too, which helped to build rapport with them. In some cases, the close family members showed an interest in expressing their opinions, too. The student researcher took notes of those points and included them in the field notes, especially if there was any significant information, such as funding history of the participant's ongoing study and the physical environment of the home or academic institute. As the interviews were taken at home and there were other family members present as well, the family members were

explained the confidentiality issues of the interviews. They, therefore, allowed the student researcher to conduct the interviews in a separate space within their homes so that the family members could not overhear the interview information; thus, the confidentiality of participants was maintained. The family members were found to be cooperative throughout this process.

c) University residential service

There were three participants living in university residential services. The student researcher conducted the interviews in their living rooms and managed to observe the physical environment there, too. The observations were kept in the field notes.

3.5 Sampling and recruitment

3.5.1 Inclusion and exclusion criteria

Inclusion criteria

1. Students who were aged over 18 years at the time of interview and had their SCI between 15 and 18 years of age. This age range was selected because, being over the age of 18 years, the participants were able to consent by themselves and the 15- to 18-year-old age range covers the period when students finish two important milestones, school and college education, in Bangladesh.
2. Patients who completed their rehabilitation at the in-patient unit, CRP, and managed to return to study after rehabilitation.

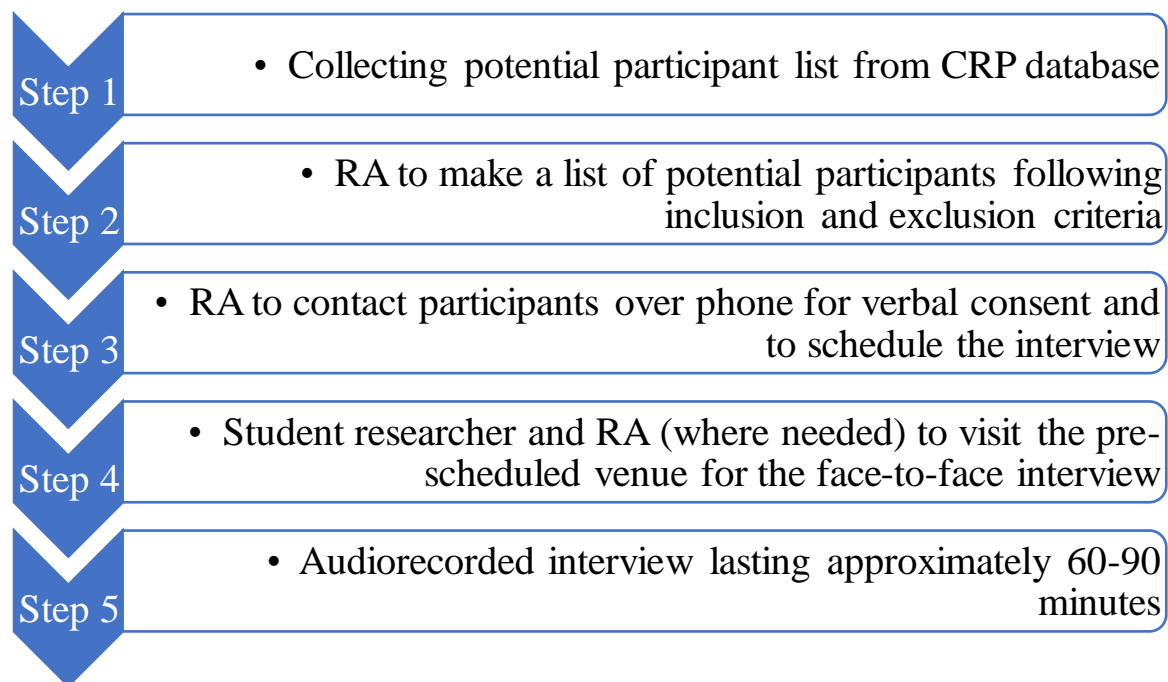
Exclusion criteria

1. SCI patients who had a history of diagnosed brain injury and/or mental illness diagnosed by the medical doctor and recorded in the CRP in-patient database.

3.5.2 Participant recruitment

Sixteen students with SCI were recruited, following purposive sampling techniques, between February 16, 2019, and April 05, 2019. Purposive sampling was used to select participants because of the unique experiences of the individuals that could not be obtained from others. This sampling strategy also provides information-rich participants from a small group who have extensive experience of a particular phenomenon (Patton, 2015). As this study aimed to gain an in-depth understanding of the lived experiences of the participants, the purposive sampling technique was a good fit to find out the unique meaning of their experiences. Below is a diagram of the flow of participant recruitment:

Figure 1. 1 Steps involved in participant recruitment



At the first stage of the participant recruitment process, the RA accessed the medical records and contact information of potential participants from the database of the Community-based Rehabilitation Department and half-way hostel logbook of CRP. A list of potential participants was made, afterwards, based on the inclusion and exclusion criteria. The list also

included the demographic and contact details of the participants, for further communication. The RA then contacted the potential participants over the phone and explained very clearly, using the Participant Explanatory Statement, what the study required of participants who agreed to participate, such as participation in a semi-structured interview, lasting 60 to 90 minutes in a place of convenience. After explaining the study over the telephone, the RA sought the consent of participants for the interview. Participants who provided consent to participate were asked for a scheduled interview. The participants were asked to select a convenient place for conducting the interview. Eventually, following the scheduled time and place, the student researcher travelled to the agreed location for the face-to-face interview.

The purposive sampling technique focuses on information-rich participants (Creswell & Poth, 2018). Hence, in order to gain a comprehensive understanding as well as representation of students with SCI from different backgrounds, the student researcher attempted to recruit potential participants from both rural and urban areas, as detailed in the demographic histories. Participants were purposefully recruited aiming for diversity in gender, area of living (rural and urban), aetiology and types of paralysis, variety in Asia Impairment Scale (AIS), assistive devices, including wheelchair and gait aids, minimum time of schooling and socio-economic background.

3.5.3 Participant overview

The student researcher interviewed 16 participants, although one was later excluded from the study. The excluded participant had no diagnosed cognitive dysfunction mentioned in the CRP database, however, during the interview, the student researcher felt that the participant provided very basic answers and was not able to contribute much insight into his experiences and feelings. Later, the student researcher was informed by the participant's family that he had suffered a congenital birth defect but, since he did not develop any physical impairment,

the family never consulted any health professional; thus, no history of birth injury was included in the CRP databases. This participant was, however, excluded as he met the exclusion criteria of the study.

According to ethical considerations, participants were coded with a pseudonym to maintain their confidentiality (NHMRC, 2018). Names familiar to both the cultures of Bangladesh and Australia were chosen, to facilitate understanding by English readers as well as to reflect Bangladeshi culture. There were eight males and seven females. Of the 15 participants, there were two people with tetraplegia and 13 people with paraplegia. Nine were using wheelchairs (W/C), three were using elbow crutches (E/C), one was using a walking frame (W/F), two were independently walking and one was using a Knee Ankle Foot Orthosis (KAFO) with E/C. The gap between injury and return to study was one to three years. Prior to injury, seven were studying at school, seven were at college and one was a student studying at tertiary level. At the time of the interview, one was studying at school, five were in college and nine participants were studying at tertiary level. An overview of the de-identified participants is given below.

Table 2. 1 *Participant's overview*

Patient's Name	Gender	Age at injury	Age at interview	Types of Paralysis	Neurological Level	Mobility Device	Year since injury	Year or month between injury and	Previous study	49
								RTS		Level of study during data collection
Neil	M	15y	19Y	Incomplete paraplegia	L2	Independent Walking	4y	1y	College	Tertiary
Daisy	F	18y	26y	Complete paraplegia	T10	W/C	8y	2y	Tertiary	Tertiary
Mila	F	16y	20y	Incomplete paraplegia	T8	Independent Walking	4y	Same year	School	College
Russell	M	18y	21y	Complete tetraplegia	C7	W/C	3y	1y	College	Tertiary
Syman	M	15y	20y	Complete paraplegia	T11	W/C Elbow	5y	1y	School	College
Sammy	M	16y	21y	Complete paraplegia	L3	Crutch	5y	1y	School	Tertiary
Sofia	F	17y	24y	Incomplete paraplegia	T10	Walking Frame	7y	3y	School	College
Debbie	F	15y	19y	Complete paraplegia	T10	W/C	4y	1y	School	College
Ronnie	M	18y	22y	Incomplete paraplegia	T12	W/C	5y	2y	College	Tertiary
Robin	M	15y	20y	Complete tetraplegia	C5	W/C	5y	1y	School	School
Millie	F	16y	19y	Incomplete paraplegia	L2	E/C, KAFO	4y	1y	College	Tertiary
Eva	F	16y	24y	Complete paraplegia	T12	W/C	8y	1y	College	Tertiary
Haris	M	16y	24y	Incomplete paraplegia	L1	Elbow Crutch	8y	1y	College	Tertiary
Leyah	F	17y	23y	Complete paraplegia	D8	W/C	6y	1y	College	Tertiary
Johnny	M	16y	19y	Complete paraplegia	T10	W/C	3y	2y	School	College

3.6 Data collection

3.6.1 Data collection method

The primary method of data collection was via in-depth semi-structured interviews.

Additionally, field notes and a reflective journal were kept.

In-depth semi-structured interview

The in-depth semi-structured interview was performed to collect the data. Liamputtong (2017) defined that, in the semi-structured interview, the researcher follows the information from a prepared question but enables the participants to elaborate on their experiences. A semi-structured interview guide was used for the interview (Liamputtong, 2017). The student researcher was careful about active listening, avoiding jargon and linguistic choices.

Although Bengali is the native language in Bangladesh, people from different districts use some local words. The student researcher rechecked the meaning in cases using the participant's local languages. Although the student researcher was mindful of language, the different linguistic patterns did not create any difficulty in understanding information conveyed during the interviews. Liamputtong (2013) suggests that the interviewer be mindful in using vocabulary and be flexible in linguistic format. In addition, non-verbal communication was observed to understand emotions. The student researcher also avoided using leading questions; instead, the questions were open-ended to facilitate the depth of participants' views (Liamputtong, 2017).

Before starting the interview, the student researcher thanked the participants for agreeing to take part, introduced herself to the participants, explained the research, including its purpose and rationale, and allowed participants to ask questions. The student researcher explained the expected length of the interview and checked participants' understanding with sample questions, concerning the aim of the study and what participants were expected to do. The participants were assured that the interview was open-ended and there were no right or wrong

answers. This approach helped to build a good rapport between the student researcher and the participants and facilitated a comfortable relationship. The participants were provided with the participant explanatory statement and consent form. Once they consented for the interview, the student researcher conducted the interview following the interview guide. The interviews were between 60 and 90 minutes, with one exception, in which the interview was around two hours. The interviews were recorded by mobile phone, which was a good quality device. The device was kept on flight mode during the interview, to make sure the audio was uninterrupted by calls or messages. The audios were transferred to the laptop and uploaded onto Lab Archives, soon after the interview.

Field notes and reflective journal

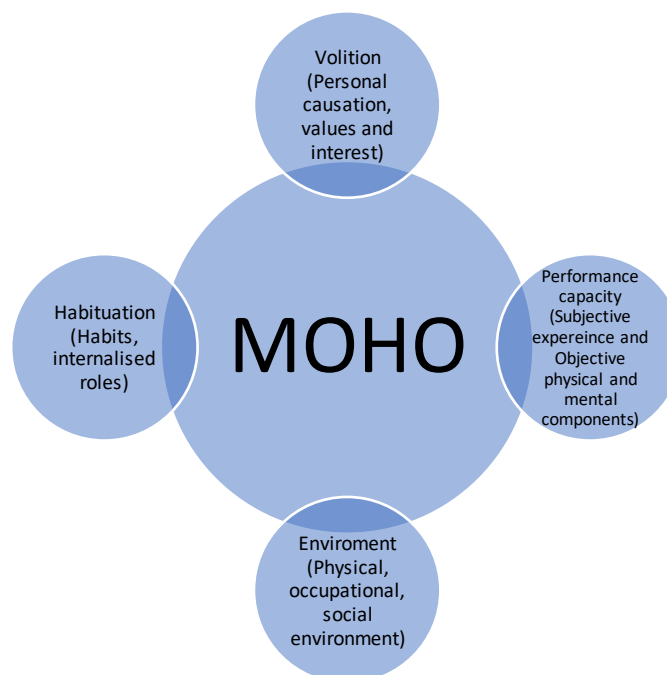
In addition to the audio recording, the other source of data were the field notes and the reflective journal of the student researcher. Field notes included issues about the physical environment of the home and the academic institute and roads, non-verbal responses of the participants, and any available information from family members. Creswell (2013) and Braun and Clarke (2013) assert that field notes and reflective journals are useful after each interview. The student researcher kept a reflection after every interview. The reflection included the personal reaction of the student researcher to the interview, how the interview went, important features of each participant's response, additional questions asked, overall understanding from the interviews, and reflection about interview techniques, to work on in the further interviews. Field notes and the reflective journal were used to write short narratives of each interview, including a brief of each participant's accident history, history of education and overall status (see Appendix H for the narratives).

3.6.2 Interview guide

Data was collected using the Occupational Performance History Interview-II (OPHI-II) (Kielhofner et al., 2004), which is based on the Model of Human Occupation (MOHO) (Taylor & Kielhofner, 2017), with some additional, self-developed questions about the physical environment of the school (see Appendix F for the interview guide).

The Model of Human Occupation (MOHO) is an evidence-based, theoretical framework of occupational therapy practice that addresses why and how human beings engage in meaningful daily activities. There are four elements of MOHO: volition, habituation, performance capacity and environment (Taylor & Kielhofner, 2017).

Figure 2. 1 The four elements of MOHO (Taylor & Kielhofner, 2017)



Volition in MOHO refers to the understanding of motivation for occupation, which consists of three types of thoughts and feelings: personal causation, values and interest (Lee & Kielhofner, 2017b; University of Illinois Chicago, 2020). Personal causation refers to “sense

of capacity and self-efficacy, i.e.: what one is capable of doing” (Lee & Kielhofner, 2017b, p. 41). Values refers to “personal conviction and sense of obligation, i.e. what is important or what things matter” (Lee & Kielhofner, 2017b, p. 41). Interest refers to “enjoyment and interests of pattern, i.e. what one finds enjoyable to do” (Lee & Kielhofner, 2017b, p. 41). *Habituation* in MOHO refers to how occupation is organized into patterns or routines within temporal, physical and social environments (Lee & Kielhofner, 2017a; University of Illinois Chicago, 2020). *Performance capacity* is “the ability to do things provided by the status of underlying objective physical and mental components and corresponding subjective experience” (Tham, Erikson, Fallaphour, Taylor, & Keilhofner, 2017, p.75). *Environment* refers to how the dimensions of environment, such as physical, social, occupational, economic, political and cultural components of the environment, impact on the person’s motivation and performance of occupation (Fisher, Parkinson, & Haglund, 2017).

MOHO is an occupation-focused model developed by Professor Gary Kielhofner, who was an Occupational Therapist based in the USA. The four elements of MOHO describe the motivation of occupational engagement of a person with a disability, how their habits and roles influence occupational performance, how the self-perception of their ability to do things is shaped by the objective assessment and opinion of therapists; to understand the human occupation, occupational therapists must understand them in terms of the physical and social environment (University of Illinois Chicago, 2020; Taylor & Kielhofner, 2017). MOHO has developed different resources, such as case examples, manuals, articles and documented programs, for the application of the model, and more than 20 assessments were developed, in addition to the model, to guide OTs in client-centred practice (University of Illinois Chicago, 2020). The Occupational Performance History Interview-II (OPHI-II) is one of them.

Keilhofner et al. (2004) described OPHI-II as a semi-structured interview, which addresses motivation, performance and organisation of occupational behaviour in everyday life. The tool is appropriate for people over the age of 12 years and is recommended for use in SCI rehabilitation programs. This is a very interactive and personal interview, where the participants share the details of their life history experiences and the way disability influences their lives.

The steps in the administration of OHPI-II include the following:

- a) Interview
- b) Rating scale, with key forms
- c) Life history narrative

The interview consists of the following areas:

- a) Occupational role
- b) Daily routine
- c) Occupational setting (Environment)
 - Home and school are considered
- d) Activity/ Occupational choice
- e) Critical life events

The section on occupational settings (environment) contains some questions regarding accessibility in the home and occupational environment. As one of the objectives of this study is to explore the environmental barriers and facilitators of returning to study for students, the researcher added some self-developed questions about the physical environment of the academic institute. The questions were informed by the literature reviewed from different parts of the world.

The additional, self-developed questions were asked to get a broader view related to the physical and institutional environments of the academic institute, regarding the following areas (for details, see Appendix F for the interview guide):

- Strategies adopted by the students with disabilities in writing tasks and group work in school and the examination hall;
- The accessibility of the classroom, toilet and other areas of school such as playground and library; and
- Availability of school assistance.

3.7 Data analysis

Thematic analysis was chosen for analysing the interview data because thematic analysis enables a deeper understanding and rich description of the data that have been gathered.

Thematic analysis includes the technique of finding out the meaning of the data in relation to the research questions, which ends with identifying themes (Braun & Clarke, 2013).

The six steps of thematic analysis were followed (Braun & Clarke, 2013). Initially, the student researcher had a discussion with the supervisors about the steps of analysis, which are described below.

Step 1: Making yourself familiar with the data

The audio recorded interviews were transcribed, verbatim, in Bengali by the RA. The student researcher translated the interviews into English, as one of the first steps in getting familiarised with data. The translated transcripts were then used for analysing the data. As the translation was done by the student researcher, it enabled her to gain an in-depth understanding of subjective meanings. The transcripts were laid out with a space of three to four centimetres on the right-hand side for note taking, and continuous line numbers were

used to keep track of specific information. Highlighters were used for marking the important points.

Step 2: Generating the initial codes

In this step, the student researcher started to generate the initial codes by writing the meaning of the highlighted points. The student researcher and supervisors discussed how to develop the initial codes. All of the interesting features were coded in a systematic fashion, across the entire data set. There was a consistent approach in writing down the meaning of the same or similar features. For example, for similar responses by different participants to the same question from the interview guide, the student researcher used the same word while writing the meaning of the initial codes.

Step 3: Searching for tentative themes

In the third phase, the student researcher wrote down the codes from every interview on sticky notes, together with the line numbers. Sticky notes were then laid out on a wall so that those with similar ideas could be easily grouped together, to find potential themes. This process was done for each interview.

Step 4: Reviewing themes

The student researcher generated an initial thematic map and discussed this with the supervisors. The discussion assisted in identifying themes and sub-themes. At this stage, eight potential themes were identified, with a few sub-themes.

Step 5: Defining and naming themes

Themes and sub-themes were revised and refined, which resulted in seven themes at the final stage. The team then generated a clear name and definition for each theme and sub-themes.

Themes and sub-themes were generated in a way that provided a chronological story of the lived experiences of students with SCI in Bangladesh.

Step 6: Producing the report

At the final step of the analysis, the student researcher started to produce the report, depending on the interpretation generated by focusing on the evidence that addressed the research question. The report contained the essence of the themes, with quotations from the participants used to clarify subjective messages from them and understanding by the research team.

3.8 Strategies to ensure trustworthiness

The trustworthiness of the research describes how much the study is reliable. In qualitative research, trustworthiness ensures the quality of the investigation (Liamputtong, 2013). Lincoln and Guba (1989) developed four criteria of trustworthiness in qualitative research, which are credibility, transferability, dependability and confirmability (Lincoln & Guba, 1989). These are parallel to internal validity, external validity, reliability and objectivity in quantitative research (Creswell & Poth, 2018; Liamputtong, 2017; Patton, 2015). However, in parallel to the rigour of quantitative studies, to ensure the trustworthiness of qualitative studies, it has been argued that the quality of a qualitative study must reflect its philosophical assumptions and aim (Creswell & Poth, 2018; Lincoln & Guba, 1989). As this is a qualitative study, the guidelines described by Fossey and colleagues have been used to ensure methodological and interpretive rigour (Fossey, Harvey, McDermott, & Davidson, 2002).

3.8.1 Methodological rigour

Fossey et al. (2002) described methodological rigour under the following criteria: a) congruence, b) responsiveness to social context, c) appropriateness, d) adequacy, and e) transparency.

Congruence: This refers to how the chosen research design fits with the philosophical approach (Fossey et al., 2002). The study was conducted following a qualitative design, which was consistent with the aim and objectives of the study. Narrative enquiry was chosen, which was congruent, as the participants shared their lived experiences in a chronology, from pre-injury and post-injury life (see section 3.2: Research design).

Responsiveness to social context: Responsiveness to social context refers to the emergent research design used to explore the real-life situation (Fossey et al., 2002). This study was responsive to social context, as the student researcher had firsthand experience with participants while conducting the interview. The real-life situation was captured, as the interview was taken in the real-life contexts of participants, such as the home, the CRP or university residential service (see section 3.4 Study setting).

Appropriateness and adequacy: This outlines the sampling, data collection and how the data analysis strategies fit the study (Fossey et al., 2002). A purposive sampling strategy was used to identify the most suitable participants for this study. Face-to-face interview was the primary means of data collection. Additionally, field notes from observations were taken and a reflective journal was kept, with reflections immediately recorded after the interviews, to be used in the data analysis. A detailed description of the participants has been provided earlier, in the participant recruitment section, with a clear description of the sampling procedure (see section 3.5 Sampling and recruitment).

Transparency: The student researcher was primarily responsible for data collection and analysis. However, an RA assisted in the data gathering process to make sure it is transparent with no bias in sampling and no history of power relationship. The supervisors were actively involved in different steps of data analysis. Initially, they taught the process of coding with a practical example by using one of the interview transcripts. Regular discussion and debriefing as analysis continued occurred with both the supervisor fortnightly. Themes and sub-themes were finally developed that were consistent with the research questions, aim and objectives (See 3.6 Data collection for more information).

3.8.2 Interpretive rigour

Fossey et al. (2002) described interpretive rigour under the following six criteria:

Authenticity: The authenticity in presentation of findings or interpretations was maintained by providing verbatim quotes of participants. In every theme and sub-theme, data were presented from participants with different demographic histories, to present a range of views. After each interview, the student researcher summarised the interview for each participant to recheck the information provided by them. The demographic data collected from the CRP database were rechecked by the participants, to make sure the information was correct. Member checking or reviewing of the analysis could not be done, however, as the data collection occurred over a restricted time frame in Bangladesh. To do this would have been a time-consuming process and required an expensive re-visit to Bangladesh. The interpretation of data was recognisable to those having had the experience of the interview, however, because the context was described, and the data were recorded verbatim (see section 3.7 Data analysis).

Coherence: Coherence refers to the “fit” between the data and the findings and the perspectives of multiple researchers (Fossey et al., 2002). The student researcher highlighted

the important features of the first transcript. The supervisors then showed how to apply the meanings of codes and discussed the details of analysis. Excerpts from every transcript were discussed with supervisors, in order to deepen the first-level coding. This afforded an opportunity to discuss emergent themes and sub-themes. Further triangulation occurred after writing the report. The ongoing critical feedback from supervisors on the written document led to a deeper understanding and refinement of the presentation of the findings. Such discussions and involvement of multiple researchers led the student researcher to clearly articulate the interpretations in the report (see section 3.7 Data analysis).

Reciprocity: Reciprocity refers to the steps taken to involve the participants in re-checking the data and interpretations of the data (Fossey et al., 2002), which Lincoln and Guba (1985) referred to as credibility. Reciprocity was maintained by only one step, which was digitally recording the interview and summarising the interview to check the understandings of the student researcher. The RA transcribed each interview, verbatim, in the next step and the interviews were translated by the student researcher, keeping the original meaning unchanged (see section 3.7 Data analysis).

Typicality: Typicality refers to the extent to which the findings can be generalised to other contexts (Fossey et al., 2002). One of the limitations of qualitative research is that the findings cannot be generalised to other contexts (Curtin & Fossey, 2007). As the research was conducted in Bangladesh, however, people from another country might find it difficult to relate to the context. Therefore, the student researcher described the context of this study, in depth, to make it easier for the readers to understand (see section 3.7 Data analysis).

Permeability of the researcher: Permeability refers to the intentions, engagements and interpretations of the researcher (Fossey et al., 2002). The student researcher had a history of working as a clinical OT with people with SCI. To keep the research role transparent,

therefore, the RA was employed and the supervisors were actively involved in the data interpretations and the writing phase. The steps of supervisor engagement have been described in the section on data analysis and coherence. Their involvement challenged, at times, my assumptions, thoughts and understandings, which was beneficial for keeping the study unbiased (see section 3.7 Data analysis).

Chapter Summary

This chapter outlined the rationale of using a qualitative methodology framework for this study. The chapter included the rationale for the research design, ethical considerations, details about the study setting, the sampling process, steps involved in recruiting 16 participants and, later, excluding one of them, methods of data collection, the six steps of data analysis and an explanation of the strategies used to ensure trustworthiness of the study. The following chapter will present the results of this research.

Chapter Four

Results

This chapter discusses the lived experiences of returning to study among adult students with SCI in Bangladesh. Participants discussed their pre-injury and post-injury experiences, the importance of education, and barriers and facilitators to their academic participation and current social participation. Seven themes regarding the lived experience of adult students with SCI were developed from the semi-structured interview data. For each theme, several sub-themes were identified. An overview of the themes and sub-themes are included in the following table:

Table 3. 1 *Themes and sub-themes*

Theme	Sub-theme
1. Accident is a critical life event	<ul style="list-style-type: none"> - Pre-injury experience: Independence is freedom - Post-injury experience: Spinal cord injury was a turning point - Return to study is the most significant success
2. Value and benefits of returning to study	<ul style="list-style-type: none"> - Education is important to me - Education leads to a job in future
3. Influence of the academic environment on student participation	<ul style="list-style-type: none"> - Accessing academic facilities - Using exam venues - Doing self-care activities whilst studying
4. Meaningful relationships at academic institute	<ul style="list-style-type: none"> - Relationships with friends and classmates - Relationships with teachers
5. Finding other productive roles	<ul style="list-style-type: none"> - Volunteering - Providing private tuition - Social activism
6. Access to home and community living	<ul style="list-style-type: none"> - Physical environment at home - Inaccessible public transport is a barrier - Participation in community events and relative's home
7. Impact of social environment	<ul style="list-style-type: none"> - Disability is stigmatising: feeling different

- Experiencing negative responses towards disability
 - Women are doubly discriminated
 - Family support
 - Social support in the community
-

Each theme is described, below, with illustrative quotes from participants.

4.1 Theme One: Accident is a critical life event

When talking about the best times of their lives, the critical times of their lives and their achievements, participants mostly differentiated their experiences pre-injury from those post-injury. As shown in the table above, their pre-injury experience was of freedom as independence, while post-injury, SCI was described as a turning point and the experience of returning to study as their most significant success.

4.1.1 Pre-injury experience: Independence is freedom

Participants said that pre-injury time was their best period of life. Several reasons made it the best time, such as being independent in self-care, having a disciplined routine, and having independence in daily movement and freedom about what they did. The wheelchair user participants and participants who were independent in walking reflected on similar experiences about independence and freedom. For example, Mila, a 21-year-old student with SCI, who is independent in walking, described that:

“Pre-injury time was the best time because I had control over my life. I could have done everything on my wish. I was able to run whenever I wanted. Nevertheless, I have to maintain a disciplined life now. There are rules for everything.”

Russell, a wheelchair-dependent participant described a similar experience:

“I was able to participate in anything and could have travelled whenever I wanted. Currently, I can do some self-care independently. Otherwise, I always need assistance.”

When reflecting on their injuries, one of the participants expressed gratitude that the condition could have been worse, comparing themselves to people with tetraplegia being treated in the service. Syman, a paraplegic and wheelchair-dependent participant mentioned that:

“I am happy that my condition is better than many patients I saw at CRP who are entirely dependent on a wheelchair. They cannot propel it and dependent for transfer activities. So, I think it is better than being in a worse condition. It was written in my fate, so it happened. As it is better than those people’s condition, so my current situation is my good time too.”

4.1.2 Post-injury experience: Spinal cord injury was a turning point

Participants identified that the SCI entirely changed their lives. The changes occurred in many different areas, such as restricted mobility, level of independence, attitudes from society and relationship problems. One key finding identified was that physical impairment led to dependency and the consequences it brought; for example, Syman mentioned that:

“If I had not the accident, and if I was in good condition, I could have planned for myself the way I want. I could get success according to that plan on anything I want to do. Now whether I can do it or not, I must consider my current situation and plan accordingly. There is no scope of thinking about my wish anymore. Whereas if I was in good health, I could make money and solve our financial problems. Now I am dependent on others on much work.”

When a SCI happens, a close relationship can often change as well. The loss of a relationship emotionally impacts the person. Daisy, a paraplegic and wheelchair-dependent participant experienced a breakup in a relationship, which made her lonely afterwards. She emphasised the importance of this relationship, especially for sharing smiles and sorrows. While she felt the need for that bond more than ever after her injury, the relationship ended, instead, because of the SCI. Daisy said that:

“We had a relationship for four years. However, he developed distance with me after the injury and eventually put an end to the relationship. The one I loved most left me. I have lost the power of my legs, and I have started to lose my dreams too.”

4.1.3 Return to study is the most significant success

Participants considered that their most significant achievement was returning to study after rehabilitation. The journey of returning to study has been full of both positive and negative experiences. Nevertheless, continuing to study was viewed as the ultimate success, by all of them.

Russell, a participant with tetraplegia, felt that, initially, returning to study after the injury was a dream to him. He believed that his physical impairment was the main reason that he would not be capable of returning to study, however, gradual physical improvement during in-patient stay made him determined for further study. He stated that:

“I started to get back the strength of my right hand, and that is when I first started to think about returning to study again. My improved right-hand function pushed me to think more about starting the study again, and I managed to do it finally”

Participants identified that, in addition to continuing study, achieving other academic milestones were equally crucial to them. Achieving milestones included passing grades and

levels, such as school, college and tertiary levels. Syman graduated from school two years before the interview was completed and will soon appear for Year 12 graduation. He mentioned that:

“My brother inspired me, saying that if I get failed in SSC (Year 10) after these ten years, my all the ten years of life would be wasted. However, if I pass, I will get success. Moreover, I got success due to my hard work, at last. An educated person can do anything to earn their livelihood. So, I want to utilise my education for earning livelihood in future.”

In summary, depending on their level of participation, participants viewed their accident as the most significant turning point in life, something that changed their life course. On the other hand, returning to study brought hope for a better future and strengthened them, as well.

4.2 Theme two: Value and benefits of returning to study

All the participants discussed that education is meaningful to them. While describing the meaning of education, they emphasised their transition in the process of returning to study. Transition means the time of discharge from the CRP to the time of returning to study. The transition experiences were valuable because they played a vital role in their decision-making regarding study. Most of the participants had a gap of one year between discharge and starting to study again, but it varied up to three years. There were also different reasons to start studying again. Most of the participants described that their own strong determination, as well as the CRP, played a significant role in motivating them to continue their studies. Two main sub-themes were identified: 1. Importance of education, and 2. Education leads to a job in the future.

4.2.1 Education is important to me

Education was viewed by participants as crucial because it grants recognition as a valued person in society and gives an identity, develops skills in communication and social interaction and helps to overcome depression. Mila, a female participant, emphasised the value of education, in two ways. She said:

“Education increases my knowledge base... it builds skills in communication and social interaction which are a basic quality of human.”

Russell added more on this, stating that:

“It (education) is about making me a skilled and valuable person that will be helpful for my identity. Because the level of education is a big deal now and people count your skill on that.”

Johny, a paraplegic male participant, discussed a different aspect. He understood the importance of education by seeing some old patients of the CRP who continued to study and staff at the CRP who were injured with a SCI, as they were in the workforce despite their disabilities and SCI. This inspired him to continue to study, by challenging traditional thoughts, such as, ‘There is no point of studying anymore, being a person with a SCI’. He said:

“I made many friends on Facebook who took treatment from CRP... They inspired me to continue the study as they have achieved a lot by education... So, I kept studying to see if it changes my future”.

Eva, a paraplegic and female wheelchair user, reported that:

“I was suffering from depression during my three years of gap between hospital discharge and college enrolment. My family advised me to start again. I thought to myself that it is important to start study again as it will help me to pass the time meaningfully, like I did before. Eventually, it helped to overcome the depression.”

4.2.2 Education leads to a job in future

All the participants highlighted the ultimate purpose of education as leading to a job in the future. Harris, a male participant who was using an elbow crutch, said that:

“One of my teachers said that education is not for having a job only, be a human first. I have been working to be a better human every day but at the same time a source of income is equally important. I cannot go for any work that requires physical effort. Therefore, education is now preparing me for the future workforce.”

Millie, a female participant using an elbow crutch and studying at tertiary level, also emphasised the importance of education for getting a job. She said:

“It is equally important for students like me to get the education, so we do not become the burden on anyone. We can contribute to the development of the country by having a good career. A school degree would not bring anything big in career, therefore, higher education is necessary for reputed job.”

A few participants also discussed that there is a 10% quota for persons with disabilities in the government job sector of Bangladesh. This legislation makes them hopeful for a job in government service. Eva, Johny, Sammy, Haris and Robin are looking forward to doing a government job following their studies. Johny mentioned that:

“Many people are working under the disability quota. So, I am studying too if it helps me to get a job through that.”

The participants further discussed that the purpose of the job is to gain financial independence for a more secure future. Sofia shared that:

“I cannot say how long my parent is going to live. There is no assurance on that. I have no elder brother who could look after me in their absence. So, it would be better to do a job so I could do something for my own and be self-reliant.”

4.3 Theme three: Influence of the academic environment on student participation

All the participants reported that environmental factors at the academic institute impacted on their academic participation. The physical environment of the academic institute consists of the entrance, classroom set-up, the exam venue, toilets, the library, the cafeteria, class materials, extracurricular/ co-curricular involvement and participation in the annual excursion. An accessible physical environment facilitated the academic participation of participants, whereas a lack of accessibility was the most significant barrier.

Three sub-themes were identified: 1) Accessing academic facilities; 2) Using the exam venue; and 3) Doing self-care activities whilst studying.

4.3.1 Accessing academic facilities

All participants reported that an inaccessible physical environment at the academic institute restricted their regular attendance. To access the academic facilities, they described different aspects, such as: a) Accessing the entrance, classroom and library; b) Class materials; c) Library; and d) Participation in co-curricular activities and the annual excursion.

a) Accessing entrance, classroom and library

Having an inaccessible entrance, with the classroom being on a different level in a multi-storied building with no lifts, was found to be the most significant barrier to regular academic participation. Most of the participants could not attend their class lectures due to such an environment and attended for the exam only. Some participants participated regularly when the academic institute was accessible. Irrespective of the type of paralysis and assistive devices, participants reported that an accessible entrance and classroom contributed to their study participation. Robin was a tetraplegic participant and dependent on his carer. He was re-admitted to the same school but never attended the class lectures, as the school was not wheelchair friendly. He described that:

“There were four or five stairs in the entrance of the school building... later school did renovate it and tried to make the ground levelled so the WC could have propelled easily. But still it was not worthy for wheelchair... The height was like three small stairs. So, my school buddies always carrier my wheelchair during my exam days.”

Ronnie and Debbie both experienced barriers to attending their academic institute, due to the presence of stairs. Debbie managed this by studying at home and only attending for exams, while Ronnie got his friends to help him build a ramp from leftover bricks at the college. Ronnie did not like to be supported; therefore, he took the initiative to solve this problem and described that:

“There was a construction work going on in the college, so there were kept some sand and brick. I brought some bricks from there in a bag. With a few attempts, there were enough bricks to make a slope. I made a slop with the bricks... Juniors and friends offered help seeing me doing that... I knew it would not be a perfect one, but at least it will do some help. Principal Sir saw this whole thing through his office window.

So, after a few days, I found that the slope turned into a beautiful ramp with replastering... Later he said he did this for me.”

On the other hand, Syman shared positive experiences on this point. Syman’s college authority was very cooperative and they installed a new ramp for him at college, just after his admission. They also changed the classroom downstairs so that he could regularly attend class lectures. Syman said:

“There is a ramp for me to enter the building. Though I need a little help to propel the wheelchair as it is little steep, but I regularly attend classes... I do my classes sitting on my wheelchair instead of sitting on the regular bench... If I seat in front of everyone, my teachers ask me to sit in the row with other students so that I do not feel different from others. This is a great motivation for me.”

All the participants, except for three, cited that there was no library in the academic institute. Millie said that, although there was a library at her college, she never went there. Now, however, she regularly goes to the library at the tertiary level, as the building has lifts and, therefore, it is easier for her to move everywhere.

b) Class materials

Most participants discussed that they had difficulties with getting class materials. They could not attend classes regularly, so collecting the class lectures was a struggle for them. The only option for them was to collect notes from friends or classmates. While speaking about collecting class materials, Daisy said that:

“This is a sad part... I was not a familiar face among my departmental friends as I never attended any class. I talked with teacher about the class lectures, but they advised to collect from friends. I found that friends were making notes based on class

lectures but refused to share with me. They used to provide less information about class. Ultimately, it made me to study harder and I got the result of my extreme hard work by hitting good result.”

Debbie reported that her friends, however, were helpful in sharing class materials. She mentioned that:

“I contact them via messenger and they regularly update me about classes share via messenger. In cases when there are any hard copies, they do a photocopy for me, and my mother goes to college to collect those.”

Millie, on the other hand, shared that, as she could not regularly attend during her college days, she used to take lessons from online sources. She said that:

“I used to take lessons from tutorials on YouTube. There are two channels named “Onnyorokom Pathshala” and “Ten minutes school”. These channels were very productive. I used to ask friends as well if there were any points that I could not understand properly.”

Participants described that they never received any class materials from the academic institute. They were given the contact numbers of the teachers, and they used to seek advice over the phone. Friends were their first-hand contact for learning resources, and some of them took tuition from private tutors, as well, at home.

c) Participation in co-curricular activities and annual excursion

All of the participants, except for Ronnie, stated that they were always the observers at co-curricular activities. Participants felt excluded, as they could not participate in co-curricular

activities anymore. There was no scope to attend cultural events. Some participants regretted being unable to play sports anymore. Robin stated that:

“I felt bad seeing the playground. I cannot play anymore due to disability. It is a sorrow for me (long sigh).”

Ronnie had a positive experience with this. He informed that:

“They (college teachers) were changed person seeing me an enthusiastic person. They came to know that I am a team member CRP wheelchair basketball team... I also write poems. All these have changed their perspective and they felt that I am a capable person. My college arranged an inter-college cultural competition. So, the teachers wanted me to be the master of ceremony and I did that very well.”

Annual excursions or study tours are not a regular practice in Bangladesh, and a few participants stated that they never attended one. Syman specified that:

“I had to do an alternative task instead of attending the study tour. It was part of the Geography subject, so I had done an assignment. I could not attend the study tour because the destination was not wheelchair friendly”.

4.3.2 Using the exam venue

The exam venue was an essential aspect of a participant’s study experiences. Students from all of Bangladesh appear for the final examination of Class VIII, Secondary School Certificate (SSC) and Higher School Certificate (HSC). These exams are held in a different academic institute than the student’s usual institution. Participants had varied experiences regarding their exam venues. Most of the participants applied earlier to the authorised personnel of the exam centre, requesting that their exam be changed to the ground floor. Most

of them had their exam venue changed to meet their mobility needs, however, this was not the case for Johnny:

“I applied for allowing me to seat in the ground floor with a forward from the Principal of our college... But they did not allow me... I had to pay for it along with the application, however they took the money but did not approve it.”

This suggests that some teachers from that academic institute were not only uncooperative but also unethical in their behaviour. Other participants had negative experiences, as well, but none of them reported any unethical behaviour. Ronnie applied for transferring his exam seat to downstairs earlier, as well, but on the exam day, he found that his allocated exam venue was upstairs. He discussed this with the centre manager, and they acted right away.

However, he stated:

“I used to sit in the corridor of the ground floor for an unknown reason. None of the teachers has ever asked me to go into the classroom.”

This was discriminatory behaviour. Some participants described their experiences of getting an extra 30 minutes of time, as a student with a disability, following the *Disabilities' Rights and Protection Act 2013* of Bangladesh. It was found that the teachers were not aware of the legislation, so the participants had to inform them about it.

Participants were not always allowed to utilise the extra time to which they were entitled.

Russell, a tetraplegic participant, who had hand function difficulty, stated that:

“I got an extra 15 minutes in the first two exams only. Then they stopped to allow that.”

On the other hand, Ronnie informed the teachers on the first day, and they permitted the extra time.

Overall, exam venue experiences were worse than in their regular academic institute. Most of the participants described that a lack of knowledge about SCI made the situation complex. As

it was exam time and teachers were busy with their responsibilities, it was not always possible for the participants to explain their conditions and needs.

4.3.3 Doing self-care activities whilst studying

Although a few participants, such as Ronnie and Syman, managed to temporarily solve inaccessibility issues related to the classroom and entrance at an academic institute, most of them continued to have issues with being able to access the facilities related to self-care, such as the toilets and cafeteria. Except for Leyah and Millie, the rest of the participants stated that they never used the toilet at the academic institute. Leyah said that:

“There was both the ramp and lift in my institute. Not every toilet was accessible for me, but as there was the lift, it was easy for me to quickly go and use the toilet in different floor whenever needed.”

The rest of the participants had different experiences. Robin said that:

“I did not use to attend classes regularly... However, if I did, I used to be there for a maximum of three hours. I had to come back home as there was no toilet for me at school.”

Russell added:

“I used to drink a minimal amount of water and had less food before the exam day. I usually avoided food on exam day as there were no toilets.”

Syman, the only participant who never usually missed classes, mentioned that there were no accessible toilets in his college. He said that:

“There is a new building being built now. It would have a toilet for wheelchair users... Making ramps and accessible toilet in all the new academic buildings is now a mandatory according to the Disability rights and Protection act of Bangladesh. It would be helpful for me once it is built.”

The new initiative is a good sign for students with SCI, in the future. A consistent finding was that the participants did not feel comfortable sharing details of their bowel and bladder complications, even with their close friends. They kept these issues hidden from everyone. When they discussed the need for an accessible toilet with their teachers, they focused only on the wheelchair access. Some of them used diapers to avoid any unexpected event.

Another facility related to self-care at the academic institute is the cafeteria. Millie, initially, faced some difficulty at the cafeteria. As the cafeteria has a self-service rule, it was difficult for her to hold the food plate in one hand and the elbow crutch in the other hand. She described her current status:

“Cafeteria staffs are very kind. They serve my food in the table now, so it is not a problem anymore.”

Leyah also regularly goes to the cafeteria. She added a different perspective:

“I take my three-time meal at the cafeteria. I can go there and collect food on my own. But the handwashing basin height is not wheelchair friendly. It is a tough job for me to clean my hands.”

4.4 Theme four: Meaningful relationships at the academic institute

The students had a variety of different experiences with friends, teachers, classmates or peers and other staff at the academic institute. Two sub-themes were identified: 1) Relationships

with friends and classmates; and 2) Relationships with teachers and other staff at an academic institute.

4.4.1 Relationships with friends and classmates

The study participants had mixed experiences in their relationships with friends and classmates. In regard to their pre-injury and post-injury status, friends showed different types of behaviour. Daisy, a paraplegic and wheelchair-dependent participant, experienced her relationship with friends quite differently. She stated that:

“I used to have a very friendly relationship with everyone before my injury. But when I stepped into that room (at dormitory) as a person with a disability, everything was completely changed (with a peal of laughter). People were completely changed in terms of attitude and behaviour.”

Some friends showed a negative attitude and behaviour. Participants described that such attitudes were a result of their lack of knowledge about disability caused by SCI. It was also found that, once friends came to know more about SCI, they started to be more cooperative. Daisy experienced the same with her friends, as well. She thinks that it happened after they saw her achieving good results and being independent in all her activities. They overcame their misunderstanding about her disability and started to accompany her. She said:

“The result of second-year exam got published and I scored a First-Class degree. I have informed everyone related to me... People around me started to show positive behaviour. I have to say people who took me negatively, at first place, eventually started to make good relationships with me. That was the harsh reality of my life. No one was there for me in first year, not even in the second year. But then everyone started to change.”

One of the most common findings of relationships with friends and classmates was, due to having a gap in study, participants lost contact with their friends. As most of them started with the junior batch, they reported a formal relationship with their classmates. Sofia, a student of Year 12, lost her friends after injury. She got re-admitted to college after a one-year study gap. Meanwhile, her friends had already passed the course and she had to start with a younger student cohort. As a result, she became lonely at college. While her classmates did not behave rudely or negatively, they were not welcoming, either. On the day when she used to attend class lectures, the classroom needed to be re-arranged so that she could sit there. She mentioned that:

“Classroom needed to be shifted to ground floor on the day I used to attend. I could feel that my classmates are not happy about it from their facial expressions. Though no one of them has said anything, their face looks like they take it as a disturbance”

Haris reported the same as Sofia. As he started studying with the junior batch, the relationship was very formal. It took a long time for him to get along with his younger class peers, yet the depth of the relationship was shallow. It can be said that a relationship with friends or classmates does not only form through verbal communication, it is also formed through non-verbal communication, as well.

Syman, a wheelchair-dependent paraplegic participant, reported a positive experience. He said that, although he is now a college-going student, he has got the same friends from his primary school. He meets his friends regularly and makes fun with them, as well. He said:

“They often come at my home and we also meet outside. We sit together and have a chat. In the month of Ramadan, we used to chat until 11 pm or midnight. We play games too, such as Ludo game in mobile phone”

A few participants reported that friends were very cooperative, especially in buying books and stationery items for the participants. Russell, another wheelchair dependent participant with tetraplegia, said that his friends visit him weekly or fortnightly, even though they live in a separate sub-urban area. He stated that:

“They usually buy my books and different stationary items and carry them for me when we meet. Even sometimes if one cannot make it, there is always the other one. I mean I always get help from the friend circle. I cannot remember any bad things... No one cheats me”

4.4.2 Relationships with teachers

The participants described a variety of relationship experiences with their teachers. Teachers play one of the most important and influencing roles in their lives. Their cooperation helps to make things easy, however, their non-cooperative behaviour can make their lives miserable, as well. Sofia stated that:

“Principal of the college did not agree to admit me in the college. He was like “what a girl like me would do after studying?” Afterwards, my father requested to a member of a governing body. Then the authority agreed to accept my admission. So, we did not ask for more help, whereas they were not welcoming at first place. I thought I could pass the exam like the way I am studying now. Let us not make it more complicated.”

Haris faced a similar experience. On his request to make a ramp in the entrance and change the classroom, his teachers responded:

“It is not our responsibility to do these. Ask the government; we cannot do anything for you.”

Regardless of this non-cooperative behaviour, he continued to study because he wanted to give his life meaning. He said that:

“A lot of students with SCI drop out because of such attitudes from teacher... Yet, I wanted to continue studying as I saw my physical improvement and assumed that at some point, I would not need the wheelchair anymore. So, I took the opportunity then... later I started using elbow crutch”

While exploring the relationships with teachers, the most common finding was that participants could reach out to their teachers over the phone. It was not a very common practice in Bangladesh. It was found that some teachers cooperated with them, and they used to respond to the phone calls regarding academic issues, whereas others did not always cooperate in a meaningful way.

Daisy explained that, after she had scored good marks in the exam, her teachers seemed to respond more positively towards her. She thinks that her good results influenced the teachers in the same way it did her friends. Sammy, a paraplegic participant, dependent on an elbow crutch and toe pick-up as an assistive device, did not regularly attend his class lectures, however, he found his teachers were helpful whenever he attended the classes. He stated that:

“Teachers do check on me when I attend the class lectures. They ensure my safety during climbing the stair if they pass by me.”

Syman's experiences with his teachers were more positive than that of any of the other participants. He maintained a good relationship with his teachers. One example that he cited is as follows:

“I could not pay the exam fees during my last exam. Then the teachers allowed me to pay the fees later. They issued my admit card without the fee and asked to deposit the fees later when I was ready.”

The relationship with teachers was an essential reinforcement regarding regular participation at class lectures and other activities at the academic institute.

4.5 Theme five: Finding other productive roles

Finding other productive roles was one of the essential themes described by all of the participants. This theme identified social participation and other social activities, comparing pre- and post-injury status. The main occupation of every participant, in both pre- and post-injury periods was that of the student. Besides, most of the participants reported some other engagements that occupied their time. These are described in Table 1 and include volunteering, paid work, provision of private tuition, social activism, writing and basketball playing. Three sub-themes were stated with respect to finding other productive roles: 1) Volunteering; 2) Providing private tuition; and 3) Social activism.

4.5.1 Volunteering

Volunteering appeared as the most reported activity among these findings. Volunteering works included working with organisations for a person with a disability, non-government organisations, community organisations, and social groups. Such engagements helped participants to overcome their feelings of loneliness and boredom. The effective use of time brought happiness to the participants as well as to other people, which was meaningful to the participants.

There were different reasons identified for the participants' volunteer participation. Daisy was involved with an organisation which works for the rights of women with disability. She

emphasised that, if a person with a disability does not stand up for themselves, there would barely be other people to do that. She mentioned that:

“I would not say I am working for others. I feel it mostly for myself. I started volunteering thinking about myself that if we the person with disabilities stand for our rights, it will be easier to make people understand that if it is done by a non-disabled person. That’s the main reason I work there and take part in their activities being invited by some other NGOs too.”

Johny was involved in a social group which mostly worked for orphan children in his local area. The group mainly operates through the social media platform, Facebook. They raise funds for orphan children and arrange different activities for them, such as sports in the local area. Additionally, arranging blood donors for people in emergency situations is another activity of this group. Johny said that he never had any such involvement before but, now, the reason he is motivated to do this activity is because, “I get peace out of this activity... I also spend my leisure time by working on it.”

Participants maintained a balance of time between study and volunteering. They reported that, although study comes first, their other involvements are also crucial for passing quality time and doing meaningful work. Haris has been volunteering on the executive committee of the village development club. He stated that:

“My main work is to assist the team in implementing the plan of government. There were no ramps in our whole union, not even in the Union office where every people need to go to seek for help. Everyone could go there except for the person with a disability. Now on my request, there is a ramp installed in the Union Office which has been very helpful for person with disabilities.”

4.5.2 Providing private tuition

Providing private tuition was mentioned as the second most reported productive activities of participants. It meant that the participants taught a group of students of different grades.

Tuition times are scheduled weekly, and the sessions are held at a participant's home. No participant was involved in such activities before injury. As a result of their SCI, most of the participants are now homebound and, therefore, providing private tuition helps them to spend their time effectively. Besides, this new role gives them financial independence and respect in society, which is valuable to them. Sofia stated that:

“I took it as a leisure, initially, when I started doing it. I enjoy their company and teaching them... But now it is more than that and I pass quality time doing this work. It feels good to pass the time.”

Additionally, it is a source of income, which marks them as an essential member of the family, as they financially contribute. They also feel that, by providing private tuition, they are recognised as an “important person” in the community. Debbie stated that:

“The guardians of my students want me to continue to teach their children which motivates me and make me feel important ... It (providing tuition) is helping financially as well. My family does not have any other income source except for some financial assistance provided by my maternal uncle. When I did not do this teaching, we did not have any income source. When I started, my income source increased. This extra earning is helping to improve my family's status a lot.”

Haris is running a coaching centre near to his home, which initially started as a private tuition activity. He said,

“I started teaching three students at home... now there are 100 students in the coaching centre.”

He has appointed teachers in the centre for effective teaching, which has now added more value to his life as a social entrepreneur.

4.5.3 Social activism

Some other participations mentioned social activism and writing. Ronnie was waiting for his first poem book to be published in the next few months (from the date of his interview). He is vigorously involved in activism, such as raising awareness about disability, specifically SCI and its impact, and once debated on the importance of the education of students with SCI, with mass people in his local area. Ronnie said that:

“When I arranged the debate, my focus was to make people aware of the academic participation of students with disability. I wanted to share the barrier that we face. So, I explored a lot about it through internet search and made a PowerPoint presentation after the debate. I also emphasised that little help and accessible environment can increase their participation like any other student. It was a new world for those audiences. They appreciated a lot.”

4.6 Theme six: Accessing home and community living

The participants in this study described different features of home and community living. The physical environment was the most commonly reported barrier in the home and the community. Three sub-themes were reported: 1) Physical environment at home; 2) Inaccessible public transport; and 3) Participation in community events and a relative's home.

4.6.1 Physical environment at home

The home was explained as their current dwelling place. Most of the participants were living with their family, others were staying at the university residential service and others at the residence provided to them by work. The home environment was described, including the inside and outside of the home, particularly the living area, the toilet and the shower space. Before the injury, none of the participants lived in an accessible area. Depending on their assistive devices, some of them modified their home environment later while some of them could not afford to do so according to the required standard.

Russell and Ronnie reported that they had to build a new house because it was not possible, at all, to modify their accommodation. Russell built a separate room and connected it to the main house, whereas Ronnie needed to build an entirely new accommodation. This initiative, however, made their lives more comfortable. Ronnie stated that:

“Since we have a big space at home, so my accommodation was built nearby the main road for my easy travel. My rooms come first when you enter the house. There are two bedrooms with the dimension of 13*13 ft. and one bedroom with 8*8 ft. I live in the smaller one and there is a single sized bed too. The toilet is a big one of 8*8 ft. in dimension. There are both low commode and high commode... There is both fountain shower and motorised water supply. So, this wheelchair friendly environment is helpful for me and I do not depend on anyone.”

The newly built living space for Russell allowed him to perform his self-care independently, except for showering. As there was no motorised water supply, he needed assistance to carry water. He said that:

“There is a tube well at home near to my shower area. So, if the water is carried, I can do the rest of the things independently, and that makes me happy”.

Participants discussed how an inaccessible home environment is a barrier for them. Sofia said:

“The house is made of woods, so if we remove it (door thresholds), it will be misfit with the design of the home. As well as the removal of that threshold will create difficulty in the structure of the house. My mother helps me to pass that. I depend on my mother for moving inside the house although... I can move with the wheelchair in the surrounding area of the home.”

Eva shared the strengths of having a modified environment for her at home. Her family removed all the thresholds inside the house and installed a ramp, following the measurements as advised by the CRP. Although most of the participants reported some form of modification inside and outside of the home, by installing a new ramp, removing thresholds, and modifying bed heights, most of the participants reported having an inaccessible toilet and shower space. Participants mostly reported that it was cheaper to make a new toilet instead of modifying the old one at home, however, most of them could not afford to modify the toilet, as it is expensive. The wheelchairs that they acquired at discharge are made in the CRP metal workshop. These wheelchairs are designed in such a way that the patient can place a pot under the seat. So, they usually position the pot by replacing the cushion during the toilet task and then seek help from family with cleaning it. Syman explained that he cannot use their regular toilet and said that:

“I do it (toilet) by fitting a pot with my wheelchair... I mean I sit the way I am sitting now. I just replace the cushion with a tube and adjust a pot below it... There is a separate space near tube well and bathroom, I sit over there... I cannot use the toilet

because it has no required set up for me. I cannot go there on my own. It is small and narrow for my wheelchair... So, it is impossible to use that one and hence I chose this alternative way.”

The other participants, except for Ronnie, Daisy and Eva, are following the same process for toilet tasks.

4.6.2 Inaccessible public transport is a barrier

Inaccessible public transport was described as a barrier by all participants. They regretted being unable to travel to places, even inside the country. Regardless of whether the transport was used for academic purposes or general mobility, the inaccessibility made the participants dependent on a carer.

Although Neil did not face any significant functional difficulty, he was not confident with travelling far away from home. Sammy experienced the same. Although Sammy was using an elbow crutch, he never felt safe in his daily movements using local transport. He said that:

“The roads are not properly constructed and there are holes over the road which makes the transports very bumpy during movement. Besides, no transport is designed in such a way that is risk free for us. This is one of the most significant reasons that discourages us to go out. Instead we prefer to stay at home.”

Daisy wanted to travel to all the 64 districts of Bangladesh, however, it was challenging for her to travel to her own local home in a separate district during the Holy celebrations, such as during Eid. Daisy mentioned that:

“It is only the Eid when I go home, but I cannot go and celebrate Eid with my family every year. Someone needs to carry me to transfer into the big vehicle like bus. I have

a cousin who helps me. However, I cannot go home if he leaves early because I cannot trust any random people to carry me in a bus. It is a safety issue... I wish we had accessible buses! If the buses were accessible, I could have afforded myself to go home independently.”

4.6.3 Participation in community events and staying at relatives’ homes

The regular community events described by the participants were attending concerts and watching sports in local areas, and other multicultural events. The participants participated in these events mostly as audience rather than as performers. Syman talked about participating in community events and said that:

“I watch sports events arranged in our local playgrounds. If there are any community events arranged by the locals, I usually go to the events with my friends. I try to enjoy event like concert if there is any program near my place”

Participation in community events was a positive experience for other participants, as well. For example, Johny and Russell regularly enjoyed sports events with friends in their local area.

Staying at relatives’ places is a common practice in Bangladesh. As a result of SCI, however, most of the participants had to stop this practice. Sofia, on the other hand, was still attending relatives. She stated:

“I go to my uncle’s house most often. My mother stays with me. She is the reason I go there as she wants me to accompany her. Nevertheless, I feel refreshed afterwards, and I like it too.”

4.7 Theme Seven: Impact of the social environment

Theme Seven illustrates the impact of the social environment on the lives of students with SCI. The social environment has both positive and negative impacts. The aspects were described in five sub-themes: 1) Disability is stigmatising: Feeling different; 2) Experiencing negative responses towards disability; 3) Women are doubly discriminated; 4) Family support; and 5) Social support.

4.7.1 Disability is stigmatising: Feeling different

The students in this study reported that they experienced stigma, and that this was one of the biggest challenges to their academic participation. They stated that, as a result of SCI, they had felt embarrassment, shame, fear and less acceptance in family and society. Most of them said that no other person was living with physical disability around them in the community and at the academic institutes. Initially, it was a great challenge for them to move around in the community and to start study. Being the only person with a disability contributed to them feeling different from others. Ronnie mentioned that the feeling of being different was a barrier to his initial participation at college. He stated that:

“I did not attend the classes in first few days... I had a different feeling that I used to go to the college by riding a bike and now I would go there on a wheelchair (smile)... I would go to that college with a wheelchair at such a young age. People are full of life at this stage, also it is an age when they start dreaming colourful. So, overall, I felt so alone.”

Millie was the only student with a disability at her college and had a similar experience, as well. She was able to walk with an elbow crutch, yet she had the feeling of being different. She said:

“In the college crowd, I was the only student with a disability which created an awkward feeling in me. Though none used to tell me anything, I had a fear of moving in the crowd and climbing the stair.”

Sofia’s experience added another perspective. She had developed an inferiority complex, which impacted her confidence and social participation. She described the feeling that:

“I only communicated with the people at home. I do not want to go out and communicate with others (extended family members) ... It is like an inner feeling. I feel ashamed. I think to myself who would I call and what they would think? That is why I do not do It”

4.7.2 Experiencing negative responses towards disability

Participants described the feeling of being the subject of curiosity, by being the only wheelchair user in the neighbourhood. This curiosity mostly brought negative experiences, not only from the community, in general, but also from family members, the academic institute, friends and relatives. They reported that they had gone through these kinds of situations, even after sharing their experiences of injury and complications with these groups of people. Some people changed their attitude after knowing the details, yet some people regard disability as a curse and believe that it is a result of the injured person’s sin.

Russell stated that:

“Whatever I do, people see me differently. My eldest brother says I am a burden to the family. A few distant family members and neighbours keep talking about the negative aspects whatever they have on their mind. They ask me questions like – Who will earn your bread now since you are a person with a disability. How would you

manage when your father passes away? I cannot control myself when I keep hearing these questions. This kind of attitudes annoys me very much.”

The stigmatised attitudes of other people were a shock to Neil. Neil walks with a minor foot drop. It creates little difference in his gait pattern from people with a regular gait pattern, yet friends negatively judge him at college. He said, “Sometimes, they pass negative comments when I take time during stair climbing”. Even this type of minor paralysis results in people showing a negative attitude. Johnny and Robin described how people in the community bullied them and criticised their parents, as well, in relation to why their parents were still paying for their education. Robin explained that:

“There were a lot of people around who teased me before exams, saying that I will never hit a good score. They even discouraged me, saying that as I faced an accident why I should even continue studying... My mother and brother used to get angry sometimes when people showed too much curiosity about me. Sometimes I feel agitated inside.”

Millie added more on this perspective. She said that:

“I had the injury on Saturday. I was fallen from a tree. There are people in village who believe that Saturday brings the bad news only. Therefore, as I had fallen on a Saturday, they thought that the Genes had done it. It was my bad idea to climb a tree on Saturday. I must have been pushed off by the Genes.”

Debbie encountered this unexpected response and was very shocked when she was asked by a teacher, “Why did you get admission at college if you are facing so many difficulties?”

4.7.3 Women are doubly discriminated

Almost every female participant reported that they were discriminated against twice; first, as a woman and then, second, as a woman with a disability. They faced double discrimination, mostly when they started studying again. Daisy emphasised that returning to study was a success for her, being a woman with a disability, because women with disabilities are more likely to be neglected. She stated that:

“I would consider the biggest success as to continue study. Now I am an educated person. I am one of those who are underprivileged in our society. Yes, that is how we are labelled. I think I am progressing well although being categorised as underprivileged of society. If you think about the grassroots of Bangladesh, still the women are falling behind. They fall behind even more when suffering from a disability.”

Participants stated that some people believe that only sons are a blessing to parents. So, when the daughter of the family lives with a disability, it must be a curse. Sofia added:

“People come from different villages with different level of curiosity. They bully me for my disability. It hurts more when they say as I am a girl child of my parents, so my disability is a result of my parents committing sins. Therefore, I should stop getting education... I have decided not to respond to them. Because it is hard to make them understand, they prefer to stick in their prejudice.”

Participants reported more discriminatory behaviour and prejudices around disability in rural areas than in urban areas. Millie had to move to a new place to avoid such instances. She explained:

“They (villagers) do not accept the person with the disabilities. They were more aggressive in attitude as I am a female as well. Let alone the person with disabilities, they keep teasing more the women with disabilities and did the same to me. It was hard for me to continue study there. Eventually, I had to move to Dhaka from my village.”

4.7.4 Family support

All the participants described family support as their primary source of inspiration and one of the main reasons that they continued their education. Ronnie mentioned:

“When I almost decided to drop out of the study, my elder brothers and my father started to make me understand. They motivated me. my elder brothers have more contribution to return to my study than my parents do.”

Russell reported the same, stating that, “I am here because of my immediate two elder brothers.” Eva suffered from depression for a long time after her discharge from the CRP. She stated that, “Despite that bad time, I have managed to start studying again only because of my parent’s support.”

a) Social support in the community

Social support encompassed support from relatives and neighbours. Participants went through mixed experiences with this group of people. The community showed a discriminatory attitude towards participants, however, participants reported having a supportive community, as well. Haris shared his positive experiences with relatives and neighbours, who were very cooperative with him. He stated that:

“The road that I used to go to the college was poorly constructed. My neighbours found that it was hard for me to travel everyday as the road was very bumpy. So, a few of them met the local administration and requested to construct the road. On their request, the administration took the action immediately. It was very helpful for me later. My community is very supportive and always keep inspiring me.”

Participants also shared the experience that, while the community was initially non-cooperative, with time, the community changed its attitude when it saw having a disability could not stop the participants from doing what they want. Debbie reported that:

“My community used to neglect me in the first place... Nevertheless, when they saw I started providing private tuition at home and at the same time, continued my study, they became more positive and supportive. It feels good now.”

In summary, positive community experiences enhanced the participation of students with SCI.

Chapter Summary

The aim of this chapter was to present the findings of the study. The chapter described seven themes, with sub-themes under each of them, using interview quotes to illustrate their meaning. The themes and sub-themes were outlined in such a way to tell the pre-injury and post-injury experiences of 15 Bangladeshi students with SCI returning to study, in a chronological way.

Chapter Five

Discussion

This chapter discusses the study findings in relation to existing relevant literature and outlines the new perspectives that the study has added to the field of research and practice. This research is the first study, to date, addressing the lived experiences of returning to study for adult students with SCI in Bangladesh. Their lived experiences included seven themes: how the accident changed their life; values and benefits of returning to study; the influence of the academic environment on student participation; meaningful relationships at an academic institute; finding other productive roles; accessing home and community living; and impacts of the social environment. These perspectives can provide valuable information about the current situation for adult students with SCI in Bangladesh, identify gaps in current research knowledge and inform plans to deliver rehabilitation for this population. Each theme is discussed, relating it to relevant literature. Then, the implications for practice, along with the strengths and limitations of this study, are presented.

5.1 Accident is a critical life event

In this research, SCI was identified as a critical event in the participants' lives. It significantly impacted their lives by restricting their mobility and causing difficulties with self-care. It also impacted their social participation and, in some cases, resulted in lost relationships. A critical review, conducted by Barclay and colleagues, found that adequate personal assistance, social support, appropriate assistive devices and OT input increased the social participation of persons with SCI (Barclay, McDonald, & Lentin, 2015). The current research participants felt that having SCI and experiencing restricted mobility was a critical life event, as the built environment then became a barrier for their social and community participation. This is

similar to the findings from Barclay et al. (2015), who discussed the barriers to community participation for people with SCI, which included inaccessible transport and an inaccessible physical environment. The narratives provided by the participants in this research described three main stages – independent pre-injury life, critical post-injury period, and returning to study by developing resilience. These stages are similar to those outlined by Clifton (2014) in an auto-ethnographic study. Clifton (2014) described how hope and determination facilitated his resilience to return to study, which was categorised as the most significant success in his life. He emphasised that having a postgraduate degree helped his positive adjustment during the period of transition. Participants in this research emphasised the importance of having a positive mindset to achieve goals, such as achieving education. In another article, Clifton identified how happiness can be achieved after SCI by connecting it to the science of positive psychology, as described by the ancient scholars, Aristotle, Aquinas and MacIntyre (Clifton, 2013). He explained how making a deep connection to the science of positive psychology can help a person with SCI overcome the barriers and achieve goals, which can be an inspiration to others person on a similar journey (Clifton, 2013).

5.2 The value and benefits of returning to study

Participants in this research identified the value and benefits of returning to study. Education was reported as important to them, as it enabled them to be recognised as a valued person in society and provided them with an identity. In addition, they felt that they could make a positive impact in society by being a role model for other students with SCI, which they valued. Given that the OPHI-II (Kielhofner et al., 2004) is informed by the theoretical framework of the MOHO, it is not surprising that these findings support MOHO's claim that the everyday things of importance to people are "those things that provide a person with meaning and identity" (Taylor & Kielhofner, 2017,p.24). The results of the current research

are also consistent with a study conducted by Paul (1999). Paul (1999) found that college education was important to adult students, who are wheelchair users, for making academic and personal achievements. He also added that the participants were more motivated to achieve higher education to prove their worth and break the misconceptions of the community about their inability as a result of their disability. However, this research extended the value and importance of education by highlighting that education develops students' communication and social interaction skills and facilitates overcoming depression by meaningful engagement in education.

This current research found that participants viewed the benefits of achieving an education as strongly related to getting a job in the future. This is consistent with several other studies which found that achieving higher education and obtaining a job were positively related to each other (Anderson & Vogel, 2002; Holmlund et al., 2017; Jang et al., 2005; Lidal et al., 2007; WHO & ISCoS, 2011). For example, Anderson and Vogel (2002) supported the findings that college education was significantly associated with employment, for both the person with tetraplegia and paraplegia, while Krause et al. (2008) reported that the more educated the person with SCI, the more likely they were to be employed. For participants in the present study, at all levels of education, the ultimate purpose of gaining an education was to secure a job to gain financial independence. The findings emphasised that this was important, as participants reported that, since their injury, they were financially dependent on their family.

In Bangladesh, to be financially independent, an alternative to getting a job is to start a business, for which education is an essential requirement, as well. The People's Republic of Bangladesh provides an amount of TK 700 (approximately AUD 12.22, according to the international currency rate on 12 February 2020) of monthly allowance for a person with a

disability (Ministry of Social Welfare, 2015). Nevertheless, no participants interviewed in this study had accessed these funds. While the average wage is expected to reach 15100.00 BDT/Month by the end of 2020, it is a very minimal income and the process for accessing the fund was reported as a complex one. Participants also reported that there is a 10% quota for persons with disabilities in the government job sector of Bangladesh, which makes them hopeful of securing a job in this sector (Ministry of Social Welfare, 2015). Ahmed et al. (2018) recently reported, however, that finding employment for a person with SCI was ‘barely possible’, due to mostly lower levels of education and/or lack of suitable vocational training in Bangladesh. In 2013, the welfare legislation, the *Rights and Protection of Persons with Disabilities Act 2013*, was introduced, which mandated the issuing of national identity cards, enrolment in regular schools, reservation of seats on all forms of transportation, equal opportunities in employment and protection of inherited property rights for persons with disability. To date, however, this act has been unsuccessful in practical intervention (Sultana, 2010).

The World Health Organisation and the International Spinal Cord Society (2011) reported that there was not enough evidence about the education participation of persons with SCI in low- and middle-income countries. Bangladesh is one such country, where low education is the second barrier to employment for a person with a disability, after the inaccessible environment (CRPD Bangladesh, 2015). However, this report included all kinds of disability, and there were no specific findings related SCI.

5.3 Influence of the academic environment on student participation

Students with SCI, in this research, reported encountering a wide range of physical barriers at their academic institute, which had a significant influence on their education participation. The most commonly mentioned barriers were in the areas of accessing academic facilities,

such as entrances, classrooms and the library, using the exam venue and doing self-care activities while studying. These findings are similar to these studies which have included students with SCI (Mulcahey, 1992; Paul, 1999; Sandford et al., 1999). These studies were, however, conducted in the 1990s, and no recent work was found in this specific area.

The present research found that accessing exam venues was a particularly significant barrier for students. During the milestone exams in Bangladesh, such as year 10 in school and year 12 in college, the exams are held in a different academic institute from the students' own institute. This research found that no explicit instructions were provided for the students with SCI, or other disabilities, to avail the administrative supports from authorities regarding arranging special accommodations for them. Administerial actions included informing the exam controlling authority to request the necessary or specialised arrangements for students with SCI, such as hiring a writer for students with tetraplegia and arranging wheelchair-accessible classrooms. According to the *Rights and Protection of Person with Disabilities Act 2013*, students with disabilities are to be allocated an additional 30 minutes of extra time in exams (Ministry of Social Welfare, 2015). Participants in this research, however, reported inconsistency or lack of cooperation from the exam authority on this matter.

Participants in this research reported that having no accessible toilet in academic institutes significantly impacted on their class participation. Students reported that sharing information about their bowel and bladder dysfunctions was too private to share with others, as people were not aware of these issues. As a result, most of them used to leave the academic institute, even before their classes were completed. The physical inaccessibility of the toilets in educational settings has also been described as a challenge by students with SCI in previous research (Mulcahey, 1992; Sandford et al., 1999).

Another architectural barrier reported in this research was the inaccessibility of classrooms. Most participants reported not having a lift at their academic institute and, therefore, classrooms were relocated downstairs to accommodate the wheelchair-user participants. A few participants also reported that their academic authority did not agree to change the classroom and, as a result, they never attended the class lectures and only appeared for the exam. Sandford et al. (1999) also identified that the relocation of classrooms impacted students' participation and relationships with friends. As most of the students in this research could not attend their classes due to architectural barriers, they collected the class materials from friends and a few of them took online lessons to substitute for attending classes. To do this, they used YouTube resources, such as 10 Minute School and Onnorkom Pathsala, which are locally popular online education platforms in Bangladesh (Sadiq, 2015; Sohag, 2012). Several other studies have reported that architectural barriers significantly restrict the participation of students with a disability (Egilson & Hemmingsson, 2009; Egilson & Traustadottir, 2009; Prellwitz & Tamm, 2000), but none of these studies included students with SCI.

In the present research, restriction on participation in co-curricular activities, sports and annual excursions were reported by participants, as a result of environmental barriers. While some other studies highlighted the importance of designing extracurricular activities, sports, drama, field trips and music events for students with disability, students with SCI were not included in these studies. (Asbjørnslett & Hemmingsson, 2008; Doubt & McColl, 2003; Lightfoot et al., 1999).

5.4 Meaningful relationships at the academic institute

The participants emphasised the importance of their relationships with their friends, classmates and teachers at the mainstream academic institute, and reported both positive and

negative experiences with these groups of people. This is consistent with several other studies that have reported the importance of having a meaningful relationship with friends, peers, teachers and other staff at the academic institute (Dockett, 2004; Doubt & McColl, 2003; Lightfoot et al., 1999; Sandford et al., 1999). Participants in this research defined friends as those close people with whom they shared their lives. This contrasted to those they referred to as classmates or peers, who were the people they shared their academic journeys with.

This finding was similar to another study where the participants referred to the classmates as their peer group, and friends were regarded as close people, which was not only limited to their academic journey (McMaugh, 2011). Although participants reported mostly positive relationships, some of them encountered negative ones, as well. Negative experiences with friends involved negative attitudes, losing friends, fear of bullying and harassment, and unwelcoming non-verbal gestures. This is similar to other studies that have investigated disability-related negative experiences with friends and peers (Dockett, 2004; McMaugh, 2011; Sandford et al., 1999). However, these studies involved students with chronic illness or disability without specifying the diagnosis.

The findings from the present research reinforce the importance of positive friendships. Peer relationships were also described as a motivating factor in two other studies involving students with SCI (Prellwitz & Tamm, 2000; Sandford et al., 1999). This research reported that participants continued to maintain their long-term relationships with friends, even after the injury. There were some new dimensions in these study findings, including that friends were helpful, especially in buying books and necessary stationery items for academic purpose. Additionally, regular meeting with friends added fun in the lives of participants.

In this research, participants reported that their relationships with teachers were one of the most important influences on their participation in class lectures, exams and other co-

curricular activities at the academic institute. Positive and negative experiences with teachers were reported. Teachers were viewed by participants as lacking knowledge about SCI, which impacted on whether they fulfilled their responsibilities, such as facilitating environmental modifications at the academic institute and taking measures to include the students in classes and exam venues. Lack of knowledge by teachers about SCI health-related issues was also reported by Sandford et al. (1999), while some other studies have reported the lack of knowledge among teachers of physical disability, in general (Asbjørnslett & Hemmingsson, 2008; Lightfoot et al., 1999). These above-mentioned studies also found that students with disabilities perform well academically if they are accommodated with the necessary adjustments at the academic institute. Both of these articles suggested that publishing the academic competency or good results of students with disabilities in the school magazine could help with raising awareness about the ability of students with disability and/or SCI. While our study participants did not mention any such constructive solutions, participants viewed their teachers as behaving more positively once they realised that students with SCI were getting results as good as other non-SCI students. Nevertheless, as most students in this study continued home-based education, due to the barriers at the academic institute, they reported teachers were mostly cooperative over the phone.

5.5 Finding other productive roles

Productive roles, such as volunteering, providing private tuition and social activism, were identified as a form of social participation and community engagement by several participants in this research. These productive roles were reported as being vital to them. Social participation has also been recognised as being important for a person with SCI in other studies (Barclay et al., 2015; Kennedy, Lude, & Taylor, 2005; Mpjm, Yavuzer, Ergin, Weitzenkamp, & Gg, 2002; Price, Stephenson, Krantz, & Ward, 2011). Volunteering was

viewed as a way for participants in this research to meaningfully use their time and, particularly when participation in classes was irregular or not possible, volunteering facilitated participants to use their time effectively. Several other studies have explored the importance of formal or informal volunteering performed by the person with disabilities (Balandin, Llewellyn, Dew, & Ballin, 2006; Roker, Player, & Coleman, 1998; Shandra, 2017). These studies have described volunteering as a means of social participation, a way to meaningfully use time, and a way to prove one's worth as a person with a disability. In addition, private tuition provided another productive role and form of meaningful engagement for some participants. This new role also gave these participants financial independence and a feeling of respect and recognition in society, which added value to their lives.

Some study participants in this research were social activists. Social activism was viewed by these participants as a crucial productive role in raising awareness about disability, including raising awareness about the rights and abilities of students with SCI. Participants felt that social activism facilitates the person with disability to be more acceptable in society and helps people, generally, to be desensitised and to better visualise their ability. Evidence also suggests that social activism by the person with disabilities has strongly influenced disability-related policies in the United Kingdom (Barnes, 2007).

5.6 Access to home and community living

The importance of having an accessible physical environment in the home, as well as to transport and the community, is highlighted by the findings of this research. In this research “home” was explained as a participant's dwelling place after discharge from hospital. Making a wheelchair-friendly home is not a common practice in Bangladesh. Participants reported that the occupational therapists, during inpatient rehabilitation and while in the accessible

environment at the rehabilitation centre, inspired participants to modify their home environment with local resources, to make it more accessible. This increased their independence in daily activities, in a similar way as has been reported in other evidence (American Occupational Therapy Association, 2008; Price et al., 2011).

The findings also suggest that inaccessible transport significantly impacted on students' participation in regular social participation, their studies and holiday travel. For example, participants reported that Bangladeshi buses tend to have a narrow door, unlevelled entrance from the footpath, no ramp and no specially designed seat for wheelchair users. The importance of accessible transport, including public transport, was also highlighted in a literature review by Barclay et al. (2015). *The Rights and Protection of Person with Disabilities Act 2013* in Bangladesh recommends that 5% of seats in buses are designed for and allocated to persons with disabilities (Ministry of Social Welfare, 2015), yet participants in this study reported that no transport was accessible for them. This highlights the gap between policies and the challenges of implementing them in real, everyday situations.

When travelling to places and attending an academic institute regularly, the participants described renting local transports, such as autorickshaws and vans, which are expensive. Evidently, inaccessible transport not only restricted their participation, but also created a financial burden on the family. This was a unique finding of this study, and an important one, given that most of the participants interviewed in this research were from rural areas. They reported that their participation in community events, such as watching sports in local areas, attending multicultural events, and visiting relatives, was disrupted by having an inaccessible environment. Similarly, a recent study in Bangladesh identified that persons with SCI in rural areas face more activity limitations, due to the inadequacy of existing infrastructure, such as architectural barriers in the community (Kader, Perera, Hossain, & Islam, 2018).

Our research found that having an SCI disrupts the interpersonal relations with relatives, which is an important component of community living. Another study also explained that having SCI restricts visiting relatives, due to the disability, which is a long-term consequence of SCI (Fougeyrollas & Noreau, 2000). Two other studies reported that community interaction increased the community participation of the person with SCI, which was consistent with our findings (Tate, Kalpakjian, & Forchheimer, 2002; Ward, Mitchell, & Price, 2007). It was likely that the wheelchair user participants faced more barriers for environmental inaccessibility than the ones using other assistive devices, such as the elbow crutch. Wheelchair user participants, therefore, tend to have less access to home and community living.

5.7 Impact of the social environment

In this research, the social environment played a vital role in the academic participation of students with SCI. There is a growing body of literature that recognises the importance of the social environment for social participation of people with SCI or other disabilities (Craig, Nicholson Perry, Guest, Tran, & Middleton, 2015; Kennedy et al., 2005; Price et al., 2011). This current research also described how the social environment could both positively and negatively impact on the life of students with SCI. The negative aspect of the social environment was the stigma of having SCI, while the positive aspects were the family support and social support in the community.

Stigmatising social attitudes from people in the community towards those with SCI were a focal point of discussion in this research. Stigmatised attitudes from society have been reported in several other studies (Barclay, Lentin, Bourke-Taylor, & McDonald, 2019; Barclay, Lentin, McDonald, & Bourke-Taylor, 2017). In this research, participants also experienced the stigmatising attitudes of other people in their community and relatives. They

reported that they were the subject of curiosity to society, were ignored and felt excluded from the *general* world. Some other studies that have included people with SCI had similar findings. Participants in these studies reported that people in the community think that, along with their paralysed limbs, their brains have stopped working (Barclay et al., 2017; Barclay, McDonald, Lentin, & Bourke-Taylor, 2016). Other studies that have included students with disability suggest that, by being the only student with a disability in an academic institute or a resident in the community, they develop the feeling of being in a minority group and face ignorant attitudes, bullying and harassment from peers or friends (Lightfoot et al., 1999; McMaugh, 2011; Ntombela, 2013; Prellwitz & Tamm, 2000). This current research also emphasised the feeling among participants of being the only student with a disability at their academic institute and how this has excluded them from general engagement with academic activities.

Students with SCI described developing an awkward feeling of being different from others, which has been reported by several other studies (Bailey, Gammage, van Ingen, & Ditor, 2016; Hearn, Selvarajah, Kennedy, & Taylor, 2018; Kisala et al., 2015). It has made them feel embarrassed, shameful and less accepted in family and society, and this feeling has disrupted their performance at the academic institute. Mulcahey (1992) supported this finding which included only students with SCI. The authors found that these feelings impacted predicants' self-identity, was emotionally overwhelming and reduced their QOL yet was quite common among this population (Bailey et al., 2016; Hearn et al., 2018; Kisala et al., 2015; Manns & Chad, 2001).

In this research, female students with SCI described that they also faced gender-based discrimination by their family and community, in relation to achieving an education. Culturally, it is still a common expectation that women will not achieve much education, and

rather be expected to be homemaker. The women students with SCI in this current research faced the same stereotypical attitude. They reported that family and community discouraged them to acquire further education, as they thought that a woman with a disability should not aim higher. UNCRPD (2007) has encouraged the protection of rights of all people with disability and, while Bangladesh was one of the first countries to ratify this convention in 2007, it has failed to implement it in practice (CRPD Bangladesh, 2015). A report on gender inequality stated that women in Bangladesh are still facing discrimination, in terms of enrolment in higher education, accessing health facilities and in employment, even in the case of women without a disability (Ferdaush & Rahman, 2011). However, recent research in Bangladesh, which included women with SCI, found that they were being excluded from formal education, the workforce, public facilities, marriage, community activities and social groups (Quinn et al., 2016).

On the contrary to the negative social impact, family support and social support in the community played a positive role in participants' lives. In the Model of Human Occupation (MOHO) theoretical framework (Taylor & Kielhofner, 2017), the environment includes both physical and social elements. For participants in this study, these social elements focus on "Family", consisting of the parents, siblings, spouses of siblings and nephew/nieces, and "Community people", that is, relatives, neighbours and residents living around the immediate neighbourhood. Consistent with the MOHO framework, participants in this study stated that having a supportive family and community around them facilitated their student participation.

5.8 Implications for rehabilitation practice

Taking into consideration the above discussion points, the implications for practice for students with SCI at the CRP in Dhaka, Bangladesh, will be now be considered.

The findings suggest that occupational therapists should start educating students with SCI, during the early stage of in-patient rehabilitation at the CRP, on the barriers, facilitators and other necessary aspects of returning to study. Recent studies have supported the approach of starting vocational rehabilitation (VR) service during the early stages of in-patient rehabilitation, to facilitate employment outcome (Johnston et al., 2016; Middleton et al., 2015). These studies were conducted on a VR program known as InVoc, a pilot intervention project based in New South Wales (NSW), Australia, where the patients with SCI received VR during inpatient rehabilitation. InVoc focused mainly on the importance of the early introduction of VR for getting employment after SCI, yet the programme was found to assist students with SCI returning to their previous education (Johnston et al., 2016; Middleton et al., 2015). Therefore, providing education to students with SCI at the early stage of rehabilitation at the CRP may facilitate them with making decisions about their return to occupation soon after discharge. It will also help them in planning their next steps, such as communicating with the authority at the academic institute and discussing their accessibility needs.

Introducing and creating a connection between successful students with SCI living in the community and patients in the in-patient rehabilitation program is also recommended. This can be done by introducing a formal peer-mentoring project. Previous research has identified that peer mentors play a significant role in facilitating self-efficacy and preventing rehospitalisation and medical complications (Gassaway et al., 2017; Ljungberg, Kroll, Libin, & Gordon, 2011). Another study identified that peer supporters make people with disability feel optimistic. The earlier the mentees met their mentors, the sooner the mentees (people with disability) were able to imagine their potential to take part in society (Barclay et al., 2016). Developing a peer mentoring service as part of rehabilitation services, by including

the successful students with SCI as peer educators, would, therefore, strengthen the rehabilitation programs offered to people with SCI in Bangladesh.

The CRP generally runs a monthly education session for people with SCI, covering their secondary complications and environmental modification needs at home. The successful students with SCI can also be invited to these sessions, to share their lived experiences. In this way, the successful students could offer themselves as “role models” for the patients at the in-patient rehabilitation service. Another option could be making videos about their lived experiences of academic participation, so that the videos could be used in the education sessions.

The current advocacy service of the CRP is offering a service to the students only when they ask for it. The team consists of the advocacy and networking officer of the CRP, social workers and occupational therapists. It can be improved by including successful students with SCI in the team, who could also work as advocates to raise awareness about academic participation among the members at the academic institutes. It is also important to work with local education authorities and local communities, to educate them on issues of environmental accessibility. Educating the teachers and other students about SCI, at the academic institutes where students with SCI are required to attend, is essential.

5.9 Strengths and limitations of the study

5.9.1 Strengths

Participants of this research were of different demographical backgrounds, which was a key strength of this research. There was a mix of types of paralysis, levels of study, gender, linguistic backgrounds within Bangladesh, and urban and rural areas of residence, which was reflected in the richness of the data. The gap between discharge from hospital and return to

study also ranged between one and three years, which added different perspectives on time after discharge. The results highlighted the gaps in the current rehabilitation and educational practices in Bangladesh, which impact on the academic participation of students with SCI. This study has identified the occupational therapy practice gap and provides insights to strengthen future practice.

The study was conducted using a qualitative methodological framework, with a strong evidence base; a step-by-step explanation of the methods followed throughout the study was provided. Participants provided rich data, following the OPHI-II interview guide. The OPHI-II is recommended to use with participants over the age of 12 years and was recommended to use in the SCI rehabilitation program, as a perfect fit for this study. Through the interactive interviews, participants shared the details of their life history experiences and how having SCI influenced their lives and academic participation (Kielhofner et al., 2004).

My clinical OT experience helped me to understand the depth of their responses and to develop probing questions. As the interviews were performed at participants' dwellings, the student researcher had the opportunity to see the participants in their own environments. The observations from the environments were recorded in the reflection journal of the student researcher. Eventually, the findings from the study reflected the actual lived experiences of students with SCI, which will help the reader to better understand each participant's circumstances.

5.9.2 Limitations

One of the identified limitations of this study was the relatively small number of participants with tetraplegia. This restricted the study's ability to effectively portray the experiences and difficulties faced by students with tetraplegia. Another study, however, identified factors related to the return to study of students with SCI in Bangladesh, and reflected the numbers

of tetraplegia and paraplegia. The study identified that there were fewer students with tetraplegia than paraplegia who have successfully completed at least one milestone after having experienced SCI (Ema et al., 2018). Additionally, there were more participants studying in rural areas than in the urban areas. People living in rural areas of Bangladesh are disadvantaged and have generally lower voice than urban people. Since the participants recruited in this research were drawn from the CRP database, this limits the transferability of the findings to other settings. On the other hand, the CRP is presently the only specialised rehabilitation centre for people with SCI in Bangladesh (Quadir et al., 2017).

The interviews were conducted in the participant's first language, Bengali, transcribed in Bengali and translated into English, later. This was a time-consuming process; it also created a possibility, in some cases, for losing a participant's meaning or for not finding a word in the English language to exactly reflect the meaning a participant had intended. The student researcher is bilingual and tried to keep as close to participants' intended meanings, as possible, when choosing vocabulary during the translation process.

Chapter Summary

This chapter provides an understanding of the current findings, how they contribute to knowledge about returning to study post-SCI, and their implications for rehabilitation practice and services in Bangladesh.

Chapter Six

Conclusion

In summary, the current research findings portray that the lived experience of returning to study of adult students with SCI involves a mix of positive and negative experiences. There exists limited information worldwide regarding the education participation of adult students with SCI after having had the rehabilitation. Two previous studies conducted at the CRP with the SCI population provided minimal information about being a student as a pre-injury occupation and factors related to return to study, which showed there is very limited information regarding this topic in Bangladesh. The results of this research highlight gaps in current rehabilitation and educational practices in Bangladesh, which impact the academic participation of students with SCI. These results contribute to the existing body of knowledge regarding the post-injury education participation of adult students with SCI living in Bangladesh. Seven themes derived from the findings were identified, as summarised below:

- The accident has significantly changed the life of students with an SCI by restricting mobility, difficulty in performing self-care and occupation, reduced social participation and lost relationship with friends and/or beloved ones.
- Education was important as it gives them an identity and make them valued in the society
- Physical barriers at the academic institute significantly restricts their education participation
- Meaningful relationship with friends/peers, teachers and other staff at the academic institute significantly influenced their education participation
- Other productive roles such as volunteering, providing private tuition and social activism improved their social participation and increased community engagement

- Every wheelchair user participant needed to modify their home and inaccessible transport in the community restricted their community mobility.
- Stigmatised social attitude to their disability made them feel discriminated

The findings show a pathway to introduce new services at the rehabilitation centre and advocate for the policy makers to improve existing laws and legislations. The main implications are:

- Occupational therapists can introduce and emphasise work rehabilitation planning from earlier stages of the rehabilitation process, so that the transition to return to study for students with SCI gets easier. Additionally, a peer mentoring service as part of rehabilitation services, by including successful students with SCI as peer counsellors, would strengthen rehabilitation practices at the CRP.
- Occupational therapists can provide stronger advocacy to students, teachers, the community and policymakers, to enable equitable participation of students with SCI, alongside their non-disabled peers.
- The legislation and policies regarding inclusive education and rights of person with disabilities are fragmented. Therefore, policymakers need to work on improving the laws and implementation of policies with an aim to ensure equitable education participation of persons with disabilities, including those with an SCI. Systematic implementation is essential to empower the students with SCI and ensure equal opportunities with their non-SCI peers.

More research on this topic area would strengthen the rehabilitation service delivery system. Some recommendations are discussed in the next section.

6.1 Recommendation for future research

This research drew mainly on the experiences of students, and a more comprehensive understanding of these issues could be gained by the following:

1. Further research including the teachers, to find out their perceptions of teaching a student with SCI, their understandings of SCI and disability, more generally, and their levels of acceptance or willingness to teach students with SCI in mainstream classrooms.
2. Critical review of education-related policies for persons with disabilities in Bangladesh. This is important because the existing policies are more focused on students suffering from neurodevelopmental disabilities rather than physical disabilities. The study, therefore, will identify present trends and future needs in education-related policies for person with disabilities or SCI in Bangladesh.
3. Research with peer groups and friends of students with SCI, to explore their attitudes towards disability and supporting a friend with SCI in the academic institute.
4. Further research with a larger group of students with SCI, to determine the factors related to returning to study for students with SCI, so as to generalise these findings to the overall population of students with SCI in Bangladesh.
5. Research on the development of resources or guidelines, by including the recommendations for teachers to facilitate students with SCI at the academic institute.

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Appendices

Appendix A Abstracts of the conference presentation

Abstract for Poster Presentation at 2018 International Spinal Cord Society (ISCoS)

Conference, Sydney, Australia

Title: *Factors associated to return to study of students after spinal cord injury: An explorative study*

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Mohammad Mosayed Ullah (Supervisor)

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Suman Chowdhury

Senior Research Investigator, icddr,b

Md. Julker Nayan

Junior Consultant and Head

Occupational Therapy Department, CRP

Introduction: This study examined the associated factors to return to study of students with Spinal Cord Injury (SCI) after getting discharged from rehabilitation centre.

Method: In this cross-sectional study, patients who were students before injury and completed rehabilitation during 2014-2016 were excerpted from the medical records of Centre for the Rehabilitation of the Paralysed (CRP), Bangladesh. All eligible participants were contacted over telephone and those who consented were interviewed by using a structured survey questionnaire. Descriptive analysis was conducted by using SPSS (Version 20).

Result: Out of 103 eligible participants, 49 (47.6%) of them responded to the telephone interview. Participants were age range between 10-30 years, and majority (53.06%) of them were at age group of 16-20 years. At the time of the interview, there were 28 (57.2%) participants who have returned to study, of whom 39.3% returned to the same institute, 32.7% continuing study. Positive support from the family members was reported by 53.1% of respondents to be most influential factor in returning to study, whereas financial hardship (28.6%) and inaccessible environment (19.0%) were found as the two most common barriers to continue their student life.

Conclusion: Around half of the students with SCI do not return to their academic role. Emphasis to improve family attitude towards returning to study, providing financial support, and improving environmental accessibility for person with SCI in the academic institute are likely to increase resuming study of students with SCI.

Abstract for Oral presentation at 2019 Australian & New Zealand Spinal Cord Society (ANZSCoS) Annual Scientific Meeting

WHAT IS KNOWN FROM THE CURRENT EVIDENCE ABOUT THE RETURN TO STUDY OF STUDENTS WITH SPINAL CORD INJURY AFTER REHABILITATION?

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²Head and Graduate Research Co-ordinator, Department of Occupational Therapy, Monash University, Frankston, Victoria, Australia

³Senior Lecturer, Department of Occupational Therapy, Monash University, Frankston, Victoria, Australia

INTRODUCTION

Returning to school after spinal cord injury (SCI) is a primary goal of rehabilitation for school-aged children to enhance their community re-integration and future work prospects. Since evidence in this area is limited, this scoping review aimed to map the breadth of available literature and identify research gaps regarding return to study of students with SCI.

Method(S)

Electronic searches of six databases were performed for peer-reviewed articles published in English between 1990 and 2019. Key search terms included: spinal cord injury, return to study, students, education participation, academic reintegration and school re-entry. Data charting was used to summarise the study characteristics.

Result(s)

Nine articles were identified that addressed the return to study of students with SCI. These studies were both qualitative and quantitative in nature, and mostly small in sample size. The participants' ages ranged between 10-42 years. The research findings addressed four main areas: experience and benefits of return to study; environmental barriers to participation in school and extracurricular activities; the importance of relationships with school staff and friends; and strategies for integration, including peer mentoring and classroom assistance.

Conclusion(S)

This review shows that the rehabilitation programs need to explore return to school plans in more depth with young people with SCI. Future research should investigate the academic participation of students with SCI in high and low-income countries, with a focus of psychosocial, social and occupational adjustment.

Appendix B: Ethics approval certificate from MUHREC



Monash University Human Research Ethics Committee

Approval Certificate

This is to certify that the project below was considered by the Monash University Human Research Ethics Committee. The Committee was satisfied that the proposal meets the requirements of the *National Statement on Ethical Conduct in Human Research* and has granted approval.

Project ID: 17877
Project Title: Lived experience of return to study of adult students with a Spinal Cord Injury in Bangladesh
Chief Investigator: Dr Linda Barclay
Approval Date: 02/01/2019
Expiry Date: 02/01/2024

Terms of approval - failure to comply with the terms below is in breach of your approval and the *Australian Code for the Responsible Conduct of Research*.

1. The Chief Investigator is responsible for ensuring that permission letters are obtained, if relevant, before any data collection can occur at the specified organisation.
2. Approval is only valid whilst you hold a position at Monash University.
3. It is responsibility of the Chief Investigator to ensure that all investigators are aware of the terms of approval and to ensure the project is conducted as approved by MUHREC.
4. You should notify MUHREC immediately of any serious or unexpected adverse effects on participants or unforeseen events affecting the ethical acceptability of the project.
5. The Explanatory Statement must be on Monash letterhead and the Monash University complaints clause must include your project number.
6. Amendments to approved projects including changes to personnel must not commence without written approval from MUHREC.
7. Annual Report - continued approval of this project is dependent on the submission of an Annual Report.
8. Final Report - should be provided at the conclusion of the project. MUHREC should be notified if the project is discontinued before the expected completion date.
9. Monitoring - project may be subject to an audit or any other form of monitoring by MUHREC at any time.
10. Retention and storage of data - The Chief Investigator is responsible for the storage and retention of the original data pertaining to the project for a minimum period of five years.

Kind Regards,

Professor Nip Thomson

Chair, MUHREC

CC: Professor Ellie Fossey, Mrs Arifa Jahan Erma

List of approved documents:

Document Type	File Name	Date	Version
Supporting Documentation	Advertisement _ RTS _ Bangla_ Arifa - November 28 2018	03/12/2018	MS Word
Supporting Documentation	Advertisement _ RTS _ Arifa - English - November 28 2018	03/12/2018	MS Word
Explanatory Statement	Participant explanatory statement - English	03/12/2018	MS Word
Explanatory Statement	Participant Explanatory Statement - Bangla	03/12/2018	MS Word
Consent Form	Consent form - Bangla	03/12/2018	MS Word
Consent Form	Consent form - English	03/12/2018	MS Word
Supporting Documentation	Withdrawal of consent - English	03/12/2018	MS Word
Supporting Documentation	Withdrawal of consent - Bangla	03/12/2018	MS Word
Supporting Documentation	Interview Guide - English	04/12/2018	MS Word
Supporting Documentation	Interview Guide - Bangla	04/12/2018	MS Word
Explanatory Statement	Participant Explanatory Statement - V2 - Bangla	17/12/2018	Version 2
Explanatory Statement	Participant explanatory statement -V2 - English	17/12/2018	Version 2
Consent Form	Consent form- V2 - Bangla	17/12/2018	Version 2



Appendix C. Ethics approval certificate from CRP, Bangladesh



পক্ষাঘাতগ্রস্তদের পুনর্বাসন কেন্দ্র (সিআরপি) Centre for the Rehabilitation of the Paralyzed (CRP)

a project of the Trust for the Rehabilitation of the Paralyzed
Head Office: CRP- Savar, CRP- Chapain, Savar Dhaka-1343, Bangladesh
Tel: +880 02 7745464-5, Fax: 7745069, E-mail: contact@crp-bangladesh.org, www. crp-bangladesh.org

Ref:

Date:

CRP-R&E-0401- 232

02.02.2019

To
Arifa Jahan Ema

Ref: *Study Title* "Lived experience of return to study of adult students with a Spinal Cord Injury in Bangladesh".

Sub: Approval of documents for *Study Title* "Lived experience of return to study of adult students with a Spinal Cord Injury in Bangladesh".

Dear Ema,

The CRP Ethics Committee reviewed and discussed your application to conduct the research entitled On "Lived experience of return to study of adult students with a Spinal Cord Injury in Bangladesh" 27th January, 2019.

The following documents were reviewed:

SL No	Documents	Version	Dated	Copy
1	Protocol	-	27.01.19	1

The following members of the ethics committee reviewed the protocol on 27th January 2019.

S. No.	Name	Role in EC	Affiliation with Institute(Yes/No) If yes, Specify.....
1.	Prof. Dr. Mohammad Alamgir Kabir	Chair of CRPEC	No
2.	Umma Kulsum	Member Secretary	Yes, Research, Monitoring & Evaluation Officer
3.	Nasirul Islam	Executive Member	Yes, Principal (Acting), BHPI
4.	Sohrab Hossain	Executive Member	Yes

CRP-Mirpur, Dhaka, Plot: A/5, Block- A, Section- 14, Mirpur, Dhaka- 1206, Tel: 02 9025562-4, Fax: 02 9025561, Email: dgm-mirpur@crp-bangladesh.org. CRP-Ganakbari, PO: Dhamsena, P.S: Ashulia, Savar, Dhaka, Tel: 02 7789227, Email: ganakbari@crp-bangladesh.org. AK Khan CRP- Chittagong, Kalurghat, Mohra, Chadgaon, Chittagong, Tel: 031- 2573412, Email: chittagong@ crp-bangladesh.org. Afsar Hussain CRP- Rajshahi, House no: 11, Mohishbathan, Rajshahi Court Rajpara, Rajshahi, Tel: 0721 771709, Email: rajshahi@crp-bangladesh.org. CARSA Foundation- CRP, Barisal, 12 Gonopara, Barisal Sadar, Barisal, Phone: 0431 71556, Email: barisal@crp-bangladesh.org. CRP- Moulvibazar, 836 Sayed Muztaba Ali Road, Poschim Bazar, Tel: 0861 52469, E-mail: moulvibazar@crp-bangladesh.org
As a donor to CRP you qualify for a tax rebate as the Government of Bangladesh have approved CRP as a Philanthropic Institution from February 2008



পক্ষাঘাতগ্রস্তদের পুনর্বাসন কেন্দ্র (সিআরপি)

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Ref:

Date:

6.	Mohammad Anwar Hossain	Executive Member	Yes, Head of Physiotherapy Department, CRP.
6.	Julker Nayan	Executive Member	Yes, Head of Occupational Therapy Dpt.
7.	Sharmin Hasnat	Executive Member	Yes, Sr. SLT & Acting Head and Lecturer, Speech and Language Therapy Department.
8.	Md Obaidur Rahman	Executive Member	No
9.	Md. Mizanur Rahman	Executive Member	Yes, Lecturer, BHPI.

We confirm that neither you nor your study team members participated in the deliberations of the Ethics Committee & did not vote on the proposal for this study.

We approve the research to be conducted in its presented form at Centre for Rehabilitation of the Paralyzed (CRP).

The CRP Ethics Committee expects to be informed about the progress of the study, any Serious Adverse Effects (SAE) occurring in the course of the study, any changes in the protocol and participant's information / informed consent and asks to be provided a copy of the final report.

Please submit to the Ethical Committee (EC) the published article of the study as per EC Standard Operating Protocol (SOP)'s.

The EC is organized & operates according to the requirements of Declaration of Helsinki and ICH-GCP, local regulatory requirements and guidelines.

Yours sincerely,

Umma Kulsum

Research, Monitoring & Evaluation Officer, CRP.

Appendix D. Participant Explanatory Statement

PARTICIPANT EXPLANATORY STATEMENT

Project title: The lived experiences of adult students with a spinal cord injury (SCI) returning to study in Bangladesh

Student	Arifa Jahan Ema
Investigator	<p>MPhil Student, Department of Occupational Therapy, School of Primary and Allied Health Care, Monash University, Peninsula Campus Building G, McMahons Road, Frankston</p> <p>Postal - PO Box 527, Frankston VIC 3199</p> <p>Call: +8801814398667 (Bangladesh)</p> <p>+61451096041 (Australia)</p> <p>Email: arifa.jahanema@monash.edu</p>
Principal investigator	<p>Professor Ellie Fossey</p> <p>Head and Graduate Research Co-Ordinator</p> <p>Department of Occupational Therapy</p> <p>School of Primary and Allied Health Care</p> <p>Monash University, Peninsula Campus Building G, McMahons Road, Frankston</p> <p>Postal - PO Box 527, Frankston VIC 3199</p> <p>Phone +613 9904 4225 Mobile +61 428 330 505</p> <p>Email ellie.fossey@monash.edu</p>

Co-investigator Dr. Linda Barclay

Senior Lecturer

Department of Occupational Therapy

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Phone: 03 9904 4493

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This information sheet is for you to keep.

What is the purpose of this research?

We are undertaking a research project that aims to explore the lived experience of transition and return to the study of adult students with Spinal Cord Injury in Bangladesh. To achieve the overall aim, the researcher will explore the personal experience of the adult students in transition and post-injury study participation, the meaning and value of education, difference between the occupational role of pre and post-injury period and the environmental barriers and facilitators.

This project involves the student researchers from Monash University, Australia. The is supervised by Professor Ellie Fossey, Head and Co-ordinator, Department of Occupational Therapy, Monash University, Australia and Dr. Linda Barclay, Senior Lecturer, Department of Occupational Therapy, Monash University, Australia. The study is being undertaken at Centre for the Rehabilitation of the Paralysed (CRP).

What does the research involve?

Please read this explanatory statement in full before deciding whether you are interested in participating in this research. If you would like further information regarding any aspect of this project, you are encouraged to contact the researchers via the phone number or email addresses listed above.

- You are invited to take part in a semi-structured face-to-face interview with the student investigator at your Community (home) or CRP. The expected time of the interview is 60-90 minutes and it will take place at a pre-scheduled time.
- You will be asked to share your experience of returning to study after the rehabilitation from CRP. We expect you to share a detail of your current occupational role in contrast to the pre-injury status, how do you pass a typical day, what are your barriers and facilitators in terms of the environment of home, school, road and transport, what was your motivation in occupational participation and your experience about the life events.
- You will be asked some short questions about your age, gender, type of injury, date of injury, length of hospital stay at CRP, living situation, occupational history and others. With prior your permission, we will also collect your medical record from In-patient database, CRP

Why were you chosen for this research?

You have been invited to participate because you have lived experience returning to study with a spinal cord injury after successful completion of rehabilitation.

Source of funding

Funding for this project is from the Monash University and Australia Awards Scholarship Program.

Consenting to participate in the project and withdrawing from the research

If you agree to participate in this research, you will need to sign the accompanying consent form and provide it to the researcher at the time of the interview. Participating in this research is voluntary and you are under no obligation to consent to participate. However, if you do consent to participate, you may withdraw from further participation at any stage up until the data are analysed. There will be no negative consequences if you choose to withdraw. You are also able to refuse to answer any questions with no negative consequences.

Possible benefits and risks to participants

You are unlikely to gain any direct benefits from participating in this research, however, information gained from this research will contribute to the ongoing development and improvement of rehabilitation service for the students with spinal cord injury, which will benefit students living with spinal cord injury in Bangladesh.

The research has been designed to have low risk. The potential risks to you includes psychological discomfort only because of sharing your experience. If it arises during the interview, the student researcher will minimise it in following way:

- You will be given a reminder that the participation is voluntary, you can withdraw from it anytime you want.
- The student researcher will offer break during interview if the discomforts impacts the interview. Additionally, the researcher will discuss about re-scheduling the interview if you prefer to continue later.

Confidentiality

All information provided by you will be kept confidential and only accessible to the researchers conducting the study. At no time will your name be used in any published documentation. Once the interviews have been completed your name will be de-identified

using a code, all data analysis will then occur using that code. No one other than the researchers will have access to the original interview transcripts with your name on it.

Storage of data

Collected data will be stored on a password-protected computer and locked cloud system, accessible only to the researchers conducting this study. Hard paper copies of data will be stored in locked filing cabinets at Centre for the Rehabilitation of the Paralysed (CRP) and Monash University. Following Monash University regulations, all data will be stored for five years post research completion, and subsequently destroyed in a confidential waste bin.

Results

Results from the interviews and other data collected as part of this research will be aggregated, analysed and written in a descriptive report. Summaries of some aspects of the results of this study may be published in a scientific journal or at conference proceedings. You may request a summary of the project results by emailing any of the project investigators using the above contact details.

Complaints

Should you have any concerns or complaints about the conduct of project number 17877, you are welcome to contact the Executive Officer, Monash University Human Research Ethics (MUHREC):

Executive Officer

Monash University Human Research Ethics Committee (MUHREC)

Room 111, Chancellery Building E,

24 Sports Walk, Clayton Campus

Research Office

Monash University VIC 3800

Tel: +61 3 9905 2052 Email: muhrec@monash.edu Fax: +61 3 9905 3831

Thank you,

Arifa Jahan Ema

Appendix E: Consent Form

CONSENT FORM

Project title: The lived experiences of adult students with a spinal cord injury (SCI) returning to study in Bangladesh

Student investigator: Arifa Jahan Ema

I have been asked to take part in the Monash University research project specified above. I have read and understood the Explanatory Statement and I hereby consent to participate in this project.

I consent to the following:	Yes	No
Participating in one semi-structured interview lasting approximately one at a location to be determined.	<input type="checkbox"/>	<input type="checkbox"/>
Audio recording of interview.	<input type="checkbox"/>	<input type="checkbox"/>
Being available to participate in further research relating to this project	<input type="checkbox"/>	<input type="checkbox"/>

Name of participant: _____

Signature of participant/ thumb print: _____

Date:

Appendix F. Withdrawal of consent form**WITHDRAWAL OF CONSENT FORM**

Project title: The lived experiences of adult students with a spinal cord injury (SCI) returning to study in Bangladesh

Student investigator: Arifa Jahan Ema

I, _____ (the participant),
wish to WITHDRAW my consent to the use of data arising from my participation. Data arising from my participation must NOT be used in this research project as described in the Information and Consent Form. I understand that data arising from my participation will be destroyed provided this request is received within four weeks of the completion of my participation in this project. I understand that this notification will be retained together with my consent form as evidence of the withdrawal of my consent to use the data I have provided specifically for this research project.

Name of participant: _____

Signature of participant/ thumb print: _____

Date:

Appendix G. Interview guide

Occupational Performance History Interview II

Occupational role

Student

1. Are you currently in school?
2. I understand that you are a student responsible for _____
3. How did you come to choose to study?
4. What do your studies involve?

Or

What kind of responsibilities do you have/ things you have to do as a student?

5. What would you say is the main thing you get out of your studies?

Or

What is the main reason that you do it?

6. What kind of student would you say you are?

— Can you give me an example of something that shows how this is so?

Friend, volunteer, amateur, hobbyist and other roles

7. In addition to your studies, is there anything else that takes up a lot of your time and energy that is really important to you?

Religious/ organisation participation

8. Do you actively participate in any organisations or in church/ temple groups?
 - Tell about it
 - What kinds of things do you do?
 - How did you get started?
9. Why do you do this?
 - Is it just for fun or more serious?

Daily routine

10. Describe a typical day during the week.

- Can you tell me about something that happened recently that typifies what this routine is really like for you?

11. Is the weekend any different?

- (If yes) Describe it?

12. Describe your typical routine?

- Does your routine allow you to get done the things that are most important?

No

- What important things are you not able to do?

13. Was your daily routine ever different?

(Or, referring to a specific previous period)

14. How was your routine different when _____?

- How would you compare these routines?
- Which was better for you?
- Did you have any hobbies or projects that were part of your routine in the past?

15. What is the most important things to keep the same about your routine?

16. What would you most like to change about your routine?

17. Do you have any ongoing hobbies/ projects that are part of your current routine?

- Tell me about _____
- How often do you do it?
- How did you get started?
- What do you like about it?
- How long has this been a part of your routine?
- Do you have enough time to do the things you enjoy?

- (If no) Why do you think you do not have time? Give me an example of the time when did not have enough time to do the things you enjoy?

If cannot answer: Why don't you think you have fun anymore?

Occupational Settings (Environment)

Home

18. Tell me about where you live. What is it like?

- Is your home comfortable?
- Do you have enough privacy?
- Can you get around in your home/ apartment/ room/ dorm?
 - o Is it adequate for that?
 - o Do you have the things there that you need to do what you want?
- Are you ever bored there?
- Are you able to keep up your home/ apartment/ room/ dorm?
- Do you like your surroundings?
 - o Are they stimulating for you?

19. Whom do you live with?

- How do you get along?
- What kind of things do you do together?

20. Is there anyone at home/ in your family who makes life stressful or difficult for you?

21. If you need help with something, can you expect your family/ spouse/ roommate/ etc. to give you a hand?

- Can you give me an example?

22. If you were feeling depressed or upset, could you expect your family/ spouse/ roommate/ etc. to give you support?

- Can you give me an example?

Major productive role

23. Tell me about the place where you go to school?

Or

Give me a little tour of your school. What is it like?

- Is it well suited for you to get your studies done?
- Do you have enough privacy?
- Can you get around okay?
- What are the main things you do at school?

... Is it adequate for that?

... Do you have the things there that you need in order to do what you want?

... Are you ever bored there?

... Are you ever stressed there?

... Do you like your surroundings?

Additional questions about school accessibility

- ✓ (Tetraplegic participant only) How do you manage to write (i.e. assignments, note taking, exams)?
- ✓ How do you participate in group work at school?
- ✓ What strategies do you adopt during exam (i.e. writing exam, hire the writer, extra time, bladder management in exam hall)?
- ✓ What about the accessibility of your classroom (i.e.: seating arrangement, supplies)?
- ✓ What about the accessibility of toilet (entrance, accessible commode, grab rail, wheelchair propelling area)?
- ✓ Describe the other accessibility issues of school (playground, library, corridor, cafeteria etc.)?

- ✓ Do you get the assistance from a school assistance (Either provided by Government or personal)?

24. How would you describe things at academic institute? (For instance, which of the following describes your school situation: loving, fighting, stressful, calm, chaotic, busy, and boring)?

Or

Tell me about something that happened at school recently that would show me what things are like there.

25. Who is the people you interact with most as a student?

26. How do you get along with your fellow students/ teachers?

27. Is there anyone at school who makes it difficult or stressful for you?

28. If you need help with something, can you expect your peers/ friends to give you a hand?

- Can you give me an example?

29. If you were feeling depressed or upset, could you expect your teachers/ friends/ peers to give you advice or support?

- Can you give me an example?

Leisure

30. Who is the people you relax/ recreate with most?

- How do you get along with them?

31. Tell me about something you did recently that would show me what kind of atmosphere you are in when you relax or recreate.

Activity/ Occupational Choice

32. How did you come to choose to study?

33. Do you get to do the things that you think are really important?

If yes

What are some of the things that are really important to you?

If no

Can you tell me about those things you do not get to do and why?

Or

What are the things you cannot do?

- Can you give me an example?
- Can you tell me about a recent situation in which you were not able to do something you really value?

34. Have you been able to choose the things in your life that are important to you?

35. Do you ever set goals for yourself/ plan for the future?

If yes

Are you able to follow through?

- If yes, can you give me an example of a time when you had a goal and followed through with it?
- If no, can you give me an example of a time when you had a goal and were not able to follow through with it?

If no

Have not you ever had something you looked forward to or really wanted to accomplish?

36. When you run into obstacles or difficulties, how do you handle it?

- Can you give me an example?

37. What do you think is the biggest challenge you are facing now?

Or, referring to a known circumstance, trauma, etc.

38. How do you think you will adjust to / handle?

- Can you give me an example of some decisions you've already made that illustrate this?

Critical life events

39. What were the events or experiences that most shaped or changed your life?

- When did things really change for you?

[Or, if a specific event is known]

- How have things changed since _____ (Ask for each event)

40. Tell me about _____?

- What happened?
- What changes did it bring about?

41. If you think about your life, what do you consider the time when you were doing best?

- Tell me about this period.
- What made it so good?

42. What do you consider your biggest success in life?

Or

Tell me about something that happened at school or work (or within a major occupational role) where you felt especially successful.

43. What do you consider the worst period in your life?

- Tell me about this period.
- What made it so bad?

44. What do you consider your biggest failure in life?

Or

Tell me about something that happened at school (or within a major occupational role) where you felt especially unsuccessful?

45. If you could make your future turn out as you wanted, what would you be doing?

— What do you think you will be doing in the future?

Appendix H. Narratives of the interviews

NEIL

Neil is a 21-year-old male student with SCI, living in a rural area of Bangladesh. He was injured with a paraplegic SCI in 2015, when he was a student in Class 9. During the interview, he was preparing to attend the final exam of HSC (Class 12). He went through rehabilitation at CRP for four months and returned to study four months following discharge from the CRP.

As Neil lives in a rural area of Bangladesh, the surrounding area was muddy and inaccessible. Neil was, however, independent in walking, so the inaccessible environment was not a barrier to his mobility. During the rainy season, he needed to be extra careful regarding safety issues so that he didn't fall. The distance between his college and home was about 2.5 to 3 km. I travelled to his home for the interview. I observed that there is local transport available all the time, which is consistent with what he reported.

DAISY

Daisy is a 26-year-old female student with paraplegic SCI. Daisy was injured on September 12, 2011 and attended rehabilitation at the CRP for four months. Before her injury, she was a student of a first-year Bachelor program in a well-known College that is accredited by the National University of Bangladesh. She tried to re-enrol after her injury but the college authority denied her this. Eventually, she went back to her local home and contacted the CRP for help. She returned to study with support from the advocacy department of the CRP. At the time of the interview, she was enrolled in a Master program. A few days prior to the interview, she finished the final exams of her Master program. She was currently waiting for the results to be published and, at the same time, she started a job.

Daisy stayed in college accommodation during the whole time of her study. Since she had completed the final exam of the Master program, she had to move out. During the interview, she was living at a hostel for working women with disabilities, in an urban area of the capital of Bangladesh, Dhaka. This residential facility is an initiative of the Bangladesh Government. She is living there with a few other people who have different kinds of disabilities, such as vision impairment, deaf-muteness and other physical disabilities, although no one else has an SCI. I met some of her friends there and had an opportunity to observe her living space, kitchen and toilet. All the facilities were accessible and easy for her to use. As a result, she is independent in all of these activities. Since the other people around her have different types of disabilities, they are compassionate and supportive of her.

MILA

Mila is a 20-year-old female student with paraplegic SCI who was injured when she was 16 years old. She is independent in walking, with a minor foot drop. She was studying Class 12 during the interview and was preparing for the Class 12 final examination, which was due to be held in two months' time.

The interview was completed at her home. Mila said that she was in Year 9 when she was injured. She had fallen from a tree and was immediately taken to a hospital in Dhaka. After receiving treatment there for a few days, she was shifted to another hospital for surgery. She was later referred to the CRP for rehabilitation. She decided to return to previous study during her rehabilitation at the CRP. After discharge, she went back to her home and re-enrolled in her earlier school. However, it took approximately seven months to start physically attending school, due to physical limitations. During that time, she studied from home and attended school only for exams. She now regularly attends college activities.

Mila was living in a rural area. She was independent in mobility, so the living environment did not impact her very much. She explained her experiences without any hesitation. Since she is independent, she has a very positive outlook on life, living and education.

RUSSELL

Russell is a 21-year-old male student with tetraplegia. Russell was injured as a result of a road accident, on April 29, 2016. He attended rehabilitation at the CRP for 10 months. He was an HSC Candidate and on his way to the exam hall for the seventh subject, when he had the road accident. He returned to study six months following discharge and attended his final exam of HSC (Class 12). He was enrolled in the first year of tertiary education in a local college at the time of the interview. Since there was a vacation going on, he was using this time to take up vocational training on computer skills at the CRP. As part of the training, he was living at the CRP accommodation as a trainee. This interview was, therefore, completed in a quiet room at the CRP premise.

Due to having tetraplegia, he was naturally a slow speaker, making it a little hard for me to keep track of the information he relayed. To assist with this, I consistently summarised whatever he said. As Russell is now living at the CRP for vocational training and the interview was taken there, I could not see his living arrangements at home. Though he described the existing situation, it would have been more helpful if I were to visit his community. He was interactive during the interview, and no emotional issues arose. Although he has had many negative experiences, he is basically strong-minded, and he has always been able to overcome emotional issues. He is also determined about his plans for the future.

SYMAN

Syman survived an SCI when he was 15 years old, eventually acquiring paraplegia. At the time, he was presenting for the final exam of class VIII. He used to work as a day labour at

the Power Development Board. His main job included cutting extended tree branches so that they do not interfere with the electric wires. He got an electric shock and fell to the ground from the ladder that he was standing on. He was at the CRP for four months for rehabilitation afterwards. On arrival at home, he enrolled in Class 9. There was only a gap of five to seven between his discharge and return to study. He turned 20 years old during the interview and was a student of Class 12. He was taking preparation for his HSC final exam.

Syman lived in a semi-urban area. The interview was taken at his home. He is from an impoverished family that has only a big room, which was in a miserable condition at the time of the interview. He tried, however, to install a little ramp in front of the entrance by using local resources. There is another slope behind his home to connect it to the main road, which doesn't follow any standard measurement. The hill is made of solid mud and, because it is a very steep one, he always needs help from his mother to climb it. There is no accessible toilet, so he uses the toilet tub on his wheelchair. Living in a very inaccessible environment, he has managed to attend college regularly. He is doing very well in his studies and spends time with friends and neighbours. As the local transports are not accessible, he goes to college by wheelchair, for which he needs to travel at least six kilometres back and forth, every day.

DEBBIE

Debbie is a female student with paraplegic SCI living in a rural area of Bangladesh. During the interview, she was 24 years old. She acquired her SCI when she was 17 years old. Her pre-injury history says that she was a student of Class 10 and appearing for her final exam. There was a gap of three years between her discharge from the CRP and return to study. As it was a long gap, she later took admission in a local college under Open University. There is no mandatory time to finish the course accredited by Open University. Students who have

gaps between studies usually enrol in the colleges accredited to Open University. She is now taking preparation to appear for her Class 12 final exam at the HSC level.

The interview was conducted at her home. She is living with her mother only. In addition to her studies, she is engaged in providing tuition to some kids living nearby. This is a helpful financial contribution to her family. Due to the inaccessible and unsupportive environment, she was never able to attend a single class held at school and college.

SOFIA

Sofia is a 19-year-old female student with paraplegic SCI. She is taking preparation for the HSC final exam. She became injured with an SCI in 2015 and attended rehabilitation at the CRP for four months. She went back home and stayed at home for around three months. She then started taking treatment at the CRP outpatient clinic for another three months. She was an SSC candidate during her injury. As the final exam of SSC had already been held, she had to re-registrar for the final exam in the year 2017. There was a gap of six months before her return to study.

The interview was taken at her home. Her living area was not very wheelchair friendly. She needed a lot of assistance from her mother in and around the house. The inside of the home was inaccessible, including the entrance door, toilet and surrounding area. This kept her at home, always. The surrounding social environment was not supportive, so she faced a lot of teasing and bullying. She said that she was happy that she could stay at home, but she did not get to meet people.

I consistently travelled a lot for every interview and found that travelling to her home was a particularly bad journey. I had to change transport four times and then had to walk more than two kilometres to reach her home. This experience helped me to relate to her own transport journey, which helped me during the interview. During my walk to her house, I randomly

found a school and a college in the same area. Local people told me that this was the only academic institute nearby. I thought, therefore, that this was possibly where the participant was studying. Since it was on my way, I took a short walk around the college premise. Later, I found that she was studying at the same college. My experience of having knowledge of the physical environment of the college helped me during the interview. The road was under construction, so I could relate to her experience of how hard it was for her to use the local transports to her college.

SAMMY

Sammy is a 21-year-old paraplegic male student with SCI. He is a tertiary-level student in the third year of the BBA program in the Department of Management at a college that was accredited by the National University. The accident happened after his SSC exam. He took rehabilitation for three months at the CRP. As there was a gap of three months before HSC admission, and since the accident took place in that time, he could have returned to study without any gap. After his discharge from the CRP, he started studying HSC. So, he has been studying for five years as a student with SCI.

The interview was taken at his home. He was the first participant I saw using an Elbow Crutch for mobility. Both his home and surrounding environment were accessible for his physical status.

RONNIE

Ronnie is a 22-year-old male student with paraplegic SCI, and a second-year student at tertiary level. Ronnie survived a road accident, which saw him injured with an SCI, in 2014, when he was attending the HSC final exam. He was immediately taken to a hospital in Dhaka. Later, he was referred to the CRP for the rehabilitation. At discharge, he had already

missed the registration for the HSC exam in the following round. Eventually, there was a gap of one year between his discharge and return to study.

Ronnie is employed at a non-government organisation (NGO) while studying and living in an urban area. The interview was taken at his current accommodation, which is a staff quarter of that organisation.

He regularly attended class lectures before starting his job recently. As the present material doesn't really matter in the course, his absence due to his current job is not a hindrance to his studies. He is doing well in his studies and manages to keep a balance with his different roles. He is living on the ground floor and the whole accommodation was quite wheelchair friendly. At the end of the interview, he showed some photos of his home, the local area and the adaptive strategies he has taken to use the local transports. Ronnie played me a video that showed how his family had built a separate and accessible home for him beside their own home.

ROBIN

Robin is a 20-year-old male student living in the rural area of Bangladesh. He is a student of the SSC final exam (Class 10). Robin dived into shallow water and survived with tetraplegia. He was admitted to the CRP for seven months of rehabilitation. On discharge, there was a gap of one year in his return to study. He started studying at his previous school.

The interview was taken in his home. The overall surrounding environment of the house was not wheelchair friendly. He was, however, dependent on a wheelchair and the family members operate the wheelchair when he moves around. There is a ramp in the front door, however, it was steep and not in standard condition. Considering the space around the home, his family have tried to make it suitable enough for his wheelchair mobility.

As Robin is a person with tetraplegia, he is functionally dependent on his caregiver. The dependency cannot stop him, however, from continuing studies. He used to hire a writer during every exam. It has been nearly four years since he commenced his study, and while facing the same obstacles, he is still determined to continue.

MILLIE

Millie is a 20-year-old female student with a paraplegic SCI. She fell from a tree in 2015, which led to her SCI. She acquired her injury during her holiday after the SSC exam. Afterwards, she took rehabilitation for three months at the CRP. On discharge, she enrolled in the HSC program in a local college, after having a gap of almost one year. It used to take her three hours to travel back and forth to college, every day. At the time, she was dependent on an elbow crutch and knee ankle-foot orthosis and she found it very hard to travel for such long hours in that condition using public transports. Besides, she was going through immense social bullying in her village. Millie, with her family supporting her, then decided to move to Dhaka, the capital. She transferred her admission to a college in Dhaka. She has been studying her HSC from there. During the interview, Millie was a first-year student in a bachelor program. She regularly attends her college and stays at the residential service provided by the university.

I conducted the interview at her hostel, so managed to observe her living area. The physical environment is accessible to her. As she has only minimal physical impairment now, she mostly needs an accessible toilet and shower, which are both available to her there.

EVA

Eva is a 24-year-old paraplegic student with SCI. She recently finished the final exam in the third year of a bachelor program and is waiting to be enrolled in the fourth (and final) year. She was a 16-year-old college going student when she acquired her injury. The injury

happened in 2011, after which she attended rehabilitation at the CRP for three months. She went through a depressive time, afterwards, and returned to study after a gap of two years. She felt very hopeless, initially, and she had low expectations of passing the HSC final exam, however, she attended the HSC exam, which worked as a motivating factor for her to continue studies later on.

I conducted the interview at her home. She has a family with a stable financial condition so that her family has been able to build her a standard ramp in the entrance, build her an accessible toilet with a high commode and grab rail, remove all the thresholds in the house, make her a wheelchair-friendly dining table and make her bed and reading table accessible for her. Eva did not regularly attend her class lectures due to an inaccessible environment at the university. If she goes, however, the teachers usually shift the classroom to the ground floor, for her better participation.

She is looking forward to graduation, with the hope of starting a desk-based job in the future. She believes that having a career will change her life and, for that, she is open to both government and private duties. She responded with short replies for most of the discussion.

HARIS

Haris is a 24-year-old male student with paraplegic SCI. He acquired the injury when he was 16 years old and he has been living with SCI for eight years, at the time of the interview. Haris was studying in class 11 during the injury and he was a student of third year at tertiary level during interview. There was a gap of one year between his discharge from the CRP and return to study.

I conducted the interview at his home. Haris lives in a rural area of Bangladesh, which is around 300 km from the capital of Bangladesh. Although Haris was discharged with a wheelchair, he is now able to walk with an elbow crutch. Over time, he has had significant

improvement in his physical condition. His home is friendly for his physical movement and the local roads are well constructed. As a result, it has been easier for him to regularly attend classes at college. He is also involved in some voluntary work and teaches in a coaching centre, at the same time.

LEYAH

Leyah is a 23-year-old female student with paraplegic SCI. She is studying in the final year, at tertiary level. Leyah became injured with an SCI when she was 17 years old, while attending the final exam of class 12. It has been six years since she continued studying, living with an SCI. On discharge from the CRP, there was a gap of one year before she returned to study.

Leyah was living at the residential house of her then academic institute. Although it was not well equipped for a wheelchair, on her request, the authority modified the toilet for her wheelchair. Otherwise, the living room and cafeteria were wheelchair friendly. Leyah used to attend classes regularly and participated in different co-curricular activities run by the academic institute.

JOHNY

Johny is a 19-year-old paraplegic student with SCI, living with his family in a rural area. He underwent rehabilitation at the CRP for six months. He was an SSC candidate before the injury and returned to study immediately after rehabilitation. He was a student of Class 11 at the time of the interview.

The interview was taken at his home and so I had the opportunity to carefully take note of Johny's living environment. His supportive family tried hard to make the environment accessible to him, as much as possible. The inside of the house is very much wheelchair-friendly, accommodating Johny moving from one room to other and his bed height, dining

table height, etc. There was a ramp in the front door and a spacious shower beside the tube well. On the other hand, the surrounding environment of the house and the local roads were inaccessible, for which he needed assistance with the pushing of the wheelchair. The rainy season used to make it worse and further restrict his participation.

Johny has never attended any class lecture, as the college environment is not friendly for wheelchair users. He has been facing a lot of social bullying in his community, and that has made him very upset.

Appendix I: Scoping review manuscript in preparation

Title: Students with spinal cord injury: A scoping review of evidence regarding education/ school participation following rehabilitation

Abstract

Introduction

Returning to school after spinal cord injury (SCI) is a primary goal of rehabilitation for school-aged children to enhance their community re-integration and future work prospects. Research evidence in this area is limited, so this scoping review aimed to map the available literature regarding the education participation of students with SCI and identify gaps for future research.

Methods

Electronic searches of six databases were performed for peer-reviewed articles published in English between 1990 and 2019. Key search terms included: spinal cord injury, education participation, students, academic reintegration and school re-entry. Data charting was used to summarise the study characteristics.

Results

Nine articles addressing the education participation of students with SCI were identified. These studies used qualitative and quantitative methods. Most recruited small samples of participant' aged between 10-42 years. Their findings addressed four main areas: experience and benefits of education participation; environmental barriers to participation in school and extracurricular activities; the importance of relationships with school staff and friends; and strategies for integration, including peer mentoring and classroom assistance.

Conclusions

This review shows that the rehabilitation programs need to explore return to school plans in more depth with young people with SCI. Future research should investigate the educational participation of students with SCI in high and low-income countries, with a focus on strategies for enhancing psychosocial adjustment and successful integration.

Introduction

Spinal cord injury (SCI) results in a dramatic change of an individual's life, leading to wide ranging disruptions in activities, health issues and participation in society [1].

Epidemiological studies show variation in the average age at which Traumatic Spinal Cord Injury (TSCI) occurs between developed and developing countries. For instance, the peak age of incidence in developed countries is 15-30 years for the males [2, 3], compared to XX in developing countries (ref). Therefore rehabilitation research and practice in developed countries is now focusing on community reintegration after rehabilitation [4], including return to school for the school-aged child with SCI and returning to income generating activities for adults with SCI [5]. [6].

UNCRPD [7] stated that an education is the right of all person with and without disabilities. Moreover, person with disabilities are entitled to get an inclusive and free primary and secondary education with an equal opportunity comparing to the others living in the community [7]. For young people with SCI then, return to education or training is an important goal of rehabilitation [8]. A number of studies also indicate that for young persons with SCI education has a positive influence on obtaining work as an adult, and more years of schooling is strongly associated with employment outcomes [6, 9-12]. Additionally, returning to study fosters a sense of accomplishment, respect and dignity in society and reduce misconceptions about the abilities of young people with SCI [13].

Several studies have investigated experiences of education participation and school participation among children and young people with disabilities, such as cerebral palsy, spina bifida, juvenile rheumatoid arthritis, polio, muscular disorders, traumatic brain injury, communication disorders and spinal cord injury [5, 13-16]. However, while there is considerable evidence regarding the work participation of people with SCI (refs), information

about participation of children or adolescents in school following SCI and of students with SCI in post-secondary education is more limited, as noted by the World Health Organisation's report on spinal cord injury and disability [6]. education participation. education participation. Therefore, this scoping review aimed to identify the available research evidence about the education participation and educational participation of students with SCI following rehabilitation.

Methods

Arksey and O'Malley [16] described a scoping review as a method for mapping the range, degree and nature of research on a subject with a purpose to identify the gaps and provide a summary of the existing literature [17]. Scoping review methodology is useful when there is limited high quality evidence in any field, as it facilitates efficiently mapping the existing literature on a defined topic and assists with identifying directions for further investigation [17]. Therefore, a scoping review was chosen to map the breadth of the published studies and identify gaps for future research about the education participation and educational participation of students with spinal cord injury. The review followed the key phases provided by Arksey and O'Malley [17] and further developed by Levac et al. [18]. These were: identifying the research question, identifying relevant studies, study selection, charting the data and collating, summarizing and reporting the results. Each is outlined below.

Stage 1: Identifying the Research Question

The identified research question was “What is the current evidence about the education participation of students with spinal cord injury after rehabilitation?”

Stage 2: Identifying relevant studies

The scoping review identified peer-reviewed journal articles published in English over thirty years: 1990-2019. A systematic search was performed in relevant databases, including PubMed, OVID Medline, CINAHL, and ERIC. The key search terms were based on the research question. Search terms were: Spinal Cord Injury* OR Tetraplegi* OR Paraplegi* AND Education participation, Students, Students with disability, Education Participation, Academic Reintegration and School re-entry. Additional steps included checking the reference lists of identified articles, citation tracking and key author searches using Google Scholar.

Stage 3: Study selection

The articles were selected for inclusion in this scoping review based on the following inclusion and exclusion criteria:

Inclusion criteria:

- Research regarding education participation of people following SCI
- Peer-reviewed articles published in English between 1990-2019

Exclusion criteria

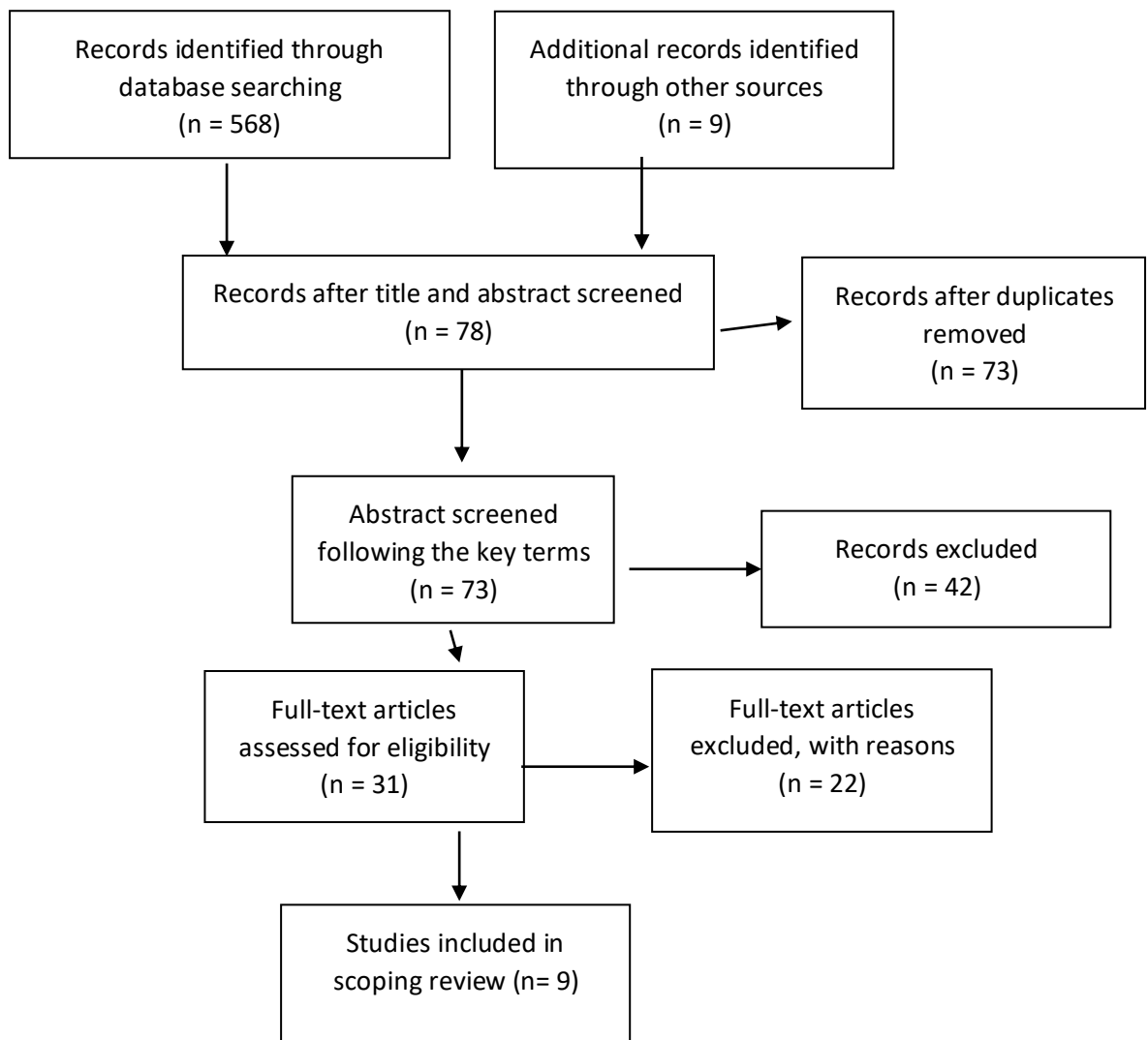
- Studies that included participants other than people with SCI, such as those with other diagnoses and caregivers
- Grey literature, such as government reports and policies

No limits were put on the age range of participants or the methodological design of the studies. An initial search indicated that most studies on the topic have been published in the last 30 years, so the search was limited to 1990-2019. Only articles published in English were included, this being the language known to all authors. Additionally, the cost and time necessary for translation meant this was not feasible [17]. This review focused on empirical evidence, and so grey literature was not considered to maintain the quality and reliability of evidence [17, 19].

The first author conducted the initial database search in February – March 2018; it was re-run in April 2019. The initial search strategy identified 568 articles, which were exported to the Endnote Bibliographic software. The first author screened the titles and identifying 78 potentially relevant articles. Five duplicates were removed, leaving 73 articles. The abstract of these articles was screened at the subsequent phase following the key words. This resulted in identifying 31 possible studies for inclusion. The full text of the 31 articles were reviewed

by all authors for eligibility. Twenty-one articles were excluded because the studies involved students with varied physical disabilities and cognitive impairments. One further study was excluded because the participants were caregivers of students with SCI and thus did not match the research question. The remaining nine articles [4, 5, 8, 12, 13, 15, 20-22] met the inclusion criteria and addressed the research question. Table 1 presents this selection process following PRISMA 2009 Flow Diagram [23].

Figure 1. Study selection process [23]



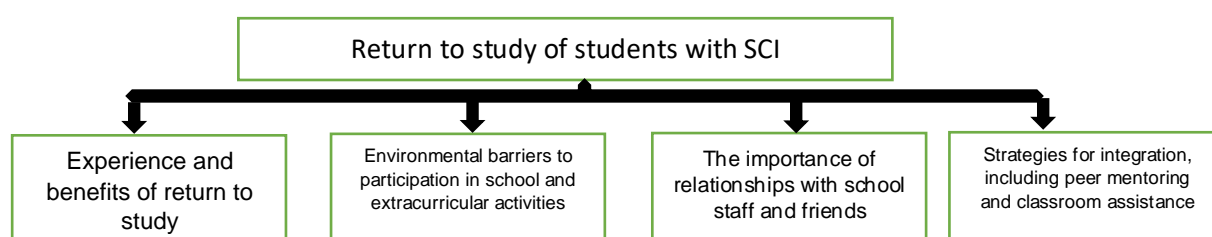
Stage 4: Charting the data

A data charting form was developed for this scoping review by the three authors, which included the key information to extract from the selected articles [17]. The following key characteristics were recorded: authors, year of publication, study location, study population, aim of the study, methods, result and limitations identified in the study. A summary of the articles is presented in Table 1.

Stage 5: Collating, Summarizing and Reporting the results

To examine the trends in the literature, the data charting form was reviewed, and the main findings of the studies summarised. The authors then analysed the content and then grouped the results into four common categories. The categories presented in Figure 2 provided a structure for reporting the findings.

Figure 2. Categories of the results



Quality appraisal

The methodological quality of the selected articles was assessed using the Joanna Briggs Institute Critical Appraisal tools [24]. Table 2. presents the critical appraisal of qualitative articles appraisal and Table 3 presents the critical appraisal of quantitative articles.

The nine studies were of variable quality. The research questions and aims in all studies fitted with the chosen methodology. All studies clearly described the participant selection criteria, demographic characteristics of the participants, and the study settings. The qualitative studies clearly described using interviews and appropriately presented the data analysis methods and subjective perspective of the participants, using quotes to illustrate themes, and drawing relevant conclusions from the findings. However, no study described philosophical perspective of the methodology and power relationship between researchers and participants. There was an unclear presentation of the process of the ethical clearance as well [13, 15]. The quantitative studies included clear descriptions of the assessment methods and interventions and measured the exposure in valid and reliable way in four out of six studies. Four studies

have used appropriate statistical analysis whereas one study presented unclear information and the other one did not include any information about the statistical analysis process.

Additionally, four studies measured the outcome in valid and reliable way [4, 5, 8, 12, 20, 22]. The case report presented the patient history in a timeline, identified the adverse event and provided takeaway lesson. However, it provided limited information about the clinical condition of the participants [21].

Results

Overview of results

This scoping review included nine studies, all of which were conducted in the USA [4, 5, 8, 12, 13, 15, 20-22], although the two studies of mentoring programs also included study sites in Canada [4, 21]. The studies included male and female participants aged between 10-42 years; most participants were below 30 years old and five studies included some participants under the age of 18 years [5, 8, 12]. One study lacked information about age [20]. Across the nine studies, participants with tetraplegia and paraplegia were included, with the exception of one study that included wheelchair users only, with no specific type of paralysis reported [15].

The nine articles included two qualitative studies [13, 15], six quantitative studies [4, 5, 8, 12, 20, 22] and one case report [21], five of which were published in the 1990s [5, 13, 15, 20, 22]. The articles reported studies involving students from urban schools more commonly than the rural schools, and one study involving students in a postsecondary education setting [ref]. Three of the studies focused on perception and experience about education participation of students with SCI [5, 13, 15], one on how implementing the existing law facilitate the reintegration [20], two on the importance of mentoring program [4, 21] and the rest three focused on the transition of young people with SCI to adulthood [8, 12, 22].

The results from the nine studies are summarised below, using the four categories presented in Figure 2.

Experience and benefits of education participation

Returning to study was both a positive and complex experience for students with SCI [5, 15]. One qualitative study interviewed students who were wheelchair users in a post-secondary education setting in the USA [15]. The author reported that lack of respect and underestimation from society motivated these students to pursue higher education. Hence, education facilitated them to grow as a person, helped to earn respect and appreciation from the society, created awareness by proving their ability, and provided economic independence and better employment [15]. The education participation experience of the students with SCI bring changes in their role, self-image and relationship with school network [refs – which studies?]. It has developed new coping strategies to deal their daily challenges at school such as ignoring the less important things, direct response to different situation rather than skipping it and also making fun [13]. Education is also found to be one of the factors strongly associated with employment irrespective of the type of paralysis [12]. Two other studies found that education has positive influence on getting employment when the person with SCI becomes an adult [8, 22].

Environmental barriers to participation at academic institute and extracurricular activities

Environmental barriers were commonly categorised as the inaccessibility in the academic environment and the inability to access extracurricular facilities. Generally reported physical barriers included small doorways, stairs without ramps, absence of elevators, small and inaccessible toilets, inaccessible cafeteria, unavailability of computers in the classroom for students and inaccessibility of transport [5, 13, 15]. Participants specified some other

barriers, such as inaccessibility in drinking fountain, lack of residential facilities for wheelchair users, inadequacy of library facilities, long distances to move between academic buildings for classes and inappropriate desk heights in classrooms [5, 15]. Restrictions to participation in education also involved physical barriers in extracurricular environments such as gym classes, social events arranged at university and other sports and recreation facilities [5, 15, 20]. Overall, the inaccessibility of these environment impacted student participation to varying extents, including being unable to continue preferred courses, needing to travel in a different transport without friends, and less participation in academic and non-academic activities [5]. Students also reported that the implementation of required adaptations was time consuming due to the bureaucratic processes involved [15].

The importance of relationships with school staff and friends

The school social environment consists of teachers, friends, peers, bus drivers and other non-teaching staff [13, 15]. Participants in some studies reported both positive and negative experiences with teachers and friends [5, 13]. Students described friends and peers with different meanings. They considered friends as the closest buddies, whereas peers were classmates and other students at school [13]. Friends appeared to be providing academic assistance, such as helping in notetaking and tasks like photocopying, typing and so on; they also provided positive social and emotional support which eased the academic journeys of students with SCI [5, 15]. However, negative relationships with peer groups were also reported, such as experiencing bullying and harassment, which caused losing them too [5, 13]. One study reported teachers too were seen as helpful in returning to study [5], whereas another study reported the perception that teachers lacked knowledge about the ability of students with SCI, which created discomforting situations [ref?]. Teachers were reported to underestimate these students' capabilities sometimes because of gaps in their knowledge

about SCI [13]. Overall, students stated that this support network of different people in their school environment increased their satisfaction and helpful for their better adjustment [15].

Strategies for integration, including peer mentoring and classroom assistance

A number of strategies to facilitate educational integration were reported in the literature.

Peer mentoring, implementation of legislation of policy and classroom assistance were reported as the strategies for integration of students in study [4, 13, 21, 22]. Peer groups of those who have faced the similar challenges plays a key role in the recovery of the person with SCI in terms of physical, emotional, academic and occupational status [21].

“Back on Track”, the mentoring program in the USA found to be effective to achieve further education and employment of youth and young adults with SCI. Although, there were some challenges like the drop out of the students and different geographic location of mentor and mentee. However, despite the challenges, the structured mentoring program appeared to be beneficial for the mentee to achieve education and employment goal with better quality of life [4, 21]. Additionally, the implementation of *Education for all Handicapped Children Act of 1975, Public Law 94-142* was found to assist in achieving the school reintegration of adolescents with disabilities living in the USA by ensuring that school reintegration programs commence during hospital care and continue through rehabilitation and discharge phases [20].

Additionally, participants reported to have experienced with some other services too, such as getting extra time in class and exam and change of location in classroom towards more accessible corner [5, 22]. However, one study finding said that lack of knowledge of teacher about SCI allowed the students extra facilities sometimes such as late at class and missing homework. This increased leniency was considered a negative experience [5].

Discussion

To the authors' knowledge, this is the first review to methodically identify the literature investigating education participation of students with SCI. It has identified the current empirical evidences, the gaps in scientific knowledge and future research priorities in this topic area.

The studies have included participants from primary, secondary and tertiary level which shows a variety in level of education and age. However, most of the studies included students who are below or equal to 18 years of old. Thus, there were a smaller number of studies conducted in tertiary level than the primary and secondary level. Therefore, it was hard to compare the findings depending on the age and level of education. All studies were conducted in the USA and two conjointly conducted in Canada. The setting being only in the two developed countries shows a great deal of lack of evidence not only from the middle- and low-income countries but also from the other developed countries. Moreover, the study findings from one culture is not replicable to the other. Additionally, the studies included more participants from urban school than the rural one. This also showed a different level of participation depending on the geographic location. The studies discussed mostly the physical barriers, whereas psychosocial, social and occupational adjustment of the students in post-injury education participation is widely ignored.

A critical appraisal of the articles showed a range of variety in the quality of the articles. Small sample sizes, variety in outcome measurement tool have restricted the generalizability of the findings.

Given the identified gap regarding the topic area, overall, more research is required to strengthen the field. Therefore, future research priorities include identifying adopted strategies of students with SCI in relation to their occupational life, daily routine and barriers

in society/ community participation. More study including peers, teachers and other staff at academic institute and family will generate deeper information because all these people are their support system. This kind of studies will also be helpful for rehabilitation professionals to design stronger rehabilitation and community service. Moreover, addressing the view of the academic staff will contribute to strengthen the policy and legislation. The perspectives may be different depending on age, gender, types of paralysis and level of education. Therefore, new studies separating this issue will provide broader insight. It is also important to conduct studies in different country because every country has got their unique issue. Thus, it will show variances in different culture.

Based on this scoping review, important gaps in current knowledge include...

Therefore, future research priorities include...

Table 1. Summary of the identified articles

Author	Purpose of the study	Participants (male (M), Female (F)), age range, type/extent of injury, time since injury, Setting	Methodological description (design, sampling, data collection, analysis)	Results	Key Limitations
					183
Graham et al. 1991	How the Education for All Handicapped Children Act of 1975, Public Law 94-142, assists in achieving the rehabilitation goal of school reintegration for spinal cord injured (SCI) adolescents	Adolescents (N= 13); Both tetraplegic and paraplegic students; USA	Descriptive data with 25 open-ended question Demographic data from medical record	Themes described: Attitude of fellow students were positive Reluctance in asking for help Supportive Parents Hostility from teacher Wheelchair accessible environment Inaccessible transports Educational and vocational counselling Assigned note-takers No participation at physical education class Occasional attendance at School activities Available Personal care aides External catheterization Clothing preferences were allowed	Published 28y ago Small sample size
Mulcahey MJ 1992	To explore the experience of returning to school of adolescents following a spinal cord injury	Adolescent (N= 4; 2F, 2M); 1 tetraplegic, 3 paraplegics; 15-18 years; 2 years since injury; at least 3 months of school attendance; rural, urban and suburban school in the USA	Phenomenological study; purposive sampling; open-ended question; Interview time: 90-120 minutes; Audio-taped, Observation of intonations in voice and non-verbal communication; descriptive theme	Six themes emerged: People around them means teachers, friends, peers, bus drivers and associated others; premorbid role change ; Changed Self-image ; Developed new Coping strategies ; Inaccessibility and limited resources; Feelings were associated with loss of control and dignity.	Published 27y ago Small sample size Adolescent only Lacked information about data analysis process
Massagli et. al 1996	To examine educational achievement and vocational success of children with SCI.	N= 53, 33M and 20F; 25 (47%) paraplegia and 28 (53%) tetraplegia; Onset of SCI before 18y; Mean length of disability: 9.4y; 23% (N= 12) primary students, 36% (N= 19) secondary students, 41% (N= 22) post-secondary students. Seattle, USA	Descriptive study; Students were emailed a survey included level of SCI, current school placement, most recent CGPA, related services, assistive technology and highest level of education Survey including both students and teachers	Predominantly descriptive information including: 18% primary students, 29% secondary students, 53% post-secondary students. Time to complete work and tests, a location change due to inaccessibility and alternative assignments were common modifications in all levels of students with different percentages. 36% college students and 71% graduate students are now employed Six major themes:	Time since publication: 23 years Lacked information about data analysis process
Paul Stanley 1999	To explore the university life experience of adult student wheel chair users	SCI participants (N=3) among (N= 6); Overall 4F and 2M and SCI 1F and 2M; Age range: 20-42y; Wheelchair user students from urban university; Both undergrad and post-grad Students; Full-time and part-time students; Campus residents and commuters.	Qualitative research; In-depth interview; Two One-on-one interviews and a third and final follow-up interview; Open ended question about university experiences, decision making of further studies, accessibility features,	Meaning of college education; Making choices was anxiety provoking; Personal support networks was helpful to achieve school-related needs and academic goals; Institutional responsibility included providing accessibility and pre-visit; Pleasant and unpleasant experience with university community; Self-promotion to achieve the needs and rights.	Urban universities only Out of Six participant, only three were SCIs Published 20 years ago

		The USA	knowledge level of university community, personal support system and employment plans.	Meta-theme: “Experience is a wholesome process” had emerged as a meta-theme connecting all six themes describing the student educational experience.	Lacked information about data analysis process
Sandford et. al 1999	To determine the typical time elapsed between discharge from an inpatient Spinal Cord Injury (SCI) rehabilitation program and the physical education participation and to identify barriers faced by patients attempting to education participation	Sustained SCI between 1989 and 1995 with resultant tetraplegia or paraplegia (N = 15); Age at injury: 8-18 years; Age at interview: 10-23 years Returned to primary or secondary school after in-patient rehabilitation; Wheel-chair users; The USA	Retrospective review; Questionnaire was mailed to subjects and followed by the telephone interview including pre-injury education history, performance, any medical problems since discharge, date of return, architectural and transportation barrier and relationships with peers and teachers.	Full-time return (N = 7); Part-time return (N = 7); One didn’t return to school because student and the family showed no interest. Median time Paraplegic: 10 days with a range of 0-168 days Tetraplegic: 62 days with a range of 0-365 days Barriers Primary barrier: Architecture and bathroom Second most barriers: Drinking fountain and accessibility within school Others: Transportation; Peer/ friendship relationship; Leniency and extra privilege from teacher Pre-dominantly descriptive information including: 99(51%) were employed; 78 (40%) were unemployed; 12 (6%) were student; 6 (3%) were homemakers Factors associated with employment: education, community mobility, functional independence and decreased medical complications Other variables: community integration, independent driving, independent living, higher income and life satisfaction	Published 20 years ago Limited sample size The study relies on recall the information from the past Lacked information about data analysis process Non-representative samples Subjects are from 2 SCI Programs only Published 17y ago
Anderson and Vogel 2002	To determine employment outcomes of adults with paediatric-onset spinal cord injury (SCI) and factors associated with those outcomes.	Participants (N= 195); 18y or younger at injury; 24y or older at follow-up; Mean duration of injury: 15y; no significant brain injury; Received care from SCI of the Shrinners Hospitals for Children in Chicago, IL or Philadelphia, PA United States/ Canada	Telephone interview; Structured question for demographic data; Univariate analysis with Mann-Whitney test by using SPSS 9.0 and logistic regression analysis; Standardized Scales included: FIM™ instrument Craig Handicap Assessment and Recording Technique Medical outcomes study-12 items Short-form Health Survey Satisfaction with life scale		
Anderson et al. 2004	To provide an overview of the adult outcomes of individuals with paediatric-onset spinal cord injuries (SCIs) and the implications of those findings for transition to adulthood	Participants (N= 265); Age at injury: 18y or younger; Age at follow-up: 24y or older; 67% M, 87% White, 59% tetraplegia, 65% living independently, 20% married; median income \$12,000; The USA or Canada	Cross-sectional study; Multiple regression analysis; Structured interview by using: Functional Independence Measure Craig Handicap Assessment and Reporting Technique (CHART), Short Form 12 (SF - 12) Satisfaction with Life Scale	College degree: 32% Employed: 57% Independent living: 65% Married: 20% Functional independence and education were significantly associated with all five outcomes (independent living, employment, income, CHART total and SWLS)	Non-representative samples Subjects are from 2 SCI Programs only Cross-sectional study which provides data from only a single point and is not a longitudinal picture of the developing outcomes Published 15y ago

Shem et al. 2011	To explore about the “Back on Track” coaching project to help the youthful grown-up of students with SCI to return to post-secondary education/work assisted by a mentee with SCI to enhance the value and satisfaction of life	Subjects were recruited from 2005 to 2010; Mentee (N= 39), Age 16-26y; Mentor (N= 17); 11 in school and 7 retired The USA	Prospective study; Community based setting; Standardized assessments were: Disability Rating Disability Rating Scale (DRS) Participation index of Mayo-Portland Adaptability Inventory – Version 4 (M2PI) Supervision rating scale (SRS) Craig Handicap Assessment and Reporting Technique-short form (CHART-SF) Diener Satisfaction with Life Scale (SWLS)	10 (34%) completed the program with 7 (24%) returning to school, 2 (6.9%) return to work, 1 (3.4%) attended school less than half time. 7 (18%) dropped out of the program before being matched; No significant difference in success rate based on employment; Positive relationship with the reintegration of study and work	Lacked information about data analysis Mentors with SCI were low in number
Kolakowsky-Hayner et al. 2012	1) to demonstrate continuing increases in standardized measures of community integration from the time of enrolment in the program to the time of exit from the program, and 2) to improve the percentage of youth and young adults with disabilities who successfully access post-secondary education or employment opportunities.	Mentee Participants: Mentees (N= 131) with TBI, SCI or other neurologic disorders recruited from 2005-2010; Average 503 days of post-injury; 67.9% M; Mean age: 20.3y; Hispanic (42.0%), Caucasian (36.6%), Asians (10.7%), African-Americans (4.6%), another ethnical group (6.1%). Mentor Participants: Trained mentor (N= 121); min 2y post-injury; successfully reintegrated to community; 57% Working, 30% attended school, 13% retired; 58%M. Mentee: 131 mentees with TBI, SCI and other neurologic disorder (CP, Stroke) Recruitment time: 2005-2010 Mean age: 20.3y Community Based Setting, USA (Back on Track to Success Mentoring Program)	Data collected by mentors and project staff; Assessments by trained Research Assistants; Meeting log for discussion; Data stored in an Access database; Descriptive and Inferential analysis by using SPSS. Scales: Same as [8]	Proportion of identified goals that were achieved: Education goals (n=53) 23/53 achieved education goals, 7/? achieved employment. Vocational goals (n=12) 5/12 achieved Vocational Goal and 1/12 achieved education Both goals (n=12) 5/12 achieved education, 1/12 achieved education Overall findings Mentoring is beneficial; Overall program satisfaction: Positive experience: 79.0%; Would participate in program again: 81.4%	Mentor mentee meeting occasionally impacted due to different geographical areas.

Table 2. Critical appraisal of qualitative articles

Y: Yes; N: No; U: Unclear, NA: Not Applicable

Criteria		Mulcahey MJ [13]	Paul S. [15]
Qualitative design	1. Is there congruity between the stated philosophical perspective and the research methodology?	N	N
	2. Is there congruity between the research methodology and the research question or objectives?	Y	Y
	3. Is there congruity between the research methodology and the methods used to collect data?	Y	Y
	4. Is there congruity between the research methodology and the representation and analysis of data?	Y	Y
	5. Is there congruity between the research methodology and the interpretation of results?	Y	Y
	6. Is there a statement locating the researcher culturally or theoretically?	N	N
	7. Is the influence of the researcher on the research, and vice- versa, addressed?	N	N
	8. Are participants, and their voices, adequately represented?	Y	Y
	9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	N	N
	10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	Y	Y

Table 3. Critical appraisal of quantitative articles

		Sandford	Anderson	Anderson	Graham	Massagli	
		Shem et al	et al	et al	et al	et al	
		188					
Criteria		[4]	[5]	[8]	[12]	[20]	[22]
Cross sectional studies	1. Were the criteria for inclusion in the sample clearly defined?	Y	Y	Y	Y	U	Y
	2. Were the study subjects and the setting described in detail?	Y	Y	Y	Y	Y	Y
	3. Was the exposure measured in a valid and reliable way?	Y	NA	U	U	U	Y
	4. Were objective, standard criteria used for measurement of the condition?	Y	NA	Y	Y	N	Y
	5. Were confounding factors identified?	N	N	N	N	N	N
	6. Were strategies to deal with confounding factors stated?	N	N	N	N	N	N
	7. Were the outcomes measured in a valid and reliable way?	Y	U	Y	Y	N	Y
	8. Was appropriate statistical analysis used?	Y	U	Y	Y	N	Y
Case reports		Kolakowsky-Hayner et al					
		[21]					
		Y					
Case reports	1. Were patient’s demographic characteristics clearly described?	Y					
	2. Was the patient’s history clearly described and presented as a timeline?	U					

3. Was the current clinical condition of the patient on presentation clearly described? Y
4. Were diagnostic tests or assessment methods and the results clearly described? Y
5. Was the intervention(s) or treatment procedure(s) clearly described? Y
6. Was the post-intervention clinical condition clearly described? Y
7. Were adverse events (harms) or unanticipated events identified and described? Y
8. Does the case report provide takeaway lessons? Y
-

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