

# Improving Quality of Life after Spinal Cord Injury: development of an intervention and feasibility study

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By

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September 2019

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**Thesis submitted to the School of Health Sciences of Cardiff  
Metropolitan University for the degree of Doctor of Philosophy**

## **Abstract**

The aims of the research was to identify (1) coping strategies that people with SCI use, (2) factors that impact on quality of life (QoL), (3) people's attitudes towards peer support groups, (4 and 5) develop and evaluate an evidence informed intervention consisting of a peer support group designed to enhance QoL for people with a spinal cord injury (SCI). According to the literature QoL in people with SCI is low and previous research has shown that peer support groups can be beneficial for other vulnerable groups. There is currently no peer support group in the UK for people with SCI. To help develop the intervention the objective was to design three studies. In study 1 a systematic review was conducted to identify if people with SCI do have a poorer QoL and what factors impact on this. A qualitative study involving several participants was conducted in study 2 which was concerned with finding out how participants cope with their SCI and what knowledge they have of peer support groups and how they feel about them. Study 3 used a quantitative method to analyse how 270 participants had reported coping since becoming spinal cord injured, how they feel about peer support groups, would they attend one and how would they like to see a peer support group structured. The findings of these three studies were used to inform the design of a peer support group as an intervention to improve QoL. The evaluation of the peer support group involved a random control trial with 20 participants divided equally between the intervention and control groups. A mixed method design was used to evaluate the intervention, quantitative (ANOVA), qualitative (Thematic) analysis. The GHQ-12, QOLS-16, Brief-COPE-28, Lifestyle questions, completed at baseline, week 8 (end of intervention) and week 24 (follow up) were used for the quantitative evaluation. Interviews were conducted with 2 participants after the intervention. Quality of Life was significantly improved in the intervention group from baseline to week 8 ( $p<.05$ ), mean differences showed that participants used emotional coping to a lesser extent after the intervention, but due to the

small sample this difference was not significant  $p>.05$ , suggesting that future research would be useful to explore this issue with a larger sample, there were no significant differences regarding forms of coping instrumentally after the intervention ( $p>.05$ ) or general health ( $p>.05$ ). Qualitative themes identified were: positive shared knowledge and experience, acceptance, coping with SCI and peer support group structure. Meeting peers, being able to share problems, being accepted and feelings of coping were positively reported aspects of the intervention. The findings of the study suggest that the peer support group was both feasible and acceptable. Participants enjoyed attending the groups and felt they benefited from shared knowledge and experiences. QOL in the intervention group improved.

## **Acknowledgements**

I would like to say a thank you to all the participants without whom this research would not have been possible. I'd like to thank my good friend Tony Stephenson for being my go-to man and for giving up your time to facilitate the peer support group.

I'd like to thank Dr Caroline Limbert for everything she has done for me not only on my PhD but for the last 12 years of supervision. Without your insight and patience, I would not be where I am today. I will miss your comments, quick-witted humorous remarks and our conversations but then again, we still have Stage 2 to look forward to. You really are one in a million and deserve a sainthood. I'd also like to thank Dr Paul Hewlett for stepping in as a supervisor and for all your quantitative input. To Dr Jenny Moses thank you for attending the supervisory meetings rain or shine and for your valuable input.

My wife Tina has been my rock and without whom I may have given up. She has had to listen to nothing but Psychology for 10 years, put up with the odd mood swing and temper tantrum especially after I received my revisions. At times it has been arduous but with the constant supply of cups of tea it has made life easier. I can't thank you enough for always being there as a listening ear even though I know it drives you crazy. I have to give a shout out to my son Dylan as he missed out on some weekend time growing up as I was stuck in front of a computer, but I am proud of the man you are becoming. I'd like to thank my closest friends Nathan, Karen and Noella for listening and for giving their support.

Finally, I would like to dedicate my thesis to my mother Christine who has been my inspiration my entire life. She raised me as a single mother with fortitude and strength and instilled that can-do attitude where you never give up.

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# **Improving Quality of Life after a Spinal Cord Injury: intervention and design feasibility study**

## **Introduction**

### **Chapter 1**

#### **1.0 Introduction**

Individuals who have spinal cord injury (SCI) are said to have a poorer quality of life (QoL) than the general population (Dijkers, 2005; Kennedy et al. 2010), this is in part due to poor coping strategies (Kennedy et al. 2000) and secondary health impairments (Noonan et al. 2008). However, there are other factors that impact on QoL and a lower life satisfaction in people with SCI, which will be discussed throughout the thesis.

After a search for a peer support group (behavioural change intervention) for people with SCI for the research project using a computerised search of the online databases PsychInfo, Medline and Pubmed and Google, no evidence to suggest they do not exist could be found. There are charities such as the Spinal Injuries Association (SIA), Aspire and Backup that have Community Peer Support Officers (CPSO) who have SCI that provide a one to one service (Haas, Price and Freeman, 2013). However, one on one peer mentoring just offers one person's perspective of their own knowledge and experience of being spinal cord injured to the individual on the receiving end of their support. Their job is also to help with other things such as legal issues, access to social workers, housing and grants etc (Haas, Price and Freeman, 2013).

The aims of the thesis were firstly to identify coping strategies people use enabling them to cope after SCI, what factors impact on QoL and how QoL can be improved in people with SCI by conducting a literature review (Chapter 1) and a systematic review of the literature (Chapter 2, study 1). The third aim will be to identify what people with SCI think about peer support groups and if they would attend one and how they would like them structured by designing and conducting a qualitative study interviewing several participants (Chapter 3, study 2) and an online quantitative study using a questionnaire (Chapter 4, study 3). The last aims were addressed via the design of an evidence based behavioural change intervention consisting of a peer support group to evaluate the impact on QoL in people with SCI and if so to identify whether it would be feasible to roll the intervention out to a larger SCI population.

The peer support group was designed for people with SCI and to be facilitated by a person with SCI. This is an important aspect of the peer support group as it is believed that individuals will open up and talk about sensitive matters that they would feel uncomfortable sharing with someone who did not have SCI (Mental Health America, 2016).

## **1.1 Chapter overview**

In this chapter, the background to the research will be described. An introduction to the important aspects of the research project will be presented, which includes information relating to SCI i.e. causation, prevalence, and incidence; factors that can impact on how a person with SCI appraises their situation and how they cope both physically and psychologically. Furthermore, the study will look at a behavioural change intervention that could help improve quality of life (QoL) in people with SCI.

## **1.2 How is the spinal cord affected by injury or illness**

SCI occurs when there is damage to the spinal cord that blocks messages from the brain to the body. After an injury to the spinal cord has occurred, an individual may have problems with sensory, motor and reflex messages being passed through the damaged part of the spinal cord. The higher the lesion/injury on the spinal cord, the more dysfunction the individual will experience (World Health Organisation (WHO), 2013; Spinal Injuries Association (SIA), 2019; Backup, 2019); however, SCI does not affect a person's intellectual ability unless that person has sustained a head injury that leads to brain damage. Cognitive impairment is said to affect between 30% and 60% of the adult SCI population (Craig et al. 2017). The human vertebral column is the backbone or spine of a human. It consists of twenty-four articulating vertebrae and nine fused vertebrae in the sacrum and coccyx and is situated in the dorsal aspect of the torso; separated by intervertebral discs. It houses and protects the spinal cord in its spinal canal. There are 33 vertebrae in the spinal column, and they are named according to region and position, from superior to inferior. The names of the vertebrae are as follows: Cervical C1 to C8 (affects head, neck, diaphragm, deltoids, biceps, wrist extensors, triceps and hands), Thoracic T1 to T12 (affects, chest muscles, abdominal muscles), Lumbar L1 to L5 (affects, leg muscles), and the Sacral S1 to S5 vertebrae (affects, bowel, bladder, sexual function) (WHO, 2013; SIA, 2019; Backup, 2019).

There are two terms that are used in the UK to identify the level of injury sustained by an individual; these are paraplegia and tetraplegia (known as quadriplegia in some countries). A paraplegic is someone who has sustained a level of injury from Thoracic 1 to 12, Lumbar 1 to 5, Sacral S1 to S5, or the Coccygeal 4 vertebrae. Tetraplegia covers the level of injury from Cervical 1 to 8 (WHO, 2013; SIA, 2019; Backup, 2019).

There are typically two types of lesions associated with SCI. These are known as a complete SCI and an incomplete SCI. A complete type of injury means there is no function below the level of injury; no sensation and no voluntary movement. Both sides of the body are equally affected. An incomplete injury means that there is some functioning below the primary level of injury. A person with an incomplete injury may be able to move one limb more than another, may be able to feel parts of the body that they cannot move, or may have more functioning on one side of the body than the other (WHO, 2013; SIA, 2019; Backup, 2019). If a person has sustained an injury to the Thoracic 1 to 12 vertebrae, and they have a complete break, they will typically have no sensation below their level of injury and have no use of their legs. The individual will have total hand and arm movement and will use a wheelchair. With injuries to Lumbar 1 to 5, the person may have sensation, but their legs are usually weak. They walk with the aid of crutches and have some use of a wheelchair. If there is a cervical level injury, sensation or impairment depends upon how close to the brain stem the injury is located. For example, a C1 – C2 injury can result in a loss of many involuntary functions including the ability to breathe; necessitating breathing aids such as mechanical ventilators or diaphragmatic pacemakers, but a person with a C8 complete injury would not have full hand function (WHO, 2013; Apparelyzed, 2014; SIA, 2019; Backup, 2019).

### **1.3 History of spinal cord injury**

Throughout scientific history, SCI and paralysis have been considered severe and irreversible conditions. Since the times of early Egypt, (2500-3000 Before Common Era or BC; before Christ), physicians recognised that SCI was an untreatable condition. Medical documents from that era mention techniques of spinal surgery, but they also expressly label SCI as an “ailment not to be treated” (Schiller and Mobbs, 2012).

In Greece, Hippocrates (460-370 BC) helped to pioneer the treatment of SCI by performing external reduction (extension bench, stretch the back) for the condition. He also associated ulcers, bladder, and bowel dysfunction with paraplegia and raised awareness for SCI complications and discussed ulcer prevention (Agrawal and Neha, 2015).

In the past 5000 years; from early Egypt (Papyrus), Greece (Homer and Hypocrates), Rome (Aulus Cornelius Celsus), Persia (Avicenna), Italy (Roland of Parma), and through to the modern times of Humphrey Davy (1800s UK) to Mackay-Sim et al. (2008, Australia), a better knowledge of SCI has been gained. Experiments are now being carried out on rats and mice where spinal cord damage has been reversed (Fouad, Hurd and Magnuson, 2013). In 2014, a man walked after having cells from his nasal cavity transplanted into his spinal cord (Kmietowicz, 2014); however, there is no evidence to suggest that this will work on other people with SCI.

#### **1.4 Causation**

There can be many ways of injuring the spinal cord. The National Spinal Cord Injury Statistical Centre (NSCISC) in the USA, state in their 2017 annual report, that motor vehicle accidents were the leading cause of SCI, accounting for more than 38.72% of new spinal injuries each year. Falls account for 30.67%. The report stated that 13.46% of all SCIs result from violent encounters, often involving gunshots and knife wounds (NSCISC, 2018). In recent times, adrenaline sports have become more common and they, along with sports in general, can account for 8.83% of SCIs. Medical/surgical complications and being hit by falling/flying objects, for example, account for 8.31% (NSCISC, 2018). However, Spinal Research UK found that falls were the biggest cause of SCI accounting for 41.7% and road traffic accidents (RTA) accounted for 36.8%. Sport accounted for 11.6% and another 10.2%



of injuries were attributed to “other” causes which included violent encounters at 2.7% (Spinal Research, 2019). Further research found that alcohol was involved in one of every four cases of SCI. This was not included in either of the reports mentioned above. Diseases such as cancer, arthritis, osteoporosis and inflammation of the spinal cord are also common causes of SCI. These were included in the “other” category in the reports listed above (Mayoclinic, 2015).

The statistics for the USA and UK are largely the same except for violent causes and falls (NSCISC, 2018; Spinal Research, 2019).

## **1.5 Incidence**

Identifying the incidence of SCI involves looking at the data and seeing how many people have become spinal cord injured in any given population over a certain period of time. The current research is looking at the UK but also trying to make a comparison with other countries such as the USA. Incidence can be reported as the number of new cases per million in any given population. It can be categorised into demographics (gender and age), occupation, or location (urban or rural). This could be refined further to identify at risk groups, thus helping possible preventative measures (Yang et al. 2014).

The UK incidence rate based on the Backup Trust is 31 cases per million per year with 2000 people each year becoming spinal cord injured (Backup, 2019). In the USA, this figure is much higher with approximately 54 cases per million or the equivalent of 17,700 new cases each year (NSCISC, 2018). According to the World Health Organization (WHO), every year there are between 250,000 and 500,000 new SCI cases worldwide. This is between 40 to 80 cases per million dependant on country (WHO, 2013; WHO, 2015; Adriaansen, 2016).

Figures now show that in the UK 2500 people become spinal cord injured each year not 1000 as previously reported by the SIA and the NHS (Backup, 2019; Aspire, 2018). The charities attribute the increased figures mainly to better reporting and record keeping as well as better definition of what constitutes SCI, which includes non-traumatic causes such as illnesses as well as accidents. The figures show a 2:1 ratio on male to females becoming spinal cord injured (Spinal Research, 2015).

## **1.6 Prevalence**

Prevalence is the number of people living in any given population with SCI at any given point in time. The USA has a prevalence rate of 906 per million (Singh et al. 2014).

According to the Spinal Injuries Association (SIA), there are currently 40,000 people in the UK living with SCI (SIA, 2015); however, Aspire and Backup Trust (two other SCI UK charities) says that number is 50,000 (Aspire, 2018; Backup Trust, 2019).

The literature shows that in the USA in the 1970s the average age of an injury was 28 years, with 50% of injuries occurred between the ages of 16–30, which is 5% fewer than the UK. In 2005, figures showed that the average age of injury increased to 42 years. This could be because of survival rates based on medical care.

## **1.7 Outcome after being diagnosed with SCI**

For patients that have been diagnosed with SCI they will initially be on bed rest in a general hospital and then they may be sent to a rehabilitation centre (Sci-Info-Pages, 2015). In the case of traumatic SCI often surgery is necessary to remove fragments of bones, foreign objects, herniated disks or fractured vertebrae that may be compressing the spine. Surgery

may also be used, in England and Wales, to stabilise the spine to prevent further damage and to prevent future pain and deformity (NHS Clinical Advisory Group, 2011). Length of time in hospital will be dependent on many things, such as whether the cause of the injury was categorised as traumatic or nontraumatic, the level of the spinal cord break (a tetraplegic will take longer to rehabilitate than a paraplegic), age of injured person (a younger person will rehabilitate faster than an older person), extent of injuries (whether it includes the head, lungs, or breaks to limbs) and whether a person has somewhere to go when leaving a specialist rehabilitation centre or general hospital (Apparelysed, 2015; SIA, 2015).

Of people leaving rehabilitation centres and general hospitals, 21% go directly to nursing homes. Nursing homes are aimed at an elderly population and people with SCI are sent there despite 55% of them being between 16 and 30 years of age. SCI costs the UK more than £500 million yearly (SIA, 2015).

As previously mentioned in the UK 21% of people with SCI leaving rehabilitation centres are going directly to nursing homes or institutions. In the USA it is 13%, no reason could be found for this figure being less than the UK. However, this could be due to there being more paraplegics than tetraplegics in the USA, as tetraplegics need more care (WHO, 2013; Apparelysed, 2015).

## **1.8 SCI and rehabilitation**

In recent times, SCI is a start to a new challenging life, personally and socially, rather than the end of a person's life. People with SCI can now look forward to better medical care. The care of people with SCI is, in part, thanks to Sir Ludwig Guttman who was one of the pioneers of SCI medicine. He recognised that the treatment and rehabilitation of people with

SCI were best delivered in specialist SCI centres. He believed that care should be provided by a specialist team and then with a lifelong follow up (WHO, 2013; SIA, 2015).

With advances in technology, medical personnel and social care, i.e. hospital equipment, beds, well-trained physiotherapists, occupational therapists, nurses, doctors and psychologists, people with SCI can now be both physically and mentally rehabilitated. Upon leaving hospital people who suffer from SCI can look forward to a more accessible environment and a social service who offer aftercare. As a result, people with SCI can look forward to a longer, more productive life. This wasn't possible for past generations in the UK and other affluent countries (WHO, 2013).

Currently in Wales the Welsh Health Specialised Services Committee (WHSSC) (2018) recommend a medium to long term rehabilitation programme to achieve the required rehabilitation goals which is typically 2 to 4 months but may be as much as 6 months. However, a more detailed breakdown of referrals, admissions and discharge times can be found for England in a report carried out between April 2015 – March 2017 by NHS England Spinal Services Getting it right first time (GIRFT) (Hutton, 2019). According to the report depending on where a person lives within England and which of the eight rehabilitation centres a person is sent to the referral times for admission can vary from as low as 5 days to as high as 56 days, admission to mobilisation takes between 0 to 40 days and from admission to being considered fit for discharge takes between 63 to 120 days. The differences between centres was possibly due to different management protocols and other factors e.g. case mix (Hutton, 2019).

Bed spaces within a specialist rehabilitation centre in the UK cannot be guaranteed and people are currently put on a waiting list (personal communication with a senior nurse at a spinal cord injury rehabilitation centre). SIA (2015) state in their own report, that was funded by the UK Government, that not everyone who sustains SCI is able to access specialist care in a rehabilitation centre in a timely manner, if they do at all. This is due to an increase in blocked beds caused by a delay in discharging patients from hospital. These delays are due to prolonged negotiations with health care services that deliver care packages to patients that leave specialist rehabilitation centres and help them to reintegrate back into society. These packages include not only the type of home care a person with a new SCI can receive, but also specialist equipment that might be needed within their home, such as wheelchairs and ventilators (SIA, 2015). Other reasons given for delayed discharge within the UK from the highest to lowest were patients not having the following in place: 35% housing, 34% care package, 11% funding, 7% nursing home placement, 5% equipment, 4% bowel training and 4% discharge destination (SIA, 2019).

The problem with delaying discharge from hospital is that people can easily forget the skills they have learned in order to better live with their SCI (SIA, 2015). Patients that are not able to leave hospital, through no fault of their own, block beds for patients awaiting a bed in a specialist SCI centre. The outcome for these patients is that whilst waiting in general hospitals they may contract urinary tract infections (UTI), pressure sores and other complications which are due to not being able to receive specialist care. Further problems happen within the NHS when people with a high-level SCI, who need ventilation for their breathing, cannot be admitted to specialist units. They then continue to use critical care beds within general hospitals which impacts non-SCI patients (SIA, 2015).

The issues that arise from decreasing lengths of stay in rehabilitation centres, or not staying in one at all, is that people with SCI will be released from a hospital back into the community lacking self-care and mobility skills to prevent secondary health care complications. This impacts their independence and puts more strain on their local health care services. The lack of or poor service to people with SCI has been investigated by the All-Party Parliamentary Group on SCI – supported by the Spinal Cord Injuries Association (SIA, 2015), however, it is not known if it has been investigated in the 4 years since.

There are currently eight rehabilitation centres in England, with a reported total number of beds for patients with SCI at 425 in 2008 but this number has decreased to 395 in 2017/18 (NHS England Spinal Cord Injury Services, 2019). There are four other specialist rehabilitation centres located in Wales, Scotland, Northern Ireland and Republic of Ireland but the number of beds in these units could not be found at this time.

### **1.9 Hospital delayed admission and delayed discharge costs**

The cost of keeping one SCI ventilated patient in a general hospital is £1800 a day, however, the cost of keeping one SCI ventilated patient in a specialist rehabilitation centre is £968 a day (SIA, 2015).

As not all specialist centres support ventilated patients, the waiting times can be long. A specialist unit in Sheffield had 15 ventilated dependent patients admitted with an average wait time of 100 days and a maximum of 286 days. The total time for all patients was 1,505 days with an estimated cost to the NHS of £367,220 which is more than if they had been in a specialist ventilated bed in SCI unit (SIA, 2015). Between 2013/2014, 34 ventilated patients waited an average of 33 days to be admitted to SCI centre but could wait up to 164 days.

Seven hundred and sixty-one non-ventilated patients waited an average of 24 days but could wait up to 279 days in England (SIA, 2015).

Delayed discharges are a financial burden on the NHS. The National Spinal Injuries Centre at Stoke Mandeville Hospital stated they had delayed discharges of at least 7% of their patients, weekly (SIA, 2015; Hutton, 2019). In 2014, delays reached a maximum of 11% with the total number of bed days being lost at 2,910. That could have helped 16 other patients for 6 months (SIA, 2015). In Sheffield, a spinal cord injury centre submitted their own report which stated that they had recorded a maximum delay in discharge for non-ventilated patients at 85 days at an extra cost to the NHS of £47,090 per patient. The delayed discharge for ventilated patients was 14 – 232 days with a maximum extra cost of £224,576 (SIA, 2015). An audit by the SIA in 2015 states that in 2013/14, 125 patients in England had a delayed discharge from specialist rehabilitation centres, which is a third of the total bed capacity for the whole of England (SIA, 2015).

### **1.10 Financial economic burden; health care costs**

It has proved difficult to find the financial facts and figures on annual health care costs of living with SCI in the UK; however, McDaid et al. (2019) whom had the same difficulty used a simulation model to estimate lifetime costs of living with SCI in the UK.

Health care costs are highest for SCIs in the first year of onset and then decrease thereafter. These costs can also be dependent on the level of injury i.e. it would cost more to look after a person with SCI who is ventilated than a low-level paraplegic. Lifetime costings can vary depending on whether the cause of the injury was traumatic vs non-traumatic, the level of injury, whether it is a complete or non-complete break, whether the injured person is male or

female and when the person had their injury i.e. earlier or later in life. These costs can also rise depending on long term care i.e. assisted accommodation, respite care and personal assistance (WHO, 2013; SIA, 2015). However, the average lifetime costs for new UK cases would be £1.12 million for a paraplegic, and £1.87 million for a tetraplegic with per annum lifetime costs for all new SCI cases exceeding £1.43 billion (McDaid et al. 2019).

### **1.10.1 Financial economic burden; cutting health care costs: peer support**

There is evidence that people with other types of illnesses (substance abuse, chronic illness, etc) that use peer support groups have reduced the need for visits or stays in hospital (White, 2007; Kyrouz, Humphreys and Loomis, 2002; Sweet et al. 2016). The cost of caring for someone with SCI could be reduced if there is education during and after rehabilitation (White, 2007; Sweet et al. 2016). Providing the injured with knowledge and skills to be able to care for themselves, long term is beneficial (White, 2007; Sweet et al. 2016). This is especially important as 79% of people with SCI go home with no further care other than annual or bi-annual checks on their physical health (Apparelyzed, 2014; SIA, 2015). Many people miss these annual and bi-annual checks. The reason for this could be inaccessible transportation, lack of family and friends or limited funds (Kroll, 2008). There is also evidence that twenty per cent of those who leave the hospital are diagnosed with clinical depression immediately upon returning home (Kennedy and Rogers, 2000; Kennedy et al. 2000).

### **1.10.2 Financial economic burden, personal living costs, and employment**

In the UK, SCI disability benefit costs the government an average of £100 million yearly with a person with SCI receiving a monthly average amount of £1600 (Citizens Advice, 2019). It



also includes incapacity benefit, disability living allowance with care component and Motability, support and employment allowance and, in some cases, people receive a housing and council tax benefit (Citizens Advice, 2019). This does not include the cost of health care or social care (Full fact, 2015; Citizens Advice, 2019). The average manual wheelchair, which needs to be replaced at least every 5 years, will cost between £400 to £7050, but this figure jumps considerably when buying an electric wheelchair (EPC Wheelchairs, 2019). Items of clothing suitable for wearing in a wheelchair, such as gloves to push, are more expensive than non-wheelchair items. Even household furniture needs to cater to wheelchair use and transfers. The most important item for an individual in a wheelchair, other than the wheelchair itself, is a bed. This can become very expensive as choosing the right orthopaedic mattress is key. The cost of living yearly, with SCI, is much higher than for abled-bodied individuals. In fact, the living costs are £570 more, on average, per month (Scope, 2019). Since becoming spinal cord injured figures show that employment rates have decreased post-injury from 87% to 37%. The reasons given for post injury unemployment were a lack of accessible work places (48%), reluctance of employers (28%), lack of accessible transport (24%), inadequate training (24%), chronic pain (23%), personal care needs (20%) and a lack of desire to work (20%) (Bucks Healthcare, 2015). There is a need for better training for people with SCI as most are going from manual labour to desk jobs. Employers are frequently not educated as to the needs of people with SCI and a very important part of that is to provide better-disabled access in the workplace (Ottomanelli and Lind, 2009).

Scope (2015) produced a report designed to help disabled people back into work and they found that if there was a five-percentage points rise in employment; it would increase the gross domestic product (GPD) by 23 billion. A 10-percentage points rise would result in a 45 billion rise. That would be a gain to the exchequer by 2030 of 6 billion based on a 5

percentage points rise or £12 billion for a 10 percentage points rise (Scope, 2015). Scope (2019) warned the UK Government if they did not help get disabled people back to work, then by 2030, poverty below pension age will rise from 19% to 30% in the disabled community.

The Multidisciplinary Association for Spinal Cord Injury Professionals (MASCIP) in 2017 published Vocational Rehabilitation Guidelines to help improve return to work rate for people with SCI. They found that a third of people with SCI return to work and that this is a huge benefit to physical and mental health, furthermore it is suggested that this is a good indicator of how well a person with SCI is coping and adjusting to their SCI (MASCIP, 2017). Being employed leads to a greater life satisfaction, improved QoL, fewer secondary health impairments and increased life expectancy (Ottomanelli & Lind, 2009, Krause et al. 2012, MASCIP, 2017).

If people with SCI became employed, they would be less of a burden on the economy but, much more than that, it would help to provide them with social support (Charlifue and Gerhart, 2004).

### **1.11 Housing**

Individuals with SCI should have the right to lead a dignified life and be able to cook, clean, and wash for themselves (WHO, 2013; Equality Human Rights Commission, 2016). They should be able to live without the worry of having to live in residential care. In general, inaccessible housing is one of the biggest issues facing disabled people and is not only specific to a person with SCI (Equality Human Rights Commission, 2016). The cornerstone of independent living is obtaining housing that is accessible and adapted to the requirements

of the person living there. Many people in the UK do not live in housing that meets their requirements (Equality Human Rights Commission, 2016).

Having somewhere suitable (adapted) to go to is a necessity for a person who has sustained SCI; a place that they can go to that has been adapted for wheelchair use (Equality Human Rights Commission, 2016). Many people leaving the hospital will have lived in a house which will need to be big enough for a floor to ceiling lift or a stair lift (NHS, 2019). The ideal property is a bungalow; however, bungalows in the UK make up 10% of the entire property market (DCLG, 2016b). At the point where, people who sustained SCI are seeking housing, social services would be involved as they will help with adaptations and modifications. If needed they will help with finding suitable accommodation (Equality Human Rights Commission, 2016; NHS, 2019). Any property will have to have lower kitchen surfaces and a bathroom that is large enough and, in some cases, a wet room (Equality Human Rights Commission, 2016; NHS, 2019).

Unsuitable housing is a common problem worldwide, but in the UK where there are high levels of home ownership and very little space, there is inadequate financial help for home adaptations. There are an estimated 78,000 wheelchair users who are said to be living in properties that are lacking adaptations and modifications that would make life easier (Joseph et al. 2010; Equality Human Rights Commission, 2016). If a person in the UK does not have the finances to buy their own property, they may end up living with a family member. If that is not possible, then social housing, maybe an alternative option. It is also worth noting that, in the UK, out of all housing that has been set aside for wheelchair users, only 22% actually contain someone who uses a wheelchair (Joseph et al. 2010). The 21% of people with SCI that are discharged from hospital without access to appropriate housing, they go into elderly

care homes (SIA, 2015). It is common practice for these individuals to live in a care home for up to 3 years (Smith and Caddick, 2012).

Local authorities in the UK are not building enough accessible housing for disabled people (DCLG, 2015a). Up until 2017, building regulations for England, Wales, and Scotland have shown that there was a lack of accessible housing especially for people in wheelchairs (DCLG, 2015a). The facts show that only 7% of homes in England had minimum accessible requirements for wheelchair users (DCLG, 2015a) and in Scotland, this dropped to 0.7% with local authorities and was 1.5% with social landlords (Independent Living in Scotland, 2017).

Without wheelchair accessible homes thousands of disabled people have to put their lives on hold (Aspire, 2019). Aspire contacted 5 local authorities and found that it would take 50 years to allocate housing to wheelchair users on their waiting list. Within the report there are quotes from people with SCI who discuss how they are feeling down, sad, depressed, heartbroken and exhausted (Aspire, 2019). In one quote a man states that he will spend the rest of his life in a care home and that he has no future. He mentions all the money spent rehabilitating him and getting him back to society and then he is just dumped in a care home where he has forgotten all he learnt in rehab. He finishes by saying he has no hope and he can't see any (Aspire, 2019). These are the people with SCI that would benefit from attending a peer support group.

### **1.12 Changes after SCI**

Upon leaving the hospital/specialist rehabilitation centre and going home, there can be much uncertainty. A “new normal” will present itself. A person will go from having a daily routine i.e. get up, go to work, or school, but when that individual becomes paralysed, they have to

learn to do things differently, it takes time to adjust (Model Systems Knowledge Translation Centre (MSKTC), 2016).

An individual will be very likely to use a wheelchair on a daily basis. They will wake up in the morning and will, in most cases, stay in their wheelchair for the best part of the day until they go to bed (Fogelberg et al. 2009). Their new routine will be to wake and shower or bath, get on the bed to get dressed, and get back in their wheelchair to start their day (Fogelberg et al. 2009). During the day, they must keep in mind to do regular lifts. This will stop the formation of pressure sores as their skin can breakdown quite easily in the early days before a person's body adapts to being seated constantly (Fogelberg et al. 2009). They will need to consider regular toilet breaks whether that's emptying a leg bag (convene drainage) or regular catheter toilet breaks. This is can be different for males and females. Some people with SCI lack bowel movement (dependant on the level of injury) and must put a bowel care regime in place to stop accidents from occurring. The level of injury will impact this routine, as a higher break will need a carer to help them achieve this (WHO, 1996; Fogelberg et al. 2009; MSKTC, 2016).

It is not easy to go from being able-bodied and active to being disabled and limited. This is also made more difficult as adapting to health issues becomes the norm. The care or help needed will depend on the level of injury sustained. Staying active is important by trying to do things that they did before their injury, such as cooking, cleaning and other household chores, even hobbies, like playing an instrument (WHO, 1996; MSKTC, 2016). Learning to manage self-care, gaining a better understanding of how to manage their own body and being happy with self-image are all key to adapting to a new life as a person with SCI (WHO, 1996; MSKTC, 2016).

### **1.13 Independence**

Once a person with SCI has learned to adapt and regain a new daily routine, they become more independent (Nas et al. 2015). Research suggests that as things start to normalise, each individual with SCI is different in how they begin to lead their lives and take care of themselves (Nas et al. 2015). It was found that important predictors of independent living were not only becoming employed (37%) (Charlifue and Gerhart, 2004), but integrating socially back into the community. Family life was a predictor of independent living i.e. marital status and whether a person had children or not. It was found that education was a strong determinant of independent living (Charlifue and Gerhart, 2004). Overcoming transportation barriers, like being able to drive and not being dependent on others to get to and from work and hospital appointments, and socialising was one of the main factors in living independently (Dejong et al. 1984).

### **1.14 SCI and comorbid affects**

Research has found that, on the whole, people who have been diagnosed with SCI do, in fact, adjust well and this is associated with good adaptive coping strategies (Kennedy et al. 2000; Kennedy et al. 2003; Pollard and Kennedy, 2007); however, some individuals do remain vulnerable. For these people, the psychological impact of SCI can be devastating with an estimated 33% of people reporting clinical levels of depression and anxiety post-injury and in some cases post-traumatic stress disorder (PTSD) (Migliorini et al. 2009). SCI is also associated with substance abuse and risk of suicide (Craig, Hancock and Dickson, 1999). In a study that looked at substance use in people with SCI, it was found that half of the large sample of adults abused drugs and alcohol after they were injured. The same study also highlighted that suicide rates were 4 times higher than the general population (Heinemann et

al. 1991; Kennedy et al. 2000). In a study in 2009 it was found that 44% of 62 people, who had received SCI, met the criteria for PTSD (Chung et al. 2006).

### **1.15 SCI and its effect on family**

Previous research has looked at how men have coped since the injury leading to SCI, as men account for 80% of those who have sustained SCI (Spinal Research, 2015). SCI can impact on men in terms of sex-role as they may be classified as the primary breadwinners and injury can result in a loss of earnings and benefits for the family (Chhabra and Batra, 2016). A similar study cited potential negative effects on the family caused by gender role reversal due to the man having limited mobility, this, in turn, could cause insecurity, fears, guilt, damaged ego, directly impacting negatively on their marriage and parenting (Craig et al. 2002).

There is limited literature to support the roles of mothers with SCI and how their families are affected. What research there has been, suggests that women with SCI who become mothers thrive in the home environment and adapt well to their responsibilities, even though there can be some negativity from other people in relation to their decision to become disabled mothers (Kocher, 1994). The negativity arises from people who still believe that individuals with SCI/disability are somehow vulnerable, dependant or incapable (Duvdevany et al. 2008), however, these traditional family roles maybe outdated now.

Earlier literature by Arnaud found that disabled parents had troubled relationships with their children, and this was due to the parent being irritable with a short temper. It was also stated that the children were bad tempered as they resented their disabled parent (Arnaud, 1959). More recent research has found that this is not the case. Buck and Hohmann (1989) found that children of fathers with SCI were well adapted and did not have any adverse

psychological factors associated with having a disabled parent. In fact, the children were said to be emotionally stable, had normal sex role identities, body image was good, and they were able to have interpersonal relationships, especially with family members. Alexander et al. (2002) studied the effects of mothers with SCI and the impact it had on their children and family. They found that the children adapted well and that there were no harmful effects on self-esteem, gender role identity and the children thought no differently about their parents after they became spinal cord injured than before they became spinal cord injured. These findings would suggest that whether a mother or father with SCI, the family adapts to the new situation and they cope well.

SCI affects not only the person with the injury, but spouses, siblings, children and parents. It is often the spouse who is left with the job of caregiver and due to this new role, they can become stressed. Research evidence suggests that the spouse or caregiver can suffer more emotional stress than the injured partner (Chhabra and Batra, 2016). It has been said that spouses of injured partners may become depressed and can have burnout, fatigue, anger and resentment (Weitzenkamp et al. 1997, Chhabra and Batra, 2016). Research has found that SCI can have a more extreme impact on a partnership or marriage that started before injury than those relationships that started after an injury (Chhabra and Batra, 2016) with a higher rate of divorce in those relationships that started pre-injury (Chhabra and Batra, 2016).

### **1.16 Adjusting after SCI**

Research suggests that people with SCI tend to have problems adjusting in the early years. Psychological adjustment can vary widely amongst individuals who have SCI, due to this there has been an increase in research looking at the factors that predict it (Dunn, 1996; Kennedy, Evans and Sandhu, 2009). There are a number of reasons why adjustment can be



difficult i.e. loss of bowel, bladder, sexual function, to daily living such as bathing, dressing and even eating, dependant on level of injury (Glass, 1999). In the first few years after injury there are signs that people with SCI find it difficult to adjust, e.g. depression, divorce and even suicide which is 4 times higher in the SCI population (DeVivo et al, 1991; Elliot and Frank, 1996; Kennedy et al. 1999; Soden et al, 2000; Kennedy and Rodgers, 2000; Pollard and Kennedy, 2007; Chevalier, Kennedy and Sherlock, 2009; Kennedy, Evans and Sandhu, 2009). Despite the issues that many people with SCI have, the majority adjust and report a greater QoL than those that have difficulty adjusting psychologically (Kennedy, Kilvert and Hasson, 2016). Kennedy et al. (2010) suggested that appraisal and coping are two key factors that help with psychological adjustment after a person sustains SCI. Individuals that adjust well will appraise their situation and depending on the appraisal process they will then adapt by using appropriate coping strategies (Kennedy, Lude and Taylor, 2006; Chevalier, Kennedy and Sherlock, 2009).

### **1.16.1 Appraisal after SCI**

‘Appraisal’ is defined as the “cognitive process of categorising an encounter, and its various facets, with respect to its significance for well-being” (Lazarus and Folkman, 1988, p. 31).

The appraisal theory has two levels; primary appraisal and secondary appraisal. Primary appraisal involves deciding whether an event is a threat, a harm/loss, or a challenge.

Harm/loss refers to the damage that has already been done to the person. A threat is the potential harm or loss that could be developed in the future and a challenge is the possible opportunity for growth and gain (Kennedy, Evans and Sandhu, 2009; Kennedy, Kilvert and Hasson, 2016). Primary appraisal, along with a person’s state of readiness and other stressors within their environment, will impact on the coping strategies they choose (Galvin and Godfrey, 2001; Kennedy, Evans and Sandhu, 2009). Secondary appraisal involves an

evaluation of what available coping resources the individual has for dealing with the situation (Galvin and Godfrey, 2001; Velichkovsky, 2009; Bippus and Young, 2012). There are three judgements that make up secondary appraisal according to Lazarus (1999); blame or credit, coping potential, and future expectations (Bippus and Young, 2012). Blame or credit is whether the harm caused was intended or not and whether the person causing the harm is responsible. The second judgement is finding a coping strategy e.g. if someone is bringing negativity into my life can they be avoided in the future? Thirdly, future expectation is whether issues that have happened to a person with SCI will improve or deteriorate. Those expectations are informed by past experiences and whether issues caused by SCI will continue to happen in the future (Lazarus, 1999; Bippus and Young, 2012; Kennedy, Kilvert and Hasson, 2016). In short, primary appraisal assesses how potentially harmful a situation is and secondary appraisal evaluates whether a person has the tools to successfully deal with the demands of the situation (Velichkovsky, 2009).

It has been argued that primary and secondary appraisal do not happen in any particular order of importance (Lazarus, 1999); however, this argument was countered by Scherer (2001) and it was suggested that people appraise situations in fixed stages: detection of the stimulus event, assessment of significance for one's goals, assessment of coping potential, and evaluation against one's internal and external norms or standards (Bippus and Young, 2012, p. 177). Lazarus (1999) upheld the belief that people move back and forth automatically between primary and secondary appraisal with each influencing the other and this happens without the person even thinking about it (Smith and Kirby, 2001; Bippus and Young, 2012). How a person with SCI initially appraises their situation is said to be important as it can have an impact on their subsequent behaviour when choosing coping strategies (Bippus and Young, 2012; Kennedy, Kilvert and Hasson, 2016). The outcome of the appraisal process

then informs how a person reacts and tries to cope with the situation and their emotional response (Kaiser and Kennedy, 2011).

A study by Kennedy, Nolan and Smithson (2011) explored the relationships between appraisal, coping strategies and support, and mood and QoL in people with SCI. Their participants included 25 males and females that had been admitted to a specialist rehabilitation centre in Dublin and were asked to take part in the study 12 weeks post-injury. The results of the study found that gender, age or employment status did not affect mood and QoL, however, they did find differences in relation to injury type. They found that how a person gets on with the rehabilitation process is influenced by how they appraise their injury. If a new patient perceives their situation as unmanageable, incomprehensible, threatening and they appraise their injury as a threat and they do not think they have the means to deal with their new found situation due to SCI, they are less likely to connect with the rehabilitation process in the same way as a person who has accepted their situation and uses problem focused coping strategies to manage their new challenges (Kennedy, Nolan and Smithson, 2011).

Furthermore Eaton, Jones and Duff (2017) measured cognitive appraisal using the shortened version of the appraisal of disability scale primary and secondary scale (ADAPSS-SF). They had a sample of 371 participants that were mainly white British males and had sustained their SCI through injury, illness and disease and all were new admissions. The results of the study found four vulnerable groups who were most likely to negatively appraise their SCI; older people at time of injury, females, AIS-A (complete sensory or motor function below level of injury) and people who had become injured through being assaulted. The results of their research suggest that people who are older and who have sustained SCI are more likely to

appraise their injury as a loss which could lead to depression, anxiety and lower life satisfaction. They found that females used maladaptive emotion-focused coping strategies because they were more likely to negatively appraise their injury. The evidence suggests that people who negatively appraise their SCI report lower levels of mood. The findings support the need for a better understanding of the role of cognitive appraisal and psychological adjustment early on in the rehabilitation process (Eaton, Jones and Duff, 2017).

Even though there was some difference found between both studies the evidence identifies the need for support during the rehabilitation process to help people cope both emotionally and physically with their SCI. If people negatively appraise their SCI whether male, female, or an older person and regardless of injury type they are less likely to connect with the rehabilitation process which could lead to secondary complications e.g. depression, anxiety, lower levels of life satisfaction and poorer QoL.

### **1.16.2 Coping strategies after SCI**

Lazarus (1966) defined coping as a person's response to a stressor, where stress is seen as experiencing difficulties in people's goal related efforts. Coping is said to be a cognitive and behavioural effort in helping to manage stress (Folkman and Lazarus, 1991; Babamohamadi, Negarandeh and Dehghan-Nayeri, 2011) and can be shaped by how people appraise a situation and the different options they have that are available for coping with it (Folkman et al. 1986; Bippus and Young, 2012). Being able to assess the situation and confront the source of stress will enable the person to seek support or remove themselves from the harmful situation (Bippus and Young, 2012, p.178).

People with SCI are not a homogeneous group. They are individuals and how each person appraises and responds to their SCI is going to be very different and unique to that individual (Pollard and Kennedy, 2007). Frank et al. (1987) found that individuals who had sustained SCI differed in the way they responded to it and the coping strategies used. The way in which someone responds to their injury and the coping strategies they use can be in response to the influence of the people helping them to rehabilitate (Moos and Tsu, 1976; Kennedy et al. 2000).

Lazarus (1999) proposed that there are two types of coping: ‘emotional-focused’ which is said to be the person’s attempt to regulate their emotional response to an unchangeable situation (Kennedy, Evans and Sandhu, 2009, p.19) and ‘problem-focused (instrumental) coping’ which is when the individual sees the situation as controllable, identifies the stressor and removes or reduces its impact (Boyd-Wilson, 2000; Kennedy, Evans and Sandhu, 2009, Bippus and Young, 2012). If a person feels that something constructive can be done about the stressor, they will use problem-focused coping. However, if they feel the stressor is something that should be endured, they will use emotional-focused coping (Carver, Scheier and Weintraub, 1989). Endler and Parker (1994) suggested that there is a third coping strategy; the avoidant strategy which is when a person is focused on avoiding a stressful situation by wanting the company of other people or by doing different activities (Garcia et al. 2018; Litman, 2006).

Both emotional-focused and problem-focused coping strategies are measured using scales such as the Brief-Cope which is one of the most frequently used tools (Monzani et al. 2015). It is a 28-item, multidimensional measure of strategies used for coping or regulating cognition in response to stressors. This measure is made up of 14 two item sub-scales and

each is analysed separately: self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioural disengagement, venting, positive reframing, planning, humour, acceptance, religion and self-blame (Carver, 1997; Garcia et al. 2018).

Trieschmann (1988) said that there should be more longitudinal research that not only looks at aspects of psychological impact after a person sustains SCI, but also explore the relationship between psychological well-being and coping strategies and adjustment (Kennedy et al, 2000, p.157). Kennedy, along with his colleagues, completed three longitudinal studies over a 21-year period all of which looked at impact and coping strategies.

The first of the longitudinal studies examined the relationship between psychological impact and coping using a sample of 87 participants with SCI (Kennedy et al. 2000). The study consisted of participants that had been admitted to a rehabilitation centre between 1990 and 1994. At the time of the original study participants were aged between 16 and 65 years with a mean age of 31.4 at time of injury, 81% were male, 68% were paraplegics and 32% were tetraplegics. Participants were asked to complete questionnaires every 6 weeks up until discharge. Follow up questionnaire booklets were sent out at 1 month, 3 months, 6 months, 1 year and 2 years. The number of participants responding went from n=80 at 6 weeks to n=36 at 2 years. All respondents were interviewed by a trained researcher during their rehabilitation and sent questionnaires following discharge. The scale used to measure coping strategies was the 60 item COPE questionnaire which consists of 15 different coping strategies and was said to have been successfully used for individuals who had SCI (Kennedy et al. 1995; Carver, 1997).

The second study was a 10-year longitudinal study carried out by Pollard and Kennedy (2007) researching the emotional impact, coping strategies and post-traumatic psychological growth following SCI. The current study extended the previous 2-year longitudinal study by Kennedy et al. (2000) and followed up the same participants 8 to 10 years later. By doing this, Pollard and Kennedy (2007) were able to investigate the pattern of coping strategies 10 years post-injury and their relationship to psychological impact. In the study, they assessed 87 participants from 12 weeks (Kennedy et al. 2000) to 10 years where 43% of the original sample responded. To establish a representation of the sample, the data collected at 12 weeks post-injury for the 37 participants in this study was compared with that of the original sample who were not included in the current study (Pollard and Kennedy, 2007, p.352). The age range of the group was 25-73 years mean age 40.9 years. The sample was made up of 81.1% men and 18.9% women with an average length of injury at 9.9 years. Of these, 59% were paraplegics and 41% were tetraplegics with 73% having complete injuries and 27% with incomplete injuries. As with Kennedy et al. (2000) the current study used the 60 item COPE scale to measure coping strategies (Carver, 1997).

The third study was a 21-year longitudinal study that analysed impact, coping, and appraisals following SCI (Kennedy, Kilvert and Hasson, 2016). This study aimed to extend the original longitudinal study by Kennedy et al. (2000) and the 10-year follow up study by Pollard and Kennedy (2007) to see how the participants from the original studies had coped and psychologically adjusted to their SCI. Participants within this study were recruited from the Kennedy et al. (2000) original study of which some (10) had taken part in Pollard and Kennedy (2007) study. Twenty-two participants from the Kennedy et al. (2000) study at 12 weeks post-injury responded with 22 participants being deceased thus allowing Kennedy, Kilvert and Hasson (2016) to look at longitudinal factors in relation to mortality rates. A total

of 50.6% of participants from the original study were included in the latest study, this included living and deceased. Out of the 44 participants, 84% were male, 16% female, mean age 33.3 years, 46% were tetraplegics 54% paraplegics, 60% complete, 40% incomplete and the average age since injury was 23.1 years. The COPE scale was used in this study to measure coping strategies and had previously been successfully used in other studies with people with SCI (Carver, 1997; Kennedy et al. 2000; Pollard and Kennedy, 2007).

Kennedy et al. (2000) found that there were mild levels of depression whilst participants were in rehabilitation and that these levels fell into normal range upon discharge. It was further found that anxiety and depression levels did not change over a 10-year period and that those participants showing signs of emotional distress at 12 weeks were significantly likely to do so at 10 years (Pollard and Kennedy, 2007). Unlike the first two studies, the 21-year follow up measured appraisal and found that positive appraisal strategies were associated with lower levels of depression and higher use of positive coping strategies whereas higher levels of depression were associated with maladaptive appraisal and negative coping strategies (Kennedy, Kilvert and Hasson, 2016). Kennedy, Kilvert and Hasson (2016) suggested their findings were similar to that of Lazarus' and Folkman's (1984) theoretical framework which found that how a person appraises their situation is linked to which coping strategies they use.

Coping strategies between 1-month and 2 years post discharge showed no significant difference. The most common coping strategies used were acceptance, positive reinterpretation in growth, active coping, and planning and social support. The least used coping strategies were behavioural disengagement, denial, and alcohol and drug use ideation (Kennedy et al. 2000). The results of the 10-year study suggest that coping strategies remain stable over time as the most frequently used coping strategy was acceptance, then active



coping and planning. The coping strategies that were used least of all were behavioural disengagement, denial, and alcohol and drug ideation (Pollard and Kennedy, 2007). The findings of Kennedy, Kilvert and Hasson (2016) were identical in that the most common coping strategy was acceptance, followed by active coping and planning. The least used coping strategies were denial, behavioural disengagement, and substance abuse ideation. It was also found that when looking at the results of all three studies more closely, that both emotional and instrumental coping strategies were used in the first (Kennedy et al. 2000) and second (Pollard and Kennedy, 2007) studies but in the third study at the 21-year follow up emotional coping was used more than instrumental (Kennedy, Kilvert and Hasson, 2016).

The findings within the three studies suggest that people in the early stages of their SCI who are vulnerable to emotional and psychological distress will continue to struggle for many years post-injury and are unlikely to resolve these issues without treatment (Craig, Hancock and Dickenson, 1994; Kennedy, 2000; Pollard and Kennedy, 2007; Kennedy, Kilvert and Hasson, 2016). Kennedy, Kilvert and Hasson (2016) found that there was an increase in depression from the 10 year follow up amongst the participants who took part in the 21-year study. These results are consistent with Krause, Kemp and Coker (2000) who found that people who had lived with SCI for over 21 years had higher levels of depression than those people who had SCI for 11 to 15 years (Saunders, Krause and Focht, 2012). The 22 participants who took part in the original study that were now deceased were found to have higher levels of depression at 12 weeks than the 22 participants who were still living (Kennedy, Kilvert and Hasson, 2016). It was also found that the deceased participants used maladaptive coping strategies at 12 weeks i.e. substance abuse ideation (Kennedy, Kilvert and Hasson, 2016).

Other studies that identified levels of depressive symptoms in people with SCI used a newer approach which is known as Growth Mixture Modelling. This is a method of identifying longitudinal change and examining differences in an unobserved population (Ram and Grimm, 2009). The first of two studies found that the majority of people with SCI in their study who were resilient had low symptoms of depression from hospitalisation through to 2 years post injury, however some participants had a dramatic increase in symptoms up to 1 year and a slight increase up to 2 years. Participants who were resilient also maintained positive psychological adjustment (Bonanno et al. 2012). The second study found that people with SCI who had moderate to high self-efficacy had lower levels of depression whilst lower self-efficacy was linked to higher levels of depression and to higher severity of secondary health conditions and negative appraisal (Craig et al. 2019).

Further findings within the studies suggest that people with SCI use more adaptive/positive than maladaptive/negative coping strategies and this is said to be due to dispositional elements of coping (Kennedy et al, 2000; Pollard and Kennedy, 2007; Kennedy, Kilvert and Hasson, 2016). These findings may give some insight as to why Cognitive Effectiveness Training (CET) reported improved well-being, but no change in coping strategies which people with SCI used most often (Kennedy et al. 2003; Pollard and Kennedy, 2007; Kennedy, Kilvert and Hasson, 2016)(CET is referenced on p.122 and p.207). Also, using appraisal measure ADAPSS in the third study provided evidence that appraisal and coping strategies are correlated. It is suggested that cognitive appraisal plays an important part in psychological adjustment and is more responsive to change than coping strategies which the evidence has shown are more dispositional (Kennedy et al. 2003; Kennedy, Kilvert and Hasson, 2016, p.99). It is also suggested that providing an intervention post SCI that presents an injury as a challenge, rather than a loss or threat, will allow for the use of more adaptive coping

strategies resulting in a positive psychological adjustment (Kennedy, Kilvert and Hasson, 2016).

Gender and level of injury showed no correlation in how someone dealt with having SCI, although Kennedy, Kilvert and Hasson (2016) did find a significant difference in age at injury between the deceased group (who were older) and the living participants, but they didn't find it surprising and may have been a key factor in mortality. All three studies had issues with attrition especially the 10-year follow up and the 21-year follow up, although they all used participants from the initial 87 individuals that took part in Kennedy et al. (2000) study. It was highlighted that future longitudinal studies should attempt to use a larger sample size so that the findings would be easier to apply to a wider SCI population.

The evidence suggests that the majority of people effectively adjust to SCI and they do this by appraising their situation and finding positive coping strategies. In all three studies, acceptance was found to be the most common coping strategy followed closely by active coping and planning. Higher levels of depression were linked to maladaptive coping strategies i.e. behavioural disengagement, denial, and substance abuse ideation. These were the least used coping strategies in all three studies. Mortality was also linked to higher levels of depression. All 22 participants that were deceased from the original study scored higher for depression at 12 weeks than the participants that were still living. The deceased had used substance abuse ideation as a coping strategy.

Finally, it was suggested that use of a peer support group for those who sustain SCI could help the individual use more adaptive coping strategies that will help them to adjust psychologically which is associated with a higher QoL, depending on the nature of the

intervention (Kennedy et al. 2000; Kennedy et al, 2003; Haas, Price and Freeman, 2013; Kennedy, Kilvert and Hasson, 2016). The current thesis aims to put this hypothesis to the by developing a behavioural change intervention (peer support group) that supports and encourages people with SCI to develop positive coping strategies to improve their QoL.

### **1.17 SCI and Behavioural change interventions**

Behaviour plays a central role in maintaining health whether psychological or physical and health care professionals have been looking at ways to use interventions to change people's health behaviours to adopt new behaviours i.e. coping strategies (Ockene et al. 2000). There are said to be 93 behavioural change models developed over the years to promote a healthy lifestyle and effectively help individuals cope (Jeffery et al. 2000; Sinnott et al. 2015) i.e. damage caused by injury or illness to the spinal cord.

The behaviour change wheel (BCW) is a relatively recent approach for applying behavioural change theory to an intervention's development. There are many theoretical models available and it is difficult to choose one. Some critical theories may be missed (Sinnott et al. 2015). Michie et al. (2011) suggested that most intervention designers were not using existing frameworks when designing new interventions or checking why some interventions were failing (Michie et al. 2011, p.3). For that reason and the number of behavioural change theories, Michie et al. (2011) designed the BCW as they thought it was necessary for the development of behavioural change interventions. They also thought by identifying all the potential intervention functions and policy categories it could prevent future policy makers and intervention designers from neglecting important options (Michie et al. 2011, p8)

The BCW includes the COM-B model (capability, opportunity and motivation) for behavioural intervention and integrates behavioural theory with the development and description of the behavioural change intervention (Sinnott et al. 2015). Michie et al. (2011) based the model on a hypothesis that there is an interaction between capability (people must have the physical or psychological strength/stamina to perform the behaviour i.e. knowledge and skills), opportunity (people must have a conducive physical and social environment i.e. affordable, accessible/location, and socially/culturally acceptable, that influence the way people think about things), and motivation (people must have strong motivation that can be reflective i.e. conscious planning or beliefs about what is good or bad and/or automatic i.e. emotional reaction and reflex responses) and this can explain why a certain behaviour is/or is not performed (Michie et al. 2011; Sinnott et al. 2015; McEvoy et al. 2018).

The BCW provides the framework for the development of an intervention (Gould et al. 2017). Figure 1 illustrates the components of the BCW. It consists of 19 pre-existing frameworks all put into a single interface, these included nine intervention functions and seven policy categories.



**Figure 1** The Behaviour change wheel (Michie et al. 2011).

### **1.17.1 Bias in behavioural change interventions**

There are many types of bias that can creep into a behaviour change intervention, one example of this is the Hawthorne effect which refers to the finding that participants may change their behaviour when they know they are taking part in a study or experiment. This could be due to the attention that they are receiving directly or indirectly by the researcher and nothing to do with the main aims of the study (Wolfe and Michaud, 2010). A systematic review by McCambridge, Witton and Elbourne (2014) aimed to find out whether the Hawthorne effect existed. They included 19 eligible studies that were randomised control trials (RCTs), quasi-experimental studies and observational studies, and all but one had been undertaken in health sciences. Six of the studies presented evaluations of effects by reporting on a participant's behaviour by being interviewed or filling out a questionnaire. In all of the other studies, participants were directly observed, or they were aware they were being studied in various ways, except one study that used both observation and questionnaires (McCambridge, Witton and Elbourne, 2014). The studies were said to be heterogeneous and

out of 19 studies, 12 provided some evidence of a Hawthorne effect; however, 2 studies had small sample sizes making it impossible to show between group differences. In the final 5 studies, there was clear evidence that there were no between group differences that could present a possible Hawthorne effect (McCambridge, Witton and Elbourne, 2014). The study concluded that they found evidence that there was no single (identical) Hawthorne effect and that they found signs that the Hawthorne effect existed in most of the studies to some extent (McCambridge, Witton and Elbourne, 2014).

### **1.18 Define QoL**

The aim of the current is to look at issues that may impact on QoL and how QoL can be improved. In the last 50 years QoL has gained more attention, especially by the social sciences i.e. researchers, clinical services which look at how physical and mental health impact upon QoL (Skevington, 1999, Dijkers, 2005; Pinto et al. 2017).

QoL has been defined as how a person measures the goodness of different aspects of their life. It encompasses a concept consisting of a few social, environmental, psychological, physical values, and spiritual dimensions (WHO, 1997; Diener et al. 1999; Pinto et al. 2017). This would include evaluating emotional reactions to life events, characteristic attitudes, how satisfying life is at any given moment, and whether there is happiness in relationships and work (WHO, 1997; Krause, 1998; Diener et al. 1999; Pinto et al. 2017). Despite this, there has been an agreement that QoL is subjective and multidimensional due to the cultural, social and environmental uniqueness of each individual person (Dijkers, 2005; Nickel and Petersen, 2008; Hill et al. 2010; Theofilou, 2013; Pinto et al. 2017).

### **1.18.1 Secondary health impairments lead to poorer QoL**

The most prevalent comorbidities after SCI are secondary health impairments (SHIs) which include bowel and bladder dysfunction, spasticity, obesity, scoliosis, sexual dysfunction, pressure sores, autonomic dysreflexia, cardiovascular, respiratory problems and pain (Kennedy, Lude and Taylor, 2006; Hetz et al. 2011; Jensen et al. 2012; Westerkam, Saunders and Krause, 2011; Adriaansen, 2016). These conditions can be physical, as well as, psychological and can be influenced directly or indirectly by the SCI (Baunman et al. 2012; Brinkhof et al. 2016; Adriaansen, 2016).

There is evidence that SHIs can cause depression leading to a poorer QoL which is frequently much lower amongst people with SCI than in the general population (Kennedy et al. 2000; Kennedy, Lude and Taylor, 2006; Noonan et al. 2008; Post and vanLeeuwen, 2012; Kennedy, Kilvert and Hasson, 2016). However, not all studies have found that SHIs affect QoL and it was stated that this could be due to some people with SCI finding ways to deal with an SHI early after injury (within 3 months) or that a person may have had the SHI for so long that they have adapted to it (Sprangers and Schwartz, 1999; Adriaansen, 2016). Studies which have looked at how an individual SHI impacted on QoL, it was found that spasticity, muscular pain and neuropathic pain were associated with a poorer QoL (Post et al. 1998; Vall et al 2006; Sakakibara et al. 2012; Westerkam, Saunders and Krause, 2011; Michailidou et al. 2014, Hagen and Rekand, 2015). Another condition that negatively impacted on QoL was pressure sores as there is a long recovery involved with the healing process and bed rest can take months (Post et al. 1998). It was found that constipation became a problem due to the time constraints of having a bowel movement and this affected a person's daily activity and a high number of people had accidents too (Cobb et al. 2014).



### **1.18.2 Social skills, social support and QoL**

Social skills have been found to be important, especially for someone with a disability (Chase, Cornille and English, 2000, Muller, Cieza and Geyh, 2012; Muller et al. 2013).

Social skills are defined as personal skills used to communicate and interact with others (Chase, Cornille and English, 2000; Muller, Cieza and Geyh, 2012; Muller et al. 2013). Poor social skills can impact negatively on an individual's life and have been correlated with a person becoming depressed and abusing alcohol and drugs which leads to decreased life satisfaction and QoL (Muller, Cieza and Geyh, 2012; Muller et al. 2013). Social skills in a person with a disability, such as SCI, are important as they help them to overcome discomfort and stigmatisation, enabling them to interact with people and to be able to ask for help if needed. It is suggested that good social skills can help with problem solving (rational, impulsive and avoidant) and confidence building, helping an individual become assertive, goal orientated or self-monitoring (Muller, Cieza and Geyh, 2012, p.94). Good social skills, such as these, can be especially useful when there is a need for communication with friends, family, peers, general public and health care professionals (Segrin, 1992).

Research has shown that there is a relationship between social support and social skills in people with SCI and they are positively linked to physical and mental health (Muller, Cieza and Geyh, 2012; Muller et al. 2013). It was also found that people who reported having a lot of social support felt they had less emotional distress. They felt they had adjusted well to their SCI and had reported fewer health-related problems and spent less time in hospital than people who reported a poorer social support (Sheman, DeVinney and Sperling, 2004; Muller, Cieza and Geyh, 2012; Muller et al. 2013). Muller, Cieza and Geyh (2012); Muller et al. (2013) also suggest that social support leads to a decrease in death. It helps with coping and improved life satisfaction. Social support impacts upon a person's positivity and can improve their QoL by an exchange of friendship and information that can benefit each other, but this

is said to be more effective when provided by a person who has been through the same situation/trauma (Cobb, 1976; Thoits, 1995; Sheman, DeVinney and Sperling, 2004; Muller, Cieza and Geyh, 2012; Muller et al. 2013). It was suggested that this type of support could be provided through an intervention which could be aimed at matching the person who is in need of social support with a peer that has been through the same type of illness, trauma and disability (Thoits et al. 2000; Sheman, DeVinney and Sperling, 2004; Whittemore et al. 2000; Haas, Price and Freeman, 2013).

### **1.18.3 Life satisfaction, QoL and peer support groups**

Sweet et al. (2016) researched the participation of people with SCI in society i.e. at home e.g. as a parent, spouse, in the community e.g. cultural, recreational activities and how it impacted positively on greater life satisfaction; especially as people with SCI generally report lower levels of life satisfaction leading to a poorer QoL. Sweet et al. (2016) suggested that a way of improving life satisfaction would be to have peer support mentoring. Peers are people that have been through the same issues and have the knowledge and experience to help others that are in the same situation as they have been (Borkman, 1976; Haas, Price and Freeman, 2013; Sweet et al. 2016). The literature on peer support found that it has value, especially during rehabilitation, helping patients learn skills to deal with their situation both physically and psychologically (Haas, Price and Freeman, 2013; Sweet et al. 2016).

There are limited studies on peer mentoring after SCI, but of those studies that have been done, it was found that people who had received peer mentoring within a year of being spinal cord injured reported greater life satisfaction than those who did not receive peer mentoring (Sherman et al. 2004; Sweet et al. 2016). Sweet et al. (2016) research found that peer support

for people with SCI was needed, but their findings also suggested the need for additional research to determine factors that can maximise the impact of peer support.

### **1.19 Define peer support**

A study by Barath (1991) defined peer support as a small group of people that share the same problems i.e. addiction, psychological issues or physical illness that join a group of their peers at regular intervals that last an extended period of time. Within these groups, members can share their own personal knowledge, experiences, learnt skills to counsel and empathise with each other (Morris and Morris, 2012; Haas, Price and Freeman, 2013; Sweet et al. 2016). This allows the members of the group to learn new skills that enable them to cope effectively both physically and psychologically leading to life satisfaction and improved QoL (Sheman, DeVinney and Sperling, 2004; Morris and Morris, 2012; Haas, Price and Freeman, 2013; Sweet et al. 2016). This learning is conducted through the process of peer education and leadership but can also be helped by a professional that is invited along to take part in the group process (Hildingh et al. 1993).

#### **1.19.1 Evidence of previous peer support and the benefits**

Ussher et al. (2006) conducted research to find out “what do cancer peer support groups provide which other supportive relationships do not? Ussher et al. (2006) included nine peer support groups in their study. They interviewed 93 participants of which 75 were women and 18 were men with a mean age of 62 years and they used participant observation and focus group interviews. The average peer support group had between 3 and 40 participants and each lasted an average of 2 hours. Focus group participation was between 5 and 29 people with an average of 9 participants.

The study designed, conducted and analysed the research with the help of an oncologist, social worker and a psychologist in an advisory capacity (Ussher et al, 2006). Participant observation was important so that the researchers could have a better understanding of what each peer support group meeting entailed, how they were structured, and what the relationship was like between participants. After each group meeting, participants were invited to stay and take part in a semi-structured focus group interview and answer three questions: what do you get out of participating in this cancer support group? How does participating in this group interact with your other social networks? Is there any way in which you think this group can be improved? Each interview length was between 30 and 60 minutes, and all interviews were transcribed and independently read by three members of the research team (Ussher et al, 2006).

The main aim of the study was to find out what peer support groups provided that other supportive relations did not. The results of the interviews provided a unique insight into how participants of the individual peer support groups felt. People who participated within the groups stated that they felt a part of a community with unconditional acceptance. They gained knowledge, experience and empathy that they could not receive outside of the peer support groups (Ussher et al, 2006). Participants also said that their relationships with family and friends improved as the burden of care was lessened which, in turn, empowered the participants and improved their QoL (Ussher et al. 2006). The results of this study are supported by previous evidence of individuals suffering with cancer by Docherty (2004); McGrath (1999) who found that sense of community, non-judgemental acceptance helped participants increase their ability to cope due to a sense of belonging. The results of Ussher et al. (2006) found that people bonded and carried on a friendship outside of the peer support groups and classed those friendships as their extended family. This was due to a shared

mutual understanding of what it is like to have cancer that those who have never had cancer could not empathise with (Coreil et al. 2004; Ussher et al. 2006).

### **1.19.2 Peer support for people with SCI**

A search for literature on peer support groups for people with SCI, that has been facilitated by a person with SCI, was attempted, but none was found. However, a few studies researching one to one peer mentoring for people with SCI were discovered (Sheman, DeVinney and Sperling, 2004; Veith et al. 2006; Hass, Price and Freeman, 2013). Haas, Price and Freeman (2013) researched peer mentoring in collaboration with the SIA and their CPSO in the UK. Peer mentoring is what charities such as the SIA, Aspire, and Backup implement to help individuals with SCI. They have CPSO's who visit people with SCI within rehabilitation centres, hospitals, or at their own homes. This is done on a one to one basis and not within a group. The difference between one to one peer support and peer support groups is that a person in need of help is only receiving one person's perspective about their knowledge and experience of illness or injury (Veith et al. 2006). CPSO's do an important job. They provide practical help and advice, encouragement, and a listening ear. Haas, Price and Freeman (2013) found that people with SCI, their families, and health care professionals all had great respect for what CPSO's do. The study also suggested that a lack of peer support may have a significant effect on QoL (Hass, Price and Freeman, 2013).

The evidence has suggested that the best support for a person with SCI is provided by their peers (Sheman, DeVinney and Sperling, 2004; Veith et al. 2006; Hass, Price and Freeman, 2013; SIA, 2015; Sweet et al. 2016). Previous research has shown the value of peer support groups in situations including substance abuse, bereavement and cancer (White, 2000; Kyrouz, Humphreys and Loomis, 2002; Ussher et al. 2006; Sweet et al. 2016), with reported

benefits including reduction in the length of hospital stays, reduced treatment costs (Chinman et al. 2001) and reduction in the requirement for long term mental health services (Simpson and House, 2002).

Mental health services recognise the needs and benefits of peer support groups in the recovery process (Moxley and Mowbray, 1997; Hass, Price and Freeman, 2013). The idea is to help people in recovery find suitable accommodation, employment, and help with social support which can all be addressed within peer support groups. This can be accomplished with a collaboration between mental health professionals and peer support specialists (Moxley and Mowbray, 1997; Hass, Price and Freeman, 2013).

The author is currently in talks with SCI rehabilitation centres in Wales and England and deciding the best plan of action to incorporate a peer support alongside existing care. The research suggests that a peer support group could be beneficial to improving QoL of people with SCI, so this current research project involves the design and implementation of such a peer support group and none have been designed or evaluated with this population to date. It is predicted that the peer support group could enhance the existing services by forming a bridge between NHS and social care provision. Such peer support groups could be overseen by professionals, but peer-led, thus providing cost-effective support that is under the control of the individuals who stand to benefit from it.

### **1.20 Summary**

The key points that were found in the research literature were that a person who sustains SCI or illness must learn to adjust to their new life by appraising their situation and finding positive coping strategies so that they are able to adapt to life with SCI (Kennedy, Lude and

Taylor, 2006; Chevalier, Kennedy and Sherlock, 2009). This adjustment starts almost immediately when they are in a hospital and with the type of care they receive (WHO, 2013; SIA, 2015). There is an issue with delayed admission to specialist rehabilitation centres or the existence of admission at all (SIA, 2015). Without the right care package, people lack the skills or knowledge to care for themselves long term (White, 2007; Sweet et al. 2016).

It was found that the majority of studies used within this literature review had used a qualitative methodology to assess their findings (Ussher et al. 2006; Haas, Price and Freeman, 2013; Veith et al. 2013; Greenwood et al. 2013), which had shown that participants who took part in a peer support group had reduced feelings of isolation, developed coping skills, and increased their knowledge enabling them to manage their own conditions (Docherty, 2004; McGrath, 1999; Ussher et al. 2006). As a result, people suffering from chronic illnesses such as cancer had reduced visits and stays in hospital (Chinman et al. 2001; Simpson and House, 2002). More importantly peer support has also been shown to improve life satisfaction leading to a greater QoL (Sheman, DeVinney and Sperling, 2004; Ussher et al. 2006; Morris and Morris, 2012; Haas, Price and Freeman, 2013; Sweet et al. 2016). This evidence suggests that people with SCI would benefit from attending a peer support group that would provide them with the support and knowledge needed to improve their own QoL, even though, to date, no such peer support group have been developed or evaluated with SCI participants.

Based on these findings the theoretical framework that will underpin the thesis will be how people with SCI cope and the coping strategies they choose (Kennedy et al, 2000; Pollard and Kennedy, 2007; Kennedy, Kilvert and Hasson, 2016) and secondly a behaviour change intervention (peer support group) that will be influenced by the BCW using the COM-B

model. As found in Ussher et al. (2006) participants who participated in a peer support group felt part of a community and accepted (opportunity i.e. social influence), (capability i.e. shared knowledge and experience), (motivation i.e. empowered, coping). These are outcomes that correlate with the design of an intervention using the COM-B model.

## **Overall aims and objectives of the thesis and outline of each chapter**

### **Aims of thesis**

1. Identify the coping strategies that people use both psychologically and physically enabling them to cope after sustaining SCI.
2. Identify factors that impact on QoL for people with SCI.
3. Identify the attitudes that people with SCI have towards peer support groups e.g. would they attend one and how would they like it to be structured?
4. Design and deliver a behavioural change intervention to improve QoL (peer support group).
5. Evaluate the intervention to see if it is feasible and can be scaled up to meet a larger audience.

### **Objectives of thesis**

1. Conduct a literature review and a systematic review (chapter 1 and 2) to review evidence on coping with SCI, SCI and QoL and behavioural change interventions i.e. peer support groups (Aims 1 and 2)
2. Design and conduct a qualitative study (chapter 3) using a questionnaire and interview several participants to see how they cope after sustaining SCI, what knowledge they have of peer support groups and how they feel about them (Aim 3).



3. Design and conduct a quantitative study (chapter 4) using questionnaires to see what coping strategies people with SCI use, what they know about peer support groups, would they attend one and how would they like to see one structured (Aims 1 and 3).
4. Design and implement a theory based behavioural change intervention (peer support group) this will be informed by the evidence from chapter 1, 2, 3 and 4 (chapter 5) (Aim 4).
5. Design and administer a quantitative questionnaire, qualitative questionnaire and a wellness ladder tool (chapter 6) (Aim 5).

### **Outline of each chapter**

**Chapter 1** - the background to the research will be described. An introduction to the important aspects of the research project will be presented, which includes information relating to SCI i.e. causation, prevalence, and incidence; factors that can impact on how a person with SCI appraises their situation and how they cope both physically and psychologically and what issues impact on QoL and how QoL can be improved. Furthermore, the study will look at a behavioural change intervention (peer support group) that could help improve QoL in people with SCI.

**Chapter 2** – study 1 will take the following steps: identify the psychological impact of SCI upon QoL using a systematic review.

**Chapter 3** – study 2 used a qualitative methodology and was designed using evidence found in chapter 1 and 2 and is concerned with finding out how participants cope with their SCI and what knowledge they have of peer support groups and how they feel about them. The chapter will further introduce the research methodology and a rationale as to why thematic analysis (TA) was chosen. The final section is reflexivity reflecting on the part played by the

researcher on the research process and their personal understanding and personal experiences (Lyons and Coyle, 2016).

**Chapter 4** – study 3 used a quantitative methodology and will draw on evidence from chapters 1, 2 and 3 which were used to aid in the design of the study (i.e. questionnaires). The aim of the study was to find out how individuals cope after sustaining a SCI, what coping strategies they use both psychologically and physically. Furthermore, what knowledge they have of a peer support group, would they attend one and how would they like to see a peer support group structured.

**Chapter 5** – develop an intervention that would improve QoL in people with SCI. This chapter was informed by using existing literature and results found in chapter 1, 2, 3 and 4. This evidence will be used to design a theory-based intervention (peer support group). The chapter will describe how the intervention was designed and conducted.

**Chapter 6** - A feasibility study (peer support group) will be conducted to see if it has a beneficial impact on the intervention group. A feasibility study has been defined as a way of determining whether an intervention works in practice and can be adapted to make it sustainable in the long term (Bowen et al. 2010) and to see whether it can be improved and scaled up in order to reach a larger audience (Tones and Tilford, 2001). This will be done by analysing the results of the quantitative data to see what differences can be found between the intervention group and the control group, participants were also interviewed to see what they thought about the peer support group which could help in the design of further peer support groups.

**Chapter 7** presents an overview of the major research findings from the present work. There will be a summary of the research findings a discussion about the design of the behavioural change intervention and evaluation and will conclude strengths and limitations for future work. This will be carried out using a process evaluation which looks at the effectiveness of a study and determines whether its success or failure is due to the intervention, implementation and design. Process evaluation help understand how interventions are delivered in everyday practice (Moor et al. 2015). The next step is to carry out an outcome evaluation which looks at whether participants circumstances have changed and if so, was the intervention a factor in causing this change (Fridrich, Jenny and Bauer, 2015).

**Chapter 2**

**2.0 Introduction**

Spinal cord injury (SCI) is caused by trauma to the spinal cord and can be debilitating and life changing for each individual case (Glass, 1993). The occurrence of such an injury will change the individual's life in all areas and in most cases for the rest of their life. Prior to World War II, people with SCI lived short lives due to poor medicine and little being known about SCI, however as advances in medicine and knowledge of SCI have come about, people with SCI have started to live longer with a life expectancy believed to be as long as that of abled-bodied people (Michael et al. 1999). With this, research has shifted focus from being primarily about the care of the person, to now being about the psychological adjustment to the injury they have sustained and how this can impact on quality of life (QoL).

Quality of life is said to be measured by one's happiness, life satisfaction and well-being, which can be affected by how a person perceives their own life and their own experiences, this would indicate that QoL is influenced by psychological factors rather than external factors (Chappell and Wirz, 2003), although other research evidence would suggest that QoL does not only encompass psychological factors but also physical and social factors (Allison et al. 1997).

Quality of life as a concept has received considerable attention in health care settings and has been widely used as a clinical outcome for people specifically with SCI (Hammell, 2004).

Research by Dijkers (2005) suggests that no agreement exists on QoL and how it is

measured, which seems to be the consensus of Hill et al. (2010) and Wilson et al. (2011) who have researched how QoL is measured in a person with SCI rather than the cause of poorer QoL. However, Dijkers (2005) did find that people with SCI reported fewer feelings of well-being on average than non-SCI participants, scored lower on physical, mental and social health and in other domains of life that people consider important to QoL; and had a health state that is preferred much less than that of the average person.

A factor causing poorer health, is that people with SCI have many complications arising from the SCI such as pressure sores, autonomic dysreflexia caused by poor bladder and bowel control, respiratory problems, dependence on others and mobility limitations which are classified as secondary health impairment (Kennedy, Lude and Taylor, 2006) that impact on their day to day lives. Issues such as these can reduce QoL and have heavy psychological impact causing thoughts of despair with many contemplating suicides rather than living with their injuries (Dijkers, 2005). Kennedy, Lude and Taylor (2006) found that secondary health impairments did in fact impact on individuals with SCI causing anxiety and depression but it's how people with SCI appraise their situation using coping strategies that can improve QoL.

Folkman and Lazarus (1986) provided a way for researchers to process the way people with SCI use coping technique, they first use an appraisal process which helps them evaluate the situation, if their well-being is threatened, they use various ways of coping with these threats (Anderson et al. 2007). It has been found that there is a relationship between positive primary appraisal and coping effectively in lowering psychological distress (Kennedy et al. 2000). Kennedy, Lude and Taylor (2006) found that acceptance and fighting spirit were the most common coping strategies with social reliance being utilised less.

There is a need for more research studies to look at the causes of poorer QoL as studies by Hill et al. (2010) and Wilson et al. (2011) look at how QoL is measured and how many measures there are, rather than how SCI impacts upon QoL. This paper consists of a systematic review of research exploring QoL in relation to people who suffer with SCI in order to establish if people with SCI do have a poorer QoL and if so, what factors impact on this. The review will be carried out by systematically searching the literature databases to identify any papers that meet the inclusion criteria so that the impact of SCI on QoL can be identified more clearly.

## **2.1 Method**

### **Inclusion and exclusion criteria**

This review was restricted to empirical studies that used quantitative methods of collecting data, studies that used SCI populations and in which standardised measures were used to assess relationships between psychological factors, physical factors and QoL. There were no constraints put on the date of publication, but each study had to be in English and peer reviewed. Qualitative studies were excluded.

## **2.2 Search strategy**

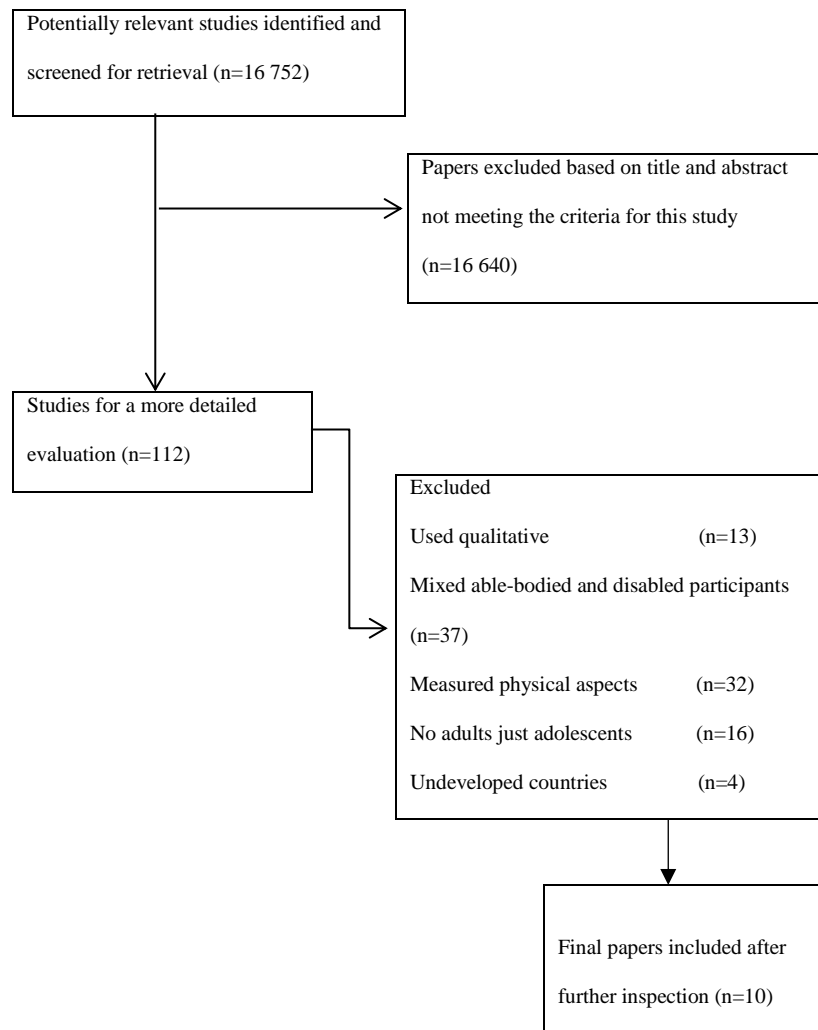
A standard quality assessment tool (QualSyst, Table 1.) was used to help identify and evaluate the quality of studies to use in this systematic review (Kmet, Cook and Lee, 2004). A structured computerised search of the online databases PsychInfo, Medline and Pubmed was carried out. Keywords used were spinal cord injury, life satisfaction, well-being and quality of life. There were 16,752 papers in the original search, of these 16,640 were excluded based on their title and abstract, 112 papers were left for further detailed evaluation.

Out of the final 112 papers 10 met the inclusion criteria on the basis of the full paper. Two reviewers assessed a sample of the papers to ensure reliability of the inclusion process. The search strategy used is shown in Figure 2.

The following information was extracted from each study and then summarised in Table 2: aim of study, sample size, origin of sample, level of SCI (if known), measures, psychological factors and findings of each study. A list of all the different instruments that were used to measure QoL is presented in Figure 3.

The first version of the systematic review was developed in 2015 early on in the research project, but in 2019 when the thesis was submitted it had become outdated so a new search using the same keywords spinal cord injury, life satisfaction, well-being and quality of life was conducted using the same online databases as the original search: PsychInfo, Medline and Pubmed for the years between 2015 and 2019. After the 2019 search was conducted 1326 papers were found but 1322 papers were excluded based on the title and abstract, 4 papers were left for a further detailed evaluation but excluded due to one using able-bodied participants, two had very little demographic information and one used mixed methods, of these one paper, by Krause et al. (2017) was suitable for inclusion. This paper has been added to Table 1, Table 2 and included in the review below.

**Figure 2** Search flowchart



**Figure 3** Index of QoL measures used in various studies of the relationship of QoL and spinal cord injury.

COMQOL-A5: Comprehensive Quality of Life Scale

IPWB: Index of Psychological Well-being

LSI-A: Life Satisfaction Index

LSQ: Life Situation Questionnaire

LSQ-R: Life Situation Questionnaire-Revised

SWLS: Satisfaction with Life Scores

WHOQOL-BREF: World Health Organisation Quality of Life Assessment Instrument



**Table 1** QualSyst analysis results for studies included within the systematic review

	Barker et al. (2009)	Charliffe and Gerhart (2004)	Decker and Schulz (1985)	Kennedy et al. (2010)	Kennedy et al. (2010)	Krause and Broderick (2005)	Krause, Broderick and Broyles (2004)	Krause et al. (2017)	Matheis, Tulskey and Matheis (2006)	Migliorini, New and Tonge (2011)	Yuen, Burik and Krause (2004)
Q1. Question or objective sufficiently described?	Y	Y	P	Y	Y	Y	Y	Y	Y	Y	Y
Q2. Study design evident and appropriate to answer study question?	P	P	P	Y	Y	P	Y	P	Y	P	P
Q3. Method of subject selection described and appropriate?	Y	P	Y	Y	P	P	Y	P	Y	P	P
Q4. Subject characteristics or input variables/information sufficiently described?	Y	Y	P	Y	P	Y	Y	Y	Y	P	Y
Q5. If random allocation to treatment group was possible, is it described?	N	N	N	N	N	N	N	N	N	N	N
Q6. If interventional and blinding of investigators to intervention was possible, is it reported?	N	N	N	N	N	N	N	N	N	N	N
Q7. If interventional and blinding of subjects to intervention was possible, is it reported?	N	N	N	N	N	N	N	N	N	N	N
Q8. Outcome measure(s) well defined and robust to measurement/misclassification bias?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Q9. Sample size appropriate?	Y	Y	Y	Y	Y	Y	Y	Y	P	Y	Y
Q10. Analysis described and appropriate?	Y	Y	Y	Y	P	Y	Y	Y	Y	Y	Y
Q11. Some estimate of variance is reported for the main results/outcomes?	Y	Y	Y	Y	Y	Y	Y	Y	Y	P	Y
Q12. Controlled for confounding	N	N	N	N	N	N	N	N	N	N	N
Q13. Results reported in sufficient detail?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Q14. Do the results support the conclusion?	Y	Y	Y	Y	Y	P	Y	Y	P	Y	Y

Note. Y = Yes    P = Partial    N = No

## Relationship between coping and life satisfaction in people with SCI

**Table 2**

Study	Aims	Sample	Measures	Psychological factors	Outcomes
1. Barker et al. (2009)	To compare QoL for people with SCI and their abled-bodied peers and investigate the relationship between QoL and disability (impairment, activity, limitations and participation restrictions) across the life span, for people with SCI.	270, Australia, Tetraplegia, Paraplegia	WHOQOL-BREF, WHOQOL-8, ASIA, SCSi, Mfim, CIM,	QoL, Impairment, Activity limitations, Participation restrictions	QoL was significantly poorer for people with SCI than the Australian norm. The single most important predictor of QoL was secondary impairments whereas the second most important predictor was societal participation.
2. Charlifue and Gerhart (2004)	The study examined how scores on measures of stress, life satisfaction, depression, and psychological well-being related to perceived QoL among people with long standing SCI.	282, UK, Tetraplegia and Paraplegia (complete and non-complete)	LSI-A, IPWB, CES-D, PSS	Depression, Perceived stress, Well-being and Life satisfaction	Perceived QoL in long term SCI was high and relatively stable over time. Significant relationships between earlier QoL and later perceived stress, depression, and well-being suggest that QoL, may itself be a predictor of other outcomes
3. Decker and Schulz (1985)	This study researched factors that contribute to the well-being of middle aged and elderly people with SCI.	100, USA, Paraplegia, Quadriplegia	LSIA-A, CES-D	Depression and Life satisfaction	Participants with SCI reported levels of well-being that were slightly lower than those of non-disabled people. Higher levels of well-being correlated with high levels of perceived control, social support and good health, this was said to be due to higher income, better education and a belief in religion which was the opposite for those who reported low levels of well-being.

**Table 2 (Continued)**

Study	Aims	Sample	Measures	Psychological factors	Outcomes
4. Kennedy et al. (2010a)	To investigate current thinking in terms of early appraisal and coping as predictors of adjustment and QoL after SCI and to what degree social and demographic variables are involved.	266, UK, Switzerland, Germany, Ireland, Tetraplegia, Paraplegia	WHOQoL-BREF, HADS, FIM, ALE, SCL CSQr, COPE, PMnac, SOC	QoL, Depression, Anxiety, Independence and Coping	The study found that there was significant difference between participating centres depending on the coping and appraisal methods used within the first 12 weeks of SCI. Overall the study found that the early stages of rehabilitation and initial appraisal are important to how an individual will cope with their injury and to their psychological well-being.
5. Kennedy et al. (2010b)	To assess the relationship between cognitive appraisals in a population living with SCI in the community, and examine how these factors affect social participation, life satisfaction and functional outcomes.	81, UK, Tetraplegia, Paraplegia (complete and non-complete)	FIM, CHART, APAPSS, LSQ, SCSi	Life satisfaction, Independence	Appraisal styles were closely related to participation, life satisfaction and functional independence. Negative perceptions of disability, fearful despondency and overwhelming disbelief impacted on the likelihood of participation, independence and life satisfaction. The results of this study suggest tackling cognitive styles to improve rehabilitation before patients with SCI are discharged from hospital.
6. Krause and Broderick (2005)	Investigated natural course of changes in activity patterns, health indicators, life satisfaction and adjustment over 25-year period among people with SCI.	256, USA, Quadriplegia and Paraplegia	LSQ	Life satisfaction	The paper challenged the assumptions that ageing will be associated with the decline in outcomes and QoL. This was due to satisfaction with employment, finances and education. There was a decline in sex life, health and increased hospital visits.

**Table 2 (Continued)**

Study	Aims	Sample	Measures	Psychological factors	Outcomes
7. Krause, Broderick and Broyles (2004)	The study looked at gender differences in subjective well-being among African-American participants with SCI.	309, African-American, Traumatic SCI, level of injury not known	QAHMI, LSQ-R, PIL,	Life Satisfaction, Well-being, Depression	There were multiple gender differences, women reporting higher scores on depressive symptoms and negative affect, but lower scores on purpose of life. Men reported greater problems with ulcers and sexual issues. The only gender difference with life satisfaction was that women had greater satisfaction with their sex life.
8. Krause et al. (2017)	To identify 40-year longitudinal changes in health, activity, employment, life satisfaction and self-related adjustment after SCI.	49, White-Americans, Traumatic SCI, level of injury not known	LSQ	Life Satisfaction, Health, Self-related adjustment	Outcomes changes substantially over a 40-year time period. Many of the declines were attributed to age this included sex life, social life, health and diminished optimism about future adjustment. It was also found that doctor and hospital visits increased after 30 years and became more sporadic. However, employment only declined after 30 years which was also attributed to age. Participants maintained satisfaction with living arrangements, finances and their overall level of adjustment.
9. Matheis, Tulskey and Matheis (2006)	To determine how spiritual-based coping relates to QoL in individuals with SCI.	75, USA, Quadriplegia, Paraplegia	SWLS, DHP, CHART, SWBS	Life satisfaction, Well-being	QoL was highest among participants who use existential spiritual as opposed to religious spiritual coping. Spiritual based coping might be encouraged as a possible strategy to improve QoL.

**Table 2 (Continued)**

Study	Aims	Sample	Measures	Psychological factors	Outcomes
10. Milgiorini, New and Tonge (2011)	To describe the subjective and objective QoL of adults with chronic non-traumatic SCI and to compare the objective and subjective QoL of adults with chronic NT-SCI with adults who have chronic traumatic SCI and the general population.	443, Australia, Tetraplegia, Paraplegia (complete and non-complete)	COMQoL-A5, SLC CSQ V1.0	Well-being, Life satisfaction	Aetiology makes a little difference to QoL outcomes after SCI. The QoL of adults with chronic T-SCI and NT-SCI fall significantly below that of the general population in most domains.
11. Yuen, Burik and Krause (2004)	To investigate the association of volunteering with personal well-being among adults with SCI.	447, USA, Level of injury not known.	LSQ-R, BRFSS, QAHMQ	Depression, Life satisfaction	Individuals who participated in volunteer activities reported higher levels of overall QoL, current adjustment, and general health with fewer depressive symptoms and hospitalisation than those who did not volunteer. Results suggest that participation in volunteer activities is an important rehabilitation goal that is associated with favourable outcomes, even in the absence of gainful employment.

## **2.3 Results**

The 11 studies that were included in this systematic review had used a range of different tools to measure QoL, two papers reported the use of WHOQOL-BREF, two used LSI-A, five used the LSQ and two of those used the LSQ-R, the final two papers used the SWLS and the COMQOL-A5. The variation in measures meant that it was not possible to carry out statistical analyses on the data, so only descriptive findings will be reported.

The design of seven studies was longitudinal (Barker et al. 2009; Charlifue and Gerhart, 2004; Decker and Schulz, 1985; Kennedy et al. 2010b; Krause and Broderick, 2005; Krause et al. 2017; Yuen, Burik and Krause, 2004) with the longest being over a 60-year period (Barker et al. 2009) and the shortest over 9 months (Decker and Schulz, 1985), the remaining four studies were cross sectional (Kennedy et al. 2010; Krause, Broderick and Broyles, 2004; Matheis, Tulskey and Matheis, 2006; Milgiorini, New and Tonge, 2011). The response rate for each study ranged from 31% to 100%. The vast majority of participants included in each study were males with SCI, outnumbering females with SCI by a ratio of between 2:1 and 9:1. Based on the studies used for this review and the National Spinal Cord Injury Statistical Centre (NSCISC); this seems to be fairly typical of sex differences among people with SCI (NSCISC, 2012). The mean age of people injured within these studies ranged from 28 to 59 years, which is in line with the NSCISC (2012) who state 41 years is the national mean age of people who have become spinal cord injured (NSCISC, 2012). The majority of studies were conducted between 2 to 20 years' post injury with the exception of two studies which purposely picked cases that were 6 weeks to 18 months' post injury (Kennedy et al. 2010a; Kennedy et al. 2010b). The participants in nine studies were a mixture of paraplegics and tetraplegics, using complete as well as incomplete breaks (Barker et al. 2009; Charlifue and Gerhart, 2004; Decker and Schulz, 1985; Kennedy et al. 2010; Kennedy et al. 2010; Matheis,

Tulsky and Matheis, 2006; Milgiorini, New and Tonge, 2011; Krause et al. 2017; Yuen, Burik and Krause, 2004), and two studies looked solely at tetraplegics (Krause and Broderick, 2005; Krause, Broderick and Broyles, 2004).

Ten papers mentioned QoL post-injury, with two papers finding that QoL was higher in long term individuals with SCI compared to those with new injuries (Charlifue and Gerhart, 2004; Krause and Broderick, 2005), but one study found this was partly due to participants re-ordering the criteria by which they assess QoL as they devalued unattainable goals and increased the value of those things they felt able to succeed in (Charlifue and Gerhart, 2004). Four studies found high levels of QoL in long term people with SCI but also said that this was nothing to do with time since injury (Barker et al. 2009; Matheis, Tulsky and Matheis, 2006; Milgiorini, New and Tonge, 2011; Yuen, Burik and Krause, 2004), with one longitudinal study finding that 50% of participants were still dissatisfied with their lives (Decker and Schulz, 1985). The last study mentioned life satisfaction and how participants health, sex life and social life had declined over 40 years which was attributed to age, however, satisfaction with employment, living arrangements and finances was maintained throughout (Krause et al. 2017).

Eight papers included both tetraplegics and paraplegics in their studies (Barker et al. 2009; Charlifue and Gerhart, 2004; Decker and Schulz, 1985; Kennedy et al. 2010a; Kennedy et al, 2010b; Krause and Broderick, 2005; Matheis, Tulsky and Matheis, 2006; Milgiorini, New and Tonge, 2011), all eight found no significant difference between level of injuries and QoL, one paper suggested that physical limitations do not affect life satisfaction (Kennedy et al 2010b). Three papers found that the majority of people living with SCI lived for more than 32 years post-injury and reported high levels of life satisfaction and well-being amongst

participants (Krause and Broderick, 2005; Krause, Broderick and Broyles, 2004, Krause et al. 2017). In contrast to the other findings, however one paper did find that there was a greater tendency for those with a greater level of disability to report lower levels of well-being (Decker and Schulz, 1985).

Several papers looked at factors that may impact on QoL among people with SCI, these included employment, religion/spirituality, marital status and rehabilitation, depression, appraisal and health.

### **2.3.1 Employment**

Of the ten papers that mentioned employment or volunteering (Barker et al. 2009; Decker and Schulz, 1985; Kennedy et al, 2010a; Kennedy et al. 2010b; Krause and Broderick, 2005; Krause, Broderick and Broyles, 2004; Krause et al. 2017; Matheis, Tulskey and Matheis, 2006; Milgiorini, New and Tonge, 2011; Yuen, Burik and Krause, 2004) three (Decker and Schulz, 1985; Krause and Broderick, 2005; Yuen, Burik and Krause, 2004) stated that people who were in employment or volunteering reported higher levels of well-being and life satisfaction than those who were not. Two papers (Krause, Broderick and Broyles, 2004; Matheis, Tulskey and Matheis, 2006) had similar findings in that no significant differences were identified between people who were employed and those who were not, and that employment status was not a predictor of well-being or QoL. Three papers (Barker et al. 2009; Kennedy et al 2010a and Kennedy et al. 2010b) mentioned employment in their demographic but did not report on it and one paper (Milgiorini, New and Tonge, 2011) did discuss employment in their discussion but stated that it was not reported.



### **2.3.2 Workability**

One paper (Decker and Schulz, 1985) found that a higher degree of work commitment among professionals did not need a large degree of physical mobility, which is an important factor when considering potential employment among individuals with SCI. Two papers reported that people with SCI adapted and were able to hold employment for the average of 25 years (Krause and Broderick, 2005; Krause et al. 2017).

### **2.3.3 Marital Status**

Six papers (Barker et al. 2009; Kennedy et al. 2010a; Krause, Broderick and Broyles, 2004; Krause et al. 2017; Matheis, Tulskey and Matheis, 2006; Milgiorini, New and Tonge, 2011) mentioned marital status in their demographics, two did not investigate differences between being single or married and QoL (Barker et al. 2009; Kennedy et al. 2010a), one did not report marital status but stated that women with SCI had better sex lives than men with SCI and reported higher levels of life satisfaction as a result of this (Krause, Broderick and Broyles, 2004). One paper did not find any significant difference between QoL and marital status (Matheis, Tulskey and Matheis, 2006); whereas one paper (Milgiorini, New and Tonge, 2011) found that there was a reported higher objective QoL associated with being married. Based on these studies the largest numbers of participants were single; however, there were inconsistent findings in relation to whether people with SCI who are either cohabitating or married do have a higher QoL than those who are single.

### **2.3.4 Religion/Spirituality**

Only one paper mentioned spirituality directly and its impact upon QoL. The results showed that spirituality (a meaningful relationship with God) was not a significant predictor of QoL

in individuals with SCI, however the same study found that existential spirituality (belief that one's life is meaningful or has purpose), did correlate significantly with QoL (Matheis, Tulskey and Matheis, 2006).

### **2.3.5 Secondary Health Impairment**

QoL was found in three papers to be significantly poorer for those people who had secondary health impairments (SHI) (Barker et al. 2009; Kennedy et al 2010b; Krause, Broderick and Broyles, 2004), with two other studies stating that health does predict QoL (Charlifue and Gerhart, 2004; Matheis, Tulskey and Matheis, 2006). One paper found that health declined over 40 years but said this was age related (Krause et al. 2017). Frequently reported SHI include medical complications such as the presence of pressure sores, bladder control (self-catheterisation), uncontrollable leg spasms and pain in the spinal cord around the injury site.

### **2.3.6 Appraisal/ Rehabilitation /Depression**

Two studies (Kennedy et al. 2010a; Kennedy et al. 2010b) found that initial appraisal (challenge or loss) of a person's injuries during rehabilitation had an impact on how individuals coped with a new SCI; it also correlated positively with well-being. The studies found that individuals with SCI scored highly on measures for depression, anxiety and stress during the early stages of rehabilitation; however, during the later stages of rehabilitation they reported lower levels of these factors. It was also stated in one paper (Charlifue and Gerhart, 2004) that early perceived QoL was a predictor of later depression, stress and psychological well-being. One paper (Krause, Broderick and Broyles, 2004) suggested that there should be more of a focus on depression during rehabilitation; however, this research study was just looking at African American women. Another paper (Decker and Schulz,

1985) found that people with SCI reported a level of depression and well-being that only differed slightly from that of nondisabled people. These findings would indicate that whether a person is disabled or nondisabled, health is unpredictable in life, as are employment and marital status; these factors affect people with SCI and affect nondisabled people and can contribute to the development of depressive symptoms.

## **2.4 Discussion**

The purpose of this review was to assess the available evidence to establish if people with SCI do have a poorer QoL, and if so, what factors impact on this. Even though all 10 papers met the inclusion criteria, no one QoL measure was used more than four times and out of those four, two used a revised version. Due to most papers using different measurements, it was not possible to carry out any forms of meta-analysis on the findings. Instead this review looked at the demographics of each study and compared findings such as sex, employment, marital status, religion and level of injury. A drawback of using this method was that although most papers included good demographic information, they did not report statistical findings for how these demographics impacted on QoL.

Depression was found to be a key factor mentioned in several of the studies, with reports of individuals scoring high for depression, anxiety and stress in the early stages of rehabilitation but scoring lower as time went on. Similar studies suggest that SCI and depression go hand in hand (Kennedy and Rodgers, 2000) and even earlier studies found that 100% of patients with SCI suffered with depression and to not suffer meant that a person was in denial (Wittokower et al. 1954). Frank et al. (1987) argued that depression and anxiety should decrease over time; however, Hancock et al. (1993) carried out a longitudinal study and found that people with SCI had a high level of anxiety and depression and this didn't change

over time. Kennedy and Rodgers (2000) argue that this is due to fewer studies examining scores across time and those that do, report conflicting findings. Nearly all the previous studies looked at depression in individuals with SCI during rehabilitation between 2 and 4 years after leaving hospital, which could be why depression is as prominent as individuals with SCI are still coming to terms with their injuries and life changes. The current review identified that depression appears to be more prominent in the early stages of SCI, but the evidence would suggest this does decrease over time spent with SCI, especially if people become educated, their finances get better and if they become employed or volunteer, leading to a better QoL (Krause et al. 2000).

Employment does seem to be an issue for people have SCI as 79% of those who are unemployed report that they want to work (Ottomanelli and Lind, 2009) the jobs they apply for do not need great levels of physical mobility (Ottomanelli and Lind, 2009) and the findings of this review show that individuals with SCI can hold on to their jobs for a long period of time. The papers in this review are not consistent in their findings regarding the relationship between levels of QoL that are reported by employed compared to unemployed people, however Krause et al. (1998) found evidence to suggest that employment may be the most recognised primary marker of successful rehabilitation outcome after disability. Krause (1990) stated that there is evidence to suggest that vocational outcomes affect both QoL and longevity.

A strong determinant of QoL, according to the papers included in this review was health; SHI such as lack of bladder (self-catheterisation) and bowel control, renal failure, pressure ulcers/sores, spasticity (spasms) and pain led to poorer QoL. This could be due to people not being able to work or socialise due to their SHI, in turn this could also lead to depression

causing a poorer QoL (Noonan et al. 2008). Krause and Broderick (2005) reported that people with SCI had poorer health than their abled-bodied counterparts and that health decreased over 25 years.

No significant differences were identified between levels of injury and QoL in the papers used within this review, suggesting that physical limitations did not impact on QoL. Lidal et al. (2008) explored the differences in health related QoL (HRQoL) between paraplegics and tetraplegics. They found that paraplegics scored higher with physical functioning (PF) compared to persons with tetraplegia; however, tetraplegics exhibited higher HRQoL. Findings from a study by Weitzner et al. (2011) concurred with those included in this review in that there were no patterns of difference between levels of injuries among people with SCI and QoL. The combined evidence would suggest that level of injury does not impact on QoL but there may be some difference between paraplegics and tetraplegics and how they cope individually with their level of injury.

The evidence indicates that people with SCI report lower levels of well-being compared to the general population or the non-disabled comparison groups identified by a few of the papers included in this review. The explanation of these differences would be easier to identify if research measured other potential determinants of QoL such as, socioeconomic status, gender and age. Even though there is evidence to suggest that people with SCI do score lower on QoL than their abled-bodied counter parts, QoL still does seem to be quite high in the majority of cases according to the papers included in this review.

The findings of this systematic review point to depression and SHI being the primary causes of people with SCI having a poorer QoL. The findings that factors associated with QoL do

appear to improve as individuals acclimatise to life with their injury is encouraging, but more research is required to look at the role of factors such as employment, marital status, and other financial and social aspects of life for people with SCI in relation to their perceived QoL. A consistent tool should be used to measure QoL in people with SCI such as the SCI-QoL, however, this is a relatively new measure (Victorson et al. 2015).

## **2.5 Conclusion**

QoL among people with SCI is lower than in their abled-bodied peers (Kennedy et al. 2000; Noonan et al. 2008; Post and vanLeeuwen, 2012), showing a great need for the factors that impact on QoL to be addressed during the rehabilitation stage. If key factors that are said to impact on QoL are addressed during the rehabilitation stage such as; SHI, employment, relationships, benefits, housing, adaptations and much more, the literature suggests that this could result in lower depression and possibly lead to higher QoL in the earlier stages of SCI. Future research should identify and investigate each of these key factors and look how to improve them. It would also be helpful if research could be conducted using consistent measures of QoL so that comparisons can be made between different demographic groups before and after interventions such as the SCI-QoL (Victorson et al. 2015).

The findings of this systematic review along with the finding of the literature review will be used to inform the design of the interviews for chapter 3 and also help in the design of the questionnaires for chapters 4 and 6. The information will further help the design of the intervention in chapter 5.

**An investigation to see how people cope after becoming spinal cord injured and what knowledge they have about peer support groups and if they would attend one:**

**qualitative study**

**Chapter 3**

**3.0 Introduction**

The approach to this study is exploratory with a focus on understanding how people with SCI have coped since becoming injured and what their understanding of a peer support group is. Within the literature it was found that most studies had used a qualitative methodology to evaluate peer support (Ussher et al. 2006; Haas, Price and Freeman, 2013; Veith et al. 2013; Greenwood et al. 2013). As a result, an initial qualitative study was considered most suitable as a first stage to understanding individuals' knowledge to help in the design of a peer support group and will build on the foundation of the literature and evidence from previous chapters.

**3.1 Aims and Objectives of the Chapter**

The aim and objective of this study which was identified as aim 3 objectives 2 in the overall aims and objectives is to find out how participants cope after becoming SCI what knowledge they have of peer support groups and would they go to one. This was done by designing a questionnaire and interviewing several participants and asking about their level of injury, whether they have secondary health impairments, how being injured affects their day to day living, who they speak to, how they cope and their knowledge of peer support groups.

## **3.2 Method**

### **3.2.1 Participant Panel**

In recent years there has been an increase in the inclusion of the population in question in planning and design of research projects and this is because it is believed that people who are the focus of research have a right to have a say in what and how research is undertaken (Staley, 2009). There is evidence that being involved in a participant panel helps the person gain new knowledge and skills and benefits them in such a way that they increase in self-confidence and improved self-esteem. Researchers have also been positive about working with a participant panel and report that they have gained a deeper understanding of health conditions and in some cases their beliefs and attitudes have been challenged (Staley, 2009).

A participant panel is made up of people who have been screened to ensure they are suitable for the research taking place and that have agreed to take part over a set period of time (Minogue et al. 2005). In the case of the current study, that is people with SCI that could make themselves available for a period of up to 3 years. Using the research population to inform the research can have a positive impact due to their own insight into the issues at hand which in the case of the current study is how people cope after becoming spinal cord injured and what knowledge they have about peer support groups (Franklin and Eltringham, 2018). The job of the current participant panel was to collaborate with the researcher and offer feedback and advice on the participant information sheets, interview schedules, questionnaires, contents of the peer support group, including choice of guest speakers and their topics and the structure of the sessions. This was done through either face to face meetings or through video conference calls so all panel members could discuss the issues as a group and give feedback to ensure the research is being carried out to the highest quality and is entirely relevant to the population in question.



The participant panel was made up of three members, all of whom were all people with SCI and two of which were peer support officers for SCI charities. All had SCI for many years and had life experiences as wheelchair users here in the UK. The participant panel was set up to help with the process of designing all aspects of the research reported in this thesis, including the peer support group. At each stage during the research and development of the peer support group the participant panel were sent information to enable them to offer their own input and guidance on the documentation and content of the peer support group.

The rationale for using a participant panel is that they have personal knowledge and experience of the circumstances underpinning the research being carried out and that they are able to provide a more personal and in-depth perspective. This will improve the quality of the research by helping make the language and content of the information more appropriate i.e. questionnaires and participant information sheets. Also helping to ensure that the methods proposed in the study are acceptable and sensitive to the situation of the research participants.

### **3.2.2 Data collection**

The data was collected using a homogenous sample more commonly known as purposive sampling where the researcher selects the participants based on a defined criterion and in the case of this study that would be that participants have SCI. Reid et al. (2005) suggest that a sample size of between 4 and 10 participants for professional doctorate is reasonable for a study of this kind

### **3.2.3 Design**

The study was qualitative and included semi-structured interviews to elicit the views of participants with SCI regarding how they have coped since having SCI and what they know and felt about peer support groups. Semi-structured interviews were selected as the method of choice for this initial stage in the research process as they allow participants to express their views in their own words and do not impose the views of the researcher through any structured or directive questioning and so are the most appropriate method for identifying issues that had not previously been thought of (Thornhill, Saunders and Lewis, 2009). Semi-structured interviews also make it possible for the interviewer to seek further clarification or probe for more information as required. The ‘collaborative’ quality of the interview, which it is believed will enhance the outcomes of the process by encouraging the interviewee to relax and express their views in an uninhibited way (Lewis and Ritchie, 2003), will be made more probable by the fact that the researcher has SCI himself, so can relate to the interviewees in a way that would not be possible if that were not the case.

### **3.2.4 Which qualitative method is most appropriate**

There was some discussion between the researcher and the supervisory team about which analysis to use for the data once it has been collected. Two types of analysis were considered; interpretive phenomenological analysis (IPA) and Thematic Analysis (TA). IPA was the researchers first consideration because this study is working with a homogeneous group (all participants have sustained SCI), using a semi-structured interview method which allows the researcher to have some flexibility and questions can be modified as other areas of interest arise (Smith, Flowers and Larkin, 2012). IPA is also concerned with interviewing each individual participant as a separate entity allowing the researcher to examine similarities and

differences between each participant (Smith, 2003), which was more in keeping with the aims of this study. Both IPA and TA seek patterns across the data, but IPA is theoretically bound (phenomenology) and can be thought of as a methodology (theoretical analysis) whereas TA is seen as a method (analytic method i.e. it does not prescribe theoretical assumptions, appropriate research questions and ideal methods of data collection) (Braun and Clarke, 2006). The final consideration when deciding on which method of analysis was to break down the aims of the study. There were two aims (i) how the participants have coped with their SCI so far and (ii) what they currently know and feel about peer support groups. Therefore, IPA was discounted based on this second part of the aims as this study is taking a pragmatic approach towards the data rather than theoretical. The data will be used to help design a peer support group so it was decided use TA as it could analyse both aims of this study (Braun and Clarke, 2006). In conclusion, TA would be used in the same way as IPA but with more flexibility and the researcher was able to look at their experiences and capture their opinions.

### **3.2.5 Thematic Analysis – an overview**

Thematic Analysis is a method for interpreting patterns and themes within qualitative data, a bad TA will use the main research question as a theme (Braun and Clarke 2006; Clarke and Braun, 2013). A good TA will identify themes/patterns within the data and will use these to address the aims of the study (Clarke and Braun, 2013). There are different ways to do TA, but the most common method used within qualitative research is by Braun and Clarke (2006) which uses a six-step framework (Braun and Clarke 2006; Javadi and Zarea, 2016; Clarke and Braun, 2017). There are two distinct levels of themes used by Braun and Clarke (2006) TA and that is semantic (explicit level) and latent (interpretive level). The semantic level is looking at the surface meanings of the data, the researcher is not looking for anything beyond

the obvious things that have been said and is not looking for deeper meanings (Braun and Clarke, 2006). The latent theme is identifying the underlying ideas, patterns and assumptions (Braun and Clarke, 2006).

### **3.2.6 Participants**

#### **3.2.6.1 Recruitment**

The study used a purposive sample, participants were recruited using a snowball effect through personal contacts of the researcher who have SCI and includes peer support officers for spinal injury charities therefore allowing them access to people who are spinal cord injured.

#### **3.2.6.2 Inclusion and exclusion criteria**

The inclusion criteria were that all participants had SCI, were over 16 years of age could be either male or female and any level of injury or any type of SCI so long as it was recognised by the spinal cord injuries association (SIA).

#### **3.2.6.3 Sample**

Seven people volunteered to take part in the study (Table 3). There were 2 women, 5 men, aged between 23 – 55, 3 were tetraplegics, 4 were paraplegics, 2 had a nontraumatic injury (e.g. illness) and 5 had a traumatic injury (e.g. accident). The participants are representative of the UK population where 80% of people with SCI are male and a higher number of people with SCI are paraplegics (Spinal Research, 2015). The research had offered no incentive, financial or otherwise to the participants in return for taking part in the interviews.

**Table 3** Demographic characteristics of participants

<u>Participant</u> <u>Alias</u>	<u>Age</u>	<u>Level of spinal cord</u> <u>injury</u>	<u>Approximate</u> <u>length time</u> <u>since injury</u>	<u>Marital status</u>	<u>Traumatic and</u> <u>nontraumatic injury</u>
Anne	41	T6/7 paraplegic	9 months	Married	Nontraumatic
Terry	46	T4 paraplegic	20 years	Single	Nontraumatic
Marcus	23	C5 tetraplegic	3 years	Single	Traumatic
Angel	34	T4 paraplegic	6 years	Single	Traumatic
Mark	55	C6 tetraplegic	24 years	Married	Traumatic
Peter	45	C6 tetraplegic	10 years	Single	Traumatic
Anthony	52	T3 paraplegic	10 years	Single	Traumatic

### 3.2.7.1 Ethics

The group being interviewed are vulnerable as they have sustained serious injury to their spinal cord and may have psychological issues with regards to their current situation. They may also feel sensitive about answering certain questions but will be able to ignore any question that makes them feel uncomfortable and they can stop at any time if they become distressed. If they need to discuss any issues that may arise from being interviewed the researcher will put them in touch with the Spinal Cord Injuries Association which are a UK charity, alternatively there will be a link at the bottom of the participant information sheet. Ethical approval was given by the School of Health Sciences Research Ethics Committee, Cardiff Metropolitan University before the study started. Supporting documentation can be found in (Appendix 1A and 1B).

### **3.2.7.2 Informed consent**

All participants were emailed a participant information sheet (Appendix 1C) however, depending on how they were interviewed e.g. in person, or skype, they were either emailed a consent form or it was given to them prior to the interview starting. The participant information sheet set out the information about the study, including the purpose of the research. As participation was voluntary participants could take as long as they wanted to read over the information sheet before contacting the researcher to say if they wanted to take part in the study.

Before the interviews commenced the researcher ensured that participants had read and understood the information they had been given and that they had read the consent form. If they wanted to continue to take part in the study, they were then asked to sign the consent form and give it back. A signed copy of the consent form was given to the participant and a second copy was kept by the interviewer (Appendix 1D).

### **3.2.7.3 Confidentiality**

Participants were assured of anonymity before commencement of the interviews.

### **3.2.7.4 Potential distress**

All participants were contacted either by email or a phone call prior to the interview to outline the study and what taking part would involve. They were all given the chance to back out, but none did. Interviews were either done via skype, or in person in a public place of their choice or their own home so that they would feel as relaxed and as comfortable as possible.

It was also reiterated to each participant that they could withdraw or take a break at any time during the interview or refrain from answering certain questions or prompts if it became too difficult or uncomfortable. At the bottom of each participant information sheet was the details of the SIA website just in case any participants needed support.

### **3.2.8 Data collection**

#### **3.2.8.1 Semi-structured interviews**

A draft interview schedule was designed to meet the aims of the research and this was reviewed by a panel of 3 volunteers who were hand-picked due to them already having SCI. All three agreed to be involved in the development of all materials for this PhD at the outset of the project. Changes were made to some of the questions on the draft interview schedule on the recommendation of the panel of 3.

A semi-structured interview schedule of 13 questions (Appendix 1E) was designed with the intention of guiding the interviews. The aims of the interviews were to explore issues in relation to the participant's quality of life (QoL) due to their SCI, their own experiences both positive and negative, who they talk to about physical and mental issues, their knowledge of peer support groups and whether they would go to one. These questions were based on the researcher's own personal knowledge and experience of being a person with SCI and a review of the current SCI literature. The schedule also included prompts and probes, this allowed the interviewer to remain flexible and pursue any answers in more depth if they were relevant. A digital voice recorder was used for all interviews. All interviews were tape recorded. They were between 30 and 70 minutes long and transcribed verbatim with pseudonyms given to each participant before being analysed using TA (Braun and Clarke, 2006).

### **3.2.9 Data analysis**

#### **3.2.9.1 Individual case analysis (step 1 and 2)**

Following the TA guidelines set out by (Braun and Clarke, 2006) each interview was transcribed and analysed in-depth individually using a semantic approach to coding. The digital recordings were listened to twice each and the transcripts were read many times. After becoming familiar with the data some notes were taken by hand about points that were relevant. The transcripts were then analysed by using a margin and breaking the text down and drawing out data from the text and coding with exploratory comments describing the initial thoughts about the contents of the interviews and language use (Braun and Clarke, 2006). The themes were drawn out based on how important they were in answering the main aims of the research question (Braun and Clarke, 2006).

#### **3.2.9.2 Initial themes (step 3)**

At this point in the analysis emergent themes were listed in order for each interview and then clustered into related themes. They were sorted into potential main themes and sub-themes using a colour coding process to make it easier to identify and develop the themes further. At this stage main themes and sub-themes had been identified, but not all the data had been discarded.

#### **3.2.9.3 Main themes and Sub-themes (step 4 and 5)**

The next step was to look at the main themes across the entire data set for patterns. From this, a list of themes was drawn up for the group and then clustered into master themes and sub-themes as can be seen in Figure 1 in the results section. At this stage the themes matched across all data sets, so no further reviewing of the data was needed.



#### **3.2.9.4 Validity and reliability**







In order to ensure reliability and validity of the analysis two internal supervisors were given one interview which was not the same to analyse. Once the interviews were coded for themes, they were then compared to the PhD student's themes of the same interviews in a supervisory meeting. This was done to ensure an acceptable level of agreement in terms of the conclusions drawn from the analysis. Upon comparing themes, it was found that both internal supervisors had found similar themes and it was agreed the similarities were acceptable and that a level of reliability and validity had been met.

#### **3.3 Results (step 6)**

When analysing the data, the researcher had to be aware of their own subjectivity given their own spinal cord injury.

During the analysis of the transcripts, 6 master themes and 29 sub-themes were identified (Figure 4). The following is a list of the most common themes that were repeated throughout the transcripts. Descriptions, which include quotations, are used to represent the themes found in the study. Copies of the interviews and coding process are in the appendix.

**Figure 4** Master Themes and Sub-Themes

Social Support	Adapting to change and coping	Lack of control and health changes	Previous knowledge and experiences	Relating to SCI	Peer support group barriers and benefits
					
1. Has friends and family to help and talk to 2. Dependence on a partner or care giver 3. Who to ask for help and support, knowing who to ask 4. Lack of access to health care professionals 5. Lack of group support from peers 6. Friends and family need support	1. Psychological adaption 2. Adapting and coping with health changes 3. Not knowing how to adapt 4. Coping with living independently	1. Bladder and bowel management 2. Pain and discomfort 3. Addiction to medication 4. Health complications 5. Taking control of own body 6. Long term suffering 7. Sense of desperation and frustration 8. Impact of psychological well-being	1. Shared experiences 2. Professionals lack knowledge and experience 3. Peers have knowledge and lived experience 4. Lack of knowledge and experience secondary health impairment	1. Friends and family unable to relate 2. Peers are able to relate	1. Accessibility 2. Location, time and frequency of group 3. Group leadership 4. Structured sessions 5. Source of support

### 3.3.1 Social Support

#### Has friends and family to help and talk to

All participants in this study received positive support from either their friends or family.

Nearly all participants referred to getting support in the early stages of their SCI and how important it had been in their recovery.

Anthony: “he told me, ‘listen Anthony’, you’ve severed your T3, you’ll never walk again but there’s life after it...and I switched on to that life straight away”.

Anne: “support I’ve had from family and friends has been really positive and really kept me going really over the last few months because it’s certainly been a really, really hard time”.

Anthony mentions being told he will never walk again by a consultant, but it helped him to move on with his life. He says it pushed him to get out of hospital in 6 and a half months and

he went to the gym every day to improve his physical health. Anne received all the support she needed over the last few months and it's really improved things for her as she had only been out of hospital for 3 months.

#### Dependence on partner or care giver

Four participants who spoke about receiving help from their friends and family were all high breaks. People with a high-level injury are more likely to be dependent on a care giver or family member to give them the support with bathing, dressing or just being able to leave their home.

Mark: "I mean I was quite lucky in that I am married to a professional who is able to help me like that".

Anthony: "I've got a 17-year-old son, he looks after me as well".

Mark states that his partner is a health care professional and because of the advice and help she gives him he has been able to change his posture and the way he transfers into the car, shower and bed. Throughout the interview he keeps repeating how lucky he is. Anthony gets terrible bedsores and he says his son helps him with the dressings, but he finishes by saying he just gets on with life.

#### Who to ask for help and support, knowing who to ask

Participants were asked, outside of their family and friends, if they knew who to contact for help and support. People with SCI are vulnerable both mentally and physically and can become ill quite fast so it's essential they know who to contact when this happens for advice or care. Out of the seven participants interviewed, three knew who to ask for help which is fewer than half of the participants.

Terry: “I’ve got a relationship with certain healthcare professionals, er and if anything, er, came up which troubled me, I can speak to them”.

Marcus: “some of the old nurses, who worked in the spinal unit I went to, I can speak to them quite easily”.

Peter: “certainly Mr xxxxx, the Consultant, you know he is sort of really my support here”.

All three participants who said they knew who to contact for help and support, outside of friends and family, all worked for different SCI charities and rehabilitation centres and have access to health care professionals, the other four participants did not know who to contact for support.

#### Lack of access to health care professionals

It is important to have access to a health care professional (HCP) even if just for professional advice as living with SCI is difficult and its common for people with SCI to suffer with bowel bladder and pressure sore issues on a weekly to monthly basis (Fogelberg et al. 2009).

Anne: “I phone them they say, oh, go to your GP or contact the District Nurse, or do this, that or the other”.

Anne was told when she left hospital that she was a patient for life, but when she tries to contact them, she is told to call her GP who has no knowledge of SCI. She says she would like one doctor she could call who knows all about SCI, but at present she does not have that kind of support.

#### Lack of group support from peers

Three participants mentioned not having a support network from their peers (other people with SCI) and that they found this hard. It’s great to have support from family, friends and

HCP's, but they would not be able to give the same support and advice as someone who also suffers from SCI.

Mark: "in my sort of life as a spinal injured person it would have been good to have spoken to other people about how they've dealt with their spasms".

Mark talks about how he is in touch with his spasms and how they have some positives, but he mentions the negatives and that he would like to have spoken to his peers to see how they had managed with their own spasms. Receiving that kind of support was important to him.

### Friends and family need support

When a person is injured it doesn't just affect them, it affects the people that they are close to, such as family and friends (Angel and Buus, 2011). The following participants were asked about whether their family and friends would like to attend a peer support group once a month, so that they could also receive support from other members' family and friends. All the participants who were interviewed thought that it was a really good idea and considered the possibility that family and friends had not met other people with spinal injuries. Going to a peer support group and meeting others would be a good way for them to have a better understanding of SCI and also provide social support for the carers themselves.

Anne: "Yes, I certainly think that's a good thing to do ...oh yes ..he's nodding his head (her husband who is accompanying her for the interview)...I think that is a really big thing".

Marcus: "Yeah I think that would be quite helpful for family and friends".

Anne says she received all the support in hospital and her partner received none and that he needed it. Marcus suggests that having friends and family go to a peer support group would help them to understand what people with SCI go through and that they would get the support they needed from other friends and family.

### **3.3.2 Adapting to change and coping**

#### Psychological adaption

Two participants spoke about the difficulties of adapting and coping psychologically with being spinal cord injured.

Anthony: “I had half a life, that’s what I keep on saying, I look at R\*\*\*\*\* now and think well at least I had half a life”.

Anthony is a T3 paraplegic and his younger friend is a C1/C2 tetraplegic. He talks about himself as, at least, having half a life and that his friend has no life as he is such a high-level tetraplegic. Anthony himself does not seem to have adjusted well to becoming spinal cord injured although he seems to justify having a better life (even though it’s not that great) than his friend because his friend has a much higher break.

#### Adapting and coping with health changes

Three participants talked about adapting to their health changes and how they cope.

becoming spinal cord injured impacts heavily on health as the body goes through a trauma and depending on what level of injury a person is, there will be no feeling or sensation below that injury level. There are all kinds of complications that can arise from not feeling or having sensation, secondary health impairments can be the single biggest problem to a person with SCI and can impact on their well-being (Bloemen-Vrencken et al. 2005; Guilcher et al. 2013).

Anne: “I am, at the moment, I seem to be going back and fore to the hospital quite a lot for this that.”

Anne talks about the endless cycle of going back and forth to hospital due to pain and other things that are happening to her because of her SCI. She mentions the endless cycle of

doctors too but finishes her sentence with a statement of hope that she is sure it will all get better as her body goes through health changes.

### Not knowing how to adapt

There are many ways that a person with SCI must learn to adapt. Being a wheelchair user, not being able to drive, and juggling work with out-patient appointments due to health problems, are just a few examples of this. These things become a part of everyday life for people with SCI and not knowing how to adapt will, once again, impact on their long-term QoL. Four of the people interviewed for this study found difficulty with not knowing how to adapt.

Terry: “er and having outpatient appointments, that can really impact on me because I’ve got to balance that with er, with work.....with work and that can be very difficult”.

Anthony: “when you’ve been a grafter all your life and you are doing things you love, it’s very, very, very hard being in a wheelchair”.

Terry talks about his skin issues and how they have impacted his life for years. He mentions having to go back and forth hospital for appointments and how that affects his ability to work and that he finds it all very difficult. Anthony has found it difficult to adapt to being less active and has found that pushing himself to be active, he now gets pressure sores. Being able to discuss health issues with peers would help manage or prevent health issues from occurring.

### Coping with living independently

Five of the interviewees mentioned aspects of living independently; from driving, doing more social activities, to being able to put themselves to bed. Living independently is essential for any person and people with SCI are no different. If a person with SCI is unable to live independently they may first have to stay in a hospital and then they may be moved to a care

home where they can be looked after, or a possible outcome is they will become dependent on a loved one (Smith and Caddick, 2012).

Marcus: “I’ve learned how to put myself to bed, so I’m a bit more flexible with evenings now which is quite good”.

Marcus lived with his parents and had to be home at a certain time so that they could put him to bed, but as a tetraplegic he has since learnt to put himself to bed which is giving him the independence to be more flexible with his life. This type of knowledge and experience would help a peer who might have the same issue.

### **3.3.3 Lack of control and health challenges**

#### Bladder and bowel management

All seven participants in this study mentioned bladder and bowel management. Although Terry said he had no bladder problems, he still self-catheterised and used convene drainage with a leg bag. Bladder and bowel management is a secondary health impairment that affects a high number of people with SCI. Depending on what level of injury a person has; will decide how severely they are affected. How they manage their bowel and bladder will impact their lifestyle and, in some circumstances, their QoL. Poor management can also cause severe health problems (Benevento and Sipski, 2002; Sezer et al. 2015).

Anthony: “they gave me a colostomy bag...and it’s the best thing that has ever happened to me in my life I should have had it 10 years ago. It’s changed my life completely”.

Anthony used a laxative to help his bowel movement because of his SCI. Due to the continual use of a laxatives he had health issues that affected how he coped daily. After receiving treatment and having a colostomy bag fitted, Anthony goes on to say how this was life changing which improved his QoL. To tell others of his own experience could change a peer’s life and stop them from struggling for years.



### Pain and discomfort

A few of the participants complained of pain and discomfort and others had mentioned it after doing the interview. As a person with SCI, pain and discomfort is something that some individuals deal with daily. Much of the pain and discomfort can be comorbid due to long-time use of a wheelchair.

Mark: “so I get a lot of discomfort now in my shoulders and my neck”.

Peter: “I’ve been getting a lot of severe sort of lower back pain”.

Mark suggests his pain and discomfort are caused from being a user of a wheelchair for 25 years and having to propel himself daily, causing repetitive strain. Peter is a tetraplegic who can walk with the help of sticks. He says that he used one stick for 8 years because he wanted to keep one hand free (he should have used 2 sticks) and this caused severe lower back pain which he is having an MRI for to see if he can be helped.

### Addiction to medication

Although many of the participants did not mention being on medication now, they had talked about being on different medications in the past but due to addiction and bad side effects they managed to stop taking them. The most common types of medication for people with SCI are for spasms and pain.

Peter: “I do, I’m on Tramadol 4 tablet a day and Pregabalin”.

Peter takes a high dose of tramadol and pregabalin. They both of have bad side effects and are used quite often for people with SCI that are in severe pain. They are considered to be highly addictive medications and very difficult to stop taking.

### Health complications

Many of the participants (5) had mentioned having secondary health impairments. Research suggests that secondary health impairments are a comorbid effect of SCI. Pressure sores are caused by a lack of skin sensation from below the break and good preventive care should be taken by checking skin and turning regular in bed. Other secondary impairments such as spasms, which is an involuntary movement caused by nerve damage to the spinal cord, can be helped with medication and daily leg stretches.

Anne: “different sensations in my feet and um I’ve got quite a few, sort of sores coming on the bottom of my feet”.

Mark: “Um, I suppose for me one of the main things that impacts is spasm, muscle spasm, it has quite a big impact”.

Anne has sores coming on her feet, but as Anne is only 3 months out of hospital she should take care to have them checked by a doctor and dressed before they turn into a severe pressure sore. They can take from months to years to heal, depending on the sores level of grading. For Mark, he considers muscle spasms to be his main secondary health impairment. Spasms can be controlled with oral medication or an intrathecal baclofen pump which needs refilling every 2 to 3 months via a needle through the abdomen. Regular dosage increases are needed as the body grows a tolerance to the baclofen drug. Both pressure sores and spasms can be debilitating and have an impact on a person’s QoL (Kennedy et al. 2000; Kennedy, Lude and Taylor, 2006; Noonan et al. 2008; Post and vanLeeuwen, 2012; Kennedy, Kilvert and Hasson, 2016). Discussing secondary health impairments within a peer support group with new and older SCI can help them to prevent or manage their own conditions so that they are able to improve their QoL.

### Taking control of own body

Being able to control one's own body comes from experience of previous issues caused by SCI. Taking control and changing behaviours can prevent same issues for recurring.

Terry: "is really up to me, making sure I don't get those skin problems in the first place, so I must admit that is down to me".

Terry has been a wheelchair user for 20 years and makes a point of saying it is his sole responsibility to keep a check on his own skin to make sure it doesn't breakdown in the first place.

### Long term suffering

Four of the participants interviewed for this study spoke about suffering for years with secondary health issues as a direct cause of their SCI. The ones who hadn't mentioned suffering from long term issues did not have SCI for as long as the participants below.

Anthony: "I've been suffering through pressure sores for the last 10 years".

At the time of the interview Anthony had 3 pressure sores on his feet. He has done everything he can to try and prevent himself from getting them. He says he has an airbed; he looks after himself and he eats a good diet. On the day of the interview, he had gone to the hospital to have the dressings changed and they noted he had thinning of the skin on his ankles. Due to this, he is not able to lie in bed for longer than 8 hours and can never have a lie in, which he says is a nightmare. A peer support group is to impart others knowledge and experience to help people like Anthony learn how to protect their skin and prevent pressure sores happening in the first place.

### Sense of desperation and frustration

Not all participants had spoken about being desperate or frustrated, but out of the ones who had, it was a mix of trying to live independently with SCI and secondary health impairments caused by having SCI.

Mark: “I was trying to live independently, and I had nobody to turn to you know, that was quite a tough, tough time really”.

Mark talks about suffering mentally, as well as, physically and no one including the hospital was there for him. Upon leaving hospital Mark said he left on his own and had no one to turn to. Twice he mentioned how tough that was for him. Mark could have benefited from a peer support group upon leaving hospital.

### Impact on psychological well-being

Of the participants being interviewed for this study, nearly all had mentioned that secondary health impairments had affected their QoL; however, only two had mentioned psychological issues.

Mark: “I ended up with PTSD which wasn’t diagnosed until about 4 years later, after I’d nearly gone mad and was you know, was having real problems with my life, with post-traumatic stress”.

Mark spoke in great detail about how he suffered psychologically and how this was never dealt with whilst in a rehabilitation centre, coming to terms with his injury. One day he was ambulant and the next he was paralysed. This had massive repercussions for Mark and he feels they were never addressed. The staff helped him physically, but he says they never thought about the psychological aspect. He did say that after about 3 months of being in the spinal unit, a psychologist visited him and asked him how he was feeling and that was that. Being able to speak to other people with SCI could have helped Mark.

### **3.3.4 Previous knowledge and experiences**

#### Shared experiences

Participants spoke positively about going to a peer support group and how they would enjoy sharing experiences with their peers and listening to other's experiences.

Anne: "it's being able to talk to other people who are having the same experience as me".

Anne says a peer support group is when everyone is singing from the same hymn sheet. It's like going to a baby group where everyone can empathise with you and help. If you speak to someone who does not have a baby, it goes straight over their heads. It's being able to go somewhere to talk to someone who knows about what you are going through. You can share experiences and information about what is happening or has happened in your life.

#### Professionals lack knowledge and experience

Three of the participants had spoken about their own experiences with professionals in the field of SCI. They didn't feel that the professionals they had come into contact with, had the experience or knowledge to deal with their issues.

Angel: "No, they don't know anything".

Mark: "I have gone to my GP about things that were related to my spinal injury and they don't really understand or have the expertise really in the problems that I may have".

Anthony: "I taught them a lot, cause there, I'm the first one they've ever looked after ....and I've taught them a lot".

Angel didn't seem to have any confidence in health care professionals. She said that doctors and nurses knew nothing. Mark has no faith in his GP and states if he had any issues he would first contact his local spinal unit. Anthony says that the district nurses that came to help him, at home, did not have any knowledge of how to deal with a person with SCI. So he feels that he himself educated them. A peer support group would be a good source of

information as peers can empathise and have both the experience and knowledge to help others in the same situation.

#### Peers have knowledge and lived experience

Five participants discussed how they thought their peers with SCI would have knowledge and the experience to help them with their own SCI, whether that was with transferring, management of secondary health impairments or coping with other comorbid effects of SCI.

Terry: “if you are newly injured you are not going to have that wide knowledge that somebody who has been injured for a while will have”.

Terry discusses newly injured patients receiving valuable expertise and knowledge from a person with SCI who has been injured for many years. He then makes a good point by emphasizing that someone who has SCI for some time, could find out new things from someone who has experienced something different to them, whether they had a new or older injury.

#### Lack of knowledge and experience secondary health impairments

A person does not have to be a new SCI to lack knowledge or experience as one of these participants has SCI for 10 years and the other 9 months, but both need help from their peers or HCP's.

Anne: “what’s that all about, is that to do with my spinal injury or not”.

Peter: “I don’t worry about it like what I used to, probably if I hadn’t gone on, or by the 5<sup>th</sup> day then I do start to worry, but that’s only happened rarely”.

Anne has not been injured long and she worries about new pain and other issues that have come about since her injury. She is unsure they are because of her SCI. Her husband is a doctor, so she is always asking him to look at her and she goes back and forth the hospital a

lot. Peter has still not learnt to manage his bowel after 10 years and does not have a bowel movement for up to 5 days which can cause other serious secondary health impairments. He says he isn't worried by this fact. A peer support group would be beneficial for both new and old SCI.

### **3.3.5 Relating to SCI**

#### Friends and family unable to relate

Five participants in this study felt that their friends and family could not relate to them after they became a person with SCI.

Anne: "there are others that, you know think they're understanding but in actual fact, yeah they really don't get it".

Marcus: "sometimes we could be the only ones that they know who are spinal cord injured and they wouldn't know or understand what we've gone through really".

Anne says she has a couple of good friends who try to understand what she is going through, but there is no way they could. Marcus talks about his friends and family not being able to understand what he is going through, and he finds it easier to talk to his personal assistant about issues that affect him. A peer support group would allow people like Anne and Marcus discuss their SCI with their peers who would empathise with them.

#### Peer are able to relate

Out of the participants who were interviewed for this study, four were excited about speaking to their peers. The same four who had mentioned that their family and friends could not relate to them. These participants show a clear need to be understood and empathised with by their peers.

Anthony: “it would be great just to sit there, if it’s only for like an hour, or 2 hours to talk to people that know what you are talking about”.

Anthony talked about his sister being a carer, but that she still is not able to understand what he is talking about. He mentions how he would be the same, if the shoe were on the other foot.

### **3.3.6 Peer support group barriers and benefits**

#### Accessibility

Some participants would have difficulty getting to a peer support group due to not being able to drive. Driving is very dependent on level of injury and length of injury. In most cases, people have to redo their driving test and certainly have to use a driving simulator and pass.

Peter: “Yeah, accessibility really for me is a bit of an issue”.

Anne: “Um, I’m not driving”.

Peter is unable to drive as the DVLA took away his license because of problems stemming from his diabetes and with his mental health. Anne is unable to drive since her SCI, but she is hoping to start driving again in the near future. When designing the peer support group people who are unable to drive would need to be taken into account and transportation provided.

#### Location, Time and frequency of peer support group

Three of the participants had standing commitments i.e. work, school, children. These were the main factors amongst participants being interviewed, as to whether they could participate in a peer support group, and how often. Location was an issue as well.

Marcus: “once a fortnight would be quite easy to attend, easier to attend.



Mark: “I mean, I would struggle to get to a peer support group I think every week personally”.

Marcus said he did things a couple of evenings a week, so he would prefer a fortnightly group meeting. Mark said newly injured people would struggle to go to a peer support group weekly as they would find it hard going out. He stated he would struggle weekly but could go fortnightly. For the purpose of the feasibility study and time restrictions the peer support group would be weekly but future groups could be once fortnightly or monthly.

### Group leadership

Participants were asked what they would like to see at a peer support group and how they would like it structured. A few of the participants had brought up leadership and control as every group has strong characters that would speak over others within the group. This would not allow the quieter participants to have a voice.

Terry: “there’s somebody who is that dominant person and wants to drive things their way constantly”.

Mark: “so I suppose whoever is in charge would need to be good at controlling what is going on really”.

Terry talked about there being dominant characters and that there needs to be someone that is in control to reign them in; as it can be awkward when one person is doing all the talking and not allowing others to speak. Mark said that a peer support group could be a challenging environment and there could be someone, like himself, who likes to talk a lot who is dominant within a group. There would need to be someone in charge to control what is going on within the discussion.

### Structured sessions

The peer support group would need some kind of structure; different topics each week, maybe a guest speaker or maybe the participants could decide on what topic would be covered the following week. When asked what structure the peer support group should take nearly all participants said there should be a set topic weekly.

Anne: “at the beginning perhaps to say well these are the kind of topics”.

Terry: “go away and think about a specific topic and come back and then discuss that topic at the next meeting”.

Anne would like there to be set topics weekly, but she said that there should be time left each session for an informal general chat amongst the participants. Terry suggested there should be a general chat of about 10 minutes at the end of each session to come up with a specific topic to discuss the following week.

### Source of support

People who suffer with SCI generally have health issues that can happen on a weekly basis and, as already mentioned, they struggle to find anyone to talk to. A peer support groups is a really good source of support for people to discuss issues and perhaps receive help from a peer who has already been through whatever issue they may have.

Anthony: “something had happened to me that week and you want to talk about it”.

Anthony, speaking from his own experience of living with SCI, was wanting to share the problems that have happened to him that week and talk about it and get everything off his chest with his peers.

### **3.4 Reflexivity**

Reflexivity involves reflecting on the part played by the researcher on the research process and their personal understanding and personal experiences (Lyons and Coyle, 2016). Smith and Osborn (2003: 51-52) recognise that access to the participants' experience is "dependent upon and complicated by the researcher's own conceptions". It is acknowledged in qualitative research that the researcher's interpretation of data during the collection and analysis stage can be regarded as a contaminating factor due to the beliefs and assumption (Lyons and Cole, 2016; Elliot et al. 1999). With this in mind the following section will comprise of a personal statement.

#### **3.4.1 Self-reflexivity**

I am a 45-year-old white British male and have lived mainly in Wales for most of my life, although I have moved around quite a lot due to my parents and myself being in the military. I grew up in a single parent family with 3 sisters after my parents divorced when I was 7 years old. I had a very happy childhood although I saw my mother struggle. I am heterosexual and currently live with my wife and I have one adult son and a grandchild. I have been in university for the last 12 years. My area of interest is SCI and how people with SCI are affected by it on a personal level. In terms of epistemology my beliefs are more influenced by constructionism and the way people make sense of the events that happen in their lives. I especially see this with people who have SCI as it can happen to anyone and people with SCI can learn from one another's experiences and knowledge. I find myself in a difficult position as a trainee health psychologist opening up to my peers about very personal issues that I suffer with on a daily basis whilst trying to raise awareness about SCI.

I suffer with secondary health impairments on a daily basis, so I was able to empathise with the participants within the study. During the interviews I noticed that I spoke about myself as well as agreeing with the participants when they spoke about their own issues with having SCI. When discussing social support, I would ask more questions if I felt my own experience had been different to the person I was interviewing. I adapted quite quickly to life with SCI, but when interviewing participants, I could see that many had a very different experience to myself because of this I found myself asking more questions. I believe my own assumptions (knowledge and experience) impacted on how I asked questions or not.

As I listened back to the recordings I did wonder why I did this and what affect it might have had on the interview process. I believe I did this so that the participants would feel I was on their side and put them at ease; we had a shared identity. Even though this may have positively affected the interview process by the participants opening up, they may also have held some things back thinking I may know more than them.

### **3.5 Summary**

The aim of the qualitative study was to identify how participants coped after becoming spinal cord injured and what their knowledge of peer support groups was and how they feel about them. Data analysis showed that in most cases people who took part in the study were negatively affected by becoming spinal cord injured and due to secondary health impairments, they had difficulty coping and adapting because of the lack of control they had over their health, these finding were supported by the literature in earlier chapters (Kennedy et al. 2000; Kennedy, Lude and Taylor, 2006; Noonan et al. 2008; Post and vanLeeuwen, 2012; Kennedy, Kilvert and Hasson, 2016). Participants who felt supported in the early stages of SCI found that it had been important in the recovery process which is what the

literature review found (Sheman, DeVinney and Sperling, 2004; Muller, Cieza and Geyh, 2012; Muller et al. 2013). Muller, Cieza and Geyh (2012); Muller et al. (2013). People with SCI did mention not knowing who to contact in case of health issues and that they felt that they could not discuss these issues with health care professionals, friends and family as they felt they could not empathise with them (Ussher, 2006). Participants also felt that health care professionals did not have the knowledge and experience to help them but they did feel that other people with SCI did could help them which was found in earlier chapters (Kyrouz, Humphreys and Loomis, 2002; Ussher et al, 2006; White, 2007; Sweet et al. 2016). However, participants were really positive about the idea of going to a peer support group and being able to gain new knowledge and share their own experiences with other people with SCI as well as learn from others experience (Ussher et al, 2006; Hass, Price and Freeman, 2013; Sweet et al. 2016).

The information that the participants provided during the interview process will be used to help design the questionnaires in chapter 4 and chapter 6 and in the development of the intervention in chapter 5. This will be done by using the result of the analysis in this study and compiling a list of questions to send to the panel of three volunteers to review. The findings of chapter 3 will be further evaluated in the discussion (chapter 7).

**How do people with a spinal cord injury cope, what is their knowledge of peer support groups and would they attend one? quantitative study**

**Chapter 4**

**4.0 Introduction**

Previous research conducted for this thesis and reported in earlier chapters has found that people with a spinal cord injury (SCI) have a poorer quality of life (QoL) than that of the general population (Dijkers, 2005; Muller et al. 2012). Secondary health impairments impact further causing anxiety and depression and in general poorer satisfaction with life (Kennedy, Lude and Taylor, 2006, Sweet et al 2016). The evidence further suggests that a peer support group, introduced as a behavioural change intervention, has been beneficial to other populations i.e. in relation to substance abuse, cancer and bereavement etc (Kyrouz, Humphreys and Loomis, 2002; Ussher et al. 2006; White, 2007; Sweet et al. 2016) and could improve QoL in people with SCI (Haas, Price and Freeman 2013).

**4.1 Aims and objectives of the Chapter**

The aims of this chapter link back to the overall aims and objectives, identify what coping strategies participants use both physically and psychologically which enabled them to cope after becoming SCI (aim 1). Furthermore, find out what participants opinions are of peer support groups, would they attend one and how would they like to see one structured (aim 3). The study used a questionnaire which was designed by using the evidence from previous chapters i.e. literature review, systematic review (study 1) and the qualitative study (study 2) (objective 3).

## **4.2 Method**

### **4.2.1 Measures**

The study used an existing questionnaire (Brief COPE) (Carver, 1997) and a scale that was constructed for the purpose of this study to assess how people with SCI live their day to day lives and to identify their views regarding peer support groups.

There are self-report measures that have been designed to see how people cope with stressful events, including Ways of Coping Questionnaire (WCQ; Folkman and Lazarus, 1988), Coping Orientations to Problem Experienced (COPE; Carver, Scheier and Weintraub, 1989) and the Coping Inventory for Stressful Situations (CISS; Endler and Parker, 1994) to name a few. Mozani et al. (2015) said that all these questionnaires validly and reliably access approach and avoidance coping responses and both problem and emotion-focused strategies, however, they believed that a drawback of these questionnaires is that they include between 48 and 66 items which may limit their usefulness (Monzani et al. 2015). Carver (1997) argued that larger questionnaires take a lot of time and effort to complete and because of this, put a larger demand on participants which makes them less likely to commit themselves to involvement in a study. With this in mind, this study utilised a shorter questionnaire (Brief COPE) which contains 28-items and has been shown to be ideal for online (Carver, 1997). The Brief COPE was designed by Carver (1997) with 2 items representing each of 14 theoretically identified coping responses: self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioural disengagement, venting, positive reframing, planning, humour, acceptance, religion and self-blame (Carver, 1997). Carver (1997) tested the Brief COPE and overall it showed good internal consistency ( $\alpha = .50-.90$ ), with all subscales exceeding .60 except venting (.50), denial (.54) and acceptance (.57). The lower Cronbach alpha scores could be due to the original questionnaire

being shortened or it could be due to a poor correlation between items as including more items in a scale automatically increases the correlation coefficient (Tavakol and Dennick, 2011). Carver (1997) stated that the test was remarkably similar to the original full inventory, although the original COPE inventory consisted of 60-items with 4 items for each of the 15 theoretically identified coping responses. The COPE inventory had alpha coefficients of between .45 and .92, with all subscales exceeding .62 except mental disengagement (Carver, Scheier and Weintraub, 1989). Monzani et al. (2015) investigated the Brief COPE and found that it was a valid and reliable assessment of the 14 specific coping responses stressors. A copy of the 28-item measure can be found in (Appendix 2E).

The additional items designed for this study consisted of 39 questions (Appendix 2D) which were designed based on the findings of the literature review (reported in chapter 1 of the thesis) and the completed analyses of the semi-structured interviews (reported in chapter 3 of this thesis). Participants who were interviewed mentioned having difficulty coping and that they were negatively affected by becoming spinal cord injured. They talked about struggling with secondary health impairments and not knowing who they could talk to as they felt friends, family and health care professionals could not empathise with them. They further discussed wanting to share knowledge and experiences with their peer as they thought they could relate to them. They spoke positively about attending a peer support group. These findings were supported by the literature review.

The first 9 questions were for demographic purposes: age now, age at the time of injury, level of SCI, gender, country of birth, place of current residence, marital status, number of children (if any) and employment status. The next 30 questions were designed to elicit how participants coped with their SCI both mentally, physically and what they felt about a peer



support group. The questions asked all about their health issues since being spinal cord injured, this also included secondary health impairments (bowel function, bladder function and sexual function etc.) Further questions included were how they felt about peer support groups or the idea of sharing their experiences and knowledge whilst attending one, how they would travel to a group, whether they would anticipate any difficulty attending etc. The questionnaire was then shown to the participant panel of three who had all been asked to review the materials used in this research project because they had SCI and experience of being peer mentors for various charities. Once feedback was received from each panel member changes were then made to the questions and then the process was repeated until a final questionnaire was agreed upon by all members and the researcher. Changes suggested were about who do people with SCI ask for help or who do they speak to about health issues e.g. 'I find that health care professionals are unable to relate to me', 'Would you find it helpful to discuss your own health issues with other SCI people at a peer support group'.

The questionnaire was designed to obtain the views of a broader range and larger number of people than was possible via a qualitative study and so build on the findings of the earlier stages of the research and to gauge whether running an intervention would be feasible.

#### **4.2.2 Sample size**

Green (1991) found that for those researchers running a multiple regression who are just interested in R squared, they should use  $N > 50 + 8(K)$  (K = independent variables) minimum participants, for those interested in R square and Beta like this study should use  $N > 104 + 1(K)$  participants. This study used 2 Dependent Variables (DV) and 14 Independent Variables (IV), so in terms of how many participants this study should use, the minimum would be 236. However, it was decided to use a power analysis using G\*Power 3.1 to establish what the

optimum number of participants was for this study using multiple regression (Foul et al. 2009). As this study was running two multiple regressions due to having two DV's the first was 'I had difficulty coping physically after spinal cord injury' and the second 'I had difficulty coping psychologically after spinal cord injury'. The G\*Power analysis for the first question was done by using the variance explained by the predictor (.142), the program then calculated effect size  $f^2$  (0.16 medium), a err prob (0.05), power ( $1-\beta$  err prob = 0.99) and number of predictors (14), the sample size calculated was 215 the study used 230. For the second question the variance explained by the predictor was (.196), the effect size calculated was  $f^2$  (0.24 medium), a err prob (0.05), power ( $1-\beta$  err prob = 0.99) and a number of predictors (14), the sample size calculated was 216 the actual sample size included in the study was 270.

#### **4.2.3 Participants**

Two hundred and ninety-seven participants were recruited from around the world by posting the Qualtrics link to the questionnaire on Facebook spinal cord injury groups and spinal cord injury charity websites i.e. Backup, Aspire and the Spinal Injuries Association as well as using a snowball technique. The inclusion criteria stated that participants must be 16 years of age or older, and have a spinal cord injury, which could be caused by accident or illness (e.g. car accident or spinal stroke) and could live anywhere in the world.

#### **4.2.4 Ethical consideration**

Participants' anonymity and welfare were given priority when recruiting people for this study. At no point were participants asked for their name or email addresses and no online link was kept for individuals who contacted the researcher directly via social media. All

participants were made fully aware of what the study was about via a participant information sheet (Appendix 2C) that was attached to the online questionnaire. They were made aware that at any time if they felt anxious or distressed they could stop and not complete the questionnaire. Implicit consent was given by submitting the finished questionnaire.

Due to the nature of the people filling out the questionnaire, there might have been some discomfort with the type of questions being asked, for this reason at the end of the online questionnaire there was a direct link to the spinal injuries association (SIA) helpline. The researcher personally made the SIA aware of the research and that some participants may contact them.

#### **4.2.5 Procedure**

The questionnaire was designed and piloted with the help of the participant panel of three. Once feedback was received, the following changes were made to the questionnaire e.g. ‘I find that health care professionals are unable to relate to me’, ‘Would you find it helpful to discuss your own health issues with other SCI people at a peer support group’, once these questions were added, the questionnaire was created using Qualtrics software. Ethical approval for this study was obtained from Cardiff Metropolitan University before making the questionnaire live (Appendix 2A and 2B).

Participants were then recruited from SCI-related organisations (SIA, Aspire and Backup) using a snowball technique involving friends and acquaintances. This method was also used to recruit via social media sites such as Facebook (SCI groups) and Twitter. Recruiting was carried out by writing a message which was then posted to all sites on various group walls

with a direct link to the live questionnaire. The links were updated on a regular basis to stimulate participation.

Once participants clicked on the link they would be initially presented with a paragraph that would tell them all about the study and details of how to fill out the questionnaire. Once the questionnaire was submitted via Qualtrics the researcher examined them for missing pages, if this was the case they were then deleted.

#### **4.2.6 Data Screening**

A total number of 297 participants initially filled out the online questionnaire, out of these 27 participants had missed pages of questions and were eliminated from the analysis, leaving 270 participants. Of the 270 participants included in the final data analysis, 39 had minor missing data that did not impact on the main analysis.

#### **4.2.7 Data analysis**

The quantitative analysis was performed using SPSS 24.0. The first measure used was a 39-item questionnaire where each item was scored 1 totally agree to 7 totally disagree. The second measure to be used was the Brief COPE where each of the 28 items were scored from 1 to 4 but then they were combined to make 14 sub scales as per the Brief COPE scoring instructions, a higher score indicates that a person is more likely to use that coping strategy.

## **4.3 Results**

### **4.3.1 Frequencies**

Means. Standard deviations and intercorrelations are shown in Table 6 which can be found below.

The mean age of participants in the present study ( $N = 270$ ) was 44.5 years ( $SD = .98$ ), of those the mean age at time of injury was 30.5 years, ( $SD = 1.08$ ), the evidence found in earlier chapters put the national average age of SCI as 42 years at time of injury (WHO, 2013). The mean length of time since injury was 14.5 years ( $SD = 17.06$ ), 99 had been injured between 0 – 5 years (37%), 47 between 6 – 10 years (17%), 30 between 11 – 15 years (11%), 17 between 16 – 20 years (6%), 26 between 21 – 25 years (10%), 14 between 26 – 30 years (5%), 15 between 31 – 35 years (6%) and 19 had been injured 36 – 60 years (7%).

Thirty-five participants were complete tetraplegics, 102 were complete paraplegics (38%), 70 were incomplete tetraplegics (26%) and 59 were incomplete paraplegics (22%). There were 136 males (51%) and 133 females (49%) who filled out this questionnaire, in the UK of all new breaks yearly 80% are male and 20% are female (Spinal Research, 2015). Participants from 12 countries filled out the questionnaire of those 119 were from the United States of America (44%) and 133 were from the United Kingdom (49%), 18 participants were split between 10 other countries (7%); of the 12 countries 180 lived in urban areas (67%) 89 lived in non-urban areas (33%). Of the participants, 86 were single (32%), 95 were married (35%), 41 were divorced (15%), 10 were separated (4%), 7 were widowed (3%), 30 were living with a partner (11%) and one person chose not to answer; 130 participants (48%) had children and 139 did not (51%). Asked how many children they had, 38 people had one child (14%), 60 had two children (22%), 16 had three children (6%). Seven participants had 4 children (3%) and one person had 5 children. Out of 263 participants who answered, 85 were in paid work (31%), 51 were in voluntary work (19%), 114 were not in paid or voluntary work (42%) and

13 were in voluntary and paid work (5%), this is consistent with the previous literature which found that 37% of people with SCI were found to be in paid employment as a total of 36% who filled out this questionnaire are in paid work.

#### **4.3.2 Descriptive findings**

The following section includes the results of the descriptive questions which were designed based on previous literature and the findings from the interviews with several participants who had SCI which were reported in Chapter 3.

##### **4.3.2.1 Spinal Cord Injury Support Questions**

Two hundred and thirty-three respondents (86%) felt that they were isolated when they first had SCI, 253 participants (96%) had suffered from a secondary health impairment which included bladder dysfunction, bowel dysfunction, pressure sores, pain and sexual dysfunction etc. One hundred and forty-three participants (53%) had symptoms ‘all the time’ and only 4 (2%) had ‘never’ had one symptom of secondary health impairments.

One hundred and fifty-one participants (56%) who filled out the questionnaire had help from friends and family at home which ranged from ‘quite often’ to ‘all the time’. During the interviews it was found that participants who had a high-level injury were more dependent of friends and family for help. Sixty-five respondents (24%) had visits or help from health care professionals which they reported as ranging from ‘quite often’ to ‘all of the time’.

It was found that 126 people (47%) were unable to talk to friends or family about health care issues, participants were asked ‘Do you discuss health care issues with a professional, such as

a doctor, nurse, social worker etc.?’ 203 reported ‘sometimes’ to ‘never’ (76%). One hundred and sixty-five participants (61%) were not that comfortable speaking to someone who does not have SCI about SCI health care issues. Participants were asked ‘I feel desperate and frustrated at the lack of professional support I receive’? 149 ‘partially’ to ‘totally agreed’ with that statement (45%).

It was found that 209 people (77%) suffering with SCI ‘partially’ to ‘totally agreed’ that they found it difficult to adapt to the changes that their bodies went through after SCI with regards to their bladder and bowel dysfunction, sexual dysfunction, pressure sores, pain and spasms.

Two hundred and eight people (77%) ‘totally agreed’ to ‘partially agreed’ they had difficulty coping physically after SCI and 186 people (69%) ‘totally agreed’ to ‘partially agreed’ they had difficulty coping psychologically after SCI. One hundred and fifty participants (56%) found that they became dependant on a partner or caregiver for support after injury.

#### **4.3.2.2 Peer Support Questions**

When asked if people who took part in this study would like to go to a peer support group whilst in a hospital recovering from their initial SCI, 194 people (72%) ‘totally agreed’ to ‘partially agreed’ they would and 17% were ‘unsure’.

One hundred and eighty-eight participants (66%) ‘totally’ to ‘partially agreed’ that they felt health care professionals could not relate to them and 25 were ‘unsure’ (9%). It was also found that 156 participants (58%) ‘totally’ to ‘partially agreed’ that their friends and family could not relate to them with 14 people (5%) ‘unsure’. The evidence from the qualitative chapter showed that when interviewing participants only 1 participant (14%) thought that health care professionals could not relate to them, but 5 participants (71%) felt that their

friends and family could not relate to them. When asking if participants thought other people with SCI could relate to them, 233 'totally' to 'partially agreed' (86%). During the qualitative interview stage, all 7 participants (100%) reported feeling excited at the prospect of going to a peer support group because they thought that people with SCI were the only ones that could relate with them.

When asked if participants would like to have gone to a peer support group upon leaving hospital 34 'totally' to 'partially agreed' with this statement (13%), and 40 were 'not sure' (15%). When participants were asked if they would like to go to a peer support group now 61 'totally' to 'partially agreed' that they would (23%) with 34 people (13%) being 'unsure'. All participants that were interviewed during the qualitative interviews said they would like to go to a peer support group now.

Participants were asked if there were any issues that might make it difficult for them to attend a peer support group. It was found that 164 people (62%) would find the location a difficulty, in the qualitative chapter this was based on level of injury and not being able to drive or catch public transport and also relying on friends, family and caregiver to take them. One hundred and forty-two participants (53%) would find difficulty finding time to go, but in the qualitative chapter this was because of people's daily routines (personal health care), work commitment and based on the time of day. Embarrassment was the least likely reason for someone with SCI not going to a peer support group with only 47 'totally' to 'partially agreed' this would be the reason for not attending (18%).

Fifty-six people (21%) said that there were other factors that would prevent them from attending a peer support group, whilst 42 people (16%) said 'maybe', participants were able to give a written description. Explanations provided by respondents as to why they felt they



could not attend a peer support group are included in table 1 below. There is a summary of all 85 statements to give a representative view of the factors preventing people from attending a peer support group:

As can be seen, by the summary of statements, health issues, distance, transport, access and people not being able to locate a peer support group for a person with SCI were the main reasons preventing people attending one (Table 4 below).

**Table 4** Summary of statements

Number of People	Are there any other factors preventing you from attending a peer support group?
18 (7%)	Distance, transport and access
16 (6%)	Health issues, depression, bowel, bladder dysfunction and pain prevent me from leaving the house.
13 (5%)	Peer support groups do not exist in my area
6 (2%)	Unsure how I might benefit or help others
5 (2%)	No time with the current schedule
5 (2%)	Been spinal cord injured for too many years and sees no point in a peer support group
3 (1%)	Independent and seeks out advice on their own
3 (1%)	Nervousness, embarrassment
2 (1%)	Already has disabled people in their life to share knowledge and experience with.
2 (1%)	Being in a protentional negative environment wants to know how people manage specific tasks but does not want to know how others are not coping.
2 (1%)	No one else has SCI in their area
1 (.4%)	Lack of available funds
1 (.4%)	Childcare
1 (.4%)	Doesn't want whole life revolving around appointments, therapy and doctors' visits
1 (.4%)	Sexuality finds hard to relate to others
1 (.4%)	Uses online sites for help
1 (.4%)	Prefers not to be an inspiration and feels overwhelmed by needing to support others
1 (.4%)	Would go but wouldn't if there were people without SCI there as could not discuss personal issues
1 (.4%)	Not their preferred method for receiving support
1 (.4%)	High functioning believes peer support groups are centred around more physically disabled clients

When asked if people would like to attend a peer support group with a defined topic of discussion 163 ‘definitely’ to ‘most probably agreed’ they would (61%) with 68 respondents ‘unsure’ (17%). One hundred and ninety-two participants (71%) in this study ‘definitely’ to ‘most probably agreed’ that it would be helpful to discuss health issues with other people with SCI at a peer support group, the qualitative data supported this as reported in chapter 3. Two hundred and twenty-nine people (85%) ‘definitely’ to ‘most probably agreed’ that they would be happy to give advice on issues relating to SCI to other people with SCI, with 22 people (8%) ‘not sure’ if they would.

Participants were asked if a family member (family, friend, partner and carer) would be happy to attend SCI peer support group with them and 143 people (53%) said ‘definitely’ to ‘most probably’ they would with 53 people (20%) ‘not sure’. Participants were then asked if a friend would be happy to attend SCI peer support group and 99 participants (37%) said ‘definitely’ to ‘most probably’ with 89 people (33%) ‘unsure’, this is most likely due to them needing to ask their friends in order to answer the question properly. When asked if there was anyone participants would like to attend a peer support group with (they could write who) the highest number of people put partner or family member with the third highest number of people saying they would like to come alone (Table 5 below). In the qualitative chapter when asked the same questions, all participants were happy to bring someone and most thought it would be great to bring their partner or family member, it depended on whom they were living with.

**Table 5** Summary of statements

Number of People	Is there anyone you would like to go to a peer support group with i.e. family, friend, partner and carer?
49 (18%)	Partner, wife, husband, boyfriend, girlfriend
43 (16%)	Family members, dad, mother, sister, brother, children, in-laws
34 (13%)	Come alone
8 (3%)	Would bring anyone they could
7 (3%)	Carer
5 (2%)	Friends
1 (.4%)	Thought it was not appropriate to have anyone who wasn't spinal cord injured at a group

In response to the questions about how often participants would like to attend a peer support group, 121 agreed they would 'definitely' to 'most probably' like to attend one once a week (45%) with 66 'not sure' (25%), 143 would be happy to go once fortnightly (53%) with 64 'not sure' (24%) and 216 people (80%) saying they would attend once monthly with 29 'not sure' (11%). It would seem from the evidence in this study that people could find the time to go once monthly but would struggle with weekly or fortnightly. It was found when interviewing people for the qualitative chapter, participants were happier with the idea of going fortnightly to weekly, this was because they were not sure if they could find the time with their daily schedules to go weekly.

When asked if a peer support group would help people with SCI to build confidence in social situation 223 participants (83%) said it would 'definitely' to 'most probably' with 28 saying they were 'not sure' (10%). Participants were then asked if going to a peer support group could help people who fear they are stigmatised because of their SCI to overcome that fear and 216 'definitely' to 'most probably agreed' that it would (80%) with 36 'not sure' (13%). Two hundred and forty-three participants (90%) 'definitely' to 'most probably agreed' that it

would be good for people with SCI to join groups that included other people with SCI sometimes with 19 participants (7%) saying they were not sure.

#### **4.3.3 Results and Tables using the Brief COPE measure**

A multiple linear regression was conducted to see which coping strategies predict how well participants coped both physically and psychologically since becoming spinal cord injured. Participants were asked if they ‘had difficulty coping physically after SCI’ and whether they ‘had difficulty coping psychologically after SCI’ (these were used as the dependent variables). The analysis then identified which of the 14 subcomponents (coping strategies) of the Brief-COPE participants used (predictor variables) to effectively help them cope after becoming spinal cord injured both physically and psychologically. The results of the analysis will help inform the design of the peer support group.

A preliminary analysis was performed to ensure there was no violation of the assumption of normality, linearity and multicollinearity. The model did significantly predict variance in factors which predicted participants having difficulty coping physically after SCI  $F(14, 217) = 4.39, p < .001$ , 17% of the variance was explained by the predictor variables (adjusted  $R^2$  of .170). Of the 14 sub-components of the Brief-COPE measure, ‘self-distraction’ ‘planning’ and ‘acceptance’ were statistically significant as can be seen in (Figure 5) below.

A further multiple regression was carried out to see what coping strategies predicted whether participants had difficulty coping psychologically after SCI. The second regression analysis was also conducted using the 14 sub-components of the Brief-COPE measure. A preliminary analysis was performed to ensure there was no violation of the assumption of normality, linearity and multicollinearity. As with the first analysis the model did significantly predict

variance in participants' difficulty coping psychologically after SCI  $F(14, 217) = 7.92, p < .001$ , the results found that 30% of the variance was explained by the predictor variables (adjusted  $R^2$  of .295). Of the 14 sub-components, five were statistically significant 'self-distraction', 'active coping', 'behavioural disengagement', 'venting' and 'acceptance'. These can be seen in (Figure 6) below.

**Table 6**

Means, Standard Deviations, and Intercorrelations for DV1, DV2 and Predictor Variables (N = 232)

Variable	M	SD	S-D	AC	D	SU	ES	IS	BD	V	PR	P	H	A	R	S-B
Coping Physically	5.25	1.75	<b>.27**</b>	-.07	<b>.20**</b>	<b>.16*</b>	<b>.14*</b>	.13	<b>.25**</b>	<b>.26**</b>	-.00	<b>.17*</b>	.02	<b>-.23**</b>	.03	<b>.29**</b>
Coping Psychologically	5.03	1.93	<b>.24**</b>	<b>-.20**</b>	<b>.30**</b>	<b>.26**</b>	<b>.16*</b>	.08	<b>.39**</b>	<b>.38**</b>	-.10	<b>.01*</b>	-.08	<b>-.32**</b>	-.03	<b>.35**</b>
Self-distraction	5.41	1.81		<b>.21**</b>	-.02	.09	<b>-.21**</b>	<b>.17*</b>	.04	<b>.22**</b>	<b>.28**</b>	<b>.25**</b>	<b>.25**</b>	<b>.16*</b>	<b>.14*</b>	<b>.14*</b>
Active coping	5.69	1.80			<b>-.17**</b>	-.13	<b>.20**</b>	<b>.33**</b>	<b>-.33**</b>	-.08	<b>.42**</b>	<b>.49**</b>	.05	<b>.33**</b>	<b>.18**</b>	<b>-.22**</b>
Denial	2.71	1.28				<b>.17*</b>	.01	.02	<b>.52**</b>	<b>.22**</b>	<b>-.17**</b>	-.03	-.09	<b>-.52**</b>	-.11	<b>.42**</b>
Substance use	2.86	1.60					.07	-.06	<b>.28**</b>	<b>.27**</b>	-.09	-.05	.01	<b>-.13*</b>	-.01	<b>.29**</b>
Emotional support	4.49	1.74						<b>.52**</b>	-.10	<b>.26**</b>	<b>.31**</b>	<b>.28**</b>	.01	<b>.15*</b>	<b>.20**</b>	.03
Instrumental support	4.19	1.51							-.08	<b>.28**</b>	<b>.29**</b>	<b>.40**</b>	.03	<b>.19**</b>	<b>.14*</b>	.09
Behavioural Disengagement	3.07	1.59								<b>.35**</b>	<b>-.25**</b>	-.10	-.02	<b>-.47**</b>	<b>-.19**</b>	<b>.50**</b>
Venting	3.75	1.46									-.05	.06	.03	<b>-.21**</b>	-.00	<b>.40**</b>
Positive reframing	4.99	1.87										<b>.43**</b>	<b>.20**</b>	<b>.35**</b>	<b>.41**</b>	<b>-.15*</b>
Planning	5.28	1.85											<b>.15*</b>	<b>.20**</b>	.11	.06
Humour	5.11	1.93												<b>.20**</b>	-.01	.12
Acceptance	6.98	1.38													<b>.24**</b>	<b>-.33**</b>
Religion	3.66	2.13														-.05
Self-blame	4.04	1.79														

Note. \*\*p < .01, \*p < .05    **Coping physically** - I had difficulty coping physically after spinal cord injury    **Coping psychologically** - I had difficulty coping psychologically after spinal cord injury  
**Coping strategies** - The higher the score the more people used that coping strategy

**Figure 5 ‘I had difficulty coping physically after spinal cord injury’**

**Model**

Self-distraction	Standardised $\beta = .24^{***}$	<div><math>R^2 (.17)</math><div>I had difficulty coping physically after spinal cord injury</div></div>
Active coping	Standardised $\beta = -.12$	
Denial	Standardised $\beta = -.00$	
Substance use	Standardised $\beta = .05$	
Emotional support	Standardised $\beta = .05$	
Instrumental support	Standardised $\beta = .06$	
Behavioural disengagement	Standardised $\beta = .06$	
Venting	Standardised $\beta = .05$	
Positive reframing	Standardised $\beta = -.05$	
Planning	Standardised $\beta = .18^*$	
Humour	Standardised $\beta = -.02$	
Acceptance	Standardised $\beta = -.20^{**}$	
Religion	Standardised $\beta = .06$	
Self-blame	Standardised $\beta = .07$	
Note. ***p < .001, **p < .01, *p < .05		



**Figure 6 ‘I had difficulty coping psychologically after spinal cord injury’**

**Model**

Self-distraction	Standardised $\beta = .24^{***}$	<div><math>R^2 (.30)</math><div>I had difficulty coping psychologically after spinal cord injury</div></div>
Active coping	Standardised $\beta = -.14^*$	
Denial	Standardised $\beta = .04$	
Substance use	Standardised $\beta = .09$	
Emotional support	Standardised $\beta = .12$	
Instrumental support	Standardised $\beta = .02$	
Behavioural disengagement	Standardised $\beta = .15^*$	
Venting	Standardised $\beta = .14^*$	
Positive reframing	Standardised $\beta = -.03$	
Planning	Standardised $\beta = .05$	
Humour	Standardised $\beta = -.11$	
Acceptance	Standardised $\beta = -.16^*$	
Religion	Standardised $\beta = .01$	
Self-blame	Standardised $\beta = .06$	
Note. ***p < .001, *p < .05		

## **4.4 Summary of all findings**

### **4.4.1 Summary of descriptive findings**

Two hundred and seventy participants filled out the questionnaires from 12 countries with the highest amount coming from the UK and the USA. The mean age at the time of injury was lower than that of the national average and the response rate was almost an even split between men and women, even though men account for 80% of all SCIs. More paraplegics than tetraplegics filled out the questionnaires and more people in this study were or had been in relationships than had been single. There was almost an even split between the number of people that had children and didn't have children. The evidence was consistent with the literature review and systematic review on the proportion of people who were in paid employment.

The descriptive findings produced good informative information to help in the design of the intervention. The highest majority of participants had felt they were isolated when they first became injured. The biggest issue for people with SCI is secondary health impairments and out of 270 participants only 4 had never had one. It was found that half of nearly all participants received help from someone whether it was friends, family or a health care professional. Nearly half of all participants found they could not talk to friends and family about health care issues, nearly double that number of participants had problems talking to a health care professional, however, 165 people felt they could discuss issues with a person who already had SCI. These findings support the idea of an intervention.

Seventy seven percent of participants were finding it hard to adapt to life with SCI due to health changes i.e. bladder and bowel dysfunction, sexual dysfunction, pressure sores, pain

and spasms. Nearly three-quarters of all participants were having difficulty coping physically and psychologically. When comparing the number of people who would only feel comfortable discussing issues with another person with SCI and the number of people frustrated with the lack of professional help they receive, the evidence would suggest there is a clear need for peer support groups.

Seventy two percent of people who filled out this questionnaire said they would like to go to a peer support group whilst in hospital. Only 13% of people said they would have liked to go to a peer support group upon leaving the hospital and 23% of people said they would like to go to one now. This does not reflect the same as what the participants within the qualitative study had said as 100% of them said they would go to a peer support group now.

Over half of all participants who took part in the study felt that friend's family and health care professionals could not relate to them, however, 86% of people felt that other people with SCI could relate to them which is consistent with the qualitative interviews.

When designing the intervention location will be a factor as 61% of participants said they would have difficulty with this. It was also found that 56% of participants would find it hard to find time to go to one this could be due to people schedules and health issues. To get a clearer picture of people's reason that would prevent them from attending a peer support group, participants were asked to write their reasons down, the main reasons identified were distance, transport, access, health issues (secondary health impairments) and peer support groups not existing.

From the information provided the main body of participants would like a defined topic at a peer support group, over three-quarters of those who filled out the questionnaire would like to discuss health issues. Nearly all the participants said they would like to share their own knowledge and experiences (advice) with other people who have SCI at a peer support group. Over half of all participants would like to bring someone with them to a peer support group and when asked to write down who that person would be (Table 5) the largest number of participants wanted to bring a partner or family member.

Although half of the participants would like to attend a peer support group weekly or fortnightly nearly all participants said they would prefer once a month. Out of 268 people who filled out the question 'would attending a peer support group build confidence' 83% of people said it would, 81% of participants said people would overcome stigmatisation by being a part of a peer support group. Finally, 91% out of 268 people said that people with SCI should join a peer support group with only 1% of people saying they shouldn't.

#### **4.4.2 Summary of Brief COPE measure results**

The results of the Brief-COPE found that self-distraction (doing things to take one's mind off the stressor), planning (thinking about dealing with the problem) were positively correlated with participants having difficulty coping physically and acceptance (learning to accept the problem) had a negative correlation with participants having fewer issues coping physically after becoming spinal cord injured. This means that amongst the sample included in this study higher levels of self-distraction and planning were associated with greater difficulty coping physically, and higher levels of acceptance were associated with lower levels of difficulty in coping.

It was also found when measuring how well people cope psychologically that five of the 14 sub-components for the Brief-COPE were significant, self-distraction (doing things to take one's mind off the stressor), behavioural disengagement (giving up dealing with the problem), venting (wanting to express feelings) were positively correlated leading to participants having poorer psychological coping and active coping (taking steps to eliminate the problem), and acceptance (learning to accept the problem) were negatively correlated meaning participants had fewer psychological issues if they used these coping strategies after becoming SCI.

As mentioned in the descriptive summary a large number of participants who took part in this study had difficulty adapting to life with SCI the findings of the quantitative study suggest that participants who used positive coping strategies such as acceptance and active coping had fewer physical and psychological issues. These findings correlate with those in the literature review that participants who use both acceptance and active coping as positive coping strategies adjust better to SCI (Kennedy et al. 2000; Pollard and Kennedy, 2007; Kennedy, Kilvert and Hasson, 2016).

#### **4.5 Conclusion**

The study has shown evidence that secondary health impairments impact on a person living with SCI as was found in earlier chapters within the thesis. People with SCI find it difficult to talk to anyone who does not have SCI about issues affecting them i.e. secondary health impairments as they feel they cannot relate (empathise). Participants would prefer to go to a peer support group whilst rehabilitating in hospital, this could be due to half of the participants saying they would find it hard with travel, location, access and health issues to go

to one after leaving hospital. However, nearly all participants said that people with SCI should go to a peer support group and that it would build confidence and lower feelings of stigmatisation. It was suggested that a group should be held once monthly.

The quantitative results in the current study suggest that people who used positive coping strategies (acceptance and active coping) rather than maladaptive coping strategies had fewer physical and psychological issues after becoming spinal cord injured. Kennedy et al. (2000); Pollard and Kennedy (2007) and Kennedy, Kilvert and Hasson (2016) found that the most common coping strategies during a 21 year longitudinal study were acceptance, active coping and planning using the COPE measure. However, in this study planning was correlated with participants having more problems coping physically after SCI which is not supported by past research Kennedy et al. (2000); Pollard and Kennedy (2007) and Kennedy, Kilvert and Hasson (2016). A conclusion that can be drawn from this finding is that the majority of participants who took part in this study did not know what steps to take and how best to handle the problem when coping physically after becoming spinal cord injured.

The results of this study along with the evidence found in previous chapters will be used to inform the design and evaluation of the intervention which are reported chapters 5 and 6.

# **Design and methodology of an intervention to improve quality of life in people with a spinal cord injury**

## **Chapter 5**

### **5.1 Introduction**

A peer support group provides an environment where people can come to express themselves safely without judgement of one's current situation. It is a place where they can build a support network, gain friends with shared experiences in turn reducing feeling of loneliness and isolation (WHO, 2017).

Mental health specialists describe peer support as a system of giving and receiving help founded on key principles of respect, shared responsibility and mutual agreement of what is helpful (Mead et al, 2001). Peer support groups are for people affected by similar issues whether that be mental or physical. People who have lived experience of similar issues are in a unique position to help others by listening empathetically and sharing knowledge and experience to help explore solutions to overcome shared challenges (Sherman et al. 2004). They also offer encouragement and support to each other even outside of the group by mentoring one another in times of difficulty (WHO, 2017).

Kelly (2007) found that peer support was an important part of rehabilitation for people with a new spinal cord injury (SCI), it was found that peer support is as important post rehabilitation because people find themselves at home without the support they received in hospital (Carpenter, 1994). Individuals who have sustained SCI find themselves wanting to help

others who have found themselves in the same predicament by sharing their own knowledge and experiences (Weitzner et al. 2011). A good example of this is the internet, especially social media with sites on Facebook e.g. spinal cord owners club, spinal cord peer support USA, spinal cord survivors', which are all groups where people share information, experiences and knowledge with each other.

There is little research in the area of SCI and peer support groups with Kennedy, Lude and Taylor (2006) suggesting there is an unmet need for peer recreation and peer support groups. However, what research there is has been focused on a therapeutic approach i.e. cognitive behaviour therapy (CBT) and coping effectiveness training (CET). CBT is a psychosocial intervention that focuses on the development of personal coping strategies that target solving current problems and changing unhelpful patterns in cognition and was first designed to treat depression (Hollon and Beck, 1994). CET was developed by Folkman et al. (1991) and was used as an intervention to help people improve their coping skills, it was based on Lazarus and Folkman's (1984) cognitive theory of stress. CET was further modified by King and Kennedy (1999) to be used in rehabilitation centres for people suffering with SCI.

A study that was conducted in the UK by Haas, Price and Freeman (2013) did show support for the role of peer support for people with SCI. The study involved interviews with 14 participants, including those with SCI, their family members and carers and found that the support from peer support officers was highly regarded due to the experience, knowledge and empathy they were able to offer, largely attributable to being a person with SCI themselves. There is very little published research evaluating group interventions with individuals who have SCI.



## **5.2 Aims and objectives of the research reported in this chapter**

The aim of this research reported in this chapter was to develop an intervention (peer support group) that would improve quality of life (QoL) in people with SCI (aim 4). This was informed by using existing literature, and the results of the interview and questionnaire studies reported in earlier chapters of this thesis in order to design an evidence and theory-based intervention (objective 4). The evaluation of the intervention will be reported in the next chapter (chapter 6).

## **5.3 Coping with SCI**

Many studies have looked at how people adapt to and cope with becoming spinal cord injured. Folkman and Lazarus (1988) researched the cognitive theory of stress and coping and devised a theory of how people cope with stressful events. According to this theory, the individual first appraises the stressful event to see if there is a threat to their well-being and the level of threat will define what coping strategies will be used (Kennedy et al. 2000, Kennedy et al, 2003 and Anderson et al. 2008; Kennedy, Kilvert and Hasson, 2016 ).

Kennedy et al. (2000) found that time since injury impacted on how a person with SCI appraised their situation and which coping strategies they adopted. Schulz et al. (1985) conducted a study including 71 patients, of whom 41 were 6 weeks post-injury and 30 were between 4- and 7-years post injury. The study found that time since injury had more impact on coping strategies than age, level of injury or social support. The findings suggest an association between higher levels of stress and coping strategies, which were predominantly

behaviour disengagements and the lack of acceptance (Kennedy et al. 2000, p.159). These findings are in line with those of the literature review.

Using a group intervention with 28 participants with SCI, Craig et al. (1998) researched how effective CBT would be in helping people who had depression, low self-esteem, issues with sexuality, problems with family relations and anxiety. They wanted to see if cognitive and behaviour skills would help individuals with SCI overcome issues that may arise when entering back into their communities. The findings showed that there were no significant differences in depression and anxiety between year 1 and year 2 follow up assessments. However, they did find that if they split the groups at baseline for those reporting elevated depression symptoms, the treatment group did do better than the control group and that CBT did in fact relieve symptoms of anxiety and depression which was the main focus of the study by giving participants the necessary skills to cope (Craig et al. 1998).

Kennedy et al. (2003) conducted a brief group-based intervention at a rehabilitation unit in the UK. They included a total of 45 participants who were all newly injured with a traumatic SCI and 40 matched controls. They asked all participants to fill out measures for anxiety, depression, self-perception and coping which were collected immediately after the intervention and at the 6 weeks follow up. Only the intervention group filled out the self-perception measure. They found that CET significantly improved psychological adjustment in a person with SCI, by changing the way participants appraised their SCI so that they were less negative, there was also a significant reduction in anxiety and depression. However, there was no significant change in coping strategies between the intervention and control groups. Participants that took part in the study reported enjoying talking about shared experience and

issues that they were having with their newly found situation with each other (Kennedy et al. 2003).

#### **5.4 Behaviour change**

After reviewing the literature on behaviour change, the evidence shows that interventions are more effective when based on theory and evidence (Brug, Oenema and Ferreira, 2005). There should be a systematic development when designing an intervention i.e. tailoring content and format to the target groups and settings (Bokhoven, Kok and van der Weijden, 2003) to give it the highest chance of success but despite this, it is common place for interventions to be designed without a systematic method and not have a theoretical basis and still be successful (Michie et al. 2014). Michie et al. (2011) conducted a systematic review and found over 93 behaviour change theories from the findings of the review the author developed 19 pre-existing frameworks into a single interface within the behaviour change wheel (BCW) COM-B system (see chapter 1, Fig.1). Michie et al. (2011) suggests that because there are many behaviour change theories it is necessary to have guidelines on how to develop a behaviour change intervention using the BCW. Michie et al. (2011) argued that this was because although there were examples of successful interventions there were many other examples of interventions that did not work. Thus, it is important to develop the science and technology of behaviour change to improve the design of interventions (Michie et al. 2011).

Based on findings by Michie et al. (2011), it was decided that the intervention should use a technique similar to the COM-B education, training and enablement frameworks as described in Michie et al. (2011) study to help participants learn to deal with aspects of their SCI

through new knowledge, skills, social influences, optimism and goals. The peer support group designed for the intervention reported here was influenced and designed with Michie et al.'s (2011) education, training and enablement frameworks in mind, but the development of the intervention also took into consideration other research in the area of peer support and how those interventions were designed.

### **5.5 Previous peer support groups**

Christianson (1985) designed a peer support group for infertile couples so that they could share their feelings and concerns in a non-judgemental setting with total confidentiality, rather than coping alone. The method used to design the intervention initially involved a nurse contacting hospitals', GP surgeries and clinics; the next step was to use a snowball technique to recruit more participants and then media outlets i.e. radio and newspapers and finally mailing people. The initial meeting for Christianson (1985) intervention was flexible i.e. no structure, the facilitator gave a brief introduction about them self and what the group was about. Further groups were planned/structured so that a guest speaker would attend each session, the participants were encouraged to either listen or join in the discussion.

Christianson (1985) stated that a speaker was a good drawing card for the initial meetings because they had set topics to speak about. After each guest speaker they would have a question and answer session which was said to stimulate group conversation. The evaluation of the outcome of the intervention showed that as couples broke through their isolation, confronted their feelings about infertility and learned new coping skills, their emotional well-being improved, and they regained control in all aspects of their lives (Christianson, 1985).

Due to the success of the initial group sessions and the positive outcomes, Christianson (1985) conducted further group sessions but this time included small informal groups with discussion led by a guest speaker, then educational presentations followed by a group discussion and testimonials from past participants. The participants of the new group were given a choice whether to have a large group informational meeting monthly or every other month with no restrictions on how many people could attend each session, alternatively they could participate in a smaller group of 8 to 10 participants that would take place once a week for 8 to 10 weeks. No further information was given on which method of meeting participants chose.

Morris and Morris (2012) designed an intervention for stroke patients, their carers and volunteer supporters during their hospital rehabilitation. They included participants (stroke patients) who were currently in hospital receiving treatment and their carers for the group sessions. Seven former patients and three carer peer supporters attended the group sessions. To participate in the study all recipients and peer supporters must have attended at least two group sessions.

There were five sessions in each phase with a training session for the peer supporters before the first session, sessions were held bi-weekly and lasted for 1 hour 30 minutes, session topic were decided by the recipients at each session and some topics re-occurred. Sessions followed a planned format, firstly there was an introduction, then all participants had a group discussion followed by refreshments, they then broke up into smaller groups and had a discussion (separate patient and carer groups), then all participants came back together for another group discussion. Due to hospital policy two staff members attended, one would

facilitate and the other would contribute to discussion and also be on hand to attend to any patient care needs if they arose.

A qualitative analysis was used to evaluate the intervention. The findings suggest that participation in the group was beneficial, the main themes that emerged were that participants could share their own experiences and express emotions in a secure environment. There was also evidence that by participating in the groups self-efficacy was improved and people developed self-esteem by helping others (Morris and Morris, 2012).

### **5.5.1 Summary of previous SCI groups**

Previous interventions designed for people with SCI were analysed to identify key ingredients for the current intervention design. As there are very few studies evaluating interventions for people with SCI, peer support groups for people with other issues were explored for ideas based on the evidence they had gathered.

Studies by Craig et al (1998) and Kennedy et al. (2003) explored how people with SCI cope. Both studies developed peer groups including participants with SCI and although the groups were therapy based the outcomes show evidence that peer support groups can work as participants expressed that they had enjoyed sharing knowledge and experience with their peers and had learnt relevant coping skills to deal with SCI.

Bokhoven, Kok and van der Weijden (2003) stated that when designing an intervention, it should have tailored content and be formatted to the target audience and settings which is how the intervention in this chapter was designed. The content and structure were tailored to

meet the needs of the participants based on the results and evidence from previous chapters and the participant panel.

Christianson (1985) used a similar structure when designing their peer support group as the present intervention, it followed a set format with a facilitator, guest speakers, they encourage participants to listen or join in group discussion, they also suggesting having a question and answer session after each guest speaker, which is how the present peer group was designed. Although when developing the present intervention there were regular refreshment breaks at which point participants could speak with each other one on one. This followed the same format as Morris and Morris (2012) who also had regular refreshment breaks, their sessions were of a similar timing, they had set topics, however, their guest speakers were former patients and carers.

Morris and Morris (2012) had 10 participants due to past patients and carers attending the groups but Christianson (1985) included 8 to 10 participants and the sessions took place once a week over a period of between 8 and 10 weeks. Both of these interventions were successful in that Christianson's (1985) participants learnt new coping skills, their emotional well-being improved, and they regained control in all aspects of their lives. Morris and Morris (2012) found that participants enjoyed sharing knowledge, experience and emotions in a secure environment and that by doing this their self-efficacy improved they and developed self-esteem by helping others.

The participants Christianson (1985); Morris and Morris (2012) groups were not that dissimilar to the participants in the current peer support group. However, Christianson (1985)

study was about infertile couples, whereas Morris and Morris (2012) participants were stroke patients whose needs were more in line with the current peer support group. The participants in these groups were struggling and needed an opportunity to share their feelings, concerns and looked to people who had been through the same situation as themselves for help with knowledge and their experiences.

The study by Christianson (1985) is an older study that discussed in depth how to design a peer support group and what it should contain but it lacked any kind of methodological analysis or findings. However, Morris and Morris (2012) study was detailed and used the same methodology as the current study, which was a qualitative (thematic analysis) to analyse the interviews. Their findings by Morris and Morris (2012) were positive participants felt accepted, communication was important, structure and topics of each session was an important factor. A concern for the group was it being too large any more than 5 or 6 participants made them feel anxious. The greatest valuable source of support was group member with similarities to one another. A negative finding was that participants did feel inhibited due to the facilitators being staff members (nurses) rather than their peers and the study by Christianson (1985) also suggested using a staff member (nurse). Both studies did summarise by suggesting that peer support groups provided a forum in which participants could share feelings, express their emotions, concerns in a secure environment. The participants who attended peer support groups could learn new coping skills by sharing knowledge and experiences, thus improving self-efficacy and self-esteem and improving emotional well-being.



The design and findings of these two earlier studies was used to inform the design of the current intervention by using a similar session structure, number of participants and amount of weekly sessions, including session timings. The aim of the current intervention was to help participants cope with their SCI and to improve their health and QoL by sharing knowledge and experience, which both Christianson (1985) and Morris and Morris (2012) successfully did.

### **5.6 Current peer support group design**

The design of this intervention was informed by the previous stages of the research within the thesis along with evidence from the design and structure of past groups that were described earlier in this chapter. Van Bokhoven et al. (2003) states that the development of an intervention needs to be systematic and have tailored content directed at the target group, which this intervention did. The detailed design of the current intervention can be seen in section (5.7 Intervention procedure) below and how it was influenced by the studies in this section.

The structure of the present intervention followed both Christianson (1985) and Morris and Morris (2012), they were very different studies in that one was for infertile couples and the other was for stroke patients, however, they followed a similar format. The design of the current intervention used between 8 and 10 participants which is considered an ideal number for a peer support group (Hildingh et al. 1993; Wilson, Flanagan and Rynder's, 1999).

Participants were recruited using a snowball technique, a facilitator was used at each session, also a guest speaker was invited to each session, there was 1 session a week for 8 weeks, this followed the same structure as Christianson (1985).

Morris and Morris (2012) peer support group format was slightly different from that of Christianson (1985) but the structure that was taken from their study to help inform the current intervention was that the current intervention used a separate topic each week which followed a set format, which included an introduction, refreshment breaks, group discussions and on certain sessions splitting the groups into small groups and then all coming back together for a larger group discussion, sessions lasted 2 hours.

Using both of the above peer support groups helped to design and structure the current intervention by using a mix of both. Firstly, as with both of the peer support groups above a facilitator was used, although the facilitator in the current peer support group was a person with SCI, which allowed participants to be more open (5.7.9 Facilitator). There would be a welcome and refreshments at the very beginning so that people could mingle and talk before the guest speaker would introduce themselves and do a talk on the topic for that week, this was then followed by a further refreshment break allowing the participants to ask the guest speaker questions, who was then asked to leave. The group would then come back together for a discussion about what had been discussed within the session, this was then followed by a further refreshment break and a chance for participants to mingle further and talk about anything they wanted too. All sessions were set to last 2 hours as this gave time for 3 refreshment breaks and time for the guest speaker to talk and time for questions and a group discussion.

Neither of the aforementioned studies by Christianson (1985) and Morris and Morris (2012) mentioned ground rules, however after reading literature on how to create a peer support group in mental health and related areas, it was advised that peer support groups should follow a code of ethics and set out ground rules, which should be developed by the group members, which was done in session one of this peer support group (White, 2007; WHO, 2017). Setting out boundaries from the very beginning allows member to feel safe and give them peace of mind about what to expect from the group (WHO, 2017). The ground rules and boundaries are explained in (5.7.10 Structure of sessions, session 1) below.

Further to using Christianson (1985) and Morris and Morris (2012) studies to help inform the design of the current study, the BCW COM-B system was used. Using the BCW a framework was identified and used to help structure each session of the current intervention and to give the peer support group the best chance of succeeding. Michie et al. (2011) designed the BCW as a theory and evidenced based tool and at the centre is the behaviour system (the COM-B system). Following on from this, the design of the intervention developed as part of this thesis used education, training and enablement and these were used to increase capability, opportunity and motivation. Capability, psychological (knowledge, interpersonal skills, decision process and behavioural regulation), opportunity, social (social influences), motivation, reflective (social role and identity, beliefs about capabilities and optimism, goals). Although these methods are not guaranteed to be successful, they do give the intervention and in this case the peer support group a better chance of success (Michie et al. 2011).

Combining the structure Christianson (1985) and Morris and Morris (2012) interventions in conjunction with the BCW (COM-B model) the peer support group was designed to give participants the chance to meet with other people who had SCI, enabling them to share knowledge, experience and in turn develop skills to help improve their life as a wheelchair user. This was helped by the fact that each session had set topics i.e. occupational therapy, physiotherapy, how to manage secondary health impairments, mindfulness and disabled rights. These topics were chosen using the COM-B model and asking the panel of three if they agreed with the topics which they did. Each sessions topic was intended to motivate participants and help them improve or change things in their own lives positively, thus improving QoL.

Using these studies as guidance the following intervention was designed and implemented.

## **5.7 Intervention Procedure**

### **5.7.1 Participant panel**

At each stage during the development of the peer support group the participant panel were sent information to enable them to give their own input and guidance on the documentation and content of the peer support group i.e. participant information sheet, interview schedules, questionnaires, guest speakers and their topics, the structure of the sessions, how long breaks should be and how often, what day to meet and time, where to meet, hence they were a part of the whole design process.

### **5.7.2 Recruitment of participants**

The ideal number of participants to be used in a peer support group is said to be between 5 and 10 (Hildingh et al. 1993; Wilson, Flanagan and Rynder's, 1999), Christianson (1985) used between 8 and 10 in their intervention. Ideally this intervention needs to use the maximum number of participants in the intervention group for the greatest chance of success as suggested by Christianson (1985); Hildingh et al. (1993); Wilson, Flanagan and Rynder's, (1999) therefore 20 participants were recruited, 10 in the intervention group and 10 in the control group, although 23 participants were initially recruited to take part in the intervention just in case there were any people that dropped out before the start of the random allocation to each group.

Participants were selected based on inclusion criteria which included a diagnosis of spinal cord damage, their age (minimum 16 years), they could be male or female, level of injury (paraplegic or tetraplegic) and type of injury (injury or illness to the spinal cord). Participants were recruited via contacts who had SCI through word of mouth using a snowball technique and via social media i.e. SCI groups on Facebook. Participants who met the inclusion criteria were given a participant information sheet, so they were able to read about what the intervention entailed. If they agreed to take part, their names were included in the draw which randomly selected half of the participants for the intervention group and half for the control group. Participants who took part in the peer support group gave informed consent by turning up to the intervention. They were then given a booklet that explained how each session would be structured, from topic to a breakdown of timings.

### 5.7.3 Allocation

When participants were recruited to the peer support group for this intervention they were initially asked a few questions about themselves i.e. ‘what is your age’, ‘age at time of injury’, ‘level of completeness at time of injury’ and whether they were male or female, these were the same initial demographic questions that were used in the quantitative study. As the intervention is a random control trial (RCT) all participants were randomly allocated to each group, this was done by putting all participants names into a hat and having the facilitator draw the names out. At this point 3 participants withdrew from the process, the rest of the participants had to be categorised into groups of males, female and paraplegics and tetraplegics which formed the basis for the randomisation of the groups, hence the need for the initial demographic questions. The names of the female participants were randomly picked from the hat and alternately put into either the intervention or control group. As all the female participants were paraplegics no stratification on the basis of disability was required. Out of the fourteen males 6 were tetraplegics so their names were separated into a draw of their own and randomly allocated to each group, with the remainder of the males also being randomly allocated to either the intervention or the control group. By doing it this way it ensured there would be an equal number of males and females and also tetraplegics and paraplegics to each group thus lowering the possibility of group bias. The main purpose of random assignment is to prevent selection bias by distributing the characteristics of the participants that may influence the outcome randomly between the groups, so that any differences in the outcome can be explained by the intervention (Roberts, 1998).

Once allocated to the intervention group participants were either emailed or called and asked where they would like the group to be held, they were given a choice between Cardiff Metropolitan University (CMU) and some other facilities in the Cardiff area i.e. church hall,

public café, pub. The greatest number of participants asked for it to be at CMU and the participants who chose other destinations agreed upon CMU after speaking to them again. They were also given a choice of days, the highest percentage of participants chose a Thursday, they were then asked a time, there were some differences of opinions, but all agreed to 6pm after some discussion via calls and email. Due to time restraints of the completion of the PhD, the decision was made to hold the intervention on a weekly basis, rather than giving the participants the option to choose their preferred frequency for the sessions.

Table 7 is a list of the intervention participants with their names (changed for anonymity), age, level of injury, approximate length of time since injury and marital status. The order in which participants were recruited are in Table 7 and will not change throughout the rest of the study when discussing participants. A table containing information about the matched control group will be in the appendix (3G).

**Table 7** Demographic characteristics of intervention participants

<u>Participant</u> <u>Alias</u>	<u>Age</u>	<u>Level of spinal cord</u> <u>injury</u>	<u>Approximate length</u> <u>time of injury</u>	<u>Marital status</u>	<u>Traumatic and</u> <u>nontraumatic</u> <u>injury</u>
Simon	25	C5 Tetraplegic	5 years	Single	Traumatic
Jane	40	T6/7 Paraplegic	2 years	Separated	Nontraumatic
Mary	45	T8 Paraplegic	14 years	Married	Traumatic
Katie	26	T1 Paraplegic	6 years	Married	Nontraumatic
David	68	L1 Paraplegic	50 years	Divorced	Traumatic
Bob	64	C2 Tetraplegic	20 years	Married	Traumatic
Benny	28	T4 Paraplegic	14 years	Partner	Traumatic
Sean	53	T5 Paraplegic	30 years	Single	Traumatic
Jake	38	C5 Tetraplegic	19 years	Partner	Traumatic
Dick	42	T10 Paraplegic	15 years	Single	Traumatic

### 5.7.4 Location

The peer support group was held at CMU in the School of Management (SM) building, the reason the participants gave for wanting the peer support group to be conducted at the university was because it was easier for them to get to as it was central. It also had the benefit of being a neutral setting i.e. not a church or health care setting, and it was cost effective, easy parking, wheelchair access and disabled facilities for the research. The group was then held in a large room within the CSM building on the ground floor as access for wheelchair users was essential, there was a number of wheelchairs and in the event of a fire it was essential to ensure they would all be able to get out safely. The room was light, airy, at ambient temperature, there was little to no noise as it was after 6pm so the group would not be disturbed, the room itself was spacious and clean with an overhead projector and computer



for guest speakers who wanted to use slides or videos. Tables within the room were positioned around the side of the room allowing ample room for wheelchair users, the tables had food and drink laid out on them and the room was near the disabled toilets, making participants feel as comfortable as possible (WHO, 2017).

#### **5.7.5 Intervention timeline**

The intervention started on Thursday September 1<sup>st</sup> 2016 and continued on a weekly basis for 8 weeks and ended on the 22<sup>nd</sup> of October 2016. Each session started at 6pm and ended at 8pm although the majority of participants did not leave until at least 10pm.

When people arrived, they had the option to help themselves to refreshments and chat for 15 minutes, then a guest speaker spoke for 45 minutes, a further refreshment break took place for 20 minutes, which gave participants a chance to ask the guest speaker further questions and then a group discussion around the focus of the session took place for a further 30 minutes and then each session finished with further time for refreshments and a chance to mingle. A detailed structure of each session is in (5.7.10 Structure of sessions) below.

#### **5.7.6 Quantitative Measures**

The following measures were used in the design and development of the questionnaire to evaluate the intervention, as the aim of the intervention was to help participants cope with their SCI and to improve their health and QoL. The General Health Questionnaire (GHQ-12) was used to measure health, the Quality of Life Scale (QoLS) was used to measure QoL and the brief-COPE was used to see what coping strategies participants were using. A further

measure was developed to see how active and social participants were in their day to day lives, at week 8 and 24 more questions were added to the intervention groups questionnaire to see how participants felt about the intervention. Participants were identified by both their IP address and their email address. The details of these measures will be recorded in chapter 6 which focuses on the evaluation of the intervention.

### **5.7.7 Qualitative Interview Schedule**

Further to having participants from both groups fill out questionnaires online, two participants who participated in the peer support group were chosen at the end of the intervention to be interviewed to elicit their own views about the content and structure of the peer support group. Further details of the results of analysis can be found in chapter 6.

### **5.7.8 Intervention Wellness Ladder**

At the beginning of each session participants in the intervention group were asked to put a mark on a wellness ladder to show how they were feeling on that particular day. The ladder includes rating from 1 to 10 with 10 representing best outcome and 1 representing worst outcome. The back of each sheet was initialled by participants so that it was possible to tell who had marked each sheet. The results identified any changes in the participants' moods at the beginning of each session on a weekly basis.

### **5.7.9 Facilitator**

Each session was facilitated by a trained peer support officer of the Spinal Injuries Association (SIA). He was chosen as a facilitator as he himself has SCI, this gave him

legitimacy within the group as he has lived experience and empathy for the participants, and he has skills and knowledge as an experienced peer support officer. He was offered compensation for his time but declined as he felt it was a worthwhile cause and wanted to be a part of the intervention.

#### **5.7.10 Structure of sessions**

The structure of the sessions was planned in advance and included a facilitator who led each session, and a guest speaker who was an expert in a relevant area. During the first session there was an introduction and discussion about boundaries and rules of participation e.g. mutual respect and confidentiality i.e. what was discussed amongst the group would go no further. This was discussed with the group so that there was complete transparency and honesty (WHO, 2017).

The overall aim for these sessions was how best to make participants feel at ease and comfortable when surrounded by people they did not know and how to get them talking, sharing knowledge and experiences with one another using education, training and enablement which is the theory of the COM-B system of the BCW (Michie et al. 2011).

The topics for each session were based on the results of previous studies within this thesis. The evidence within this thesis found that some people struggled with becoming spinal cord injured and did not have full independence, they felt frustrated and desperate. Participants had problems physically and psychologically coming to terms with their health due to secondary health impairments after becoming spinal cord injured. It was also found that the

majority of people had difficulty adapting and coping. Participants had said they would like friends and family and a peer support group as they felt that they lacked support.

From these findings guest speakers were sort out who were experts in these relevant areas and asked if they would speak to the participants. In the case of this intervention, the speakers were all specialists in the area of SCI who were an occupational therapist (independence and difficulties), physiotherapist (pain and posture), a doctor of physiology (exercise and diet), nurse (health care issues), mindfulness therapist (stress and coping), a person who had SCI and was a TV personality (motivation), a carer who looked after a person with SCI (motivation) and a mother who has SCI with 4 children and who runs her own business (knowledge, experience and motivation).

Session 1 was led by the PhD candidate and was an introductory session. All the participants were introduced themselves to the other group members and said a little about their SCI. They were then given a handbook that was designed to give them details about each weekly session and were told how the intervention would be run and also had the guidelines explained to them i.e. data collection and confidentiality and what is peer support involves. They were also asked to discuss their own expectations of what they would like to take away from the intervention. The group also made some basic rules and agreed to them.

The rules that were agreed upon included:

In general:

- Try to be aware of how you're feeling. If you're not feeling well discuss with the facilitator, you might find hearing about other people's experiences more difficult.

- You should feel free to share what you feel comfortable with but it's worth thinking about how it makes you feel and how it might affect others.
- If you're not sure how to express yourself, try to focus on sharing how you feel (i.e. angry, sad, scared).
- If you feel like
- you need a break for any reason, it's okay to take some time out from the session.
- Try not to interrupt or speak over each other

Session 2 was led by a guest speaker who is an occupational therapist who specialises in working with patients with SCI and talked about ways of overcoming challenges of being spinal cord injured, doing more for themselves and becoming independent.

Session 3 was led by a guest speaker who was a spinal cord injury specialist nurse and she came along to discuss secondary health impairments and other health issues to do with complications caused by SCI. Participants were asked to break off into pairs to discuss issues they may have and then they were asked if they would like to discuss these issues with the group.

Session 4 was led by a guest speaker who is a wheelchair user and who specialises in mindfulness. The group talked about techniques they may use themselves to manage stress and challenges whilst having SCI. They also went through some mindfulness exercises with the guest speaker.

Session 5 included a guest speaker and his wife. He is a musician, TV presenter and disability advocate as he himself has SCI. He spoke about his 36 years of being a wheelchair user and all the hurdles people can overcome to have a positive life. He told the participants; life does not end when a person becomes paralysed. The group then discussed the positives in their own lives and the goals they had set themselves.

Session 5 continued, this was a session that participants could bring their friends and family. The partners, friends and family members joined the researcher and the wife of the guest speaker in the coffee shop to discuss life being with someone who has SCI and their own obstacles. It was a session where partners, friends and family could receive their own support and share knowledge and experiences.

Session 6 was led by a guest speaker who is a physiotherapist specialising in SCI from Rookwood Spinal Injuries Hospital. She spoke about aches, pain and posture with participants. The participants were then invited to discuss as a group their own problems with aches, pains and adjusting.

Session 7 was held by a doctor of physiology who specialises in exercise and diet. He discussed his own experiences working with people with SCI over the years and worked through some exercise techniques with the participants. As a group they then discussed their eating habits and how they could include exercise into their daily routines.

Session 8 was supposed to be led by a guest speaker who was a professional sports personality, but he was unable to make it, so an alternate guest speaker who runs a well-known charity in the North of England did a video link talk for the first 20 minutes of the

session. The guest speaker talked about her own experience of having SCI, being divorced, running a household with 4 young children and running her own business. A second guest speaker came into CMU to talk for the next 20 minutes of the session about being a lead carer for a high-level tetraplegic, his life story and all he has achieved even though he is unable to breath for himself. The guest speaker had permission from the man she looked after to show a personal video of him about his life and achievements to the participants, this video was also uploaded onto the internet (YouTube).

#### **5.7.11 Reflection of sessions**

The sessions all started and finished on time, attendance for each session was good. The topic that each guest speaker spoke about each week seemed to be enjoyed by participants as they engaged in questions and discussion and were always complimentary about the person who had come to speak. The facilitator allowed discussion to run freely whilst not letting the stronger participants in the group take complete control. At the end of the final 8<sup>th</sup> session participants were asked by the facilitator and the researcher verbally how they felt the sessions had gone, there was no negative feedback only positive. Each week a select number of participants would stay to talk to each other after the session had finished until quite late.

### **5.8 Summary**

The purpose of this chapter was to document and explain the design and implementation of a theory-based evidence informed behaviour change intervention involving a peer support group that would improve QoL in people with SCI. The peer support group was designed using the BCW COM-B as the theoretical underpinning (Michie et al. 2011) and guided by

the structure of studies by Christianson (1985) and Morris and Morris (2012) and how they were developed as they were reported as successful peer support groups.

The design of the peer support group was tailored around the literature and results found in previous chapters. Participants were recruited using a snowball effect and both the intervention and control group were matched based on gender and level of injury, it was done this way so differences in the outcome could be explained by reducing group bias (Roberts, 1998). Details such as location, time and type of meeting place had all been taken into consideration based on what participants had said. The structure of each session and guest speakers were based on previous findings within the thesis, the COM-B model and past successful peer support groups. Previous evidence had said how important it was to have a facilitator and one of the main aims of the present study was to have a facilitator who has SCI allowing participants to speak freely about sensitive issues that affect them daily.

The purpose of the peer support group was also to develop a comfortable relaxed setting where people suffering with the same condition (SCI) could meet in a place where they felt comfortable and relaxed enough to openly talk about problems that arose from being a person with SCI, an environment where they were able to share their own knowledge, experiences and skills with the other members of the group.

The overall aim was that by being a part of the group and contributing to it, participants would gain valuable information and develop a support network for the future which would help them to develop better coping skills enabling them to cope better and improve QoL. By conducting this feasibility study, the intent is to assess the accessibility and validity of the



intervention, whilst identifying any problems related to the feasibility of conducting a peer support group with individuals who have SCI.

In the following chapter (6) the intervention will be evaluated, and the results reported.

**Evaluation of a peer support group to improve quality of life in people with a spinal cord injury**

**Chapter 6**

**6.1 Summary of previous findings within this thesis**

Previous chapters within this thesis helped to guide the theoretical framework for the intervention designed for this thesis. The theoretical framework includes a focus on how people with SCI cope and the coping strategies they use (Kennedy et al, 2000; Pollard and Kennedy, 2007; Kennedy, Kilvert and Hasson, 2016) and also BCW using the COM-B model (Michie et al. 2011) for the intervention design and the implementation of the feasibility study. The following are the results of a feasibility study i.e. is an evidence-based intervention, which in this case was a peer support group for people with spinal cord injury (SCI).

The literature review, presented in chapter 1 of the thesis, identified that people found it difficult to both cope and adapt physically and emotionally after becoming spinal cord injured if they did not have a social network in place (Sherman, DeVinney and Sperling, 2004). People who were said to have received better social support, perceived themselves to be better adjusted to their injury, they were also found to deal better with their injury emotionally (Post et al. 1999) reporting a higher quality of life (QoL) (Dowler et al. 2001). The Spinal Injuries Association (SIA) provide peer support officers that can be beneficial in a one to one situation providing some form of social support, however, there are no peer support groups in the UK for people with SCI that are facilitated by a person with SCI. This

is despite the fact that the SIA have said that the best support for a person with SCI is provided by their peers (SIA, 2015). Thoits (1995) has said that the most effective support for people with SCI is by people that have been through the same types of stressful situations and can provide the best emotional support for this reason. The evidence in the literature review found that people who had attended a peer support group had reduced feelings of isolation, developed coping skills and increased knowledge allowing them to cope with their condition (McGrath, 1999; Docherty, 2004; Ussher et al. 2006) (see chapter 1, p.38, 1.19.1)

The findings of the literature review suggested that how people cope and adapt to their newly found circumstances can affect their QoL (Kennedy, Lude and Taylor, 2006; Chevalier, Kennedy and Sherlock, 2009). As a result of this, the current research has investigated ways of improving QoL by using a behaviour change intervention (peer support group). Previous studies discussed within this thesis focused on how people with SCI coped and adapted and how they felt about peer support groups.

The systematic review reported in chapter 2 (study 1) of the thesis compared 10 empirical studies that used a quantitative methodology to see what the psychological impact of SCI was on QoL. Depression was one of the main issues that affected people with SCI in the early stages (Wittokower et al. 1954; Hancock et al. 1993; Kennedy and Rodgers, 2000). It was found that employment helped improve QoL but 79% of people with SCI were unemployed (Krause et al. 1998; Ottomanelli and Lind, 2009). One of the main reasons for an individual with SCI having a poorer QoL was secondary health impairments (SHI) i.e. lack bladder and bowel control, pressure sores and spasticity (Krause and Broderick, 2005; Noonan et al.

2008). Other factors that impact on QoL were found to be socioeconomic status, gender and age.

The findings of the qualitative study (study 2) showed evidence that participants were negatively affected by becoming spinal cord injured and this was in part due to having secondary health impairments. Further evidence showed that having difficulty adapting and coping with SCI leads to a poorer QoL (Kennedy et al. 2000; Kennedy, Lude and Taylor, 2006; Noonan et al. 2008; Post and vanLeeuwen, 2012; Kennedy, Kilvert and Hasson, 2016). Participants found it difficult to speak with able bodied friends and family about their SCI, they did not know who to talk to professionally, they found it difficult to access health care professionals and overall had a poor support network, these findings were similar to previous evidence found within the literature review (Kyrouz, Humphreys and Loomis, 2002; Ussher et al, 2006; White, 2007; Sweet et al. 2016). However, most participants that took part in the interviews showed positivity at the prospect of having a peer support group where they could talk to individuals who could empathise with them and share their own knowledge and experiences due to living with SCI themselves (Ussher et al, 2006; Hass, Price and Freeman, 2013; Sweet et al. 2016).

The main aim of the study reported in Chapter 4 (study 3), in which 270 participants filled out a questionnaire, was to find out how people coped with their SCI and how they felt about peer support groups, for example would they attend one and if so what structure would they like to see being implemented? The findings of this study further developed those of qualitative study that preceded it (see chapter 3). People with SCI found it hard to find health care professionals to talk to and found it difficult to open up to friends and family, they also

struggled to adapt and cope with their SCI both mentally and physically with all but 1.5% reporting having a secondary health impairment (SHI). The number of people who said they may attend a peer support group was low, however, this was because they said they would find it difficult to attend depending on location and time of day. A high percentage of participants said a peer support group should have a defined topic of discussion, especially on health issues and they would also like to take a family member. Nearly all participants who took part in the study thought that going to a peer support group would help people build confidence and help people who feel stigmatised overcome that fear. Out of all 270 participants 90% thought that people with SCI should join groups which include other people with SCI (their peers).

Chapter 5 reported on the design and implementation of the peer support group which included looking back at previous evidence found within this thesis and at past research by many authors including Christianson, 1985; Kennedy et al. 2003; Brug et al. 2005; Morris and Morris, 2012; Michie et al. 2014, to design an evidence and theory-based behaviour change intervention to give it the best chance of success. It has been suggested that using theory in the design of a behaviour change intervention will improve it by making it possible to assess the design, implementation and evaluation of the intervention to measure how effective the intervention has been in changing behaviour outcomes (Bluethmann et al. 2017). Although there have been calls by Michie and Abraham (2004) to have more differentiation between theory informed interventions (vaguely describing the use of theory) and theory driven interventions (integrating theory throughout the entire process of designing, planning and evaluating the intervention) (Bluethmann et al. 2017).

The design of the behaviour change intervention included the BCW COM-B by using education, training and enablement frameworks that have been described in previous chapters (Michie et al. 2011) and was guided by the structure of Christianson (1985) and Morris and Morris (2012). The peer support group was designed so that the location was assessable to all participants and the time it took place. The structure of each session and guest speakers were based on the COM-B model by using the model's sources of behaviour change capability, opportunity and motivation (see chapter 1, p.31) (Michie et al. 2011) and past successful peer support groups (Christianson 1985 and Morris and Morris, 2012), the group also included a facilitator who has SCI. By designing the peer support in this way, the aim was that participants would openly share knowledge and their experiences with each other, therefore providing new or better ways of coping leading to an improved QoL.

## **6.2 Aims and Objectives of this Chapter**

The aim of this chapter is to evaluate the peer support group to see if it's both feasible and can be scaled up to meet a larger audience (aim 5) and this was done by designing a quantitative and qualitative questionnaire and a wellness ladder (objective 5)

Tickle-Degnen (2013) said "the outcomes of most feasibility and pilot studies should be measured with descriptive statistics, qualitative analysis, and the compilation of basic data related to administrative and physical infrastructure" (p.172).

The study will analyse the results of a quantitative evaluation of data to see if there were any differences found between the intervention group and the control group that could be attributed to the peer support group using mean scores. There will be a further analysis of

qualitative data to see what participants thought of the peer support group and if their views could help with the design of further peer support groups and finally participants put a score on a wellness ladder before each weekly session started to measure their mood at that time, so the results of these will also be analysed. The study will also see if there was any unforeseen problems with the peer support group and the outcomes.

### **6.3 Method**

The peer support group was a behaviour change intervention influenced by the behaviour change wheel (BCW, Michie et al. 2011) and was a randomised control trial (RCT) made up of an intervention group and a control group. An RCT is the most scientifically rigorous method of hypothesis testing available and is regarded as the gold standard trial for evaluating the effectiveness of interventions (McGovern, 2001). Data was collected via semi-structured interviews and questionnaires, including a lifestyle questionnaire, GHQ-12, Brief COPE and the QOLS, which were used for the main part of the evaluation. Participants also filled out a wellness ladder before the beginning of each session to record how they were feeling. All data collected was kept in a folder on the researcher's desktop which is password protected and will be kept for any possible publications.

The main aim of the intervention was for participants attending the peer support group to improve their QoL by sharing knowledge, experience and learnt skills of dealing with their day to day lives and health problems within the peer support group process. The peer support group was designed to educate the participants but also included them by asking them to openly discuss their own experiences, and by networking and socialising.

### **6.3.1 Measures**

The following measures were used evaluate the intervention.

#### **General Health Questionnaire-12 (Goldberg, 1992)**

The GHQ (Appendix 3H) was designed by Goldberg in 1972 to detect mental health conditions in the general population such as people in the community and medical out-patient settings using a self-report questionnaire (Liang, Wang and Yin, 2016). The GHQ-12 is a shortened version of the well validated full version, GHQ-60, it uses a 4-point scale: ‘less than usual’, ‘no more than usual’, ‘rather more than usual’ or ‘much more than usual’. There are four scoring systems for the GHQ (Likert method (all items coded 0-1-2-3), GHQ method (all items coded 0-0-1-1), and C-GHQ method (PP items coded 0-0-1-1; NP items coded 0-1-1-1) (Hankins, 2008): however the GHQ-20 and GHQ-12 can be scored by at least two methods, originally the bimodal method (0-0-1-1) and the scoring method this study used, the Likert scoring responses, where responses score 0, 1, 2 and 3 respectively with final scores ranging from 0-36. The method of scoring this study used is more useful for comparing degree of distress to assess well-being as it produces a less skewed distribution of the total GHQ scores (0-36) (Bratas, Gronning and Forbord, 2014). A higher score of 36 indicates a greater probability of clinical disorder (Goldberg et al. 1997). The reliability of the GHQ-12 (Cronbach’s alpha) using the Likert-type scoring (0-1-2-3) has been found to be 0.79, indicating satisfactory internal consistency (Kim et al. 2013). The GHQ-12 was subsequently selected as a measure of general psychological well-being as it is said to be robust and works as well as the longer instruments (Goldberg et al. 1997).



## **Quality of Life Scale-16**

For the purpose of this study it was decided that the QOLS-16 items (Appendix 3I) would be used as it was purposely developed by Flanagan (1978) for chronically sick people i.e. people with SCI, however Burckhardt et al. (1989) further adapted it into a 16-item measure from a 15-item measure adding independence (Asnani, Lipps and Reid, 2009).

The 15 item QOLS questionnaire was developed in the 1970's by Flanagan (1978) using a critical incident technique involving nearly 3000 people of all ages, backgrounds and ethnic groups, from all areas of the United States. Flanagan (1978) and his team tried to include as many groups as possible, this included low income and minority groups, but they did not do this to gather accurate estimates of frequencies, it was so they could identify different points of view, they wanted to know their experiences of being poor or part of a minority group (Burckhardt and Anderson, 2003). The original 15 item instrument measured five conceptual domains of QoL: material physical well-being; relationships with other people; social community and civic activities; personal development; fulfilment and recreation (Burckhardt and Anderson, 2003).

The 15-item measure was adapted by Burckhardt et al. (1989), by using three open ended questions to identify domains of QoL in people with chronic illness, these illnesses included diabetes mellitus, ostomy, osteoarthritis and rheumatoid arthritis. During the interviews all of the above-mentioned groups used similar terms that were important to them i.e. being active, taking care of themselves, and wanting a relationship with others, but the key finding was independence (being able to do for oneself), this was mentioned by all four groups. Since the inception of the 16-item questionnaire, researchers have administered it to all kinds of

populations. i.e. diabetes mellitus, osteoarthritis, gastrointestinal disorders, rheumatoid arthritis, systemic lupus erythematosus and many more, but more importantly SCI (Burckhardt and Anderson, 2003).

The QOLS is scored by adding up the scores on each item which will make a total score between 16 and 112 and the higher the score the higher the quality of life (Burckhardt and Anderson, 2003). The QOLS is reliable and has good internal consistency of 0.88 (Asnani, Lipps and Reid, 2009).

### **Brief COPE Scale**

The Brief COPE was designed by Carver (1997) and consists of 28-items with 2 items for each of the 14 conceptually differentiable coping reactions (Appendix 3J). The 14 sub scales are active coping, planning, positive reframing, acceptance, humour, religion, using emotional support using instrumental support, self-distraction, denial, venting, substance use, behaviour disengagement and self-blame. Carver (1997) tested the Brief COPE and overall it showed good internal consistency ( $\alpha = .50-.90$ ), all exceeded .60 except Venting (.50), Denial (.54) and Acceptance (.57).

The Brief COPE was used to evaluate the intervention because it is a reliable measure, on the whole. Another factor that was key in using the Brief COPE is that Carver (1997) designed it for the recent past, so when participants complete it, they are to bring to mind recent stressors (Monzani et al. 2015). As the participants completed the Brief COPE questionnaire at baseline, 8 weeks and 24 weeks follow up, this made it possible to analyse whether the

intervention had helped participants cope with any recent stressors in their lives during and after the peer support group.

### **Lifestyle Questionnaire (Quantitative and qualitative elements)**

Altogether there were 18 lifestyle questions (Appendix 3K) on the questionnaire with the first 8 questions designed to obtain information about whether people were active or social i.e. did they socialise on social media? did they exercise? e.g. ‘how often do you exercise weekly? and did having SCI stop them achieving their goals? There were a further 3 questions, ‘how confident are you that going to a peer support will help you to be more independent?’, this was based on the findings reported in chapter 4 when participants were asked about going to a peer support group, the aim of these questions was to see if participants answers would change between baseline, week 8 and 24. The next question ‘right at this moment how would you rate your mood’, was included because these questionnaires were filled out at baseline, end of intervention (week 8) and at follow up (week 24), so it made it possible to gauge whether people’s moods had changed at different stages of the intervention. The last question, ‘how happy are you, with the direction your life is taking?’, was designed to identify if the answers to this question had changed after participating in the peer support group.

Five additional qualitative questions were included with the lifestyle measure just for the intervention group at 8 weeks and 24 weeks, post intervention, to help with the development and optimisation of future peer support groups. The extra questions asked the intervention group how many sessions each participant had attended, their reasons for non-attendance at any session. Participants in the intervention were also asked: ‘which session did you enjoy

the most?’, ‘what did you enjoy most about being a part of the peer support group?’, and ‘was there anything that you disliked about the peer support group?’. Open responses were invited for these questions.

The overall aim of these 18 questions was to see if by participating in the peer support group sharing experiences, listening and interacting with each other as well as the guest speakers, that participants would obtain information that could be helpful, and gain new knowledge and coping skills to be able to deal with their SCI. The aim was to see if their QoL would improve and whether this would be reflected in the results. The additional questions would also provide information that could be helpful in improving future peer support groups.

### **Wellness Ladder**

The tool used to rate the participants moods before each session was a self-anchoring, one item scale that was developed by Cantril (1965) (Appendix 3L). When it was first developed, the ladder had 11 rungs and measured a person’s own perception, assumptions, goals and values. More recently it was adapted to include 10 rungs (Glatzer and Gulyas, 2014). It has since been found to be an effective tool when measuring happiness and is quick and easy to administer. The participants just add a tick to a rung on a picture of a ladder which is scored from 0 to 10 (Mazur et al. 2018). In a 2014 study that compared Cantril’s scale to other well-respected scales that were used to measure mental health, it was reported that Cantril’s scale had good convergent validity and reliability (Levin and Currie, 2014).

### **6.3.2 Ethical considerations and anticipated risks**

Ethical approval was given by the School of Health Sciences, Cardiff Metropolitan University before the intervention started (Appendix 3A). The study involved a vulnerable group as they are people who have sustained a serious injury or illness that affected their spinal cord and may have some psychological issues with regards to their current situation. They also maybe sensitive about certain topics during the peer support group and so were able to leave if they felt uncomfortable.

At the start of the first session, participants in the intervention group were all made aware that at any time if they felt uncomfortable, distressed or anxious and needed to leave the group they could. There were two people (facilitator and researcher) at the groups at all times, so if someone felt distressed there was always someone available who could leave the group with them. Participants were given a manual at the beginning of the first session with details of what each session would contain over the duration of the peer support group (Appendix 3B) that had details of the SIA who are a charity that have a helpline for people with SCI who need urgent help.

Online questionnaires had detailed guidelines at the very beginning explaining that if any participant felt distressed or anxious whilst filling out the questionnaire, they could skip a question or stop altogether. At the bottom of each questionnaire was a website link to the SIA.

Once the intervention sessions were completed, two participants were chosen to be interviewed and were given a participant information sheet (Appendix 3C) and consent form

(Appendix 3D). They were told that if they felt distressed or anxious at any point during the interview they could skip a question or withdraw from the interview process at any time and be given the details of someone they could speak to if they needed help.

## **6.4 Intervention method of data analysis**

### **6.4.1 Quantitative Evaluation**

Participants in the intervention and control group were asked to fill out baseline measures a few days before the intervention began i.e. Lifestyle questions, GHQ-12, Brief COPE and the QOLS. The measures were uploaded onto Qualtrics which is an online system used for collecting survey data. Links were emailed to all participants in the intervention and control groups simultaneously. When the intervention ended on October 22<sup>nd</sup>, 2016 an email was forwarded to participants from the intervention and control group with a link to the online questionnaire, once all questionnaires were completed and returned the data was then analysed to identify any differences in responses between the two groups and the two time points.

A further follow up with the participants of both the intervention and control groups was carried out 4-months after the end of the intervention using the same process as above, a link was emailed to both groups to see if there were any long-term differences between the intervention and control groups on the questionnaire items.

### **6.4.2 Qualitative Evaluation**

A draft interview schedule was developed during the peer support group so that it could be informed by the feedback and comments that emerged during the sessions. This then underwent a review by the participant panel of 3 people with SCI who had agreed to be involved in the development of materials for this PhD. There was some feedback about the questions on the interview schedule and changes were made due to not all participants of the panel agreeing on some of the question and prompts. The panel suggested that questions and prompts be added during the development process of the interview schedule. Due to this the panel members and the researcher had a meeting to discuss the interview schedule and agreed upon what questions should be used. During the meeting it was agreed that a second prompt be added to Q6 ‘are the things you learnt useful?’ a prompt was added to Q8 ‘if so how could the group be improved?’ there was a minor change on Q9 prompt ‘anything at all’. There were two questions added Q13 ‘Would you like an open or closed group?’ and Q14 ‘Would you like a session with friends and family?’. The original questionnaire before the changes were added can be found in the appendix (3F).

When designing the intervention, it was deemed necessary to receive qualitative feedback about the how the intervention had been received by the participants and to see if they had any suggestion for changes to be made to future peer support groups. Two participants from the intervention group were chosen to be interviewed. Two out of 8 participants were considered to be suitable proportion of the overall number of participants that took part in the peer support group given that all participants that took part in the intervention group were asked open questions about their participation in the group and how they thought it had gone using questionnaires filled out in weeks 8 and 24.

After a discussion with the facilitator of the group it was decided that the youngest member of the group who had turned up to most sessions and was quite vocal. The second participant to be chosen was a female who had been quite quiet at the start of the sessions but became more vocal during the latter sessions.

The interviews were semi-structured (Appendix 3E) as this allowed the participants to express their views in their own words and did not impose the views of the researcher through any structured or directive questioning and so was considered to be the most appropriate method for identifying issues that had not previously been thought of (Thornhill, Saunders and Lewis, 2009).

Interviews were tape recorded and transcribed verbatim and pseudonyms given to each participant. Interviews were then analysed to identify what key points the participants mentioned about being a part of the peer support group and to identify any concerns they may have had about the support group. Both interviews were then analysed using thematic analysis (TA) (Braun and Clarke, 2006) to extract information that could be used to inform the development of future peer support groups.

Thematic Analysis had been previously described in detail as it was the method of analysis in chapter 3. However, a brief overview of TA is that it interprets patterns and themes within qualitative data (Braun and Clarke 2006). This type of analysis is being used as it identifies themes/patterns within the data and will address the aims of the qualitative part of the study (Clarke and Braun, 2013).



## **6.5 Comparison between intervention and control group**

### **6.5.1 Descriptive analyses**

There were 20 participants included in this study. In the control group there were 7 males and 3 females, 3 males had tetraplegia and all the rest of the participants had paraplegia. The intervention group mirrored the control group and there were 7 males and 3 females, 3 males had tetraplegia and 7 participants had paraplegia. All participants were randomly allocated to either the intervention or control group, a detailed description of process stratified random allocation can be found in chapter 5 (p.133, 5.7.3).

In the quantitative descriptive section, qualitative interviews and the wellness ladder results all participants in the intervention group will be labelled participant P1 through P10 and each will keep their position throughout the results section, this will also be the same for the control group (C1 - C10).

### **6.5.2 Quantitative results**

#### **6.5.2.1 Data analysis**

All quantitative analyses were performed using SPSS 24.0. All items on the GHQ-12 were scored from 0 to 3 with a total possible summed score of 0 to 36, with the higher score indicating poorer well-being. For the QOLS each item was scored from 1 through to 7 with 1 being terrible and 7 being delighted, all scores were added up, totalling a score of between 16 and 112, with a higher score indicating a greater QoL. The third measure to be used was the Brief COPE where each of the 28 items were scored from 1 to 4 but then they were combined

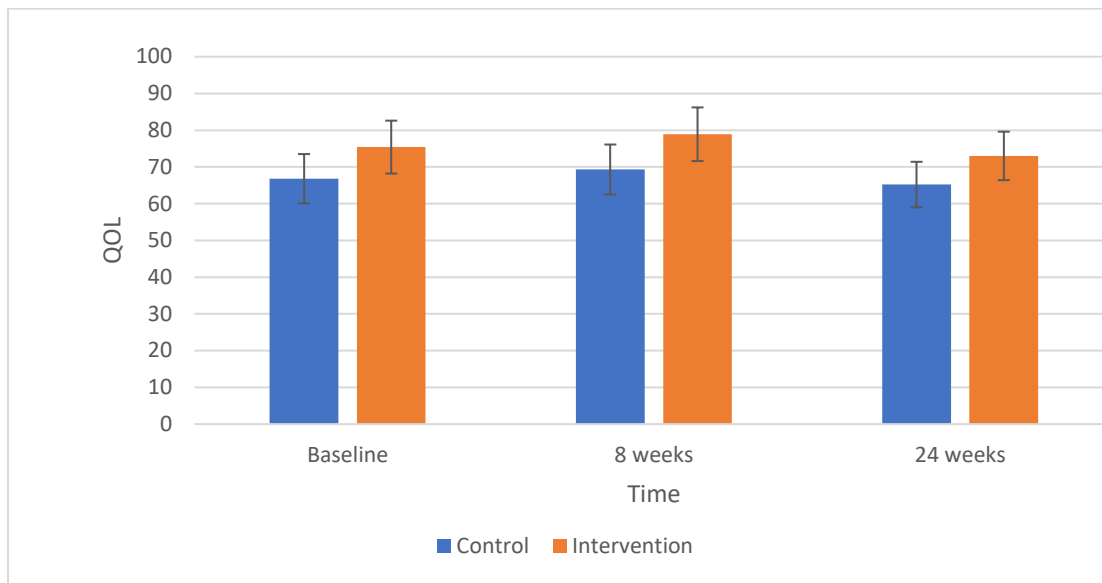
to make 14 sub scales as per the Brief COPE scoring instructions, a higher score indicates that a person is more likely to use that coping strategy.

#### **6.5.2.2 ANOVA result**

The QOLS, Brief COPE and GHQ-12 data were analysed using a repeated measures ANOVA to find the mean scores for both the intervention and control group. A Mauchly's test of sphericity was used on all three analyses and it was found that assumptions of sphericity were not violated, feasibility studies such as this are not expected to have large sample sizes that enable an adequate power of analysis to test the null hypothesis (Tickle-Degnen, 2013). However, Billingham, Whitehead and Julious (2013) found that although feasibility studies did not need to do a formal calculation a study should justify its sample size. The sample size for the current feasibility study was based on previous peer support groups that used between 5 and 10 participants as this was said to be the ideal number as it provided continuity, promotes familiarity and thereby a safe environment (Christianson, 1985; Hildingh et al. 1993; Wilson, Flanagan and Rynder's, 1999).

Below are the four figures used to show the mean scores of the control and intervention group using the QOLS, Brief COPE and GHQ-12 questionnaires which the participants filled out at baseline, 8 weeks (peer support group finished), then at 24 weeks (follow up).

**Figure 8** was analysed by taking each participants' mean score at baseline and subtracting it from what each participant had scored at week 8, then repeating this method for each participants' mean score between week 8 and week 24. Then using the means and standard deviations these were put into excel to configure a graph of individual changes in each group.

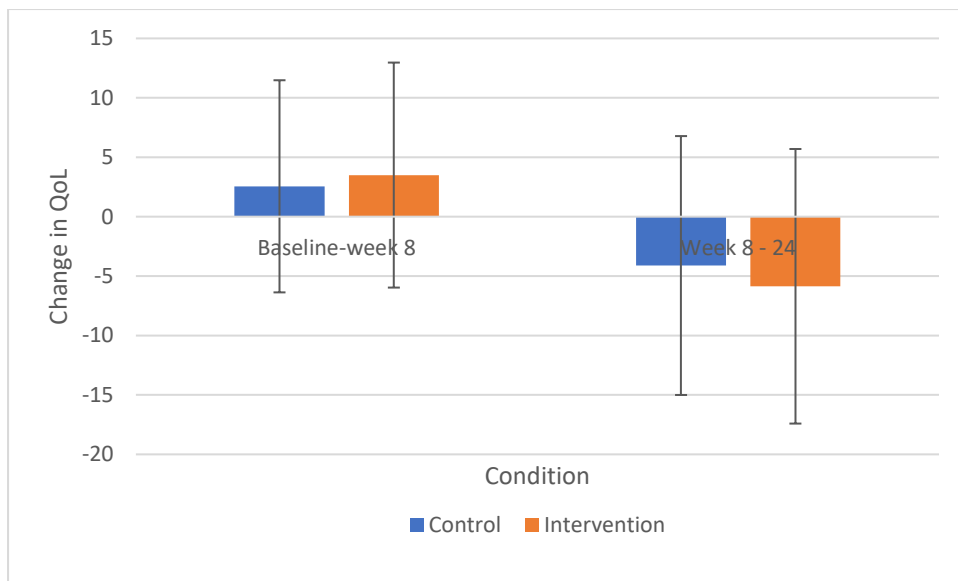


**Figure 7** Mean QoL by time and condition (error bars show standard error)

## QoL

As can be seen in Figure 7 at each time point the intervention group scored higher than the control group on the QoL measure and both control and intervention groups scores rose between baseline and week 8 and then fell again between week 8 and week 24, such that they were lower than baseline.

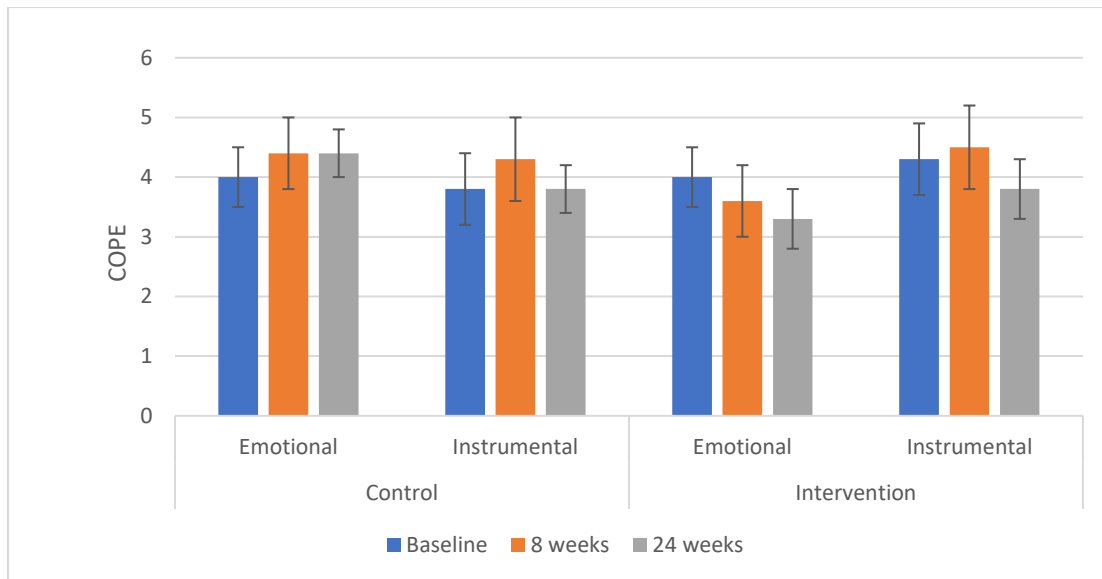
Although the data shows statistically that there was a significant effect of condition on QoL,  $F(1, 15) = 5.83, p < .05$ , because the effect already exists at baseline and there was no interaction with time, the effect of condition is explained away (see Figure 2).



**Figure 8** Change in QoL by time and condition (error bars show standard error)

The data in Figure 7 shows no main difference between groups at baseline and week 8.

However as can be seen in Figure 8 more clearly the difference between baseline and the end of the intervention (week 8) was bigger in the intervention group than the control group. At week 8 to 24 weeks the intervention groups QoL dropped lower than that of the control group.

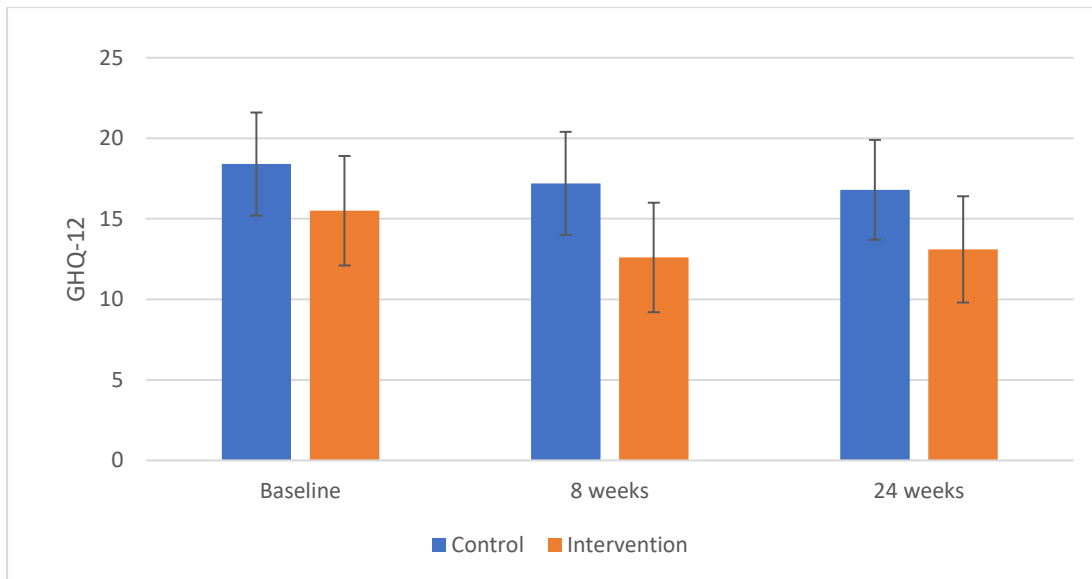


**Figure 9** Mean Brief COPE by time and condition (error bars show standard error)

### Brief COPE

In the intervention group their reliance on emotional coping methods reduced over time whereas in the control group it increased between week 8 and week 24. The intervention group had higher scores at baseline and at week 8 than the control group when measuring instrumental support even though their score was lower at 24 weeks than the control group.

The intervention had no significant effect of condition over time on whether participants used emotional or instrumental support in order to cope,  $F(1, 15) = .25, p > .05$ .



**Figure 10** Mean GHQ-12 by time and condition (error bars show standard error)

## GHQ-12

General health as measured by the GHQ-12 did not improve as a result of the intervention.

The intervention had no significant effect over time on general health in the intervention group,  $F(1, 15) = .78, p > .05$ .

A summary of the quantitative findings can be found below (6.7.1).

### 6.5.2.3 Results of Brief-COPE

The following Table shows what coping strategies participants in the intervention group used at baseline, end of intervention and follow up.

**Table 8** Descriptive Statistics Brief-COPE

Mean scores of coping strategies						
	Baseline	Baseline	End of Intervention	End of Intervention	Follow up	Follow up
	N = 10	N = 10	N = 8	N = 8	N = 10	N = 10
Coping Strategies	Mean	Std. Deviation	Mean	Std. Deviation	Mean	Std. Deviation
Acceptance	6.00*	2.31	4.75*	2.96	4.70*	2.58
Humour	5.00*	2.67	3.50	2.27	4.40*	2.80
Active coping	5.00*	2.49	4.75*	2.12	4.00*	1.94
Planning	4.90*	2.33	4.50*	2.45	4.00*	1.94
Self-distraction	4.60	2.22	3.75	1.67	3.60	1.96
Positive reframing	4.50	2.07	3.88	1.89	4.00	1.94
Emotional support	4.40	1.78	3.63	1.69	3.60	1.90
Instrumental support	4.40	1.43	4.50*	2.07	3.50	1.35
Self-blame	4.20	2.39	3.88	2.47	3.20	1.48
Venting	3.40	1.84	3.50	2.14	3.40	1.17
Behaviour disengagement	3.20**	1.99	3.25**	2.05	3.00**	1.41
Religion	3.20**	1.62	2.63**	1.41	2.80**	1.62
Denial	3.00**	1.89	3.38**	2.07	3.10**	1.97
Substance use	2.70**	1.64	2.00**	.00	2.20**	.63

Top four highest used coping strategies \*      The lowest four used coping strategies \*\*

The most frequently used coping strategies at baseline were acceptance, humour, active coping and planning, at the end of the intervention they were acceptance, active coping, planning and instrumental support and at follow up acceptance, humour, active coping and planning. The least used coping strategies were substance use, denial, behavioural

disengagement and religion at all three time points. These findings are similar to that of Kennedy (2000); Pollard and Kennedy (2007); Kennedy, Kilvert and Hasson (2016) who also found that acceptance, active coping and planning were the most used coping strategies and that behaviour disengagement, denial and substance use were the least used coping strategies during a 21-year longitudinal study. The difference was that the current study found that humour was the second most used coping strategy at baseline and follow up, however during the intervention it was one of the least used coping strategies.

### **6.5.3 Qualitative results section**

The results of the qualitative section of the lifestyle questionnaire can be found below, and the results of the TA used to analyse the data from two interviews that were carried out with 2 participants that attended the peer support group.

Due to the size of the intervention group it was decided that 2 participants would be interviewed as the peer support group had 8 participants over the 8 weeks and it was deemed that interviewing 2 people would be appropriate and elicit meaningful data. These interviews would be used in conjunction with the open questions from the lifestyle questionnaire to complement the quantitative descriptive section and give a more in-depth evaluation of how the participants thought the peer support group was implemented.

#### **6.5.3.1 Qualitative section of lifestyle questionnaire (Appendix 3K)**

This section will detail what the participants had to say about the peer support group using open questions that were added at weeks 8 and 24 as part of the intervention groups Lifestyle



Questionnaire. The questions were repeated at week 24 to see if the participants would add anything new.

The response to the open questions is summarised below:

Out of ten participants who were recruited to the intervention group, four attended 8 sessions (David, Bob, Benny and Sean), one attended 6 sessions (Simon), three attended 5 sessions (Jane, Mary and Katie), and two did not attend any (Jake and Dick). The reasons given for missing sessions included work commitments, childcare, illness and injury. Of the participants who didn't attend any session, Dick had no transport and Jake had to attend a sporting event, which meant he would have missed most of the sessions due to training for the event as well as attending it.

When participants were asked at week 8 and 24 (some participants enjoyed more than one session) 'which session did you enjoy most?', Jane said session 1, which was the introduction to the peer support group, Simon said session 3 which was about secondary health impairments and other health issues, David session 4, which was a mindfulness session, Katie and David mentioned session 5, this was about the positives of having SCI, Simon, Bob and Sean enjoyed session 7, a talk about exercise and diet, and Katie said session 8, which was a talk via skype by a person who runs a charity and by a carer who takes care of a tetraplegic person and Mary and Benny said they enjoyed every session equally.

An important question for the design of future peer support groups was, ‘what did you enjoy most about being a part of a peer support group’? The answers to the question are listed below under week 8 and week 24:

#### Week 8

The common themes amongst the 8 participants was meeting people who were in the same position as them, sharing and listening to stories, tips and tricks to help overcome issues that may arise from being a person with SCI and methods of coping both emotionally and physically.

#### Week 24

The common themes amongst the 8 participants at week 24 were the same as at week 8.

Participants said they enjoyed meeting new people who were in the same situation as themselves, they enjoyed sharing and listening stories in a relaxed atmosphere where they felt comfortable talking about their problems both physical, emotional and being able to share knowledge and experiences with others who could empathise. Social support is important when adjusting to SCI or illness and people deal better emotionally if they feel they have sufficient social support (Post et al. 1999). These comments support Thoits (1995) who said the most effective support was by peers who have been through the same situation and they provide the best emotional support for that reason.

The final question that the intervention group was asked, which would help in the design of future peer support groups, ‘was there anything that you disliked about the peer support group? Simon and David put no answer at all, Benny and Katie simply said ‘no’, the other

participants (Jane, Mary, Bob, and Sean) said that it was enjoyable and that there was nothing that they disliked about going to the peer support group.

### 6.5.3.2 Qualitative interviews

### 6.5.3.3 Participants

The two participants who took part in the interviews (Table 9 below) were purposively selected to be as different as possible, i.e. different genders, they had different SCIs; i.e. Simon is a tetraplegic due to an accident and Jane is a paraplegic due to an illness, Simon was single with no children and Jane was separated with children, time since injury was 5 years and 2 years respectively. Simon and Jane were leading different lives from each other, as Simon was coping well with life and is a peer support officer helping others in the SCI community, whereas, Jane felt low and didn't want to leave the house and felt it was hard to cope with being spinal cord injured. This information was found out during the intervention when the participants were discussing their lives. It was thought including these two participants would elicit the broadest data as they provided a contrast in personality, situation and experience of the sessions. Demographic characteristics of the intervention group can be found in table 7.

**Table 9** Demographic characteristics of participants

<u>Participant Alias</u>	<u>Age</u>	<u>Level of spinal cord injury</u>	<u>Approximate length time of injury</u>	<u>Marital status</u>	<u>Traumatic and nontraumatic injury</u>
Simon	25	C5 Tetraplegic	5 years	Single	Traumatic
Jane	40	T6/7 Paraplegic	2 years	Separated	Nontraumatic

#### **6.5.3.4 Materials and procedure**

A semi structured interview schedule of 14 questions and 8 prompts was designed with the help of the participant panel. This allowed the interviewer to remain flexible when asking questions. Both interviews were carried out at the participants' homes, they were given an information sheet and consent form to sign and all interviews were recorded using a digital recorder. Both interviews lasted around 20 minutes and were transcribed verbatim and pseudonyms given to both participants before being analysed to ensure anonymity.

TA is a flexible method of analysis that is considered a method (does not prescribe theoretical assumptions) rather than a methodology unlike IPA or grounded theory, which are theoretically bound (Braun and Clarke, 2006). Both participants interviews were analysed as per the instruction guide of TA (Braun and Clarke, 2006). This was done using the same six-step process the same process as in chapter 3. Step 1 and 2 involved transcribing the interviews and listening to the recordings of the interviews a few times during which handwritten notes were taken. Then the transcripts were coded using margins on the transcripts. Step 3 was a process of looking at the codes and looking for interesting features and patterns that were relevant to the aim of the study and drawing out themes. Steps 4 and 5 were to cluster the themes into master and sub-themes as can be seen in Figure 11 below. Step 6 involved writing the results of the analysis.

The aim of the interviews was to identify the participants' own experiences of how they felt the peer support group had helped them (if at all) and how they had helped others with their own experiences and knowledge. To find out what their opinions were about the structure of the sessions, and whether there was anything they thought that could be changed to improve

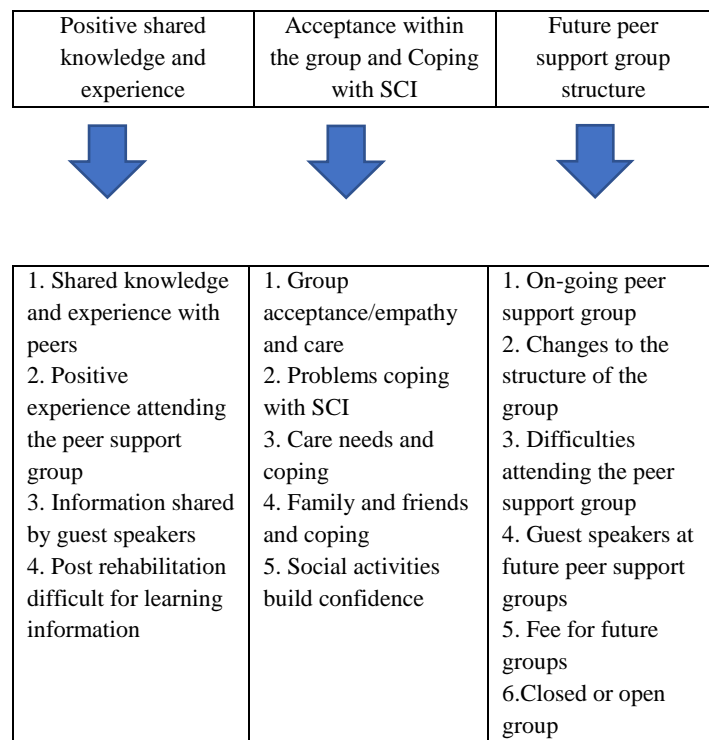
future peer support groups. This type of analysis allows for the opportunity to look for patterns within individual data sets as well as the entire data set. The results of the interviews were used in supporting the findings of the quantitative analysis and to help with designing future peer support groups.

#### **6.5.3.5 Results**

Whilst coding the participants individual data sets it became clear that Simon and Jane had some differences in their emerging themes and what themes were the same, they had given different perspectives.

Figure 11 shows the 3 master themes that emerged from the analysis. It was important to show all sub-themes (15) as some were exclusive to individual participants as they were very different people with different experiences of living with a SCI. The themes are important evidence of how each participant experienced the peer support group in their own words and what their thoughts were. Figure 11 includes quotations that represent the themes found within the analysis.

**Figure 11** Master themes and sub-themes



### 6.5.3.6 Positive shared knowledge and experience

#### Shared knowledge and experiences with peers

The reason for developing the peer support group was to help improve quality of life and the way to do that through a peer support group is by sharing knowledge and experience.

Simon: “I hoped to get out, to be able to share experiences and learn from each other”

Jane: “listening to their stories and you know asking them questions because I have only been in a wheelchair for a couple of years”.

Both participants said their main reason for attending the peer support group was for the knowledge and experience they could share and obtain from their peers, which is exactly what the peer support group was designed to do.

### Positive experience attending the peer support group

Both participants were asked if attending the peer support group had been a positive experience and both agreed that it had been, however neither participant extended their answer any further than stating this.

Simon: “It was a very positive experience”.

Jane: “Oh definitely, definitely a positive experience, yeah”.

### Information shared by guest speakers

Guest speakers were a very important part of the peer support group, no one session had the same guest speaker, and each talked about a different topic to do with SCI. The guest speakers were a mixture of health care professionals and people who had either had SCI or cared for someone with SCI.

Simon: “the different sessions where we had different speakers in, rather than just it all be the same thing every week, it was good to explore different um, subjects, I suppose, a good variety”.

Jane: “I enjoy listening to other peoples’ stories and you know finding out what happened to them, and how it....so yeah I think more speakers would be good....”.

Both Simon and Jane had enjoyed having different guest speakers each week discussing different topics to do with SCI and talked positively about what they had gained from meeting new people and hearing their stories.

### Post rehabilitation difficult for learning information

During the intervention participants had discussed that after they were discharged from hospital they had little to no contact with their peers or health care professionals, which led to difficulties coming to terms with their SCI.

Jane: “it took me nearly 18 months to find out all this, Gareth, there was nothing, once you leave xxxxxx Hospital that’s it, you’re out on your own, what do you do”.

During the interview Jane showed concern for other people who will become spinal cord injured and where they will get their information about things such as benefits and housing.

### **6.5.3.7 Acceptance within the group and Coping with SCI**

#### Group acceptance/empathy

The peer support group was designed so that participants could feel accepted and comfortable enough to share knowledge and experiences with one another, this helps knowing that their peers have been through comparable issues. When speaking with the group, knowing that someone may have been through similar problems can help with empathy for one another (WHO, 2017).

Jane: “You know, not being myself and being relaxed around people in the chairs”

Jane had discussed how she was able to be herself during the peer support group and not feel like an outsider as she had done many times whilst going out with her friends who were not users of wheelchairs. Going to the group she felt comfortable and relaxed and she really enjoyed it.



### Problems coping with SCI

Going to a peer support group and learning from others experience can help participants learn new coping skills and increase the knowledge they have in order to manage (Mead and MacNeil, 2004).

Jane: “because I was just so, I was just, I was in, I was just so overwhelmed with everything”.

Jane had problems coping as can be seen by her comment with different aspects of life as a person with SCI as she had not been injured long and didn’t know whether she was coming or going.

### Coping with care

Being able to discuss care needs and how others cope with health issues that arise from their SCI was important to the participants as it is a topic that arose each session. Secondary health impairments are the number one issue that affects a high number of people with SCI and can be debilitating and can impact on a person’s QoL (Post et al. 1998; Westerkam, Saunders and Krause, 2011; Sakakibara et al. 2012; Michailidou et al. 2014).

Simon: “Yeah and I think you know just being able to talk to other people about different care, and, um those kind of things, it was good to just...just long conversations about all those kind of things”.

Jane: “I didn’t have to pretend, you know, I could just be myself, if I wanted to ask a question about their bowels, or their bladder, it was just ...it was just normal”.

Both participants were interested in gaining a better understanding of how to help manage their health condition and cope better. Simon found it particularly helpful to have long conversations about care. Jane is relatively new to being spinal cord injured, she still hasn’t

learnt to cope with her bowel and bladder routines, learning from others experiences was really helpful.

### Family and friends, support and coping

It is not only the person who becomes SCI that is affected by their injury, family members are too. It could be a parent, partner or a friend that is affected and have difficulty coping with caring for or living with someone with SCI (Chhabra and Batra, 2016). The idea was that friends and family could meet at the same group but separately so that they could make new friends and receive support and new coping skills.

Simon: “they would be able to hear other people’s um partners, or, parents, how they’ve dealt with their children’s’ or partners’ injuries and stuff, so that would be another good thing to carry on sharing”.

Jane: “I think if you bring your family and get them involved as well then I think that is a good thing”.

Simon thought it would be a really good idea to invite friends and family once every couple of months. He believes they could gain knowledge and experience from other people’s family and friends about how they dealt with their loved ones who became spinal cord injured. Jane mentioned bringing friends and family after 5 or 6 sessions once all the participants had got to know one another, she thought it was a really good idea.

### Social activities build confidence

When asked how the group could be improved the participants wanted the group to go out sometimes for more social activities, they felt that with some people this would help build confidence and it was felt it would be enjoyable and a change of pace.

Simon: "...like going out for food, exploring town or going out into the City".

Jane: "definitely going out maybe for lunch, or evening meals or something...but you know I would like that as well.....".

Simon suggested that the peer support group should go out for food and explore town as a group as this might build confidence in participants. Jane suggested something similar, she liked the idea of going out for lunch or evening meals and said she would like that. She did mention at a later point in the transcript that she doesn't think the peer support group should be held in a public place like a pub but she did think nights out might be a good idea.

#### **6.5.3.8 Peer support group: Positives vs Negative**

##### On-going peer support groups

Participants were asked if they would like to see a peer support group for people with SCI become an ongoing process?

Simon: "Yes".

Jane: "Definitely....yeah, definitely".

Simon just said yes to this question, but Jane did expand a little and said that people would benefit from going to a peer support group and said there wasn't enough of them.

##### Changes to the structure of the group

Participants were asked if there was anything they would change about the group as this would be important in developing future peer support groups?

Simon: "What would improve the group.....I found it quite smooth, like, it worked quite easily, um kind of can't think what I would change to make it better...".

Jane: "no....nothing at all...I was quite happy with the way it was..yeah".

Neither participant would expand on the quotes above as they found that the structure and contents of the group were good and that they were happy with the way they were setup.

#### Difficulties attending the peer support group

Participants were asked if they had experienced any difficulties with any aspects of the group i.e. finding time, location, health issues, so anything that would stop them going to a peer support group?

Simon: “Um, the time could have been a bit of a problem”.

Jane: “unfortunately, I’m a single mum of 4 children”.

Simon thought the location of the peer support group was great, but for him it should have been later than 6pm as he got stuck in rush hour, other than that he was happy with everything. Jane had difficulty attending the group as she is a single mum and has 4 children, she said if something came up then she could not participate that week.

#### Guest speakers at future peer support groups

To help with the design and implementation of future peer support groups it would be helpful to know if participants thought that guest speakers were an important part of the sessions.

Simon: “have speakers every so often”.

Jane: “yeah I think more speakers would be good....”.

Clearly they did but they did not expand on their answers, although earlier they had talked about guest speakers and the topics discussed and how enjoyable they were.

### Fee for future groups

For the importance of designing and running future peer support groups the interviewer asked participants if they would be willing to pay a nominal fee to attend a future peer support groups as the intervention had been funded by the PhD candidates funding body.

Simon: “Well enough to pay for some food, £10 a session”.

Jane: “I would be willing to come to the group and maybe pay £10 a session...you know I would be quite happy to do that you know, if you get tea and coffee and if it helps toward paying for something so we can keep a room or something then.....”.

### Closed or open group

Both participants were asked whether they would like to go to an open group (anyone can turn up) or closed group (same participants for the duration of the peer support group) in the future, both of these terms were explained to them, so they could answer with clarity. The answers that were given were quite long as Jane explained that when she first found out about the group she liked that it was closed and only had 10 people, however, in the future, she would like an open group as she could come when she had time as she has children. Both participants said the same that there should be a closed group for newcomers and then an open group.

Simon: “also to have a closed group that people could go to first if they haven’t been to a support group before.....“then they can move on to the...so we can have like, maybe two groups, so they can work hand in hand....”.

Jane: “But I think a closed group for beginners, for first time people going to the meetings, like myself, I think definitely a closed group,”..... “but then after you’ve done your 8-week session then I think an open group would be perfect”.

A summary of the qualitative section can be found below (6.7.2).

#### **6.5.4 Wellness ladder results**

Before each session began each wellness ladder was initialled with a participant's name.

Participants were then given a piece of paper which had a picture of a ladder. At the top of each sheet read the following statement, "Assume that the ladder is a way of picturing how you are feeling today. The top of the ladder represents your best possible mood and the bottom rung of the ladder represents your worst possible mood. Indicate where on the ladder your mood is today?".

Below is a graph (Figure 12) of how the participants scored themselves using Cantril (1965) wellness ladder. How they marked themselves could have been due to a good or bad day or week. The graph also shows how many sessions each participant attended.

Using the information from this section along with the result of the intervention it is hoped that the reader will have a better understanding of each participant (also see Table 1, P.17, chapter 5). The ladder is scored 1 being in a low mood and 10 being in an excellent mood. The description of the participants below is for the purpose of giving a little insight to how each participant contributed to each session.

Simon attended six of the eight sessions. He worked as a peer support officer and contributed a lot to each group session that he attended. He rated his own mood as improving from week 1 to week 8.

Jane was unable to attend all sessions as she found it difficult to get a child minder, however she came when she could. She was quite quiet in the early sessions but as the weeks went on she asked a lot of questions and she marked her own mood as improving at the beginning of each session she came too.

Mary was having health issues during the course of the intervention which meant she was unable to attend all the sessions. When she did attend she asked questions and also shared her own knowledge and experiences with the group. She rated her moods as going up and down during the course of the intervention which could have been due to her on-going ill health.

Katie joined in and contributed a lot to the sessions she attended but on week 4 broke both wrists so missed three sessions but still came back to the last two sessions and by week 8 scored her mood at 8 out of 10 which was higher than week one which was 6.

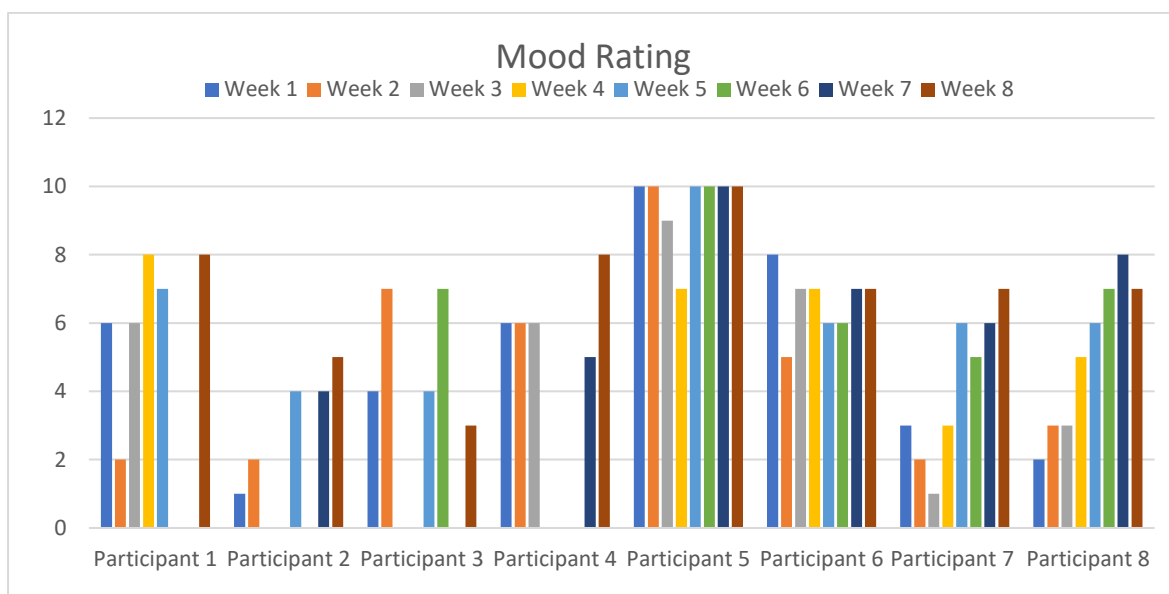
David had been a successful athlete who was always upbeat and had a vast array of knowledge, experience and stories to share. He rated his mood as being excellent every session.

Bob needed constant help and support from his wife, he was always smiling and very outgoing, he listened and shared with the group at every session. He rated his mood as being good before each session he attended.

Benny was shy in the early sessions but became more talkative and very inquisitive, he asked a lot of questions, he came to every session and his mood before each session had improved from week 1 he marked his mood as a 3 to week 8 where he marked his mood as a 7.

Sean came to every session and shared his vast experience of being a person with a long-term SCI, his mood improved every week, week 1 he marked himself down as a 2 and in week 8 he marked his mood as 7.

**Figure 12** Shows participants mood scores



## **6.7 A brief overview of the quantitative and qualitative results section**

Summarising the findings of the peer support group, it was considered to be feasible and acceptable based on the qualitative findings. However, the intervention was a feasibility study and used a small sample, which is both common and acceptable (Tickle-Degnen, 2013). The



results of the quantitative section of the study were not all significant. The quantitative and qualitative results will now be discussed.

### **6.7.1 Quantitative findings summarised**

The quantitative section used three questionnaires. Due to the intervention being a feasibility study limiting sample size, graphs were used to show the results using means scores at baseline, week 8 and week 24 for both the control and intervention group. Mean scores were used to see if there were any differences found between both groups that could be attributed to the peer support group.

The intervention group had a higher QoL across all time points than the control group but the intervention group's QoL improved from baseline (mean score 75.38) to week 8 (78.88) but at the 4 months follow up the intervention groups QoL had dropped to (mean score 73.00) which is lower than their original baseline score. At this point a further analysis was conducted by subtracting each individual participant's mean scores from baseline and week 8, and then for week 8 and week 24 for both the control and intervention group. This was done because there was no main difference between groups at baseline and week 8 (Figure 1). At this point there was a difference between baseline and week 8, the intervention group had improved more than the control group. It was found that between week 8 and week 24 that the intervention groups QoL had worsened since the intervention had finished (Figure 2).

The Brief COPE questionnaire states that the higher the score on each scale the more likely that person is to use that specific coping strategy. The intervention groups mean score for emotional support (4.00) was higher at baseline than at 8 weeks (3.63) and again at 24 weeks

(3.25), this could be described as a positive reaction to having the support of the peer support group to help them cope with emotional support (Figure 3). In section 6.5.2.3 participants who took part in the peer support group spoke positively about the support they received. They were not dependant on themselves for emotional support because they had the group to help them with support they needed whereas the control groups emotional support means score was higher at 8 weeks and 24 weeks than baseline which could be possibly due to them not having the emotional support of the peer support group. It was found in the literature review that participants of peer support groups who had the support of the group were able to cope effectively using physical and psychological support strategies leading to a greater life satisfaction and improved QoL (Sheman, DeVinney and Sperling, 2004; Morris and Morris, 2012; Haas, Price and Freeman, 2013; Sweet et al. 2016).

Instrumental support is defined as the tangible help people receive from others and the mean score increased from baseline to 8 weeks for both the intervention and control group on this scale. The intervention groups mean score was higher at week 8 than that of the control group but the intervention groups mean score **at** the largest drop off at week 24. An increase in mean score for instrumental support in the intervention group could have been due to the advice given from their peers. Instrumental support is identifying and reducing or removing problems, which they might have done during the peer support group (Van Leeuwen et al. 2010; Van Lankveld et al. 2011).

A higher score on the GHQ-12 indicates a greater probability of a lower psychological well-being (Goldberg et al. 1997). As can be seen by the graph (figure 4) general health did not improve in either the control or intervention group from baseline to week 8 over time.

A further analysis was completed to see which coping strategies participants in the intervention groups used most and least. The results of the Brief-COPE using mean scores found that the most frequently used coping strategies by participants during the intervention were similar to those found in a longitudinal study that was carried out over 21 years which were acceptance, active coping and planning (Kennedy, 2000; Pollard and Kennedy, 2007; Kennedy, Kilvert and Hasson, 2016). The findings of this study also support previous evidence that the least used coping strategies are substance use, denial and behavioural disengagement (Kennedy, 2000; Pollard and Kennedy, 2007; Kennedy, Kilvert and Hasson, 2016).

### **6.7.2 Qualitative findings summarised**

The interviews with Simon and Jane provided a more in-depth account of how well the peer support group had worked for them as they were asked more questions and were able to give fuller answers. However, the feedback received by the intervention group as a whole in response to the qualitative open lifestyle questions corroborated the results of the thematic analysis. The shared master themes were ‘positive shared knowledge and experience’ and acceptance within the group and coping with SCI’. The summary below will include examples of how the BCW COM-B model (capability, opportunity and motivation) maps onto the findings of the qualitative analysis.

Participants enjoyed the peer support group sessions which both Simon and Jane said they had done. Jane said that she had enjoyed listening to the other participants stories which was reflected in the groups feedback that they had enjoyed sharing and listening to stories. The group had said that they felt relaxed and comfortable. These comments map on to the

Opportunity aspect of the Behaviour Change Wheel and include social influence, which is a key component of the Behaviour Change Taxonomy. The group feedback also found that they shared knowledge and experiences (capability i.e. knowledge and skills) with others during the peer support group which Simon and Jane had talked about during their interviews. The group feedback had found that they had learnt new methods of coping both emotionally and physically since taking part in the peer support group (motivation i.e. coping and emotional reaction). Whilst interviewing Simon and Jane, Simon talked about learning new methods of coping physically with his care needs (capability), whereas Jane discussed how the group had helped with her physical needs (e.g. secondary health impairments) (capability) as well as supporting her emotionally as she had felt overwhelmed with everything (opportunity and motivation). These were the shared themes between the group as a whole and the two participants that had been interviewed.

A summary of what the two participants found was that both Simon and Jane had said their main reason for attending the peer support group was for the knowledge and experience they could share and obtain from their peers (capability and opportunity). They found the intervention to be a positive experience and they enjoyed the weekly topics discussed by guest speakers. Feeling relaxed and comfortable in the company of their peers was a positive aspect of the intervention (opportunity and motivation). Both participants learnt new coping skills and how to manage with different health issues that they had (capability). They mentioned social activities would help build confidence (motivation).

Further findings from the interviews with Simon and Jane was that both participants wanted more peer support groups in the future, neither would change the structure of future groups,

including guest speakers. They believed the initial group for new participants should be kept closed for 8 weeks and then run an open group alongside it for participants that had already been to the closed group. The intervention groups response to the open questions was that they found the peer support group enjoyable and that there was nothing they disliked.

### **6.7.3 Quantitative and qualitative results summary**

It was found that QoL had improved significantly in the intervention group during the peer support group between baseline and week 8. The findings of the qualitative section support and add detail to the quantitative findings from the current study by providing evidence that participants had shared knowledge and experience, they felt relaxed and comfortable in the company of their peers (acceptance/empathy) and they had felt supported both emotionally and physically. A study by Ussher et al. (2006) which explored cancer peer support groups found similar relationships as current qualitative study in relation to improvements in QoL.

It was also found during the quantitative part of the current study that emotional support was reportedly lower at week 8 than at baseline as this was said to be due to the intervention group being supported emotionally by their peers during the peer support group which was corroborated in the qualitative results. The participants stated they felt relaxed and comfortable and Jane said she felt supported emotionally during the peer support group and in the quantitative summary it was found that this also led to an improved QoL.

### **6.8 Feasibility and acceptability of the intervention**

A possible potential threat to the feasibility of this study was the fidelity of the intervention itself. Fidelity is when an intervention follows the original design (Mowbray et al. 2003).

Fidelity is important in any intervention's effectiveness, and to not measure fidelity can weaken outcomes which leads to faulty conclusions (Dobson and Singer, 2005). However, Knittle (2014) suggests fidelity refers to the number of treatments aspects of the behaviour change intervention and not the way the protocols are set out. The UK Medical Research Council have said that measuring fidelity of an RCT should be done at the pilot stage before running a full RCT (Knittle, 2014). Knittle (2014) further suggested that assessing fidelity of a pilot study could be done on a budget by providing a checklist of behaviour change techniques (BCT) to the facilitator/provider to use during the sessions. Also asking participants to fill out a questionnaire after each session. Focusing on the fidelity of the BCT that are said to have the greatest impact on participants e.g. self-monitoring, goal setting, action planning and problem solving (Knittle, 2014). Participants could also take a questionnaire home to fill out to assess the BCT that they use outside of the intervention sessions (Knittle, 2014).

The current study is a feasibility study not a pilot study so therefore did not measure for fidelity data. However, all participants that took part in the intervention read all information that was sent to them and filled out the questionnaires at each stage of the intervention, this included both the control and intervention group. Participants filled out a wellness ladder to gauge their mood before each session. The peer support group also adhered to the original design of the intervention.

Feasibility and acceptability of the intervention was assessed using five open questions within the lifestyle questionnaire and also semi-structured questions during the qualitative interviews. The questions were based around satisfaction and the participants experience with

being a part of the intervention, there was no negative feedback just constructive comments that would help with the design and implementation of future peer supports groups. It had been mentioned that lack of transport would prevent participants from attending the peer support group and also childcare. It was suggested that illness due to SCI might stop someone from attending a group. These are issues that could be overcome with planning of future peer support groups.

## **6.9 Comparisons of intervention feasibility and acceptability across SCI peer support group studies**

There is a lack of published research on the feasibility and acceptability of behaviour change interventions in relation to peer support groups for people with SCI, which makes it impossible to compare the current feasibility study to previous interventions. There is also no previous research that has been published that has run a peer support group for individuals with SCI facilitated by a person with SCI which means it is possible to make a comparison with other intervention results following a similar format. Tickle-Degnen (2013) found that published feasibility studies are rare and ones that are published are typically focused on drug trials in which a single active ingredient is being tested.

## **6.10 Strengths and limitations of present study**

### **6.10.1 Strengths**

- The intervention was designed by gathering evidence using a literature review, systematic review, several interviews and a questionnaire which was fully completed by 270 people with SCI.

- The location used for the pilot peer support group had good accessibility for wheelchair users and was in a central location for all.
- The group was designed so all sessions had a guest speaker who were experts in their field, timings were exact with regular breaks allowing for further interaction between participants.

### **6.10.2 Weakness**

- Initially it was difficult to recruit people from the target population to take part in the intervention and it was quite time consuming as a snowball technique was used (Chapter 5, p.131)
- Some weeks not all participants turned up, guest speakers also changed, and session timings also changed (they went on longer than initially planned).
- More men than women were recruited, reflecting the fact that there are a greater number of men with SCI than women.
- The sample size was too small to give credible results using a quantitative methodology.

### **6.11 Implications for the intervention design**

Due to the current lack of research in the area of SCI peer support groups and there is a need for further research in this area to examine the effectiveness of future interventions. However, the current study suggests the need for the continued development of peer support groups for people with SCI especially ones that are facilitated by a person with SCI. The findings of the current study suggest a pilot study be designed and implemented using the same method as



the current feasibility study but scaled up to incorporate a much larger sample – perhaps involving several small peer support groups across different geographical areas. For participants without transport maybe there could be a pickup and drop off service and for participants with children childcare could possibly be at the peer support group location. For participants of future groups who become ill during the group closed group period a facilitator could visit them in hospital to keep them updated and give them support.

### **6.12 Intervention costs**

The cost of the feasibility intervention was exactly £570 as the premises were on the university campus and free to use for the purpose of the research. The university also provided catering at a cost of £40 per week, which came to £320 across the 8-week period of the intervention. The catering included tea, coffee, squash, wraps/sandwiches, crisps, biscuits and pasta salad; this could be cut down to make any future intervention more cost effective. The speakers were offered £20 for their time and travelling costs but nobody claimed it. One speaker who had SCI requested his travel costs and overnight stay be paid for at a cost of £250 as he travelled from London and this was considered acceptable because he was a TV, radio presenter and author and hence his talk was expected to be particularly valuable for the participants in the group. However, he did wave his standard fee for doing public talks. It was thought it was worthwhile having someone who had accomplished so much since being a user of a wheelchair to speak. All other speakers did not want payment for their time as they stated they wanted to be a part of making the peer support group a success as it was a worthy cause, however it cannot be guaranteed that this would continue to be the case going forward,

so costs for speakers would have to be factored into the costs of the peer support groups in the future.

Whilst interviewing participants during the qualitative section they said they would be happy to pay a weekly fee of £10 per session, this would be used for the hire of a premises and for refreshments. The refreshments were lower as the university's catering service was used. The average peer support group (closed or open) would have 10 participants and if they were each willing to pay £10 a session based on the original design of 8 sessions that would be a total of £800, considering the cost of a premises, paying for refreshments and also paying guest speakers, it is felt this would not be enough unless costs could be cut.

Peer Connect are a web-based site all about peer support networks, they are a part of a project called the Disability Support Organisation that help with setting up and running peer networks. Peer Connect state on their website that in order to hire some locations an insurance cover letter may be required in case of injury to a participant (average cost £70 a year). They suggest that budgeting is very important so that it is possible to be able to keep offering a peer support group in the future (Peer Connect, 2019). This would include making estimates of likely costs, comparing what has been spent to what the estimated expenditure is. Taking the costs of the of the current feasibility intervention into account and what participants would be willing to pay per session for future peer support groups, it is plausible to continue the group using the same structure as the current feasibility peer support group. However, this would be dependent on whether guest speakers would charge for their time and travelling costs and possible overnight stays. However, the evidence from this intervention is that guest speakers do not charge unless they are e.g. TV, radio and sport personalities.

However, taking into consideration that people who act as guest speakers do have to make a living so it is possible that not charging to speak could have been a one off and these costs would need to be factored into any future peer support group costings.

Current groups (not for people with SCI) that are held around the UK are run by charities including MacMillan and undertake fund raising events to meet the costs, they also offer grants to help with the setup costs of the groups e.g. SCI peer support group (MacMillan, 2019).

### **6.13 Summary**

The aim of this study was to evaluate whether the design and implementation of the peer support group intervention for people with SCI was feasible so that it could be scaled up to reach a larger audience. The evidence that was discussed and summarised using the qualitative data found that there was a positive pattern running throughout the results. The qualitative data showed that the participants who participated in the intervention group had a positive experience and felt that they benefited from attending the peer support group.

The key findings from qualitative section was that participants enjoyed socialising, sharing knowledge and experience with each other. They mentioned enjoying the different topics discussed during the peer support group. There was a difference of opinion about how often guest speakers should attend and whether there should be more. Participants who were interviewed said they would pay a fee of £10 a session for any future peer support groups. There was agreement that there should be a closed group initially but then an open group to run alongside the closed group after the initial 8 weeks.

The quantitative findings found a significant difference in QoL but the difference between the intervention and control group was only small. There were no significant changes over time when measuring emotional and instrumental coping, although the intervention group did use emotional coping less and based on previous literature this could be due to the support of the group and a feeling of acceptance (emotional focused coping strategy (Carver, 1997; Litman, 2006) during the intervention. Ussher et al. (2006) found that people who took part in peer support group felt acceptance which increased their ability to cope due to a sense of belonging.

The results of this evaluation of the peer support group also found that general health did not change over time in either group. There are some positives to take away from the quantitative analysis, however due to the sample size there was not enough data to give an effective analysis.

Based on the findings the next step would be to design a pilot peer support group study using the exact same design and structure, however, for a pilot study fidelity should be assessed and look further at budgeting/costings for future peer support groups to ensure they are economically viable in the long term and can be scaled up to meet a larger audience.

The findings of chapter 6 will be fully discussed in chapter 7.

## **General Discussion**

### **Chapter 7**

#### **7.0 Aims of the thesis**

The aims of the thesis were to identify coping strategies people with spinal cord injury (SCI) use enabling them to cope better, factors that impact on quality of life (QoL) and how QoL can be improved in people with SCI by designing an evidence informed, theory-based intervention and feasibility study and conduct a process evaluation. This was done by running a theory-based behaviour change intervention consisting of a peer support group which was found to improve QoL in people with SCI. Furthermore, it was found that the peer support group was feasible and could be rolled out to a larger SCI population.

#### **7.1 Summary of research findings**

The current research set out to design, implement and evaluate a peer support group for people with SCI that would improve QoL. This was achieved through the use of a mixed methodology using qualitative (chapter 3, study 2) data to help in the design of a questionnaire for the quantitative study (chapter 4, study 3). The results of both studies were integrated along with the evidence from the literature review (chapter 1) and systematic review (chapter 2, study 1), which informed the development of the peer support group. The results of the peer support group were then evaluated in chapter 6.

The quantitative evaluation of the intervention found a significant improvement in QoL, even though it was a small difference, between the intervention and control group and between baseline and end of intervention. This was supported by the qualitative findings which provided a clear pattern of evidence that a positive experience was had by all the participants who attended the peer support group. The results of the current study are consistent with the findings of Ussher et al. (2006) who conducted a qualitative study monitoring nine peer support groups for cancer patients. They found that participants who had attended the peer support groups improved their overall QoL. The peer support groups were similar to the current work where participants engaged in open discussions with one another and shared knowledge and experience.

Another aspect of the current research involved exploration of coping strategies used by people with SCI. A 21-year longitudinal study by Kennedy et al. (2000); Pollard and Kennedy, (2007); Kennedy, Kilvert and Hasson, (2016) looked at the impact of psychological trauma after SCI and the relationship with coping strategies. The intervention groups' time since injury varied from 2 years to 50 years but eight of the participants had been injured fewer than 21 years ago. Pollard and Kennedy (2007); Kennedy, Kilvert and Hasson (2016) found that people who had become SCI 21 years ago used the same coping strategies at 10 years and 21 years follow up and they were acceptance, active coping and planning (positive coping strategies). Members of the intervention group in the current study were found to be using positive coping strategies which were found to be correlated with lower levels of depression and improved QoL (Krause, Kemp and Coker, 2000; Kennedy, Kilvert and Hasson, 2016). The evidence from the qualitative and quantitative findings within the thesis

would suggest that the participants who took part in the peer support group had a positive experience whilst attending the group, with no negative implications.

Further to this, it was suggested that providing an intervention post SCI would help people with SCI adjust psychologically with the use of positive coping strategies (Kennedy, Kilvert and Hasson, 2016). In chapter 4 it was found that active coping and acceptance were associated with participants having fewer psychological issues and during the intervention in chapter 6 it was found that the most commonly used coping strategies were acceptance, active coping and planning. During the Kennedy et al. (2000); Pollard and Kennedy, (2007); Kennedy, Kilvert and Hasson, (2016) longitudinal study no intervention was given; however, they did provide evidence for which coping strategies helped people with SCI cope better and improve QoL. This was consistent with the findings of the current study.

## **7.2 Establish the need for a peer support group intervention**

The literature and systematic review focused on the issues that affect a person with SCI and provided a rationale for the research in the current thesis, which was how to improve QoL in a person with SCI. The evidence provided showed that people with SCI have a poorer QoL than that of the general population due largely to secondary health impairments (Dijkers, 2005; Kennedy et al. 2010) and they lack the knowledge and experience to help them cope since becoming spinal cord injured (Kennedy et al. 2000). Both chapters 1 and 2 discussed the changes that have impacted on a person since the injury or illness that paralysed them. There are currently 50,000 individuals in the UK that suffer from SCI (Aspire, 2018; Backup Trust, 2019). The literature provided evidence that people with SCI only spend 2 months on average in a specialist rehabilitation centre with some individuals only ever spending time in

a general hospital without ever learning the skills they need to reintegrate back into society (Sci-Info-Pages, 2015; SIA, 2015). The literature also indicated that the majority of those affected by SCI have trouble adjusting to their new found situation. It was suggested that a third of people with SCI suffer with depression, especially within the first few years, which leads to low levels of life satisfaction which in turn leads to a poorer QoL (Migliorini et al. 2009). The main reasons for this was comorbidities such as bowel, bladder, and sexual dysfunction, spasticity, pressure sores and pain (Kennedy et al. 2000; Kennedy, Lude and Taylor, 2006; Noonan et al. 2008; Post and vanLeeuwen, 2012; Kennedy, Kilvert and Hasson, 2016). This was supported by the findings throughout this thesis including the results of the qualitative interviews where all seven participants had said they have suffered with secondary health impairments and the quantitative analyses where 96% of 270 participants had said that they had suffered with secondary health impairments since becoming SCI. The research within the current thesis had looked at how well people cope psychologically and physically with SCI. The difficulty people have with SCI is adjusting to life with paralysis (Dunn, 1996; Glass, 1999; Kennedy, Evans and Sandhu, 2009), which provided a clear rationale for the work in this thesis as the evidence showed that after SCI people have issues that they have problems coming to terms with i.e. dressing, eating, secondary health impairments, leading to depression and a poorer QoL (DeVivo et al, 1991; Elliot and Frank, 1996; Kennedy et al. 1999; Soddien et al, 2000; Kennedy and Rodgers, 2000; Pollard and Kennedy, 2007; Chevalier, Kennedy and Sherlock, 2009; Kennedy, Evans and Sandhu, 2009).

Previous research has identified how well peer mentoring works in improving life satisfaction in people with SCI (Sheman, DeVinney and Sperling, 2004; Ussher et al. 2006; Morris and



Morris, 2012; Haas, Price and Freeman, 2013; Sweet et al. 2016). The difference between peer mentoring and a peer support group (current work) is that the latter is when a group of people meet with the same condition to share knowledge and experience, whereas peer mentoring is one on one and only offers one experienced person's perspective (Haas, Price and Freeman, 2013). The literature review found that people with SCI who had received peer mentoring within the first year after their injury or illness reported greater life satisfaction than those who did not receive any type of mentoring (Sherman et al. 2004; Sweet et al. 2016). Individuals who had attended peer support groups with cancer said they felt a part of a community (Ussher et al. 2006). They felt accepted and they gained knowledge and experience, which in turn, increased their ability to cope and increased their QoL (Ussher et al. 2006). The findings of the intervention in the current work found that people who attended the peer support group said that friends and family could not empathise with them, this was also found by Ussher et al. (2006) who found that participants in their studies did not feel supported by their relations. Participants in Ussher et al. (2006) study felt they could share knowledge and experience with their peers during peer support group sessions; this was found in the current work too. Further to this McGrath (1999); Docherty (2004); Ussher et al. (2006) found that participants who attended peer support groups felt part of a community, they felt they were not being judged and they felt accepted, this supports the current research where participants who had been interviewed said the same about attending the current peer support group. This evidence suggests that a peer support group would work effectively to improve QoL in people with SCI.

### **7.3 Selection of theoretical framework**

The previous research presented in the literature review and systematic review (chapter 1 and 2) provided the evidence that people with SCI who have a higher QoL appraised their situation, and adapted by using acceptance, active coping and planning coping strategies (Kennedy, Lude and Taylor, 2006; Chevalier, Kennedy and Sherlock, 2009). In a 21-year longitudinal study, acceptance, active coping and planning were said to be the most used coping strategies by people with SCI and have been shown to be associated with higher QoL (Kennedy et al, 2000; Pollard and Kennedy, 2007; Kennedy, Kilvert and Hasson, 2016). This evidence from previous research provided a theory-based framework for the current research which explored how people cope both physically and psychologically with their spinal injury and how that is associated with positive coping strategies and is predictive of a higher QoL. The second framework used for the current intervention was a behaviour change model which, in this case, was the behaviour change wheel (BCW) COM-B system (Michie et al. 2011). By developing interventions that change individuals' behaviours, new coping strategies can be adopted as in the case of the current intervention to help improve and maintain physical and psychological health (Ockene et al. 2000) by sharing knowledge and experiences which also help to improve QoL. The use of the Behaviour Change Wheel was chosen as a theoretical framework as it is suggested as a way of improving the implementation of evidence-based practice (Michie et al. 2011; Michie et al. 2014). Behaviour change interventions are important in public health and can be effective, they are defined as sets of activities that can change people's behaviour patterns (Michie et al. 2011; Bluethmann et al. 2017). The BCW using the COM-B system is a theoretical approach to designing an intervention and could be successful in improving QoL in people with SCI. The BCW was chosen over other methods as it has been designed by identifying all potential

intervention functions and policy categories allowing the design of the current peer support group and minimising the risk of neglecting important options (Michie et al. 2011). By using the BCW it allowed the design of the current peer support group to be custom fitted to the needs of the participants by using the COM-B system. According to Michie et al. (2011) using a theory-based behaviour change intervention offers the best chance of success.

However, to date, no peer support groups have been designed for people with SCI using the BCW COM-B system. This means there is nothing to compare the current peer support group design to directly so future researchers may wish to continue this exciting new research which could lead to important findings to inform interventions to enhance QoL in people with SCI.

Choosing a peer support group as an intervention to try and help improve QoL was justified as previous evidence reported throughout the thesis has shown that people who had attended a peer support group (although for populations other than SCI) had improved their knowledge, and their experience around their condition, and developed more effective coping skills (McGrath, 1999; Docherty, 2004; Ussher et al. 2006). They also gained empathy and emotional and social support as they felt accepted and part of a community and had reduced feelings of isolation (McGrath, 1999; Docherty, 2004; Ussher et al. 2006).

In earlier qualitative (chapter 3) and quantitative (chapter 4) studies within this thesis, it was found that participants had difficulty adapting and coping with their SCI. They lacked knowledge and experience relating to their condition and secondary health impairments were a challenge. They also had difficulty talking to people about things that affected them after SCI. The results of the qualitative evaluation of the peer support group, developed for the

current project (chapter 6), found that participants generally used positive coping strategies i.e. acceptance, active coping and planning (coping strategies that that reduce anxiety and depression, help improve how people cope and enhance QoL) (Kennedy, 2000; Pollard and Kennedy, 2007; Kennedy, Kilvert and Hasson, 2016). In the current project participants reported using these coping strategies at baseline, at the end of intervention and at follow up, but there was no change in coping strategies due to taking part in the intervention. However, the mean differences showed that participants did use emotional coping to a lesser extent after the intervention which could be due to the sharing and receiving information from their peers during the intervention, but due to the small sample this difference was not significant. It was found that overall QoL did improve during the peer support group for the intervention group. Individuals talked about feeling comfortable during the peer support group sessions as they were amongst other people with SCI, they discussed empathy with their peers (emotional support). They wanted to be a part of the peer support group (active coping) where they actively shared knowledge and experience with their peers (instrumental support). People expressed their concerns about having little to no contact with their peers or health care professionals after discharge from hospital and discussed their secondary health impairments with each other (venting). Participants who filled out the descriptive section of the questionnaire spoke about the positives of SCI (acceptance). Finally, they mentioned they would also like to attend more peer support groups in the future (planning); these answers were further supported by those of the two interviewed participants. The findings of the current peer support group were the same as Ussher et al. (2006) who analysed nine previous peer support groups with cancer patients using qualitative methodology. The findings of Ussher et al. (2006) were that participants who were interviewed gained knowledge, experience, they could empathise with other participants, they felt accepted and

they built new friendships that lasted outside of the peer support group. However, it is difficult to compare the current work with the methodology of Ussher et al. (2006) as their study monitored nine separate peer support groups with people who have cancer. What comparisons can be made are in relation to the population; they included people with a long term condition (cancer), the current study looked at people with SCI, they used a mixture of men and women although they interviewed 93 participants of which 75 were women and in the current study 3 out of 10 participants were women, the mean age was older at 62 years compared to 43 years in the current study. The average peer support group Ussher et al. (2006) monitored was between 3 and 40 participants, the current study had 8 participants and each session lasted 2 hours on average, which was the same as the current study.

The BCW has been successfully applied in a number of ways and has been recognised as an effective way to help in the development and implementation of an intervention (Michie et al. (2014). However as previously mentioned it has not been applied in this context and the following will show how it was operationalised to guide the development of the current intervention. The reason for developing the peer support group was so that people with SCI could educate each other by sharing knowledge and experience. It was to enable them to share skills with each other that had either been learnt whilst in rehabilitation or over a lifespan and lastly to support one another whether this was with help and advice about sports, work, holidays, financial benefits or just being able to live without being dependant on others. The features that a peer support group would need to provide to help participants change their behaviour were found to map onto the components of the COM-B system. The design of the current peer support group used the BCW COM-B system intervention functions. Education, which included sharing verbal knowledge and experience with each

other and providing information to help with coping with SCI. Training, which includes sharing skills with each other so that the people that attended the group could develop new skills providing help with transferring themselves from their chair to their bed or car etc., wheelchair skills. Enablement which can be defined as a way of giving support and advice enabling participants within the group to set goals or look at factors in their life that influence their behaviour and help them overcome barriers i.e. internal or social. The next part of the COM-B system is sources of behaviour. Michie et al. (2011) said that in their behaviour system capability, opportunity and motivation interact to generate behaviour, the behaviour can then influence each component in the COM-B system e.g. opportunity can influence motivation as can capability. Participants who had attended the peer support group who were interviewed said they felt comfortable with being a part of the peer support group i.e. capability; they had the physical and psychological capacity to take part in the group and they shared knowledge and experience. Opportunity is defined by Michie et al (2011) as all the factors that lie outside the person that make the behaviour possible or prompt it; the participants in the intervention took part in the group therefore taking the first step in making a change to their behaviour and the ways in which they cope. Finally, motivation is defined as learning from other experiences; setting goals, optimism for the future and beliefs about one's capabilities/empowerment, in relation to the peer support group they were motivated to attend each session, they had also discussed wanting future peer support groups, employment, going on holidays and education.

The theoretical approach used within this thesis is a strength of the current research because it makes it clear that by attending the peer support group participants continued to use positive coping strategies from baseline to follow up as was identified by analysing the Brief-COPE

measure in chapter 6. It was further illustrated that using the BCW COM-B system had a positive impact on the design and outcomes of the intervention, for example participants said they had shared knowledge and experiences with each other and learnt new skills and were making plans for the future and overall had a positive experience.

#### **7.4 Intervention design**

The aim was to design an intervention that would improve QoL in people with SCI. As with Christianson (1985), Morris and Morris, (2012), the design of this peer support group involved structured weekly sessions, but it had the added benefit of being theory based.

The design of the peer support group started first, with the literature review and previous evidence of past peer support groups. Although there had been peer support groups that had involved people with SCI, they tended to focus on therapy, so only parts of their design were considered helpful in the design of the current project (participant numbers, number of sessions, length of session, the use of a control group) (Craig et al. 1998; Kennedy et al, 2003). Both of the previous interventions involving SCI participants consisted of an intervention group and control group but used health care professionals to deliver cognitive behaviour therapy (CBT) and cognitive effectiveness training (CET) to newly injured patients in specialised rehabilitation centres. The groups included between 5 and 9 participants in each session and lasted between 60 minutes and 120 minutes. The sessions ran weekly for between 7 and 10 sessions which included directed discussion and practical exercises which were structured around the theoretical underpinning of the intervention i.e. CBT and CET. Craig et al. (1998) found that the intervention group had scored high for anxiety and depression before treatment but were significantly less depressed and had reduced anxiety after treatment which

lasted up to 1 years afterwards compared to similar participants in the control group.

Kennedy et al. (2003) did find a reduction in anxiety and depressive symptoms in the intervention group compared to the control group but they found no significant change in coping strategies between the two groups, however, there was difference found between the current studies groups and the coping strategies. Both the intervention and control group used acceptance and active coping at all three time points, the main difference in coping strategies was at baseline and follow up the intervention group used humour and the control group used self-distraction, at the end of the intervention the participants who attended the peer support group used instrumental support whereas the control group used planning. No previous reports of peer support groups were found for people with SCI that had structured sessions where peers could help each other just by talking openly and honestly to one another and gaining knowledge from their peers and guest speakers with set topics weekly. However, two peer support groups were found that contained a very similar design as the current project Christianson (1985) and Morris and Morris (2012). One peer support group was designed for couples that were infertile and the other was for stroke patients. Although the peer support group for stroke patients was for inpatients the sessions were structured around what participants wanted to discuss and involved open discussion unlike the studies by Craig et al. (1998) and Kennedy et al. (2003). The study involving infertile couples had between 8 and 10 participants and ran for 8 to 10 weeks which consisted of structured sessions with guest speakers and was a closed group. That is very similar to how the current peer support group was designed. The stroke peer support group used 7 participants and 3 carers, there were 5 sessions per phase which lasted 90 minutes per session. They had an open discussion and refreshment breaks, they also broke into smaller groups and separated the patients and carers and then they all came back together for a group discussion, which is the same structure as



the current intervention except that the two separated groups were participants and friends and family sessions. Both groups were designed so participants could share their feelings and concerns in an open and honest group with total confidentiality where they would not be judged, this was one of the main design themes for the current peer support group.

Christianson (1985) found that participants learnt new coping skills, regained control in all aspects of their life and emotional well-being improved. The current study found that participants that were interviewed said they had learnt new ways of coping with health issues. The findings of the Morris and Morris (2012) group using a qualitative methodology were that participants found they could share their own experiences, the current study found that participants could share both knowledge and experiences with other participants. The participants in Morris and Morris (2012) study said they could express emotions in a secure environment helping to improve both self-efficacy and self-esteem to help their fellow peers. In the current study participants had discussed feeling comfortable in the environment and being able to share with their fellow peers. Further to this, no peer support group could be found for individuals with SCI that was facilitated by a person with SCI. This is important as previous research has identified that participants may feel inhibited when discussing personal issues amongst groups that include people who do not suffer from the same condition as they themselves do (Ussher et al. 2006).

One of the key attractions of the intervention design was the fact that the facilitator has SCI himself and had lived experience of the condition that was of relevance to the peer support group members. He was able to facilitate the discussion within the group and take responsibility for the development and functioning of the group (WHO, 2017). The facilitator of this peer support group arrived on time for each session and ensured that the group stuck to

timings and that everyone had a turn in talking. When it was time for the guest speaker to leave so the group could have a discussion privately about the session topic, the facilitator would politely ask them to do so. People said they felt able to discuss issues freely and were supported during the intervention process. However, at times, the facilitator did have trouble controlling the group as there were some strong characters in attendance. Some of the early sessions were a little chaotic at the start, as everyone who attended would break off into little groups whilst getting to know each other. By the third session, the facilitator started to control each session and ran the group discussion as it was structured.

Further to having a facilitator, the design had considered all past evidence that was found in previous chapters. This included the results of both chapters 3 and 4 where participants had discussed how they would like a peer support group structured e.g. health issues discussed, set topics weekly, friends and family sessions, time, location and how often a group should be held. The results of the qualitative and quantitative research reported in previous chapters provided evidence that participants had struggled to adjust, adapt and cope with becoming spinal cord injured. They were affected by secondary health impairments which led to a poorer QoL. People had found it difficult to talk to their friends and family after SCI and felt they couldn't openly discuss health problems with health care professionals. People said when attending a group, they did want to talk openly and feel understood without feeling judged. They needed help coping and help with future opportunities such as employment, travel and relationships. The results of the two studies reported in chapters 3 and 4 showed that overall people with SCI had a poor support network suggesting they could benefit from a peer support group. The outcomes of both of these previous studies found that participants who had filled out questionnaires and who had been interviewed showed positivity towards

the idea of a peer support groups and had said they wanted to share their knowledge and experiences with their peers. The participants had said they wanted structured sessions with defined topics including topics on health care issues, they also wanted sessions where friends and family could attend. They felt that by structuring the sessions this way they could build confidence and would help them overcome their fears of being stigmatised because of their SCI.

Using the results from the previous studies reported in chapters 3 and 4, combining these with the design of interventions by Christianson (1985) and Morris and Morris (2012) studies and basing the design on the BCW COM-B system the current peer support group was designed specifically to meet the needs of participants with SCI. There were 8 sessions once weekly, with 8 participation in attendance, a guest speaker each session with a set topic about health or living with SCI and how to cope. There were refreshments breaks which gave participants a chance to mingle with each other and have candid chats about themselves helping them to build friendships. In each session participants were encouraged to join in and openly and honestly discuss any problems they may have or need help with by the facilitator.

However, there were things about the group that did not go as well as they could have. Some participants were not as outgoing as others and could easily be lost in the group. The facilitator had to be strong and take control and invite contribution from those that did struggle to be heard. As the sessions went on, the quieter people began to be more vocal. Not all participants turned up to every session with various reasons given e.g. childcare, holidays, illness, and difficulty with transport. Most of the issues could be overcome with future peer support groups. For example, a children's play area with a qualified person to

look after the children could be set up. If a participant was in hospital, it would be possible to visit them and inform them about the session topic and talk this through with them until they are able to attend again. For people who have difficulty with transport it is may be possible to arrange transportation when attending future peer support groups. A potential difficulty with providing these types of facilities could be the expense, so options for funding would have to be considered.

The location and frequency of meetings were of great importance. The current group was ideally located as the accommodation was free of charge, there was plenty of disabled parking, wheelchair access and disabled facilities e.g. toilets. Participants were emailed after they had been allocated to the intervention group and asked where they wanted the group to be held (options were provided), which day of the week they wanted sessions to be held on and at what time during the day. The largest number of participants said Cardiff Metropolitan University, on Thursday and at 6pm. A consideration for future groups is accessibility; making sure people can get to the group easily, considering the physical and logistical issues. The building, where the peer support group took place, needed to be big enough for a group of between 8 and 10 participants in wheelchairs. For the current peer support group, tables had to be put around the sides of the room and stacked on top of each other along with the chairs to make room for wheelchairs in the centre of the room. The consensus, during the data collection throughout the thesis, was that once monthly would be an acceptable frequency to meet, although the current peer support group was once weekly because of the time restraints on completing the thesis, participants accepted this and the qualitative data suggested they didn't mind.

## **7.5 Process evaluation**

Participants who attended the group did have some issues with illness, transport, childcare and work commitments. Not all participants were able to attend every group session; however, the minimum amount of sessions anyone tuned up to was 5 and half of the participants turned up to all 8 sessions.

The benefit of the peer support group was that participants had a positive experience as measured using interviews and open questions on the questionnaire (chapter 6). The peer support group was held in an environment that was quiet, accessible and was only attended by people with SCI. During the interviews, participants had said they enjoyed the structure of the sessions and the topics. The participants who attended the current peer support group expressed that they were able to share their emotions and thoughts with their peers in a way they felt unable to do with friends and family who did not have spinal injuries. They felt they were able to share knowledge and experience and by doing this, participants could discuss solutions to certain problems and overcome challenges that each of them faced daily. It was discussed, during the interviews, that learning from others that are in the same situation as themselves is paramount as it enables participants to cope and adopt new coping strategies. The findings were similar to those found in the literature review, which was that the way people adapt and cope with their SCI is influenced by those people helping them and in this case their peers with SCI (Moos and Tsu, 1976; Kennedy et al. 2000). Participants who attended the intervention said that they were able to share skills with each other, e.g. wheelchair skills, picking items up, getting dressed, and bathing. The peer support group provided much more. It enabled participants to make new friendships and strengthen their social support network. Evidence in the literature review had found that people with injuries

and illnesses can often find themselves isolated and feeling lonely. Going to a peer support group can reduce their feelings of isolation (McGrath, 1999; Docherty, 2004; Ussher et al. 2006). Within the group, participants discussed other groups, for example wheelchair rugby, basketball and even crocheting classes. These were community resources that, individually, participants did not know about. Other issues discussed during the group were travel e.g. how to get on a plane or train, accessible hotels, and the best places (countries) to visit with accessibility. Some participants did not know what disability benefits they were entitled to or how to go about getting employment or entering education. For the participants, the peer support group enabled them to learn new information, share information, provide and receive support and make new friendships that will last beyond the closed group peer support group sessions.

The current peer support group was very positively evaluated, and participants said they had a positive experience. There were some attendance issues, but overall attendance was good. There is a lack of research on the feasibility of a peer support group for people with SCI, but based on the findings of the evaluation of the current intervention it can be argued that it would be feasible to design and run a pilot peer support group for people with SCI. The pilot study should measure fidelity (see chapter 6, section 6.8) and can be done by involving the facilitator (providing them with a checklist of behaviour change techniques to use during sessions) and participants by asking them to fill out a questionnaire after each session to ensure the peer support group is providing the kind of support for which it has been setup (Knittle, 2014). Overall, based on the structure of sessions, the topics, the guest speakers, attendance and the positive feedback from the participants themselves, a future peer support group would be feasible.

## **7.6 Outcome evaluation**

Overall, the outcome evaluation shows that there was a slight improvement in QoL in the intervention group at the end of the intervention even though QoL in the control group also improved, the intervention group had improved more. These findings were further supported by the qualitative results which provide evidence that the participants of the peer support group had a positive experience and were happy with how it went. The reason for the lack of significance in the quantitative results was the small sample size. Having a small sample size reduces the power of the study and increases the margin of error, which in some cases can render the results of the study ineffective (Faber and Fonseca, 2014). This could be overcome in the future by developing a larger randomised control trial; however, running one peer support group with 10 participants would not be sufficient as it would take far too long to gather enough data, there would need to be more peer support groups running concurrently and data collected at regular intervals.

## **7.7 Future research and implications**

The research presented in this thesis reported a number of important findings that could inform future research. It would be beneficial to build on this research by incorporating the strengths of the current peer support group design. Future peer support groups should use theory and research evidence to inform the design and tailor content to the target group (Bokhoven, Kok and van der Weijden, 2003; Brug, Oenema and Ferreira, 2005; Michie et al. 2011). The evidence from the current study is of great value as there is a lack of research in the area of SCI peer support groups.

Key findings of the current research include the importance of participants being able to openly discuss topics that affect them daily, having a facilitator who has SCI themselves, having a group no larger than 8 to 10 participants, time for free conversation between participants, having a structure to the sessions that includes key speakers and refreshments (Christianson, 1985; Hildingh et al. 1993; Wilson, Flanagan and Rynder's, 1999; Morris and Morris, 2012). Participants were able to build friendships which is an important coping strategy (emotional support). A main factor that people liked was the refreshment breaks where they could talk amongst each other and they really enjoyed being able to bring friends and family to specified peer support group sessions.

Future peer support groups should run a longitudinal study to be able to run an effective quantitative evaluation. Craig et al. (1998) carried out a longitudinal study and had 28 participants in their intervention group and 41 in the control group and measured them at the end of the intervention, 12 months and at 24 months after completion of the intervention, at which point they still had 27 participants in the intervention group and 31 in the control group. Kennedy et al. (2000) had 87 participants involved in their intervention, who completed questionnaires every 6 weeks during rehabilitation. The participants then filled out questionnaires at 5 different time points up to 2 years after discharge when only 37 of the original participants responded but original data from the participants who hadn't responded were analysed in order to make comparisons. The quantitative results at the 1 and 2-year points for both studies were reported as having significant results, in Craig et al.'s (1998) study at the 1-year point participants from the treatment group were significantly less depressed than those in the control group. The results of Kennedy et al. (2000) showed that participants in the study were still using the same positive coping strategies at 2 years post



discharge as they were using at 1-month post discharge. The evidence of both longitudinal studies suggests that to run an effective quantitative longitudinal study 69 participants would be enough based on the evidence of the two studies reported. As the current peer support group had 8 out of 10 participants who attended in the intervention group and 10 in the control group, participants from 4 peer support groups would be required, data could be collected at the end of each peer support group when participants would fill out a questionnaire. A system could be designed where a questionnaire is automatically sent out to past participants every 6 months to see how they are coping since leaving the closed group. It is believed that there could be a cost-effective way of doing it electronically, but a researcher would need to be employed to run the system, collect the data, and be in control of arranging and running future peer support groups. Further to this funding would be needed for a venue, guest speakers and refreshments.

### **7.8 Strength and limitations of the research**

The main strength of the research reported within this thesis is that there is no pre-existing research of past peer support groups for a person with SCI that is facilitated by a person with SCI. This clearly provides a need for this research to see if a peer support group is feasible and what the benefits may be to people with SCI.

The study was designed by gathering information from individuals with SCI. This was done using a qualitative and quantitative mixed methodology which adds strength to the current design. McKim (2017) stated that mixed method studies add value by increasing validity in the findings and gain a deeper, broader understanding of the research being investigated. It was also found that people had more confidence in the results of mixed method studies due to

the integration of the two methods qualitative and quantitative (O’Cathain, Murphy and Nicholl, 2010). By interviewing people with SCI, it provides clear evidence of what they want and need from their own prospective from a peer support group. The second phase was to ask people from all over the world how they were affected by SCI and what they thought of a peer support group. The results of that quantitative study provided strong evidence in support of the development of a peer support group as 270 participants completed the questionnaire and endorsed providing a peer support group for people with SCI. The results found that 83% of the participants who filled out the questionnaire said that attending a peer support group would build confidence, 81% said that they would overcome stigmatisation by being a part of a peer support group and 91% said that people with SCI should join a peer support group. As well as these two methodologies, a vast amount of evidence was garnered from the literature review and systematic review. The evidence from previous studies involving people with SCI (Craig et al. 1998; Kennedy et al. 2003) was used to help inform the design of current study, as well as, two previous peer support groups that were successful in improving QoL but did not involve people with SCI (Christianson, 1985, Morris and Morris, 2012). The current intervention was designed using theory, based on the behaviour change model the BCW using the COM-B system (Michie et al. 2011) which adds strength to the design as evidence has suggested that interventions are more effective when based on theory (Brug, Oenema and Ferreira, 2005). The structure of the sessions received positive feedback from the participants who had attended the current peer support group. Participants had said they enjoyed the topics, accessibility, location and timings and had only positive comments to give. The current study used a mixed methodology to analyse how effective the peer support group was in providing a beneficial intervention and improving QoL. This enabled a comparison which, although the sample size was too small for a reliable

quantitative analysis it provided preliminary evidence for the value of a peer support group which was further supported by the entirely positive feedback from the qualitative analysis.

The weaknesses of the research were that there had been no template to work from with this population, so the design of the current peer support group had to start from scratch eliciting views of people with SCI and the findings of support groups that used other populations.

However, this was also considered a strength as it allowed the creation of something entirely new based on the views of people with SCI. As previously mentioned, the sample size of the intervention and control group was too small to be able to garner enough quantitative data to conclusively evaluate the effectiveness of the intervention. It was also found to be difficult to recruit individuals with SCI to the intervention, but eventually this was overcome by using a snowball technique which was time consuming. Not all participants turned up to all sessions, but this can be improved in the design of future peer support groups as this was mainly found to be due to transport and childcare. Guest speakers can be unreliable, and it would help to provide a plan B in the case of being let down as this happened with the current study on one occasion. Sessions ran longer than initially planned, but this is both a strength and weakness as participants enjoyed the peer support group so much, they did not want to leave. More men than women were recruited, but this was to be expected as 80% of people with SCI are men.

## **7.9 Reflexivity**

I chose the current research based on my own lived experience of being a person with SCI. I had a car accident whilst serving in the army and spent the next 6 months in a specialist rehabilitation centre. Even though I had become paralysed I found the relationships I built with my fellow SCI patients would see me through the toughest of times in those first

months, we belly laughed most days. During the next 5 years of being a person that used a wheelchair with no contact with other people with SCI I would barely leave the house and if I did, I thought everyone was staring at me. I did not feel comfortable in my own skin. It was around the 5-year point that I was asked by my solicitors to see a Psychiatrist who diagnosed me with posttraumatic stress disorder my QoL was as poor as it could be. At that point I decided enough was enough, my son was born, and I started to live life again.

When I first decided to research the impact of SCI on QoL both psychologically and physically I had no idea how hard it would be. For the first 2 years of reading the literature for the background of my thesis I felt depressed and went to my GP and was prescribed citalopram. The studies I was reading were so negative about how SCI impacted on a newly injured person and even an ageing SCI. Of course, deep down I knew that this was not the same for everyone with SCI, this spurred me on further to do my own research.

The first interviews I did for chapter 3 gave me hope nearly all the participants who took part in the process seemed to be living life to the full with the exception of one or two who were quite negative about life in general. However, I found whilst interviewing participants that I would interject and conversate to much as I found myself agreeing with them. Due to the lived experience that I have had myself I could empathise, but I do believe it did impact on the interview process but in a positive way. I did learn from the first two interviews and spent more time listening and only speaking when I needed to for the other interviews. When it came to analyse the interviews, I do believe that I could be biased and had to take a step back and re-evaluate the situation before proceeding. However, the interview process really got me enthusiastic about moving forward with my PhD. I had really struggled with chapter 3 so to complete it felt like a win. The process was a positive experience and I felt that most of the

participants really enjoyed life despite the issues they had, and they were all genuinely excited about the prospect of a peer support group.

In chapter 4 participants from 12 countries filled out the questionnaires. What I discovered in that chapter is that it doesn't matter where you are from SCI affects people with SCI in the same way. The results of the studies reported in chapter 3 and 4 found that nearly all participants suffer with secondary health impairments which has the biggest impact on QoL, since I have had SCI, I have suffered every day with pain and spasms. The findings of this chapter supported the findings of chapter 3 and that is people with SCI want to go to a peer support group or believe people with SCI should go to one to share knowledge and experiences with one another. At this point I felt like my PhD could help change things for people with SCI in a positive way.

I next part of my PhD was the hardest, developing a peer support group and actually running it. It was hard to recruit participants; it was hard to recruit guest speakers and the logistics of finding accessible premises in the right location was quite difficult as everyone who was attended the peer support group had a say. The development stage was a stressful time but also enjoyable and it was exciting due to it being the first peer support group of its kind. The sessions were great watching people grow week after week, some had been quiet and became quite vocal. You could see they were learning from one another and being supportive. What struck me most is what I got from the sessions, I was learning things that I didn't know and found myself interested in what the guest speakers had to say. The process worked for me and I grew throughout the process.

The PhD research process was quite challenging. I have never really done much qualitative research so found that particularly challenging and spent a long time on chapter 3. I did feel like I had accomplished something and had grown as a qualitative researcher by the time I finished the write-up of that particular chapter. I had done more quantitative research in the past so felt more comfortable with that part of my thesis although that became challenging at times. The design phase of the peer support group was difficult as there was not much evidence of past peer support groups that had been conducted with people with SCI.

However, I managed to find some evidence and included peer support groups that had participants with other types of conditions. I believe I did produce a successful peer support group that people enjoyed attending and for that I am proud of myself. I believe I have grown with confidence throughout this entire process. I really did not believe I would get this far and at times I wanted to give up and would have if it wasn't for the support of my wife and supervisor. Now when I look at my completed thesis, I feel a sense of accomplishment and pride but more than that I really hope that I can change at least one person's life by being able to attend a peer support group. I never want anyone to feel like I did in those first 5 years of being spinal cord injured.

## **8.0 Conclusion**

There are no known peer support groups for people with SCI in the UK that are facilitated by a person with SCI. The main findings found that the peer support group was beneficial in a range of ways. In participants' own words they found it a positive experience. They enjoyed the structure, sessions, topics, the social aspect and meeting new people, sharing knowledge and experiences with one another. They spoke of wanting more open groups so they can

continue meeting. Finally, people gained new friends within the SCI community where they receive continued support.

Ultimately, the peer support group has been effective in improving QoL for those who participated even though a larger sample size is needed to build on these results; however, based on the evidence of the evaluation the intervention was feasible and could be scaled up to meet a much larger audience. The results also provided evidence that participants during the peer support group used emotional support less, instrumental support more and overall QoL had improved which was the main aim of the thesis.

Moving forward, the findings of this research suggest that the design of future peer support groups would benefit from including key features such as: SCI facilitator, SCI participants only, guest speakers who are health care professionals or influential people with SCI, family and friend sessions, refreshment breaks and a closed group to start with so participants feel comfortable enabling them to open up.

A large benefit of the support group was from the relationships that developed between the participants that helped to build knowledge, confidence and social competence that has the potential to outlive the peer support group and so provide long term benefits to the participants that will also have the potential to help reduce reliance on health and social services. More large-scale research is required to support these initial conclusions.

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## **Appendices**

## **Appendix 1: First Stage in the design of the peer support group using qualitative methodology**

**Project title:** What is a peer support group and how will it support me with a spinal cord injury?

## Appendix 1A

### Ethical approval

Thursday, 08 January 2015  
cshs-srec/ethics /approved/nht/6306

Thomas, Gareth  
MPhil/PhD  
Cardiff School of Health Sciences

Dear Applicant

**Re: Application for Ethical Approval:**

**What is a peer support group and how will it support me with a spinal cord injury**

**SREC Project Reference Number : 0063-SREC-2014(02)**

Your ethics application, as shown above, was considered by the School Research Ethics Committee (SREC) on 1/7/2015.

I am pleased to inform you that your application for ethical approval was **APPROVED**, subject to the conditions listed below – *please read carefully*.

#### Standard Conditions of Approval

1. Your Ethics Application has been given a Project Reference number as above. This **MUST** be quoted on all documentation relating to the project (E.g. consent forms, information sheets), together with the full project title.
2. All documents , must also have the approved University Logo and the Version number (in the footer).
3. A full **Risk Assessment** must be undertaken for this proposal, as appropriate, and be made available to the Committee if requested.
4. Any changes in connection to the proposal as approved, must be referred to the Panel/Committee for consideration **without delay quoting your Project Reference Number**. Changes to the proposed project may have ethical implications and so must be approved.
5. Any untoward incident which occurs in connection with this proposal must be reported back to the Panel **without delay**.

This approval is valid for 12 months from the date of approval. Please set a reminder on your Outlook calendar or equivalent if you need to continue beyond this approval date. It is your responsibility to reapply / request extension if necessary.

Yours sincerely



**Prof. Jorge Erusalimsky**  
**Chair of School Research Ethics Committee (SREC)**  
Tel : 029 2041 6853  
E-mail : jderusalimsky@cardiffmet.ac.uk

Cc: Limbert, Caroline

**PLEASE RETAIN THIS LETTER FOR REFERENCE**

## Appendix 1B

### Feedback from Ethics Committee

17 December 2014  
cshs-srec/ethics/appinprinc/nht/6286

Thomas, Gareth  
MPhil/PhD  
Cardiff School of Health Sciences  
Llandaf Campus  
Cardiff CF5 2YB

Dear Applicant

**Re: Application for Ethical Approval : What is a peer support group and how will it support me with a spinal cord injury**

Your Ethics Application, as shown above, was considered by School Research Ethics Committee on 10/12/2014.

As a result, your application was **APPROVED IN PRINCIPLE** as being ethically sound. However, full approval was withheld because the Panel/Committee felt that some amendments/further information were required as follows:

- 1) Please clarify how the participants will be recruited.
- 2) In the participants' information sheet – last paragraph – please replace the information regarding complaints or concerns to the following: - should you require further information or have any queries regarding the project please contact my supervisor Caroline Limbert at [climber@cardiffmet.ac.uk](mailto:climber@cardiffmet.ac.uk).
- 3) In the event of a complaint please contact:  
<http://www.cardiffmet.ac.uk/study/student-services/Pages/Complaints.aspx>

Please make these amendments to your application/supporting documents as soon as possible, highlighting the changes made, and submit to the relevant Panel /Committee for reconsideration.

**Please note that this is not final approval. Do not commence any activity on this project until you receive the final approval confirmation.**

Yours sincerely



**Prof. Jorge Erusalimsky**  
Chair of School Research Ethics Committee (SREC)

Tel : 029 2041 6853  
E-mail : [jderusalimsky@cardiffmet.ac.uk](mailto:jderusalimsky@cardiffmet.ac.uk)

Cc: Limbert, Caroline

## **Appendix 1C**

### **Participant information sheet 2014/15**

**Project title: What is a peer support group and how will it support me with a spinal cord injury**

#### **Welcome**

The aim of the research project, of which this interview forms a part, is to design an intervention involving a peer support group to develop self-efficacy and improve quality of life for individuals with SCI who are leaving rehabilitation centres and for those with long term SCI.

To take part in this study/interview the only requirements are that all participants be over 16 years old and have a spinal cord injury.

The researcher will be asking for up to an hour of your time so that they are able to interview you. You will be asked questions about yourself, your injury, your day to day life, how your injury affects you physically/mentally and how you think a peer support group may be able to help you and others like you.

If you feel unclear about anything the researcher has asked, you can ask them to clarify or if you feel uncomfortable with the interview you are able to take a break or stop at any time.

All interviews are confidential, and anything said will be kept within the research team. Once the interviews have been transcribed and the study is finished, all interviews will be deleted. All interview data will be stored on a code protected computer or in a locked cupboard. No names will be recorded on the transcripts so it will not be possible for anyone to identify anything that you say. You will be offered a copy of the transcript to approve before it is used in the research.

Please remember that participation in this research study is completely voluntary. Even after you agree to participate and begin the study, you are still free to withdraw at any time and for any reason.

You will be able to keep a copy of this information sheet. If you have any complaints or concerns about this research, you can direct these, in writing, to the Head of Applied Psychology by email at: CSHS@cardiffmet.ac.uk. Alternatively, you can contact us by post at: Ethics Committee Chair, Cardiff Metropolitan University, Llandaff Campus, Western Avenue, Cardiff, Cf5 2YB.

If you would like any further help and advice about your SCI this is available at:  
<http://www.spinal.co.uk/page/contact-us>



## Appendix 1D Participant Consent Form

**Reference Number:**

**Participant name:**

**Title of Project:** What is a peer support group and how will it support me with a spinal cord injury

**Name of Researcher:** Gareth Thomas

Participant to complete this section: Please initial each box.

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.

☐

3. I agree to take part in the above study.

☐

4. I agree to the interview / focus group / consultation being audio recorded

☐

5. I agree to the use of anonymised quotes in publications

☐

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Name of person taking consent

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of person taking consent

\* When completed, 1 copy for participant & 1 copy for researcher site file

## **Appendix 1E**

### **Semi-structured interview questions**

#### **Interview Questions**

Welcome, and thanks for agreeing to take part in this interview. My name is Gareth Thomas and I am a PhD student looking at the possibility of developing a peer support group for people with SCI so your view is really important in shaping the way we go on to develop the plans for this potential peer support group.

I am going to ask you a few questions, but largely I hope we can just have an open discussion about your thoughts on a peer support group. If you don't want to answer any questions, or you want to terminate the interview at any point, that is fine. Please just let me know.

Okay, are you okay if we start?

1. Please can you tell me your name, age? (optional)

2. What is your level of spinal injury and how long have you been spinal cord injured?

3. What do you think are the main factors that impact your quality of life?

**Prompt:** do you suffer with secondary health impairments; do you think they affect your QOL?

4. What would help to overcome any negative issues?

5. How do you find out about things that trouble you in relation to your life with SCI?

**Prompt:** doctors, nurses, occupational therapist, health professionals, friends who suffer with a SCI?

6. Who do you talk to about things that trouble you?

**Prompt:** friends, family, health care professionals

**Prompt:** do you feel comfortable speaking with someone who is not SCI?

7. What do you know about peer support?

8. Do you know of any peer support groups relevant to your situation?

a. if yes, tell me about them - what is good what is bad what could be better?

b. if no, do you think you would enjoy going to a peer support group if one were available?

9. What would be the barriers?

**Prompt:** Location, accessibility, timing of meeting, ability to discuss your situation with others.

10. What would be the benefits?

11. What would you like to see at a peer support group / how would you like it to be organised?

12. Is there anything you would particularly dislike about a peer support group?

**Prompt:** Such as having family or friends at one meeting a month?



**13.** Are there any alternatives that would be of more value to you, or you would enjoy more rather than a peer support group?

## **Appendix 2: Second Stage in the design of the peer support group using quantitative methodology**

**Project title:** Improving Quality of Life after Spinal Cord Injury: intervention and design feasibility study

## Appendix 2A

### Ethical approval

Thursday, 21 April 2016  
cshs/ethics /approved - iterim/

Thomas, Gareth  
PhD  
Cardiff School of Health Sciences

Dear Applicant

**Re: Application for Ethical Approval: Improving Quality of Life after Spinal Cord Injury: intervention design and feasibility study.**

**Ethics Reference Number : 8006**

Your ethics application, as shown above, was considered by the Psychology Ethics Panel on 21/04/2016

I am pleased to inform you that your application for ethical approval was **APPROVED**, subject to the conditions listed below – *please read carefully*.

#### **Standard Conditions of Approval**

- Your Ethics Application has been given a Project Reference number as above. This **MUST** be quoted on all documentation relating to the project (E.g. consent forms, information sheets), together with the full project title.
- All documents must also have the approved University Logo and the Version number in addition to the reference and project title as above.
- A full **Risk Assessment** must be undertaken for this proposal, as appropriate, and be made available to the Committee if requested.
- Any changes in connection to the proposal as approved must be referred to the Panel/Committee for consideration ***without delay quoting your Project Reference Number.*** Changes to the proposed project may have ethical implications and so must be approved.
- Any untoward incident which occurs in connection with this proposal must be reported back to the Panel/Committee ***without delay.***
- If your project involves the use of **samples of human origin**, your approval is given on the condition that you or your supervisor **notify the School** of your intention to work with such material by **completing Part One** of the form entitled "*Notification of Intention to Work with Human Relevant Material or Human Bodily Material*" which **must** be obtained from the PD (Sean Duggan), **BEFORE** any activity on this project is undertaken.

This approval expires on **21/04/2017** . Please set a reminder on your Outlook calendar or equivalent if you need to continue beyond this approval date. It is your responsibility to reapply / request extension if necessary.

Yours sincerely

A handwritten signature in blue ink, appearing to read 'A. Watt', is positioned above the printed name.

**Dr Andrew Watt**  
**Chair**

**Psychology Research Ethics Committee**

Cardiff School of Health Sciences

Tel : 029 20416923

E-mail : [awatt@cardiffmet.ac.uk](mailto:awatt@cardiffmet.ac.uk)

Cc: Limbert, Caroline

**PLEASE RETAIN THIS LETTER FOR REFERENCE**

## Appendix 2B

### Feedback from Ethic Committee

**14 April 2016**  
ethics /appinprincipal

Thomas, Gareth  
PhD  
Cardiff School of Health Sciences

Dear Applicant

**Re: Application for Ethical Approval: Improving Quality of Life after Spinal Cord Injury: intervention design and feasibility study.**

Your Ethics Application, as shown above, was considered by Psychology Ethics Panel on 14/04/2016.

As a result, your application was **APPROVED IN PRINCIPLE** as being ethically sound. However, full approval was withheld because the Panel/Committee felt that some amendments/further information were required as follows:

- 1) **Clarify recruitment process in detail.**
- 2) **Inform participant that after data has been submitted, data cannot be withdrawn as it is anonymised.**
- 3) **Requirement to feedback to associations the outcome of the survey, with request that they distribute the information.**
- 4) **Aim of the study should specify that the aim is to canvas opinion amongst people with SCI.**

Please make the amendments to your application, highlighting the changes made, and/or provide the supporting documents as applicable, and submit them to the relevant Panel /Committee for reconsideration.

**Please note that this is not final approval. Do not commence any activity on this project until you receive the final approval confirmation.**

Yours sincerely



**Dr Andrew Watt**  
Chair

**Psychology Research Ethics Committee**

Cardiff School of Health Sciences

Tel : 029 20416923

E-mail : [awatt@cardiffmet.ac.uk](mailto:awatt@cardiffmet.ac.uk)

## **Appendix 2C**

### **Participant information sheet 2016**

**Project title: Improving Quality of Life after Spinal Cord Injury: intervention and design feasibility study**

#### **Welcome**

The aim of the research project, of which this questionnaire forms a part, is to design an intervention involving a peer support group to develop self-efficacy and improve quality of life for individuals with SCI who are leaving rehabilitation centres and for those with long term SCI.

#### **Why you?**

You are being asked to take part in this study because you have SCI. Your participation is entirely voluntary.

#### **What will happen?**

We will ask people who are either 16 years old or above and have SCI and live anywhere in the world to fill out a questionnaire either online or via a hard copy that can be sent to you through the post or by hand. The questionnaire should take no longer than 20 minutes to fill out. If you choose to fill out the questionnaire then by doing so you give informed consent. All questionnaires are completely anonymous, you will not have to give your name or email address. If you send a copy by email, your email address will be deleted, and a copy of your questionnaire will be kept in a secure encrypted folder. At no time will we be able to connect you with your questionnaire. At the end of the study all questionnaires will be destroyed, and no data will be used by third parties.

#### **Do I have to take part?**

Participation in this study is entirely voluntary. If at any time during the process you feel that you cannot answer a question then please just move to the next, if at any point you feel you must stop, please do so and the questionnaire will not be used. In the unlikely event that you feel distressed and would like some information or support you can contact the Spinal Injuries Association (SIA) direct at <http://www.spinal.co.uk/page/contact-us>

#### **What do we do?**

Once we have your questionnaires, they will be scored using a scoring system and the data from all the participants will be compiled together and statistical analysis will be used to give us answer to our questions. We will then write a report that will be used in our study and this information will help inform other researchers and possibly the health care system to improve their service to SCI people.

#### **Have you got any questions?**

If you have any questions just ask.

#### **Contact**

Gareth Thomas

Email [gpthomas@cardiffmet.ac.uk](mailto:gpthomas@cardiffmet.ac.uk)

SIA help and advice contact details: <http://www.spinal.co.uk/page/contact-us>

## Appendix 2D

### Questionnaire developed using previous literature and findings (chapter 1, 2 and 3)

#### Study of Spinal Cord Injured People

First of all, I would like to thank you for completing the following questionnaire. If you do not feel comfortable at any time while you are completing the questionnaire, or you come across a question that makes you feel uncomfortable, then you do not have to answer that question and you can choose, if you wish, not to go any further with the questionnaire. The answers that you give will only be used for my research project and may be included as part of journal publication based on the overall findings. In no case will your individual responses be identifiable or linked to you in any way.

All of the information that you provide will be strictly confidential. You will not be asked for your name at any point, so all answers are anonymous.

Please write your responses or highlight or underline the answer that applies to you in response to each of the following questions.

1. What is your age now: \_\_\_\_\_ years \_\_\_\_\_ months
2. Age at time of injury: \_\_\_\_\_ years \_\_\_\_\_ months
3. Level of completeness of injury:
  - a. Functionally complete tetraplegia/quadruplegia ☐
  - b. Functionally complete paraplegia ☐
  - c. Functionally incomplete tetraplegia/quadruplegia ☐
  - d. Functionally incomplete paraplegia ☐
4. Please mark as appropriate:
  - a. Male ☐
  - b. Female ☐
5. Country of birth .....
6. Place of current residence:
  - a. Urban/metropolitan (e.g. living in a town or city) ☐
  - b. Non-urban/Non-metropolitan (e.g. living in a village or in the countryside) ☐
7. What is your current status:    Single, never married ☐    Married ☐    Divorced ☐  
   Separated ☐    Widowed ☐    Living with partner ☐
8. Do you have children



- a. How many\_\_\_\_\_
- b. What are their ages\_\_\_\_\_

9. Employment (please tick or highlight as many options as appropriate)

- a. In paid work ☐
- b. Carry out voluntary work ☐
- c. Not in either paid or voluntary employment ☐

**Instructions:** Please read each statement carefully, and then pick out the one response in each case that best describes your own situation since your time of injury. **Highlight or underline** the statement you have picked.

1. To what extent did you feel isolated when you first had your SCI injury?  
All the time frequently quite often sometimes from time to time rarely never
2. Do you suffer with secondary health impairments, such as bladder, bowel dysfunction, pain, spasms etc.?  
All the time frequently quite often sometimes from time to time rarely never
3. Do friends or family help you at home?  
All the time frequently quite often sometimes from time to time rarely never
4. Does a health care professional visit or help you at home?  
All the time frequently quite often sometimes from time to time rarely never
5. Are you able to talk about things that are bothering you or health care issues with friends or family?  
All the time frequently quite often sometimes from time to time rarely never
6. Do you discuss health care issues with a professional, such as a doctor, nurse, social worker etc.?  
All the time frequently quite often sometimes from time to time rarely never
7. Do you feel comfortable discussing health care issues with someone who is not SCI?  
All the time frequently quite often sometimes from time to time rarely never

**Q8 to Q18 - 'To what extent do you agree or disagree with the following statements'**

8. 'I feel desperate and frustrated at the lack of professional support I receive'?  
Totally agree agree partially agree not sure partially disagree disagree totally disagree
9. 'I found it difficult to adapt to health changes after spinal cord injury, such as bladder, bowel dysfunction, pain, spasms etc.?'  
Totally agree agree partially agree not sure partially disagree disagree totally disagree
10. 'I had difficulty coping physically after my spinal cord injury'?  
Totally agree agree partially agree not sure partially disagree disagree totally disagree
11. 'I had difficulty coping psychologically after my spinal cord injury'?  
Totally agree agree partially agree not sure partially disagree disagree totally disagree
12. 'I am dependant on my partner or caregiver for support'?  
Totally agree agree partially agree not sure partially disagree disagree totally disagree

13. 'I would have liked to go to a peer support group whilst in hospital recovering from my initial spinal cord injury'?
- Totally agree   agree   partially agree   not sure   partially disagree   disagree   totally disagree
14. 'I find that health care professionals are unable to relate to me'?
- Totally agree   agree   partially agree   not sure   partially disagree   disagree   totally disagree
15. 'I find that my friends and family cannot relate to me'?
- Totally agree   agree   partially agree   not sure   partially disagree   disagree   totally disagree
16. 'I find that other people with spinal cord injury can relate to me'?
- Totally agree   agree   partially agree   not sure   partially disagree   disagree   totally disagree
17. 'I would have liked to go to a peer support group upon leaving hospital'?
- Totally agree   agree   partially agree   not sure   partially disagree   disagree   totally disagree
18. 'I would like to go to a peer support group now'?
- Totally agree   agree   partially agree   not sure   partially disagree   disagree   totally disagree
19. To what extent do you agree or disagree that the following issues might make it difficult for you to attend a peer support group?
- a) Getting to the location
- Totally agree   agree   partially agree   not sure   partially disagree   disagree   totally disagree
- b) Finding the time to go
- Totally agree   agree   partially agree   not sure   partially disagree   disagree   totally disagree
- c) Embarrassment
- Totally agree   agree   partially agree   not sure   partially disagree   disagree   totally disagree
20. Would you like to attend a peer support group with a defined topic of discussion?
- Definitely   almost certainly   most probably   not sure   probably not   almost certainly not   definitely not
21. Would you find it helpful to discuss your own health issues with other SCI people at a peer support group?
- Definitely   almost certainly   most probably   not sure   probably not   almost certainly not   definitely not
22. Would you be happy to give advice on issues related to SCI to other SCI people at a peer support group?
- Definitely   almost certainly   most probably   not sure   probably not   almost certainly not   definitely not
23. Would a family member (mother, father, sibling or partner) be happy to attend a spinal cord injury peer support group?
- Definitely   almost certainly   most probably   not sure   probably not   almost certainly not   definitely not
24. Would a friend be happy to attend a spinal cord injury peer support group?
- Definitely   almost certainly   most probably   not sure   probably not   almost certainly not   definitely not
25. Is there anyone you would like to go to a peer support group with?
- Family   friend   partner   other (who)\_\_\_\_\_
26. If a peer support group was once a week would you like to attend?
- Definitely   almost certainly   most probably   not sure   probably not   almost certainly not   definitely not
27. If a peer support group was once a fortnight would you like to attend?
- Definitely   almost certainly   most probably   not sure   probably not   almost certainly not   definitely not
28. If a peer support group was once a month would you like to attend?
- Definitely   almost certainly   most probably   not sure   probably not   almost certainly not   definitely not

29. A peer support group would help people with SCI to build confidence in social situations  
Definitely almost certainly most probably not sure probably not almost certainly not definitely not
30. A peer support group could help people who fear they are stigmatised because of their SCI to overcome that fear  
Definitely almost certainly most probably not sure probably not almost certainly not definitely not
31. It is good for people with SCI to join groups which include other people with SCI sometimes  
Definitely almost certainly most probably not sure probably not almost certainly not definitely not

## Appendix 2E

### Brief-COPE questionnaire

The following items deal with ways you have been coping with the stress in your life since you had your spinal cord injured. There are many ways to try to deal with being spinal cord injured. These items ask what you've been doing to cope since you had your spinal cord injured. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with your condition. Each item says something about a particular way of coping. It would be really helpful for us to know to what extent you've been doing what the item says. How much or how frequently. Please don't answer on the basis of whether it seems to be working or not—just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can. **Highlight or underline** the statement you have picked.

29. I've been turning to work or other activities to take my mind off things.  
I haven't been doing this at all                      I've been doing this a little bit  
I've been doing this a medium amount                      I've been doing this a lot
30. I've been concentrating my efforts on doing something about the situation I'm in.  
I haven't been doing this at all                      I've been doing this a little bit  
I've been doing this a medium amount                      I've been doing this a lot
31. I've been saying to myself "this isn't real."  
I haven't been doing this at all                      I've been doing this a little bit  
I've been doing this a medium amount                      I've been doing this a lot
32. I've been using alcohol or other drugs to make myself feel better.  
I haven't been doing this at all                      I've been doing this a little bit  
I've been doing this a medium amount                      I've been doing this a lot
33. I've been getting emotional support from others.  
I haven't been doing this at all                      I've been doing this a little bit  
I've been doing this a medium amount                      I've been doing this a lot
34. I've been giving up trying to deal with it.  
I haven't been doing this at all                      I've been doing this a little bit  
I've been doing this a medium amount                      I've been doing this a lot
35. I've been taking action to try to make the situation better.  
I haven't been doing this at all                      I've been doing this a little bit  
I've been doing this a medium amount                      I've been doing this a lot
36. I've been refusing to believe that it has happened.  
I haven't been doing this at all                      I've been doing this a little bit  
I've been doing this a medium amount                      I've been doing this a lot
37. I've been saying things to let my unpleasant feelings escape.  
I haven't been doing this at all                      I've been doing this a little bit  
I've been doing this a medium amount                      I've been doing this a lot
38. I've been getting help and advice from other people.  
I haven't been doing this at all                      I've been doing this a little bit  
I've been doing this a medium amount                      I've been doing this a lot

39. I've been using alcohol or other drugs to help me get through it.  
 I haven't been doing this at all I've been doing this a little bit  
 I've been doing this a medium amount I've been doing this a lot
40. I've been trying to see it in a different light, to make it seem more positive.  
 I haven't been doing this at all I've been doing this a little bit  
 I've been doing this a medium amount I've been doing this a lot
41. I've been criticizing myself.  
 I haven't been doing this at all I've been doing this a little bit  
 I've been doing this a medium amount I've been doing this a lot
42. I've been trying to come up with a strategy about what to do.  
 I haven't been doing this at all I've been doing this a little bit  
 I've been doing this a medium amount I've been doing this a lot
43. I've been getting comfort and understanding from someone.  
 I haven't been doing this at all I've been doing this a little bit  
 I've been doing this a medium amount I've been doing this a lot
44. I've been giving up the attempt to cope.  
 I haven't been doing this at all I've been doing this a little bit  
 I've been doing this a medium amount I've been doing this a lot
45. I've been looking for something good in what is happening.  
 I haven't been doing this at all I've been doing this a little bit  
 I've been doing this a medium amount I've been doing this a lot
46. I've been making jokes about it.  
 I haven't been doing this at all I've been doing this a little bit  
 I've been doing this a medium amount I've been doing this a lot
47. I've been doing something to think about it less, such as going to movies,  
 watching TV, reading, daydreaming, sleeping, or shopping.  
 I haven't been doing this at all I've been doing this a little bit  
 I've been doing this a medium amount I've been doing this a lot
48. I've been accepting the reality of the fact that it has happened.  
 I haven't been doing this at all I've been doing this a little bit  
 I've been doing this a medium amount I've been doing this a lot
49. I've been expressing my negative feelings.  
 I haven't been doing this at all I've been doing this a little bit  
 I've been doing this a medium amount I've been doing this a lot
50. I've been trying to find comfort in my religion or spiritual beliefs.  
 I haven't been doing this at all I've been doing this a little bit  
 I've been doing this a medium amount I've been doing this a lot
51. I've been trying to get advice or help from other people about what to do.  
 I haven't been doing this at all I've been doing this a little bit  
 I've been doing this a medium amount I've been doing this a lot

52. I've been learning to live with it.  
I haven't been doing this at all I've been doing this a little bit  
I've been doing this a medium amount I've been doing this a lot
53. I've been thinking hard about what steps to take.  
I haven't been doing this at all I've been doing this a little bit  
I've been doing this a medium amount I've been doing this a lot
54. I've been blaming myself for things that happened.  
I haven't been doing this at all I've been doing this a little bit  
I've been doing this a medium amount I've been doing this a lot
55. I've been praying or meditating.  
I haven't been doing this at all I've been doing this a little bit  
I've been doing this a medium amount I've been doing this a lot
56. I've been making fun of the situation.  
I haven't been doing this at all I've been doing this a little bit  
I've been doing this a medium amount I've been doing this a lot

#### THANK-YOU FOR YOUR HELP

SIA help and advice contact details: <http://www.spinal.co.uk/page/contact-us>

C:\Users\user\Desktop\imac\University of Miami, Psychology.html

### **Appendix 3: Main study in the implementation and evaluation of the peer support group using a mixed methodology**

**Project title:** Improving Quality of Life after Spinal Cord Injury: intervention and design feasibility study

## Appendix 3A

### Ethical approval

**Monday, 22 August 2016**

cshs/ethics /approved - iterim/

Thomas, Gareth  
PhD  
Cardiff School of Health Sciences

Dear Applicant

**Re: Application for Ethical Approval: Improving Quality of Life after Spinal Cord Injury: intervention design and feasibility study.**

**Ethics Reference Number : 8164**

Your ethics application, as shown above, was considered by the Psychology Ethics Panel on 22/8/2016

I am pleased to inform you that your application for ethical approval was **APPROVED**, subject to the conditions listed below – *please read carefully*.

#### **Standard Conditions of Approval**

- Your Ethics Application has been given a Project Reference number as above. This **MUST** be quoted on all documentation relating to the project (E.g. consent forms, information sheets), together with the full project title.
- All documents must also have the approved University Logo and the Version number in addition to the reference and project title as above.
- A full **Risk Assessment** must be undertaken for this proposal, as appropriate, and be made available to the Committee if requested.
- Any changes in connection to the proposal as approved must be referred to the Panel/Committee for consideration ***without delay quoting your Project Reference Number.*** Changes to the proposed project may have ethical implications and so must be approved.
- Any untoward incident which occurs in connection with this proposal must be reported back to the Panel/Committee ***without delay.***
- If your project involves the use of **samples of human origin**, your approval is given on the condition that you or your supervisor **notify the School** of your intention to work with such material by **completing Part One** of the form entitled "*Notification of Intention to Work with Human Relevant Material or Human Bodily Material*" which **must** be obtained from the PD (Sean Duggan), **BEFORE** any activity on this project is undertaken.

This approval expires on **22/8/2017** . Please set a reminder on your Outlook calendar or equivalent if you need to continue beyond this approval date. It is your responsibility to reapply / request extension if necessary.



Yours sincerely

A handwritten signature in dark ink, appearing to read 'A. Watt', with a stylized flourish at the end.

**Dr Andrew Watt**  
**Chair**

**Psychology Research Ethics Committee**

Cardiff School of Health Sciences

Tel : 029 20416923

E-mail : [awatt@cardiffmet.ac.uk](mailto:awatt@cardiffmet.ac.uk)

Cc: Limbert, Caroline

**PLEASE RETAIN THIS LETTER FOR REFERENCE**

**Appendix 3B**  
**Participant Manual with details of each sessions**

**Manual for**  
**Peer Support Group for Person's with a Spinal Cord Injury**

**Prepared By**  
**Gareth Thomas B.Sc (Hons), MSc, Psychol**

**Introduction**

**Principles of Peer Support Group**

The term peer support is used to describe help and support that people with lived experience are able to give another person similarly situated, i.e. a person who has been spinal cord injured (SCI) for many years can provide support to somebody who has been newly SCI injured, also a long term SCI person can gain valuable knowledge from the process. This support could be emotional, practical, social or could be all of these.

Peer support includes a range of activities and actions that help improve/enhance a participant's quality of life and ability to cope with daily life and set and achieve goals. In the case of people with SCI this could be achieved with new knowledge, in areas such as community resources, community connections, housing, education, employment, emotional support and health care support etc.

Peer support involves a helping relationship between participating individuals that promotes respect, trust and warmth and empowers people to make changes and decisions to enhance their lives.

**Basic Assumptions about SCI Peer Support Programme**

- Peer supporters are survivors of SCI
- All people with SCI, like the participants, have diversity in skills, characteristics, talents and abilities;

- Not every person with SCI has the stability and ability to be a good peer supporter
- Not every person with SCI wants to be a peer supporter or to be involved with peer support groups
- Professional support/input needs to be available when requested

### **Fundamental elements for the peer support group:**

**Facilitator** – this is the person(s) who will be conducting the group sessions and are hired specifically for facilitating the peer support group in the case of the current group that will be Tony Stephenson. Whoever does the facilitating needs to have a good understanding of the goals, objectives and policies of the peer support group program in their area, they need to be skilled in communication and able to facilitate a group. It is suggested that there be at least 2 people involved in the facilitating of the group in order to provide support to each other, and the people being facilitated. Guest speakers (e.g. sports personalities, person living with a specific spinal condition, nurses, OT, physio therapist) provide expertise in a specific area. This also provides an opportunity for variety in the format of the peer support group sessions.

**Group size** – group size will vary according to the number of people who want to participate in the group, this may vary from session to session. The suggestion is that group sessions be kept to a minimum of 8 and a maximum of 12 participants, although if it is a closed group this should be consistent. This is large enough to allow for people to open up and discuss their individual issues, but not too large so as to become overwhelming.

**Facilities needed** - it is important to pick a site that is accessible for everyone. This means that the location must be able to be reached by bus, or be within easy walking/pushing distance of the majority of participants. The site must also be wheelchair accessible, and in a place that people feel comfortable going to. As it is a group with wheelchair users it is advised that the peer support group be held on the ground floor for safety issues. There needs to be enough space to allow the group to break into smaller subgroups for peer support exercises (if required). Also refreshments should be made available for when the group takes a break.

**Length of peer support group** – the peer support group was designed for 8 sessions. It is up to individual programs to decide whether they want to organise the sessions weekly or once fortnightly. Each session has been designed to last 2 hours. It is recommended that this is the amount of time for each session, and it is up to the facilitators to manage the time effectively. Each session needs to be structured but also be informal.

**Overall aims of the sessions** – is for participants to learn from each other's own experiences and knowledge. To change attitudes and beliefs which might predict or mediate a behaviour (gain knowledge and support). The hopeful outcome is to enhance well-being and self-efficacy improving overall quality of life.

### **Guidelines**

Discuss the basic guidelines, which include;

- Confidentiality must be respected at all times. What is said in group stays in group.
- Smoking (if you smoke do it in the breaks please)
- Interaction and participation is welcomed. Respect everyone's airtime.
- Comfort and boundaries (at any point if you feel uncomfortable or unhappy with anything that is being discussed, please say something to the facilitator)
- Let the group and the facilitator know if you can't come to a group or if you are dropping out.
- Relax, have fun and enjoy yourself
- This is an informal peer support group

### **Structure of the Sessions**

#### **Session 1: Building Rapport (speaker Gareth Thomas)**

**(15 Minutes)** Welcome and refreshments

**(35 Minutes)** Introduction: facilitator and participants

**(10 Minutes)** Guidelines i.e. data collection, confidentiality

**(15 Minutes)** Group discussion: "What is Peer Support?"

**(25 Minutes)** Discuss expectations

**(25 Minutes)** Refreshments and mingling

### **Session 2: Independence and difficulties**

**(10 Minutes)** Welcome and refreshments

**(40 Minutes)** Guest speaker Emma Wallace Gibbons OT will discuss ways of overcoming challenges of being spinal cord injured

**(15 Minutes)** Refreshments and questions

**(30 Minutes)** Group discussion about overcoming obstacles and coping

**(25 Minutes)** Refreshments and mingling

### **Session 3: Health and self-care**

**(10 Minutes)** Welcome and refreshments

**(40 Minutes)** Guest speaker Sue Williams (nurse) will discuss health issues i.e secondary health impairments

**(15 Minutes)** Refreshments and questions

**(20 Minutes)** Participants break off into pairs and discuss with each other

**(20 Minutes)** Group discussion, pairs discuss issues with the group

**(15 Minutes)** Refreshments and mingling

### **Session 4: Managing Stress and Challenges**

**(10 Minutes)** Welcome and refreshments

**(40 Minutes)** Guest speaker Simon Barnes will introduce participant to mindfulness and how to do it.

**(15 Minutes)** Refreshments and questions

**(30 Minutes)** Group discussion about techniques of managing stress and challenges of SCI

**(25 Minutes)** Refreshments and mingling

### **Session 5: Positives of having SCI**

**(10 Minutes)** Welcome and refreshments

**(40 Minutes)** Guest speaker Mik Scarlet will talk about the positives of SCI

**(15 Minutes)** Refreshments and questions

**(30 Minutes)** Group discussion about the positives in their own lives and goals

**(25 Minutes)** Refreshments and mingling

### **Session 5: Friends and family**

**(10 Minutes)** Welcome and refreshments

**(40 Minutes)** Guest speaker Diane Scarlet discuss the positives of being married to someone with SCI and their own hopes for the future

**(15 Minutes)** Refreshments and questions

**(30 Minutes)** Friends and family discuss their own positive or negatives

**(25 Minutes)** Refreshment and mingling

### **Session 6: Body change (aches and pains)**

**(10 Minutes)** Welcome and refreshments

**(40 Minutes)** Guest speaker Kelly Morris physiotherapist Rookwood

**(15 Minutes)** Refreshments and questions

**(30 Minutes)** Group discussion on aches and pains and adjusting

**(25 Minutes)** Refreshments and mingling

### **Session 7: Exercise and diet**

**(10 Minutes)** Welcome and refreshments

**(40 Minutes)** Guest speaker Dr Paul Smith will discuss exercise and diet

**(15 Minutes)** Refreshments and questions

**(30 Minutes)** Group discussion about their own diet and exercise or how they can change

**(25 Minutes)** Refreshments and mingling

### **Session 8: Life skills and reaching goals**

**(10 Minutes)** Welcome and refreshments

**(40 Minutes)** Guest speaker Paul Davies MBE

**(15 Minutes)** Group discussion about life skills and reaching your goals

**(20 Minutes)** Both groups come together to share as one group

**(20 Minutes)** Refreshments and everyone mingling

## **Session 8: Friends and family**

**(15 Minutes)** Welcome and refreshments

**(40 Minutes)** Guest speaker Mrs Davies

**(25 Minutes)** Group discussion about being a partner and carer

**(20 Minutes)** Both groups come together to share as one group

**(20 Minutes)** Refreshments and everyone mingling

## **Sessions Explained**

### **Session 1:**

#### **Introduction: facilitator and participants**

- At this point the facilitator(s) should introduce themselves and explain who they are.
- Do an exercise where people pair off and talk to one another and mention one thing that is interesting about themselves.
- Then bring the group back together and have each person introduce their partner to the rest of the group.

#### **Guidelines i.e. aims and procedures**

- Gareth Thomas should take the time to explain the aims and procedures of the peer support group i.e. how the data will be collected, how it will be used and that all data will be kept confidential and will be destroyed once the pilot study has finished which will be 6 months in total.
- It should also be mentioned that everything that is discussed within the group is also confidential i.e. participants should agree not to talk about things that are discussed outside of the group.

#### **Group discussion: “What is Peer Support?”**

- Participants discuss what they think peer support is;
- and that the hope is that attending the peer support group sessions will be both fun and will increase the knowledge of the group members.

**Discuss expectations:**

- Have a group discussion about people's perceptions of peer support?
- What are their expectations by participating within the group?

**Session 2: Independence and difficulties****Introduction: Facilitator and guest speaker**

- At this point the facilitator(s) should introduce the guest speaker Emma Wallace Gibbons OT.
- Emma will then talk a little about her own background, as she has many years' experience as an OT at Rookwood spinal unit.

**Aims and objectives of the session**

- To discuss being independent inside and outside the home.
- How easy is it to get out and about i.e. accessibility, driving?
- Who to contact if people have difficulties in their own home and especially if adaptations are needed.

**Group discussion**

- The group will discuss issues they feel they might have about independence or living independently and getting out and about in public.
- They can share their own positive or negative experiences about driving, public transport and any other areas of concern.
- They could also talk about any adaptations they may have had in their own homes to make life easier.

**Refreshments and mingling**

- There will be three refreshment breaks, this will give the participants a chance to talk one on one with other people, they also might have some personal issues they did not want to mention or share with the group as a whole.
- There is also a refreshment break after each guest speaker has finished speaking, this is a chance for asking private questions to the speaker that you might not want to share with other people.

**Session 3: Health and self-care****Introduction: Facilitator and guest speaker**



- At this point the facilitator(s) should introduce the guest speaker Sue Williams who has spent 36 years as a nurse and is an expert in SCI and has published work in the field.
- Sue will talk about her own background in SCI rehabilitation and share her expertise.

### **Aims and objectives of the session**

- To talk about health issue such as secondary health impairments i.e. bladder, bowel, pressure sores, sexual function, pain management etc.
- She will also talk about care management for people with SCI.

### **Group discussion**

- Participants will break off into pairs and discuss health issues i.e. secondary health impairments in general and not necessarily about themselves. This might help participant to open up due to the personal nature of the topic.
- Participants then come back together as a group and if they are happy to disclose what they had spoken about in their pairings.

### **Refreshments and mingling**

- There will be three refreshment breaks, this will give the participants a chance to talk one on one with other people, they also might have some personal issues they did not want to mention or share with the group as a whole.
- There is also a refreshment break after each guest speaker has finished speaking, this is a chance for asking private questions to the speaker that you might not want to share with other people.

## **Session 4: Managing stress and challenges**

### **Introduction: Facilitator and guest speaker**

- At this point the facilitator(s) should introduce the guest speaker Simon Barnes who teaches Mindfulness.
- Simon will talk about his own background and why he chose to become a teacher of Mindfulness.

### **Aims and objectives of the session**

- To talk about how using mindfulness can help with managing stress and the challenges that participants may be faced with.
- Simon will also give a tutorial on how to do mindfulness.

### **Group discussion**

- How do participants manage their own stress and the challenges of being spinal cord injured, they can share their own experiences and perhaps knowledge about how they deal with these issues?

### **Refreshments and mingling**

- There will be three refreshment breaks, this will give the participants a chance to talk one on one with other people, they also might have some personal issues they did not want to mention or share with the group as a whole.
- There is also a refreshment break after each guest speaker has finished speaking, this is a chance for asking private questions to the speaker that you might not want to share with other people.

## **Session 5: Positives of having SCI**

### **Introduction: Facilitator and guest speaker**

- At this point the facilitator(s) should introduce the guest speaker Mik Scarlet.
- Mik will talk about his background as SCI musician, actor and presenter, he is also an advocate for disabled rights.

### **Aims and objectives of the session**

- Mik will talk about his career and all the positive things that he has done since being spinal cord injured.
- Mik will talk about his travels, what were the best places he visited and any challenges that he overcame.
- How things have changed since becoming spinal cord injured.
- Relationship advice

### **Group discussion**

- Give participant the opportunity to talk to Mik about his life and the positives in their own lives, i.e. employment, education, sport, relationships and travel.

### **Refreshments and mingling**

- There will be three refreshment breaks, this will give the participants a chance to talk one on one with other people, they also might have some personal issues they did not want to mention or share with the group as a whole.
- There is also a refreshment break after each guest speaker has finished speaking, this is a chance for asking private questions to the speaker that you might not want to share with other people.

## **Session 5: Friends and family**

### **Introduction: Facilitator and guest speaker**

- Gareth Thomas will facilitate this session and introduce Diane Scarlet wife of Mik Scarlet.

### **Aims and objectives of the session**

- Share advice on being the partner and carer of a person with SCI.
- What it's like to travel all over the world with someone in a wheelchair.

### **Friends and family discussion**

- They can ask advice and share their own experiences.

### **Refreshments and mingling**

- There will be three refreshment breaks, this will give the participants a chance to talk one on one with other people, they also might have some personal issues they did not want to mention or share with the group as a whole.
- There is also a refreshment break after each guest speaker has finished speaking, this is a chance for asking private questions to the speaker that you might not want to share with other people.

## **Session 6: Body change (aches and pains)**

### **Introduction: Facilitator and guest speaker**

- At this point the facilitator(s) should introduce the guest speaker Kelly Morris.
- Kelly will talk about changes that may occur to a wheelchair user and how to adapt.
- Kelly will also give advice and show some stretches that can be done when alone.

### **Aims and objectives of the session**

- To give advice on how to reduce aches and pains and exercises to help.
- To give a demonstration of stretches or movements that can be done alone or with a helper at home.

### **Group discussion**

- Participants can discuss their own experiences of changes to their own bodies and the issues that these changes make.

- How do they deal with these changes and do they have advice for others on how to intervene?

### **Refreshments and mingling**

- There will be three refreshment breaks, this will give the participants a chance to talk one on one with other people, they also might have some personal issues they did not want to mention or share with the group as a whole.
- There is also a refreshment break after each guest speaker has finished speaking, this is a chance for asking private questions to the speaker that you might not want to share with other people.

## **Session 7: Exercise and diet**

### **Introduction: Facilitator and guest speaker**

- At this point the facilitator(s) should introduce the guest speaker Dr Paul Smith who is an exercise physiologist.
- Paul will talk about his background in sport and fitness and what he does.

### **Aims and objectives of the session**

- To talk about exercise and how important it is, even though participants are in wheelchairs they can still exercise and keep fit which has many other advantages.
- Paul will give an example of exercises that can be done in a wheelchair.
- Discuss diet and how eating right can help reduce weight gain and can benefit participants in other ways.

### **Group discussion**

- Gives participants the opportunity to share their own experience of exercise and share with the group how they do it or how it can be done.
- Discuss diet and weight gain or even how they stay fit and healthy.

### **Refreshments and mingling**

- There will be three refreshment breaks, this will give the participants a chance to talk one on one with other people, they also might have some personal issues they did not want to mention or share with the group as a whole.
- There is also a refreshment break after each guest speaker has finished speaking, this is a chance for asking private questions to the speaker that you might not want to share with other people.

## **Session 8: Identity, change, life skills and reaching goals**

### **Introduction: Facilitator and guest speaker**

- At this point the facilitator(s) should introduce the guest speaker Mr Paul Davies MBE.
- Paul will talk about his life after becoming a C4 tetraplegic whilst serving in the army. He went on to become a successful businessman and sportsman. He became the team manager for the wheelchair rugby team winning major championships including the Paralympics.

### **Aims and objectives of the session**

- To discuss how becoming disabled and how this changed his life and goals.
- He will talk about his marriage and the things they have done and do together.
- Did he become dependent on his partner for care or others i.e. family, friends, or strangers?
- What life skills has he learnt and how did he reach his goals.

### **Group discussion**

- The group will talk about how their own lives have changed since becoming spinal cord injured and has it affected their identity.
- Are they married, do they have a partner has their partner become a carer, how has this affected their relationship?
- If single how do they feel about having a relationship?
- Are they dependant on a partner, family member or even a stranger for care?
- Are they employed or in education could they share their own experiences?
- What life skills have they learnt and have they set goals and reached them?

### **Joint Groups**

- Both groups will come back together and discuss any issues that they are happy to disclose in front of everyone.

### **Refreshments and mingling**

- This will give the participants a chance to talk one on one with other people, they also might have some personal issues they did not want to mention or share with the group as a whole. They will also have a chance to mingle with friends and family and connect with other people.

## **Session 8: Identity, change, life skills and reaching goals - Friends and family**

### **Introduction: Facilitator and guest speaker**

- Gareth Thomas will facilitate this session and introduce Mrs Davies who has been married to Paul for many years and shared all his ups and downs.

### **Aims and objectives of the session**

- She will share her own experiences of being a partner of someone in a wheelchair with SCI and any barriers they came across together.
- Has she found it hard being both a partner and carer?

### **Friends and family discussion**

- This will give them a chance to discuss any issues they may have with other members i.e. relationship, friendship, carer.

### **Joint Groups**

- Both groups will come back together and discuss any issues that they are happy to disclose in front of everyone.

### **Refreshments and mingling**

- This will give the participants a chance to talk one on one with other people, they also might have some personal issues they did not want to mention or share with the group as a whole. They will also have a chance to mingle with friends and family and connect with other people.

## **Appendix 3C**

### **Participant information sheet 2016**

#### **Project title: Peer Support Group for Person's with a Spinal Cord Injury**

#### **Welcome**

The aim of the research project, of which this interview forms a part, was to design an intervention involving a peer support group to develop self-efficacy and improve quality of life for individuals with SCI who are leaving rehabilitation centres and for those with long term SCI.

The aim of this interview is to find out your thoughts about the peer support group that you attended and if there is anything that could be improved for future groups.

To take part in this study/interview the only requirements are that all participants be over 16 years old, have a spinal cord injury and have already taken part in the peer support group.

The researcher will be asking for up to an hour of your time so that they are able to interview you. You will be asked questions about yourself, your injury, did you attend the group, did you learn anything from the group, is there anything you would change, did you personally experience any difficulties etc.

If you feel unclear about anything the researcher has asked, you can ask them to clarify or if you feel uncomfortable with the interview you are able to take a break or stop at any time.

All interviews are confidential, and anything said will be kept within the research team. Once the interviews have been transcribed and the study is finished, all interviews will be deleted. All interview data will be stored on a code protected computer or in a locked cupboard. No names will be recorded on the transcripts so it will not be possible for anyone to identify anything that you say. You will be offered a copy of the transcript to approve before it is used in the research.

Please remember that participation in this research study is completely voluntary. Even after you agree to participate and begin the study, you are still free to withdraw at any time and for any reason.

You will be able to keep a copy of this information sheet. If you have any complaints or concerns about this research, you can direct these, in writing, to the Head of Applied Psychology by email at: CSHS@cardiffmet.ac.uk. Alternatively, you can contact us by post at: Ethics Committee Chair, Cardiff Metropolitan University, Llandaff Campus, Western Avenue, Cardiff, Cf5 2YB.

If you would like any further help and advice about your SCI this is available at:  
<http://www.spinal.co.uk/page/contact-us>



## Appendix 3D

### Participant Consent Form

Reference Number:

Participant name:

Title of Project: Peer Support Group for Person's with a Spinal Cord Injury

Name of Researcher: Gareth Thomas

---

**Participant to complete this section: Please initial each box.**

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.

☐

3. I agree to take part in the above study.

☐

4. I agree to the interview / focus group / consultation being audio recorded

☐

5. I agree to the use of anonymised quotes in publications

☐

---

Signature of Participant

Date

---

Name of person taking consent

Date

---

Signature of person taking consent

*\* When completed, 1 copy for participant & 1 copy for researcher site file*



## Appendix 3E

### Semi-structured interview questions

#### Interview Questions for the Intervention

Welcome, and thank you for agreeing to take part in this interview. My name is Gareth Thomas and I am a PhD student, I designed and implemented the peer support group that you attended.

I am going to ask you some questions, but largely I hope we can just have an open discussion. I would like to ask you about your thoughts about the peer support group you attended and if there is anything that can be improved for the design of future groups? If you don't want to answer any questions, or if you want to terminate the interview at any point, that is fine, please just let me know.

Okay, are you okay if we start?

1. Please can you tell me your name and age? (optional)
2. What is your level of injury and how long have you been spinal cord injured (SCI)?
3. Did you attend the peer support group?
4. Why did you decide to attend a peer support group for SCI?
5. What did you hope to get out of going to a group?

**Prompt:** was it a positive experience?

6. Did you learn anything new from going to the peer support group?

**Prompt:** if so, what things did you learn?

**Prompt:** are the things you learnt useful?

7. What were the best things about the group?
8. Is there anything you would change about the group?

**Prompt:** if so how could the group be improved?

9. Did you personally experience any difficulties with any aspect of the group?

**Prompt:** finding time, location, health issues, anything at all?

10. Would you like to see a peer support group for SCI become an ongoing group?

**Prompt:** if so, what content would you like to see included i.e. more or less speakers, more topics (what kind), outings (bowling, meals)?

11. How best might the peer support group be sustained in the future?

**Prompt:** e.g. in a pub, in people's houses or do you have an alternative idea?

12. Would you be prepared to pay anything to attend a group?

**Prompt:** if yes, what would be a justifiable fee?

13. Would you like an open or closed group?

14. Would you like a session with friends and family

## Appendix 3F

### Semi-structured interview questions before panel changes

#### Interview Questions for the Intervention

Welcome, and thank you for agreeing to take part in this interview. My name is Gareth Thomas and I am a PhD student, I designed and implemented the peer support group that you attended.

I am going to ask you some questions, but largely I hope we can just have an open discussion. I would like to ask you about your thoughts about the peer support group you attended and if there is anything that can be improved for the design of future groups? If you don't want to answer any questions, or if you want to terminate the interview at any point, that is fine, please just let me know.

Okay, are you okay if we start?

1. Please can you tell me your name and age? (optional)
2. What is your level of injury and how long have you been spinal cord injured (SCI)?
3. Did you attend the peer support group?
4. Why did you decide to attend a peer support group for SCI?
5. What did you hope to get out of going to a group?

**Prompt:** was it a positive experience?

6. Did you learn anything new from going to the peer support group?

**Prompt:** if so, what things did you learn?

7. What were the best things about the group?
8. Is there anything you would change about the group?
9. Did you personally experience any difficulties with any aspect of the group?

**Prompt:** finding time, location, health issues?

10. Would you like to see a peer support group for SCI become an ongoing group?

**Prompt:** if so, what content would you like to see included i.e. more or less speakers, more topics (what kind), outings (bowling, meals)?

11. How best might the peer support group be sustained in the future?

**Prompt:** e.g. in a pub, in people's houses or do you have an alternative idea?

12. Would you be prepared to pay anything to attend a group?

**Prompt:** if yes, what would be a justifiable fee?

## Appendix 3G

### Matched control group participants

<u>Participant</u> <u>Alias</u>	<u>Age</u>	<u>Level of spinal cord</u> <u>injury</u>	<u>Approximate length</u> <u>time of injury</u>	<u>Marital status</u>	<u>Traumatic and</u> <u>nontraumatic</u> <u>injury</u>
Jake	38	C3 Tetraplegic	7 years	Single	Traumatic
Jenny	42	T8 Paraplegic	6 years	Single	Traumatic
Angie	52	T8 Paraplegic	17 years	Married	Nontraumatic
Sarah	28	T1 Paraplegic	4 years	Single	Nontraumatic
Steven	49	T4 Paraplegic	25 years	Married	Traumatic
Brian	69	C5 Tetraplegic	27 years	Married	Traumatic
Barry	46	T3 Paraplegic	19 years	Partner	Traumatic
Carl	56	T7 Paraplegic	29 years	Single	Traumatic
Jim	28	C4 Tetraplegic	9 years	Separated	Traumatic
Donald	51	L1 Paraplegic	30 years	Single	Traumatic

## **Appendix 3H**

### **General Health Questionnaire-12**

Instructions: We should like to know if you have had any medical complaints and how your health has been in general, over the last few weeks. Please answer ALL the questions simply by underlining or highlighting the answer which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those that you had in the past.

It is important that you try to answer ALL the questions

Thank you very much for your co-operation.

#### **HAVE YOU RECENTLY....**

1. Been able to concentrate on whatever you're doing?

Better than usual

Less than usual

Same as usual

Much less than usual

2. Lost much sleep over worry?

Not at all

Rather more than usual

No more than usual

Much more than usual

3. Felt that you are playing a useful part in things?

More so than usual

Less than usual

Same as usual

Much less than usual

4. Felt capable of making decisions about things?

More so than usual

Less than usual

Same as usual

Much less than usual

5. Felt constantly under strain?

Not at all

Rather more than usual

No more than usual

Much more than usual

6. Felt you couldn't overcome your difficulties?

Not at all

Rather more than usual

No more than usual

Much more than usual

7. Been able to enjoy your normal day-to-day activities?

More than usual

Less than usual

Same as usual

Much less than usual

8. Been able to face up to your problems?

More than usual

Less than usual

Same as usual

Much less than usual

9. Been feeling unhappy and depressed?

Not at all	Rather more than usual
No more than usual	Much more than usual

10. Been losing confidence in yourself?

Not at all	Rather more than usual
No more than usual	Much more than usual

11. Been thinking of yourself as a worthless person?

Not at all	Rather more than usual
No more than usual	Much more than usual

12. Been feeling reasonably happy, all things considered?

More so than usual	Less than usual
About same as usual	Much less than usual

## Appendix 3I

### Quality of Life Scale-16

Please read each item and circle the number that best describes how satisfied you are at this time. Please answer each item even if you do not currently participate in an activity or have a relationship. You can be satisfied or dissatisfied with not doing the activity or having the relationship.

23. Material comforts home, food, conveniences, financial security

Delighted   Pleased   Mostly-Satisfied   Mixed   Mostly-Dissatisfied   Unhappy   Terrible

24. Health - being physically fit and vigorous

Delighted   Pleased   Mostly-Satisfied   Mixed   Mostly-Dissatisfied   Unhappy   Terrible

25. Relationships with parents, siblings & other relatives- communicating, visiting, helping

Delighted   Pleased   Mostly-Satisfied   Mixed   Mostly-Dissatisfied   Unhappy   Terrible

26. Having and rearing children

Delighted   Pleased   Mostly-Satisfied   Mixed   Mostly-Dissatisfied   Unhappy   Terrible

27. Close relationships with spouse or significant other

Delighted   Pleased   Mostly-Satisfied   Mixed   Mostly-Dissatisfied   Unhappy   Terrible

28. Close friends

Delighted   Pleased   Mostly-Satisfied   Mixed   Mostly-Dissatisfied   Unhappy   Terrible

29. Helping and encouraging others, volunteering, giving advice

Delighted   Pleased   Mostly-Satisfied   Mixed   Mostly-Dissatisfied   Unhappy   Terrible

30. Participating in organizations and public affairs

Delighted   Pleased   Mostly-Satisfied   Mixed   Mostly-Dissatisfied   Unhappy   Terrible

31. Learning- attending school, improving understanding, getting additional knowledge

Delighted   Pleased   Mostly-Satisfied   Mixed   Mostly-Dissatisfied   Unhappy   Terrible

32. Understanding yourself - knowing your assets and limitations - knowing what life is about

Delighted   Pleased   Mostly-Satisfied   Mixed   Mostly-Dissatisfied   Unhappy   Terrible

33. Work - job or in home

Delighted   Pleased   Mostly-Satisfied   Mixed   Mostly-Dissatisfied   Unhappy   Terrible

34. Expressing yourself creatively

Delighted   Pleased   Mostly-Satisfied   Mixed   Mostly-Dissatisfied   Unhappy   Terrible

35. Socializing - meeting other people, doing things, parties, etc

Delighted   Pleased   Mostly-Satisfied   Mixed   Mostly-Dissatisfied   Unhappy   Terrible

36. Reading, listening to music, or observing entertainment

Delighted   Pleased   Mostly-Satisfied   Mixed   Mostly-Dissatisfied   Unhappy   Terrible

37. Participating in active recreation

Delighted   Pleased   Mostly-Satisfied   Mixed   Mostly-Dissatisfied   Unhappy   Terrible

38. Independence, doing for yourself

Delighted   Pleased   Mostly-Satisfied   Mixed   Mostly-Dissatisfied   Unhappy   Terrible



## Appendix 3J

### Brief-COPE questionnaire

The following items deal with ways you have been coping with the stress in your life since you had your spinal cord injured. There are many ways to try to deal with being spinal cord injured. These items ask what you've been doing to cope since you had your spinal cord injured. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with your condition. Each item says something about a particular way of coping. It would be really helpful for us to know to what extent you've been doing what the item says. How much or how frequently. Please don't answer on the basis of whether it seems to be working or not—just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can. **Highlight or underline** the statement you have picked.

29. I've been turning to work or other activities to take my mind off things.  
I haven't been doing this at all                      I've been doing this a little bit  
I've been doing this a medium amount                      I've been doing this a lot
30. I've been concentrating my efforts on doing something about the situation I'm in.  
I haven't been doing this at all                      I've been doing this a little bit  
I've been doing this a medium amount                      I've been doing this a lot
31. I've been saying to myself "this isn't real."  
I haven't been doing this at all                      I've been doing this a little bit  
I've been doing this a medium amount                      I've been doing this a lot
32. I've been using alcohol or other drugs to make myself feel better.  
I haven't been doing this at all                      I've been doing this a little bit  
I've been doing this a medium amount                      I've been doing this a lot
33. I've been getting emotional support from others.  
I haven't been doing this at all                      I've been doing this a little bit  
I've been doing this a medium amount                      I've been doing this a lot
34. I've been giving up trying to deal with it.  
I haven't been doing this at all                      I've been doing this a little bit  
I've been doing this a medium amount                      I've been doing this a lot
35. I've been taking action to try to make the situation better.  
I haven't been doing this at all                      I've been doing this a little bit  
I've been doing this a medium amount                      I've been doing this a lot
36. I've been refusing to believe that it has happened.  
I haven't been doing this at all                      I've been doing this a little bit  
I've been doing this a medium amount                      I've been doing this a lot
37. I've been saying things to let my unpleasant feelings escape.  
I haven't been doing this at all                      I've been doing this a little bit  
I've been doing this a medium amount                      I've been doing this a lot
38. I've been getting help and advice from other people.  
I haven't been doing this at all                      I've been doing this a little bit  
I've been doing this a medium amount                      I've been doing this a lot

39. I've been using alcohol or other drugs to help me get through it.  
 I haven't been doing this at all I've been doing this a little bit  
 I've been doing this a medium amount I've been doing this a lot
40. I've been trying to see it in a different light, to make it seem more positive.  
 I haven't been doing this at all I've been doing this a little bit  
 I've been doing this a medium amount I've been doing this a lot
41. I've been criticizing myself.  
 I haven't been doing this at all I've been doing this a little bit  
 I've been doing this a medium amount I've been doing this a lot
42. I've been trying to come up with a strategy about what to do.  
 I haven't been doing this at all I've been doing this a little bit  
 I've been doing this a medium amount I've been doing this a lot
43. I've been getting comfort and understanding from someone.  
 I haven't been doing this at all I've been doing this a little bit  
 I've been doing this a medium amount I've been doing this a lot
44. I've been giving up the attempt to cope.  
 I haven't been doing this at all I've been doing this a little bit  
 I've been doing this a medium amount I've been doing this a lot
45. I've been looking for something good in what is happening.  
 I haven't been doing this at all I've been doing this a little bit  
 I've been doing this a medium amount I've been doing this a lot
46. I've been making jokes about it.  
 I haven't been doing this at all I've been doing this a little bit  
 I've been doing this a medium amount I've been doing this a lot
47. I've been doing something to think about it less, such as going to movies,  
 watching TV, reading, daydreaming, sleeping, or shopping.  
 I haven't been doing this at all I've been doing this a little bit  
 I've been doing this a medium amount I've been doing this a lot
48. I've been accepting the reality of the fact that it has happened.  
 I haven't been doing this at all I've been doing this a little bit  
 I've been doing this a medium amount I've been doing this a lot
49. I've been expressing my negative feelings.  
 I haven't been doing this at all I've been doing this a little bit  
 I've been doing this a medium amount I've been doing this a lot
50. I've been trying to find comfort in my religion or spiritual beliefs.  
 I haven't been doing this at all I've been doing this a little bit  
 I've been doing this a medium amount I've been doing this a lot
51. I've been trying to get advice or help from other people about what to do.  
 I haven't been doing this at all I've been doing this a little bit  
 I've been doing this a medium amount I've been doing this a lot
52. I've been learning to live with it.  
 I haven't been doing this at all I've been doing this a little bit  
 I've been doing this a medium amount I've been doing this a lot

53. I've been thinking hard about what steps to take.  
I haven't been doing this at all I've been doing this a little bit  
I've been doing this a medium amount I've been doing this a lot
54. I've been blaming myself for things that happened.  
I haven't been doing this at all I've been doing this a little bit  
I've been doing this a medium amount I've been doing this a lot
55. I've been praying or meditating.  
I haven't been doing this at all I've been doing this a little bit  
I've been doing this a medium amount I've been doing this a lot
56. I've been making fun of the situation.  
I haven't been doing this at all I've been doing this a little bit  
I've been doing this a medium amount I've been doing this a lot

THANK-YOU FOR YOUR HELP

SIA help and advice contact details: <http://www.spinal.co.uk/page/contact-us>

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## **Appendix 3K**

### **Lifestyle questions**

#### **Questions both groups completed at baseline, end of intervention and follow up**

How many times a week do you go out by choice e.g. for shopping, social, entertainment or leisure?  
Write a number in the box below.

To what extent do you use social media?

Always   Frequently   Rarely   Never   Occasionally

How often do you exercise weekly e.g. going to the gym, exercise in your home, gardening, doing sporting activities etc?

Always   Frequently   Rarely   Never   Occasionally

Has having a spinal cord injury stopped you achieving your goals?

Always   Frequently   Rarely   Never   Occasionally

To what extent do you try to eat a healthy diet?

Always   Frequently   Rarely   Never   Occasionally

How confident are you that going to a peer support group will help you to be more independent?

Right at this moment how would you rate your mood?

How happy are you with the direction your life is taking?

#### **Questions only the intervention group answered at end of intervention and follow up**

How many peer support group sessions did you attend?

If you were unable to attend the peer support group or just some sessions could you, please give your reasons why you didn't please as this would be really helpful?

Could you tell us which sessions you enjoyed the most?

What did you enjoy most about being a part of the peer support group?

Was there anything that you disliked about the peer support group?

### Appendix 3L

#### Wellness Ladder – Week

Assume that the ladder is a way of picturing how you are feeling today. The top of the ladder represents your best possible mood and the bottom rung of the ladder represents your worst possible mood.

Indicate where on the ladder your mood is today?

I Feel Great – top rung



I feel awful – bottom rung