

DISABILITY, DEPRESSION AND SUICIDE IDEATION IN MULTIPLE SCLEROSIS

By

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Overview

This thesis is comprised of three individual research placements, two of which were carried out within out-patient clinics within NHS services in Birmingham; one specialising in acquired brain injury and the other in multiple sclerosis. The remaining placement was based at the university and had a forensic focus exploring the sexual experiences of urban street gangs in Birmingham.

Section I: Are Interventions for Return to Work in Acquired Brain Injury Effective?

A systematic review. Working with two occupational therapists and a clinical psychologist, I was introduced to an out-patient clinic that provided specialised employment support for people with an acquired brain injury. I was required to carry out a systematic review in order to assess the variety of interventions used to facilitate employment following a brain injury. Following the advice from my supervisor, I was directed to the Cochrane library for Systematic reviews and the Scottish Intercollegiate Guidelines Network for how to write a systematic review. These guidelines were essential in my understanding of how to present a clear and meticulous search strategy. They also enabled me to develop a quality rating based on the methodology for each study, which I used to rate the evidence for the effectiveness of an intervention.

I gained a good insight into employment-related rehabilitation for people with brain injury and how this is facilitated by the role an occupational therapist, as well the outcomes methods used to measure return to work success.

Section II: The Social and Sexual Experience of Urban Street Gangs in the West Midlands

Qualitative analysis using phenomenological analysis. This placement involved the qualitative analysis of a focus group transcript comprising members of a Birmingham street gang. This experience provided me with an insight into two vantage points for interpreting the text that came from working with a forensic and clinical psychologist. This led to a dynamic process of transcendence - going

beyond the written words of the text in order to understand the 'lived experience' of a street gang.

Despite the lack of direct behaviour-observation involved in analysing language as text, a great depth of understanding can be drawn from words alone. Consequently, I have become to appreciate the differences in the ways that people perceive the world around them. This has enabled me to recognise the complexity of interpreting human behaviour without considering a person's cultural, familial and social influences; a consideration that I will take with me beyond this degree.

Section III: Disability, Depression and Suicidal Ideation in Multiple Sclerosis

Quantitative research using correlation analysis. My final study involved exploring the relationship between disability in multiple sclerosis (MS) and the impact this has on a person's feelings of depression and thoughts of suicide. The study was based in an out-patient MS clinic in Birmingham and was overseen by a consultant specialising in rehabilitation medicine.

The initial stages of this project were not without problems; delays in ethical approval and governance procedures reduced the time I was able to collect data. Fortunately, the therapy team at the hospital were able to offer their support alongside my postal recruitment method by recruiting people during their clinic appointments and over the phone. I found that good communication and my personal presence within the hospital was important in order to maintain the momentum of the recruitment process.

At the start of the placement I attended a number of patient clinics which gave me the opportunity to observe the strikingly-varied symptoms of the disease and its impact on patients' lives; made worse by their young age. The clinics were lead by a highly motivated and committed multidisciplinary team, driven by person-centred care. From the personal accounts given by patients during their clinic appointments, I was able to observe the psychological impact of MS: the impact on intimate relationships, having to rely on carer support and the sense of not knowing what the disease will lead to next. It surprised me then, that a psychologist was not an integrated figure within the team, reflecting the lack of NHS funding for the role.

Psychological aspects of MS are therefore currently being addressed by other therapy disciplines.

Most individuals who were recruited to the project were unable to write due to their disability. Consequently, I delivered the scales verbally whereby I was able to gather valuable anecdotal evidence regarding the impact of MS. I was often concerned about the emotional impact of the study on the patient; the mood was often solemn and some participants appeared to adopt a 'brave face'. However, I was able to build a rapport with the patient, providing me with the opportunity to offer support through active listening. As a result, I was able to meet the aims of the study, whilst also gaining a rich sense of participants' experiences of living with a debilitating disease. Conversely, I was often struck by the resilience of the participants who frequently reflected upon times where "I wanted to kill myself" but since, adjustments have been made and symptoms are tolerated. Furthermore, this resilience would be expressed by participants with more severe disabilities, with one patient expressing great positivity towards his life despite his profound functional limitations. This highlighted the influence of personality traits, coping styles and social support on a person's sense of esteem and mood.

I sought supervision following each appointment whereby my supervisor offered advice of how to support someone with suicidal thoughts, whilst recognising the risks of working with this patient group in a lone-working environment. Supervision also provided me the opportunity to identify the personal impact of the study, of which I found to be an emotional one at times due to the distress expressed by participants. Discussing this impact regularly with my supervisor following participant visits, helped relieve the inevitable emotional burden of recognising a person in distress but being limited in being able to offer immediate help.

Concluding Comments

Over the last year my understanding of clinical psychology as a discipline has grown considerably and I am now able to recognise the importance of research in shaping best-clinical practice. I have become more receptive to critical feedback which I feel is essential for growth as a successful researcher. Whilst I have become

more confident with the application of research methods, I have also strengthened my ability to perform statistical analyses - an aspect of psychology that I felt particularly inexperienced with. Overall, this Masters degree has taught me that no matter how daunting a new endeavour initially appears, commitment and determination will help me find the necessary resources to overcome its challenges.

Dedication

To my fiancé James.

Acknowledgments

Dr. Theresa Powell for her continuous support throughout this degree.

The MS team at the West-Midlands Rehabilitation Centre, to include: Dr. Chit Ko-ko, Rachel Fisher, Vivienne Gregory and Jane Hill, for taking the time to recruit participants to my final project, without whom, the project may have not been viable.

With special thanks to the patients who participated in my final study.

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List of Definitions

Terms/Abbreviations	Definition
ABI	Acquired Brain Injury
FDA	Foucauldian Discourse Analysis
Job Coach	Someone that provides employment support in a work environment. This person will liaise with the employer as well as help the individual to overcome any work-related challenges to ensure the longevity of the work placement/job role
Job Matching	Matching a person's skills and abilities to a relevant job role
Job/Work Re-entry	Re-entering employment following an acquired brain injury
IPA	Interpretive Phenomenological Analysis
Resource Facilitator	An over-the-phone assistant for someone with an acquired brain injury that aims to inform and refer patients to specific services of need.
USG	Urban Street Gang
Work Adjustment	Involves adapting any work-based equipment to the needs of the individual
Work Hardening	Refers to using simulated work activities to develop work competencies and behaviours, for example, punctuality and fatigue management
Work Placement	A person is supported to apply and attain a job role in a desired place of work. Work placements usually represent a person being in competitive employment; however programme support may still continue via a job coach
Work Trial	A simulated work environment supported by rehabilitation-programme facilitators to assess and develop a person's work-skills.

SECTION I

**ARE INTERVENTIONS FOR RETURN TO WORK IN ACQUIRED BRAIN INJURY
EFFECTIVE?**

A SYSTEMATIC REVIEW

Abstract

Background: Studies have shown that only a small percentage of people successfully return to work following a brain injury. Evidence is needed to identify the best practice for vocational-rehabilitation in order to improve return to work success.

Objective: To identify the effectiveness and variety of return to work interventions and determine which are best-practice based on employment outcomes.

Methods: A systematic review was conducted to determine return to work outcomes for people with acquired brain injury. A total of 8 studies were selected for inclusion in this review.

Results: A variety of interventions were identified and categorised according to whether they aimed to a) improve general post-acute difficulties resulting from injury, b) improve job readiness, or c) establish a successful work placement. When compared with regular care, vocational programmes were found to have a positive influence on return to work success. However, sample sizes and outcome measures varied greatly between studies and a lack of follow-up measures meant that the impact of vocational rehabilitation on return-to-work over and above regular care was unreliable.

Conclusions: Vocational-rehabilitation is multidimensional in its delivery; identifying the effectiveness of an individual intervention is unfeasible and best-practice remains unclear. However, successful return to work is likely to involve support to improve work-ready skills specific to the needs of the individual, alongside a supported work placement. Improved outcome and follow-up measures are required to evidence the effectiveness of vocation-based programmes.

Introduction

"I think the biggest fear from the very beginning was, you know, how are we going to do it? I mean, because I was the main bread winner " (Hartke, Trierweiler & Bode, 2011, p. 344). Sixty-three per cent of all individuals affected by an acquired brain injury are adults of working age (Gilworth, Eyres, Carey, Bhakta, & Tennant, 2008), the majority of whom (60-90%) are unable to return to employment following their injury (Trexler, Trexler, Malec, Klyce, & Parrott, 2010). This has a devastating effect

on the livelihood of those affected whilst also impacting on self-identity and quality of life (Gilworth et al., 2008). Brain injury vocational rehabilitation programmes strive to support individuals back to work and regard employment as a hallmark for rehabilitation outcome (Groswasser, Melamed, Agranov, & Keren, 1999; Wall, Rosenthal, & Niemczura, 1998). However, the availability of these programmes are limited to users based on: where the programmes are located, waiting lists, lack of personal resources, and/or inadequate funding (Trexler et al., 2010). Consequently, returning to work is not only limited by a person's disabilities but also by the support available.

Furthermore, certain participant characteristics have been found to predict return to work success, thereby adding further complexity to the evaluation of vocational programmes. Variables that have been found to predict return to work success include: socio-economic status, previous work history, length of post-injury rehabilitation, injury severity, substance abuse, time since injury and age at injury (Kowalske, Plenger, Lusby, & Hayden, 2000; Murphy et al., 2006). Some of these variables are overlapping whereby the length of post-injury rehabilitation is likely to coincide with injury severity. Severe injury is associated with poorer prognosis for successful return to work (Kowalske et al., 2000). It is therefore likely that return to work success will be governed both by the effectiveness of an intervention and the characteristics of the participants.

In order to facilitate return to work, vocational programmes combine functional and work-related interventions that might include a fatigue management programme alongside work-placement support. A commonly cited and influential return-to-work model from the US is that of Wehman et al. (1989) called supported employment. The model describes the use of on-the-job supports referred to as job coaches. It follows a 'place and train' strategy that involves 'placing' the individual in a job placement and 'training' them to do the job (Odom & Upthegrove, 1997). This model has pioneered the development of vocational models and programmes for example: a Work Re-Entry programme (Haffey & Abrams, 1991), the Co-worker Model (Curl, Fraser, Cook, & Clemmons, 1996) and a Transitional Job Coaching Model (Preston & Ulicny, 1992). The variety of interventions that comprise these models need to be

determined in order to identify the methods in which people are supported to return to work.

Although supported employment has been successful, many of the outcomes lack empirical evidence and follow-up measures. These findings are consistent with other return-to-work studies that use measures such as: time from programme admission to a work placement, employment retention after discharge, number of hours worked per week, cost of interventions and job readiness (Niemeier et al., 2010; Preston & Ulicny, 1992). When used alone, these measures do not provide a complete picture of return-to-work success, and hence the effectiveness of the intervention cannot be fully determined. For example, 'employment retention after discharge' does not account for whether employment has been maintained in a single role or multiple roles over time. Lack of job stability during a period of employment could indicate continued vocational difficulties; a possible reflection on the effectiveness of the intervention. It therefore remains unclear what interventions work most effectively to support individuals with acquired brain injury back to work.

Aims

The aim of this review will be to determine the effectiveness of return to work interventions for individuals with acquired brain injury as determined by employment outcomes. Employment will include attaining a new job or returning to a pre-existing job role. This will be presented by way of a narrative synthesis of relevant return to work literature. The objectives are as follows:

1. Identify the variety of return to work interventions
2. Establish which interventions are best practice.

Methods

Search Strategy

The literature search involved a systematic review of five electronic databases; AMED, CINAHL, PsycINFO, MEDLINE and PubMed. All databases were selected based on their focus in behavioural, life and medical science. The Cochrane Library and Web of Science were also used but failed to generate articles that hadn't already been identified.

Using the matched subject headings option, keywords were searched based upon the concepts in the objectives: acquired brain injury, return to work and intervention and permutations thereof. Within each concept, keywords were combined using the "OR" Boolean strategy followed by "AND" to combine keywords between concepts. Details of these searches are listed in Appendix A. The titles and abstracts from each search were manually scrutinised based on the inclusion and exclusion criteria (Table 1.1) as driven by the Population, Intervention, Comparison, Outcome (PICO) framework to identify key areas required (*Systematic Reviews: CRD's Guidance for Undertaking Reviews in Health Care*, 2009).

Table 1.1

Inclusion and Exclusion Criteria using PICO Framework

Framework	Inclusion	Exclusion
Population	Acquired brain injury Head injury Traumatic brain injury Stroke	Substance abuse Psychiatric illness Long-term sickness Chronic pain
Intervention	Work trials Natural supports ^a Employer Support/education Supported employment Work-coordinator Vocational rehabilitation Employer education	Community integration No intervention described
Comparators	Pre and post injury work status Rate of pay Working hours Waiting list control Regular care	Unspecified productivity
Outcomes	Increase working hours Employed status Return to existing role/new role Perceived effectiveness of intervention Sustained employment following discharge	Return to work predictors Perceived barriers and facilitators Costs of intervention Patient experiences
Study design	RCT Quasi-experiments Cohort (retrospective and prospective) Observational Case study Case series	Regression studies Reviews

^a Natural supports involve the support from work-place colleagues as oppose to programme facilitators

Results*Screening Procedure*

Reference lists from the selected articles were scanned to reveal any other relevant articles which were then combined with the search results (Table 1.2). Duplicates were removed as identified through RefWorks reference manager. The search results are presented in Figure 1.1 using a PRISMA (Transparent Reporting of Systematic Reviews and Meta-analyses) diagram (Moher, Liberati, Tetzlaff, & Altman, 2009).

Table 1.2

Results Retrieved from Database Search

Database	Results	Eligible	Duplicates	Remaining
PsycINFO	311	83	47	36
Medline	17	3	0	3
CINAHL	215	12	5	7
AMED	16	6	2	4
PubMed	13	10	4	6
Totals	572	114	58	56

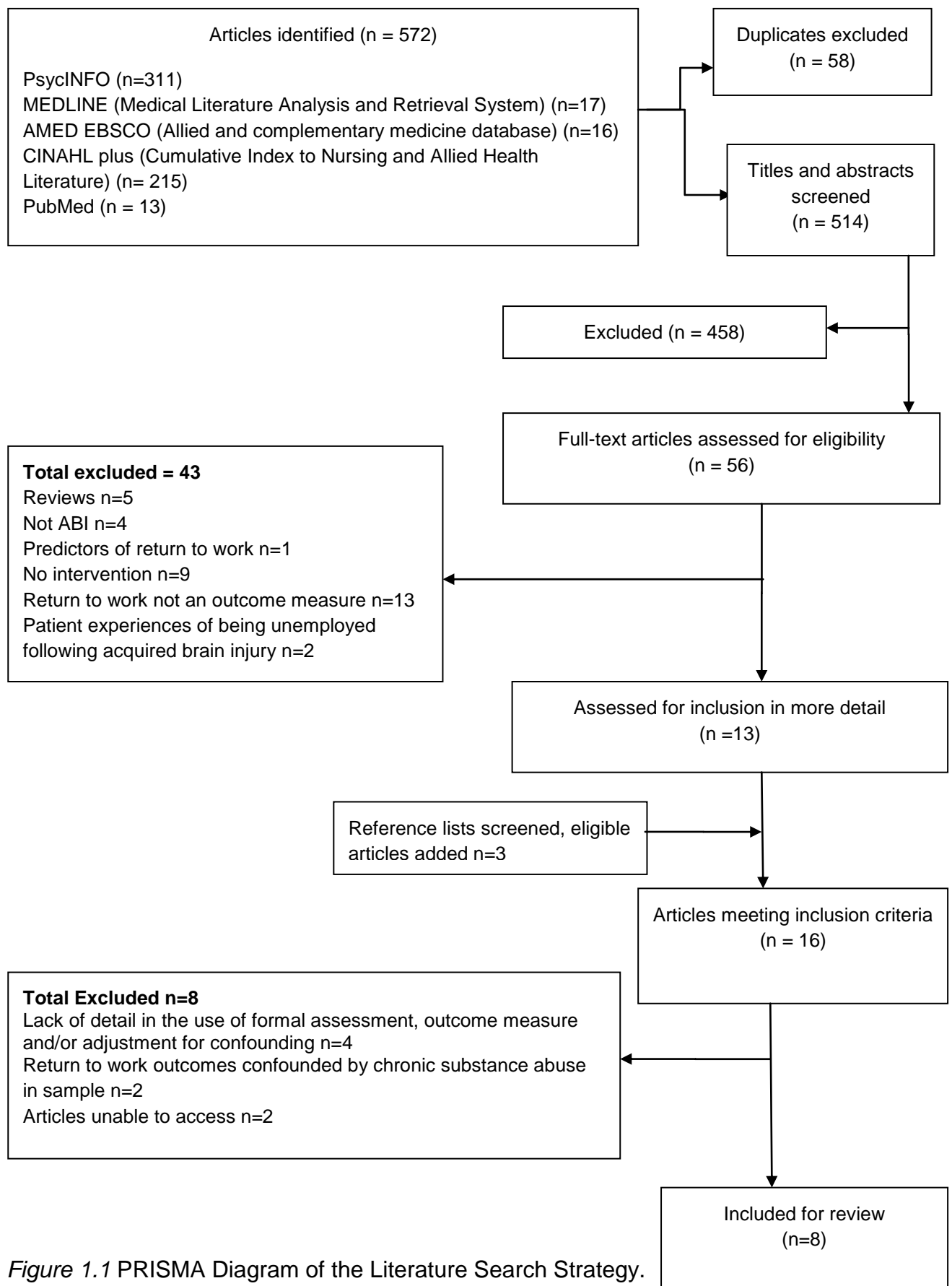


Figure 1.1 PRISMA Diagram of the Literature Search Strategy.

Data Extraction

The following data were extracted: author, study design, sample demographics, intervention(s), outcome measure(s), employment outcomes, pre-injury employment status, duration of intervention and length of follow-up.

Quality Criteria

Downs and Black's (1998) quality criteria checklist for randomised and non-randomised designs was utilised (Appendix B) for 8 studies and the single-case experimental design scale by Tate et al. (2008; Appendix C) was used for one study. The quality scores for all articles (Appendix D1 & 2) were converted to percentages that could be measured against the Scottish Intercollegiate Guidelines Network for methodological quality (2013; Appendix D3). This was achieved by dividing the quality score (measured using the checklist) of the study by the maximum quality score and multiplying by 100 (maximum scores: Down and Black's checklist = 32, SCED scale = 11). Each article was assigned a level of evidence (from one to four) based on the study design (Appendix D4) giving an overall quality rating (Table 1.3).

Table 1.3

Quality Criteria Scores

Author	%	Rating
Haffey & Abrams (1991)	56	2+
Malec & Moessner (2006)	50	2+
Murphy et al. (2006)	53	3+
Niemeier et al. (2010)	59	2+
O'Brien (2007)	48	3-
Ownsworth (2010) ^a	36	3-
Preston & Ulicny (1992)	31	3-
Trexler et al. (2010)	66	1+

^a Quality measured against single-case experimental design (SCED) scale

Categorisation of Interventions

In order to identify return to work interventions that facilitate successful employment, I have divided all of the interventions described within the studies into one of three categories (see Figure 1.2). I have identified two other interventions that involve the integration of a) the relevant employer and b) the family unit to support return to work. I refer to these interventions as 'employer education' and 'family involvement' which are incorporated at any time within a programme. The former describes how employers are educated by programme facilitators to raise their awareness about the impact of acquired brain injury in general.

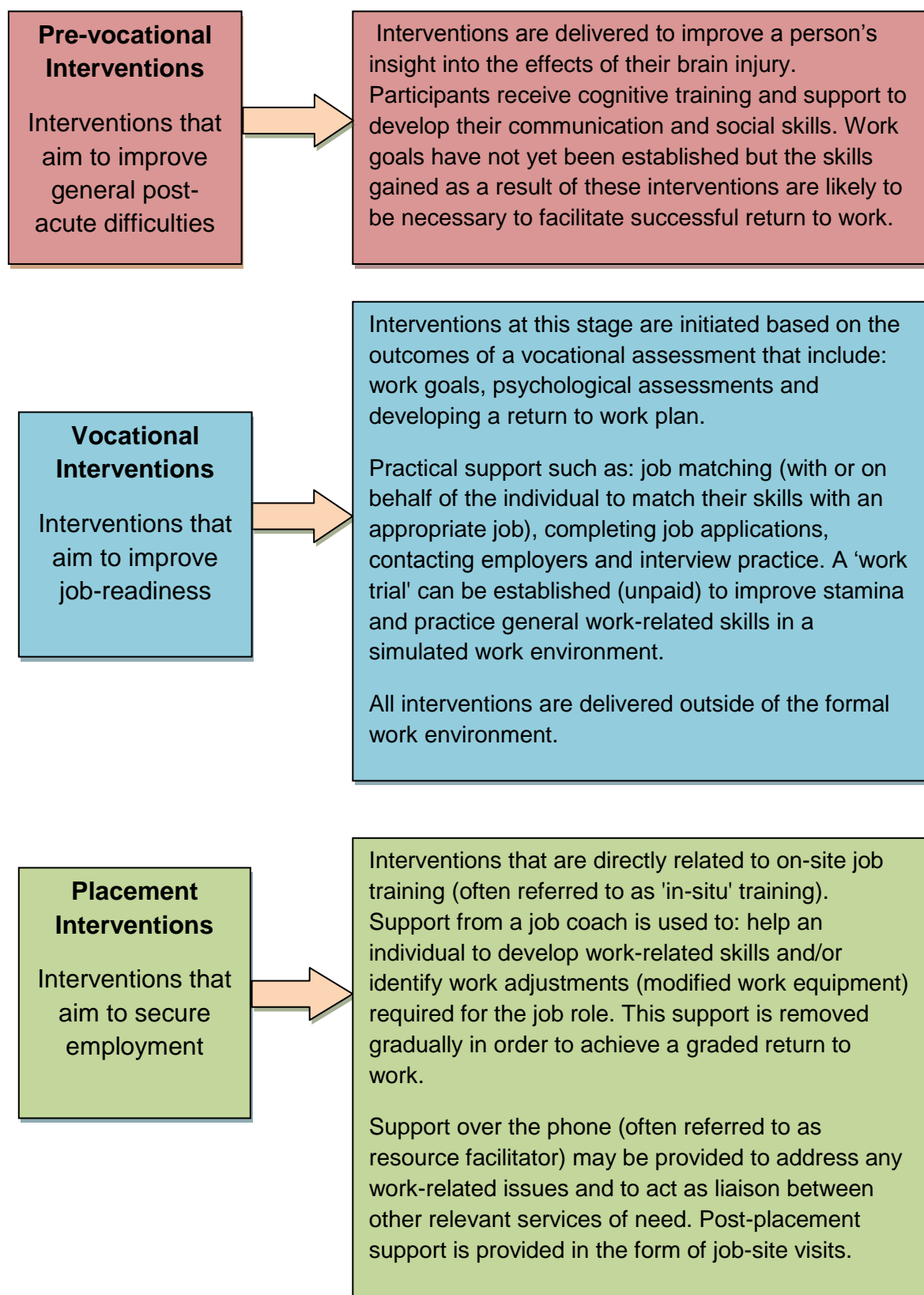


Figure 1.2. Three Categories of Interventions.

The 8 studies fall within one of the following groups based on the combination of interventions described therein:

- A. Pre-vocational, vocational and placement interventions with employer education and family involvement.
- B. Pre-vocational, vocational and placement interventions with employer education.
- C. Pre-vocational, vocational and placement interventions.
- D. Vocational and placement interventions only.
- E. Pre-vocational and vocational intervention only.

Table 1.4 provides a summary of outcomes from each study. Injury severity and interventions are described in Tables 1.5 and 1.6 respectively.

Table 1.4

Data Extraction and Summary of Outcomes

Author	Group	Design	Sample				Programme Title	Follow up	Injury to Intervention <i>M</i>	<i>SD</i>	Outcomes
			Age (<i>M</i>)	<i>SD</i>	No.	Description					
Haffey & Abrams (1991) USA	D	Comparison Cohort	32	-	130	White (80%) Male (71%)	Work Re-entry Programme (WRP)	Every 6 months following placement for 2 years	-	-	68% of treatment group returned to competitive employment in comparison with 34% of the comparison cohort group
Malec & Moessner (2006) USA	A	Referral Cohort	34	14.2	138	White (94%) Male (61%)	Hospital-based Vocational Case Co-ordinator (VCC)	1 year following placement	3.5 years	8.1 years	87% placed (with and without support) during programme, 56% were placed at follow up
Murphy et al. (2006) UK	B	Pre/post Comparison	33	-	232	White (80%) Male (82%)	Rehab UK	-	5.5 years	6 years	72% of clients were discharged into meaningful independent activity.
Niemeier et al. (2010) USA	E	Non-Randomised Control Trial	43	12.3	71	White (70%) Male (69%)	"Vocational Transitions Programme" (VTP)	6-months from starting the programme	-	-	No significant difference in employment status between or within groups pre- and post treatment. Significant difference in productivity ^a post treatment between treatment and control groups.

Table 1.4

Data Extraction and Summary of Outcomes (continued)

Author	Group	Design	Sample				Programme Title	Follow up	Injury to Intervention <i>M</i>	<i>SD</i>	Outcomes
			Age (<i>M</i>)	<i>SD</i>	No.	Description					
O'Brien (2007) AUS	C	Pre/post Comparison	42	-	27	-	Commonwealth Rehabilitation Service (CRS) Australia	-	4.5 years	-	37% returned to existing role and 63% placed in a similar role pre-injury.
Owensworth (2010) AUS	A	Case Series	42	-	3	Two males one female.	"Metacognition programme"	6 months from discharge	5 years	-	Paid employment was achieved between 2 to 16 weeks from admission to the programme.
Preston & Ulicny (1992) USA	B	Pre/post Comparison	32	-	84	-	"Transitional Job Coaching programme" (TJC)	-	1.8 years	-	61% placed in complete employment or were deemed job ready. Half of these returned to existing jobs.
Trexler et al. (2010) USA	A	RCT	43	12	22	Male (64%)	Resource Facilitation	6 month from admission	65 days (T) 124 days (C)	46.9 yrs (T) 107.4 yrs (C)	64% of treatment group were employed at follow- up compared with 36% from control group.

Note. (T) = Treatment group, (C) = Control group.

(-) Indicates missing data.

Follow-up times vary from when they are taken and not all are taken following discharge from a programme; follow-up records may include times when programme support was still on-going.

^a Productivity refers to working and volunteering, entering education or further training.

Table 1.5

Injury Severity of Participants

Author	Severity Measure	Injury Severity
Haffey & Abrams (1991)	Length of coma	The authors do not clarify the cut-off points for severity based on this measure. Majority of sample deemed severe.
Malec & Moessner (2006)	GCS	16% Unknown 42% Severe 24% Moderate 18% Mild
Murphy et al. (2006)	Post-traumatic amnesia (up to 1 hour = mild) (1-24 hours = moderate) (>28 days = severe)	More than half of the total sample were deemed severe.
Niemeier et al. (2010)	-	-
O'Brien (2007)	GCS for TBI Neuropsychological assessment for ABI	41% Severe 45% Moderate 7% Mild 7% unknown
Owensworth (2010)	GCS	Two severe, No details of third participant.
Preston & Ulicny (1992)	GCS	100% Severe
Trexler et al. (2010)	Mayo-Portland Adaptability Inventory (M2PI) as a measure of impairment	Not given. Treatment group significantly more impaired than control group.

Note. GCS = Glasgow Coma Scale, severity scores: severe = <9, moderate = 9-12, mild = >1.

(-) Indicates missing data.

Table 1.6

Return to Work Interventions Described within each Programme

Author	Pre-vocational Interventions	Vocational Interventions						Placement Interventions						Employer Education	Family Involvement
		Assessment of needs	Job match	Interview practice	Work hardening	Job applications	Employer contact	Job coaching	Work placement	Work trial	Work adjustment	Resource facilitator	Post-placement support ^a		
Haffey & Abrams (1991)		X			X		X	X	X	X			X		
Malec & Moessner (2006)	X	X			X			X	X	X	X	X	X	X	X
Murphy et al. (2006)	X	X	X	X		X	X	X	X	X			X	X	
Niemeier et al. (2010)	X			X		X									
O'Brien (2007)	X	X	X	X	X	X	X		X	X			X		X
Owensworth (2010)	X	X	X				X	X	X	X			X	X	X
Preston & Ulicny (1992)	X	X	X			X		X		X	X			X	
Trexler et al. (2010)	X	X					X					X		X	X

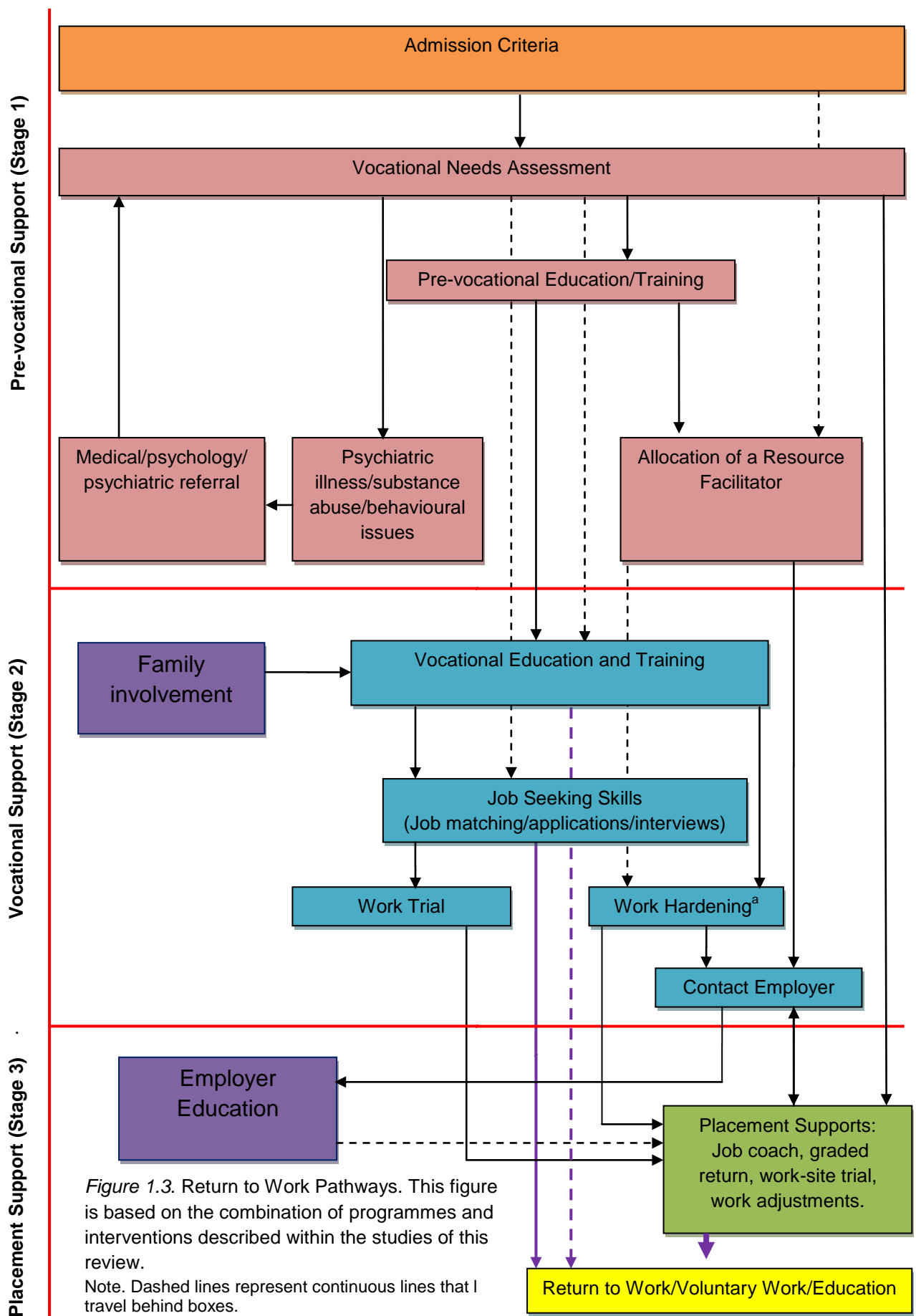
Note. These interventions do not reflect the interventions that every individual received whilst taking part in that programme. Programme facilitators selected interventions based on the needs of the individual (following an assessment of vocational needs). ^a Post-placement support will involve support over the phone or liaising with an employer to resolve any issues following a placement.

Synthesis Summary

Of the 8 studies that are included for review, five are from the US, two from Australia and one from the UK. Two studies use a comparison group and one study uses a control group - a randomised control trial by Trexler et al. (2010). The remaining five studies employ observational methods including: pre and post comparisons (3 studies), a case series and a referral cohort. The ethical constraints of withholding rehabilitation are likely to contribute to the lack of comparison groups used within the selected studies. This compromises the methodological rigour of the research designs which is reflected by the quality scores shown in Table 1.3. It is therefore difficult to evaluate the effectiveness of the vocational programmes described; conclusions and clinical recommendations that can be drawn from these studies are limited.

The admission criteria for these studies involved participants either having a return to work goal or who were deemed able to return to work but needing some intervention beforehand. Most studies found that time since injury had a substantial relationship with time to placement, with chronic injuries relating to poorer vocational outcomes. Details of each programme and their clinical settings are described in Appendix E. An overview of return-to-work outcomes for each study is given in Table 1.13 (page 27).

As described in Figure 1.2, the interventions within the studies for review have been categorised according to their overall aim. I have labelled each category from 1 to 3 (see Figure 1.3), representing a pathway of returning to work (1 indicating the earliest stage in the pathway). Not all stages are necessary to facilitate successful return to work; some individuals may not require pre-vocational support whereas others may require more vocational than placement support. However, the stages remain uniform in their delivery with earlier stages preceding later ones. Pathways that individuals may take when returning to work and the interventions delivered therein are shown in Figure 1.3.



Return to work outcomes

Category A. Pre-vocational, vocational, and placement interventions with employer education and family involvement.

Three studies fell into this category: Malec & Moessner (2006), Ownsworth (2010) and Trexler et al. (2010). The studies received quality ratings of 2+, 3- and 1+ respectively. Studies by Malec & Moessner (2006) and Trexler et al. (2010) are distinguishable from other programmes based on their focus on early intervention. In the former study, 'time since injury' is highly skewed with a standard deviation of 8.1 years since injury; 64% of the participants however were admitted within the first year of their injury.

Small sample sizes in two of the three studies (Trexler et al., 2010; and Ownsworth, 2010), enable programmes to be tailor-made to the needs of the participants. This is likely to have facilitated the successful return to work outcomes within these studies. For example, Trexler et al. (2010) describes vocational outcomes following the allocation of a resource facilitator to 11 individuals (the treatment group) in comparison to 11 controls. Those allocated to a facilitator received over-the phone support once every two weeks where return to work was encouraged by: sourcing and promoting vocational rehabilitation, educating employers and catering for more specific needs (for example, organising transport to and from a place of work). Those in the control group were contacted by the resource facilitator 6-months from enrolment for general follow-up support. Some participants in the control group did receive vocational rehabilitation but not as a result of input from the resource facilitator. There were no significant differences between groups for the type of rehabilitation received, nor were there any differences between age, sex, education, or diagnosis. Vocational outcomes following 6-month enrolment to the programme, as measured by the Mayo-Portland Adaptability Inventory (see Table 1.12, page 25) significantly differed (Wald-Wolfkowitz $z = -3.2$, $P = <0.0001$) in favour of the treatment group (Table 1.7). However, the control group had more chronic illness, possibly reducing their likelihood of returning to work. Furthermore, caregivers were required to participate in the programme; the purpose of this inclusion is not clear

and it is unknown whether caregivers encouraged the participants to use the facilitator more effectively.

Table 1.7

Employment Outcomes following Resource Facilitation (Trexler et al., 2010)

Group	N	Employed	Full time	Part time	Unemployed
Treatment	11	7	4	3	4
Control	11	4	3	1	7

The second study within this group is that by Ownsworth (2010), a case-series describing the delivery of a "metacognition" programme to three individuals, all of whom returned to work. In one particular case, family involvement was paramount in order to enable a participant to balance work-life commitments. Two of three participants had a severe injury as measured by the Glasgow Coma Scale (see Table 1.5). However, severity scores were not reflective of their functional abilities at the time they enrolled on to the programme (an average of 5 years post-injury). For example, one participant was described as having only a mild cognitive impairment and another, a partial disability. Despite this finding, the individuals within this sample were unable to attain employment independently for at least 12-months prior to the programme.

In the largest study of this group, Malec & Moessner (2006) describe the vocational outcomes of 138 participants that were involved in a case-coordination model during 1998-2001. Of 138 participants, 120 participants were placed into work. Figure 1.4 shows that from the total sample (excluding 4 people lost to follow-up) 80% were in community based employment with and without support (level 3-5) at 1 year follow-up (measured using the Vocational Independence Scale; Figure 1.5). Over 50% of those participants were in competitive employment (level 5) comprising some individuals who had progressed from transitional support over the year. Malec & Moessner (2006) found individuals who were admitted less than a year post-injury were more likely to achieve competitive employment, highlighting the importance of early intervention.

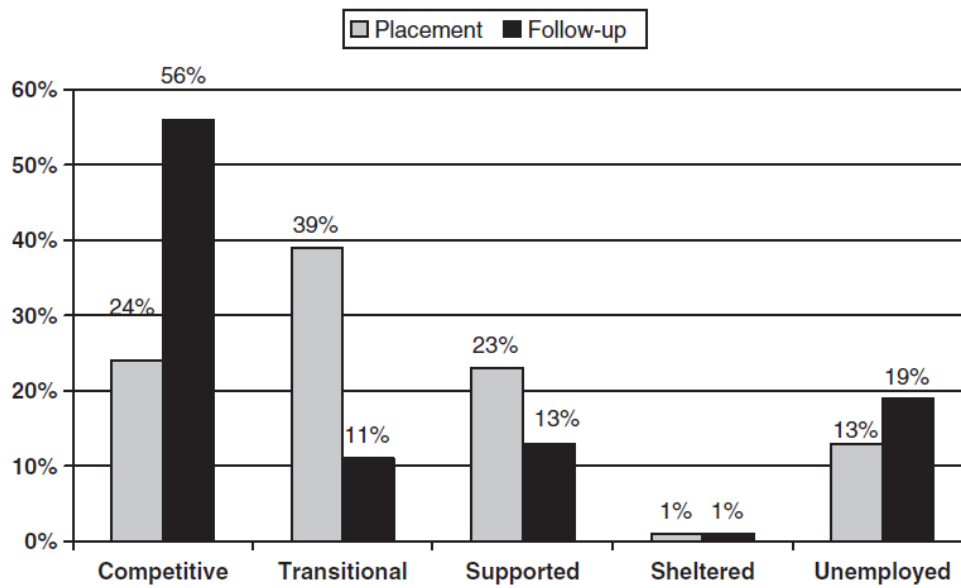


Figure 1.4. Outcomes from Initial Placement and at Follow-up (362 days post-placement; Malec & Moessner, 2006).

Level 5	Competitive: Community-based work without external support for more than 15 hours/week.
Level 4	Transitional: Community-based work with temporary supports (e.g. initially less than 15 hours job coach) or in training or school.
Level 3	Supported: Community-based work with permanent supports or less than 15 hours; volunteer work.
Level 2	Sheltered: Work in a sheltered workshop.
Level 1	Unemployed.

Figure 1.5. Vocational Independence Scale by Malec & Moessner, (2006)

Group B. Pre-vocational, vocational, and placement interventions with employer education.

Two studies, one of Preston & Ulicny (1992) and Murphy et al. (2006) fall within this group, scoring 3- and 3+ respectively for methodological quality. Both models described within this group are based on the supported employment model by Wehman et al. (1989).

The first study by Preston & Ulicny (1992), describes an intensive transitional job coaching model whereby participants were selected from a post-acute, residential community-based rehabilitation programme. Vocational outcomes were divided into categories as shown in Table 1.8. This study also measured a person's 'job readiness' whereby participants were deemed employable by rehabilitation staff but awaiting job openings in their local area. Competitive employment and job-readiness outcomes were combined; the outcomes for each measure alone are unknown.

Table 1.8

Return to Work Outcomes following a Transitional Job Coaching Programme
(Preston & Ulicny, 1992)

Category	%
Competitive employment/Job ready	61
Sheltered employment	14
Voluntary work	11
No placement	14

Note. Sheltered employment represents full-time supported employment earning less than minimum wage.

In the largest study of this review, Murphy et al. (2006) describe the return to work outcomes of all individuals attending a national rehabilitation programme, Rehab UK between January 2000 and December 2002. Outcomes are presented in Table 1.9 and were not related to injury type, severity, or pre-employment status. A lack of

follow-up measures in this study means that the long-term effectiveness of the interventions cannot be determined.

Table 1.9

Return to Work Outcomes Following Rehab UK Programme Completion (Murphy et al., 2006)

Outcomes	%
Competitive employment	41
Voluntary work	16
Education	15
Medical referral made	15
Withdrew	13

Group C. Pre-vocational, vocational, and placement interventions.

A study by O'Brien (2007) employed a retrospective design scoring 3- for quality, which evaluated and described the outcomes from a rehabilitation service in Australia. The study outcomes were achieved by way of a staff survey (n=7) and a retrospective closed-case audit (n=27) of individuals who successfully returned to work and were discharged the previous year (2003-2004). Staff were asked to rate the effectiveness of the interventions and assessments they used. They considered the most effective to be: graded return to work programmes, teaching compensatory strategies in work, coaching clients, vocational counselling and behaviour coaching. These interventions predominantly fall within 'placement interventions' whereas 'vocational interventions' are described secondary to these: mock interviews, career planning, and completing job applications. Where clients did not have a job to return to (11/27), they were supported with the practicalities of job searching, writing applications, and developing their CVs. The perceived effectiveness of assessments and interventions in this study do not specifically relate to the successful return to work outcomes of the closed-case files.

Group D. Vocational and placement interventions only.

A comparison cohort study by Haffey & Abrams (1991) fell within this category. This study scores 2+ for quality. The authors describe the return to work outcomes following completion of a work re-entry programme (WRP) in comparison to a regular care (control) and a day treatment (non-vocational) programme. There were no significant differences between groups in regards to participant variables affecting return to work. Table 1.10 gives the vocational outcomes for people within the work re-entry programme, based on the most recent follow up in 1990 (two years since the start of the study). Of those who returned to work (88/130), 62 remained employed at the most recent follow-up with over half of the participants being placed in their job roles for up to a year. The remaining participants changed job roles mostly on account of dismissal and employee dissatisfaction. Overall, return to work outcomes for the WRP were greater than outcomes in the comparison groups (see Table 1.11).

Table 1.10

Vocational Outcomes for 130 Participants Enrolled on Work Re-entry Programme
(Haffey & Abrams, 1991)

Vocational outcomes	%
Employed	68
Continued with the programme	17
Inactive, chronically unemployed	25

Table 1.11

Return to Work Outcomes across comparison groups (Haffey & Abrams, 1991)

Group	%
WRP	68
Day treatment	39
Control	34

Group E. Pre-vocational and vocational interventions only.

A study by Niemeier et al. (2010) is the only study to fall within this group. The authors describe employment and productivity outcomes following a vocational transitional programme. The study scores 2+ for quality given the presence of a control group. Participants were assigned to the treatment (n=39) and control (n=32) groups using a waiting-list control method (all participants were due to receive the intervention), following the advertisement of the programme for purposes of improving productivity post-injury. Vocational outcomes were measured at the start and at 6-months post programme. Between-group analysis revealed no significant differences for employment or productivity pre-treatment or for employment post-treatment. However, between-group analysis revealed that productivity was significantly greater in the treatment compared to the control group (Chi-square = 7.06, df = 1, p-value = 0.0079) post-treatment. Within-group analysis showed no change in the treatment or control group for employment outcomes pre to post treatment.

Table 1.12

Outcome Measures

Author	Outcome Measure	Description
Haffey & Abrams (1991)	Descriptive Outcomes	Employment outcomes following initial placement.
	Preliminary Diagnostic Questionnaire (PDQ)	Developed by the West Virginia Research and training Centre. Comprises of 8 subscales assessing factors associated with employment, cognition, emotional and physical functioning.
Malec & Moessner (2006)	Vocational independence scale (VIS; Primary measure)	Descriptive outcomes based on level of support (Figure 1.5).
	Time to placement (admission to placement)	Duration of support from admission required to achieve work placement.
	Independent living scale (ILS)	Measure of disability used prior to intervention.
Murphy et al. (2006)	Descriptive outcomes	Paid competitive employment; education or training; voluntary work; discharge to other services; client withdrew; discharge for other reasons.
Niemeier et al. (2010)	Employability rating scale (ERS)	Developed by Rusk Institute New York. A 10-point scale assessing present and future capabilities of a person gaining work or becoming productive following injury. Predictions for future employability are made based on personal demographics and characteristics known to influence likelihood of return to work. Delivered by rehabilitation staff.

Table 1.12

Outcome Measures (continued)

Author	Outcome Measure	Description
Niemeier et al. (2010)	Rehabilitation intensity of therapy scale (RITS)	Level of effort applied by participants during the programme as determined by the rehabilitation staff.
	Clubhouse Member Satisfaction Questionnaire (CMSQ)	Delivered by staff and completed by clubhouse members at the end of every session. Addressed what skills were learned and how helpful it was.
O'Brien (2007)	Descriptive outcomes	Return to pre-existing role; job salaries; occupation category.
Ownsworth (2010)	Descriptive outcomes	Time from programme to placement and number of hours/days required for on-the-job support.
Preston & Ulicny (1992)	Descriptive outcomes	Competitive employment; job readiness; volunteer work; sheltered employment.
Trexler et al. (2010)	Orientation Log (O-Log) and Cognitive Log (C-Log)	Determine severity and initial cognitive impairment by assessing memory, attention, orientation and executive functions.
	Participation Index of the Mayo-Portland Adaptability Inventory (M2PI)	Measures the extent to which the participant experiences difficulty with social contact, self-care, transportation, financial management and voluntary or paid work.

Table 1.13

Overview of Return to Work Outcomes

Author	Participants ^a	% Employed at injury	% Employed on admission ^b	% Employment outcomes	% Outcomes at follow up
Haffey & Abrams (1991)	130	82	-	68	71
Malec & Moessner (2006)	138	-	16	24	56
Murphy et al. (2006)	232	70	8	41	-
Niemeier et al. (2010)	39	87	14	23	-
O'Brien (2007)	27	-	37	100	-
Ownsworth (2010)	3	67	0	100 ^c	100 ^c
Preston & Ulicny (1992)	84	97	0	61	-
Trexler et al. (2010)	11	100	-	-	64

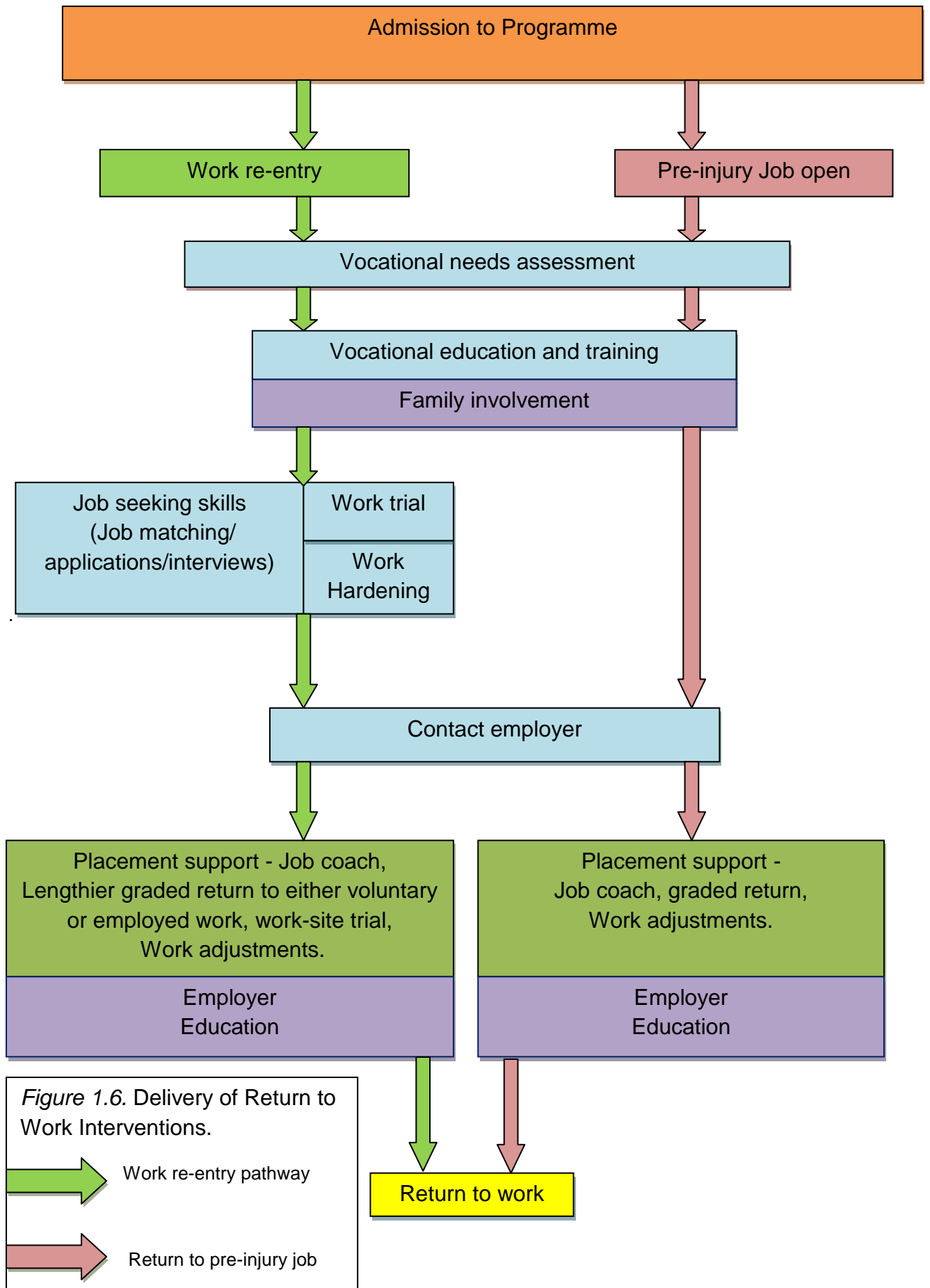
Note. (-) indicates missing data.

^a Numbers are based on participants that completed the programme and/or treatment groups only. ^b Includes those who are on sick leave but are considered employed and/or individuals struggling in employment (figures not distinguished). ^c Outcomes differ in number of working hours and job stability.

Discussion

There are many varieties of return to work interventions none of which, based on the studies within this review, are delivered in isolation. Instead interventions are combined to strengthen job readiness and secure work placements; determining the effectiveness of each input alone appears indistinguishable. Participant variables add further complexity to this issue such as: whether a job remains open, injury severity, and previous work history. Without accounting for these individual variables, it is difficult to determine the greater influence on successful return to work - the vocational programme or the characteristics of the individual.

The type of interventions delivered by a programme varies depending on whether a pre-injury job remains open or not, whereas the intensity and duration of that delivery is mediated by injury severity. Hence there appears to be two, but not exclusive, pathways whereby vocational interventions serve to; maintain existing work or to support work re-entry (Figure 1.6) as identified through an assessment of vocational needs. Consistent with O'Brien (2007), participants re-entering the workforce benefit more so from job-seeking support and voluntary work to facilitate gradual work re-entry.



Determining the best practice for delivering return to work interventions therefore may start by establishing whether or not a person's job remains open. However, the type or specificity of interventions used to support an individual may not be the only factor contributing to successful return to work. In a randomised control trial, Trexler et al. (2010), although based on a small sample, suggest that directing patients to relevant services through resource facilitation is as important as taking part in vocational rehabilitation itself; a significant difference in employment outcomes were found between the two groups (in favour of the treatment group) despite both groups engaging with vocational rehabilitation. A lack of information given to patients regarding relevant services may be contributing to poor employment outcomes.

The importance of employer education and family involvement is not always apparent within the studies, with the impact likely to be specific to the individual. Employer education has previously been found to be important in cases where there is no 'visible injury' (Gilworth et al., 2008) helping colleagues to understand the effects of having an acquired brain injury, thereby impacting positively on employment stability.

In summary, based on the findings of this review, best-practice interventions are likely to involve a combination of: early-intervention, including identifying if a person's job remains open; specificity of support; referring and directing individuals to relevant services; and incorporating an in-situ work support element.

Although studies in this review have revealed the varieties of interventions, the impact they have on return to work above regular care remains unclear; a consequence, in part, of poor methodological rigour. However, Malec & Moessner (2006) describe how change elicited by an intervention in this context should be evaluated within the social model of disability, which considers the individual within their environmental and cultural context. A randomised control trial may not provide the best evidence for vocational outcomes as the individual is not the only aspect required to change; the individual's environment, expectations and the attitudes of others are change agents in themselves (Malec & Moessner, 2006, p. 228). Employment status alone, is therefore an unreliable measure of successful return to work (Oppermann, 2004), nor does it take into account the stability of employment following discharge from a programme. Methodological rigour could therefore be

improved by combining different measures that account for the multi-dimensional aspects that define successful return to work.

Limitations and future implications

A second assessor was not used in the process of including, excluding, or quality assessing each study. However, supervision was sought to ensure that all selected studies met the inclusion criteria. Dividing interventions into categories revealed a return-to-work pathway, demonstrating how vocational rehabilitation is multidimensional in its delivery towards achieving employment. However, this did not reveal the effectiveness of one intervention over another.

Future research should aim to identify the best quality outcome measures that demonstrate positive vocational outcomes. These findings will also help determine the cost effectiveness of vocation-based interventions; an important consideration at a time where financial outcomes are key and where extended rehabilitation is required for more severely-injured persons to achieve successful work placements.

Reflective Account

This placement involved working with two occupational therapists and a consultant clinical psychologist within an NHS rehabilitation centre called Moor Green - an outpatient clinic held at Moseley Hall hospital in Birmingham. The clinic provides general post-acute services for adults with acquired brain injury as well as providing a return to work programme to support individuals back into work. The service is currently reviewing where its vocational input is situated in terms of what other services provide; the clinicians within the service want to know the best-practice of when to deliver vocational services to post-acute patients. Consequently, the return to work programme was the focus of my placement. I was asked to a) identify a variety of return to work interventions and b) help to map the return to work pathway for patients attending the clinic.

To achieve my first aim, I was asked to carry out a systematic literature review of return to work interventions. This was my first experience of performing this type of literature review and so I sought advice from a library officer in order to ensure that my search strategy reflected a systematic approach. I developed the necessary skills

needed for the review, including: identifying key words to search, combining key words using Boolean headings, refining search results and extracting the results into RefWorks reference manager. As I became more familiar with the terminology in this research area, I was able to add key terms to my search strategy in order to produce a more detailed approach. Once I had selected my relevant studies, I could see that outcome and follow-up measures varied greatly between them making it difficult to evaluate the effectiveness of the interventions. The data extraction process of my selected studies provided an essential step towards helping me to synthesise and categorise seemingly incomparable research designs.

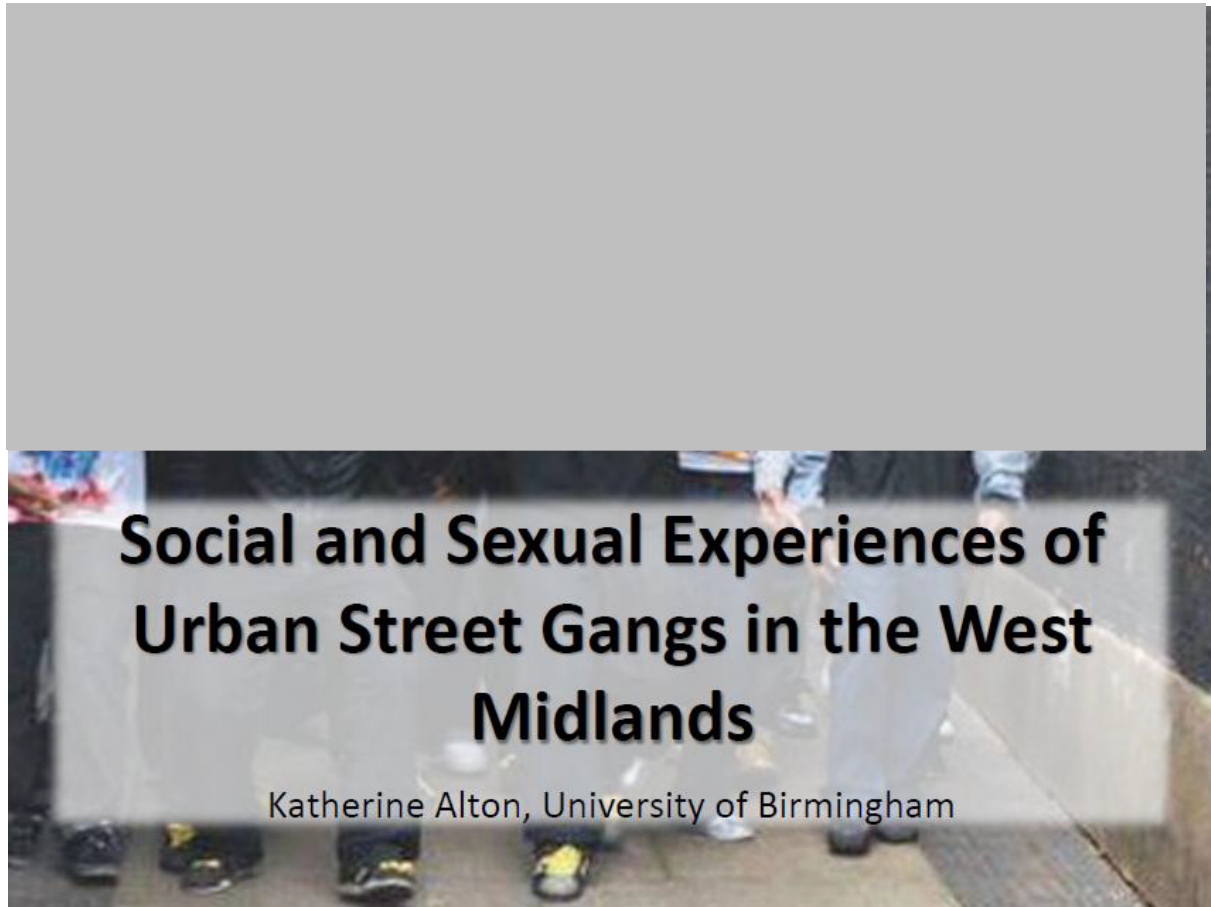
The return to work pathway had already been developed by the occupational therapists at Moor Green but further clarification was required. For example, what interventions are offered and what advice is given by other services to individuals wanting to return to work? Therefore, in order to achieve my second aim, I attempted to interview primary, secondary and third sector services that were indirectly and directly involved with Moor Green. Interviewing members from outside organisations proved to be arduous; I was confronted with resistance regarding my research from the Department of Work and Pensions and despite much persistence, I was unable to make contact with an acute rehabilitation ward at the Queen Elizabeth hospital.

I received regular supervision from a consultant clinical psychologist Theresa Powell, who provided me with placement and academic support. Supervision was essential to further my knowledge in research methods in order to critically evaluate relevant studies. Theresa also helped me to identify measures required for methodological rigour, for example the use of participant and researcher blinding; control groups and randomisation; multiple baseline measures; and adjustment for confounding variables.

Overall this placement has increased my ability to critically appraise research outcomes as well as identify different research designs. It has also made me more aware of some of the services available for patients with acquired brain injury and the interventions that are used to support individuals to return to work. As a result of this placement, I feel confident with literature searching and evaluation, an essential skill for all aspects of clinical psychology research.

SECTION II

**SOCIAL AND SEXUAL EXPERIENCES OF URBAN STREET GANGS IN THE
WEST MIDLANDS**



Slide 1. Introduction

This placement contributes towards a qualitative research project exploring the sexual and social experiences of urban street gangs (USGs) in the West Midlands. Individuals living in Handsworth in Birmingham who were thought to be affiliated with USGs were recruited to the project via a youth worker. The project received ethical approval from the University of Birmingham. Participants were interviewed individually and/ or took part within a single-sex focus group. The researcher was not involved in this project during the phases of recruitment or data collection. Consequently, this placement is concerned only with the analysis of the female focus group using interpretative phenomenological analysis (IPA) and foucauldian discourse analysis (FDA).

The focus group comprised of five females aged 21-28 and were asked to respond to five different vignettes giving situations of rape and sexual coercion.

Prompts were used throughout the discussion to explore:

- gender roles
- social context
- personal meaning
- sexual experiences

Background information. Definition of a street gang: Any durable, street-oriented youth group whose involvement in illegal activity is part of its identity (Klein & Maxson, 2006). There are 50,000 young people in England and Wales affiliated to violent youth gangs (Centre for Social Justice, 2009) with 400 known members across Birmingham (Barton, 2010). Street gangs are growing within the UK with affiliation starting as young as 12 years and are associated with criminal activity and female sexual exploitation (Pearce & Pitts, 2011). Understanding the social and sexual behaviour amongst street gangs is imperative for the prevention and suppression of female sexual exploitation.

All extracts throughout this presentation have been taken verbatim from the transcript.



OBJECTIVES

1. Project Aims
2. Analytic Strategy
3. IPA Outcomes

Objects of concern and emerging themes

4. FDA Outcomes

Objects, positions, actions and subjectivity

5. Summary



Slide 2. Presentation Content

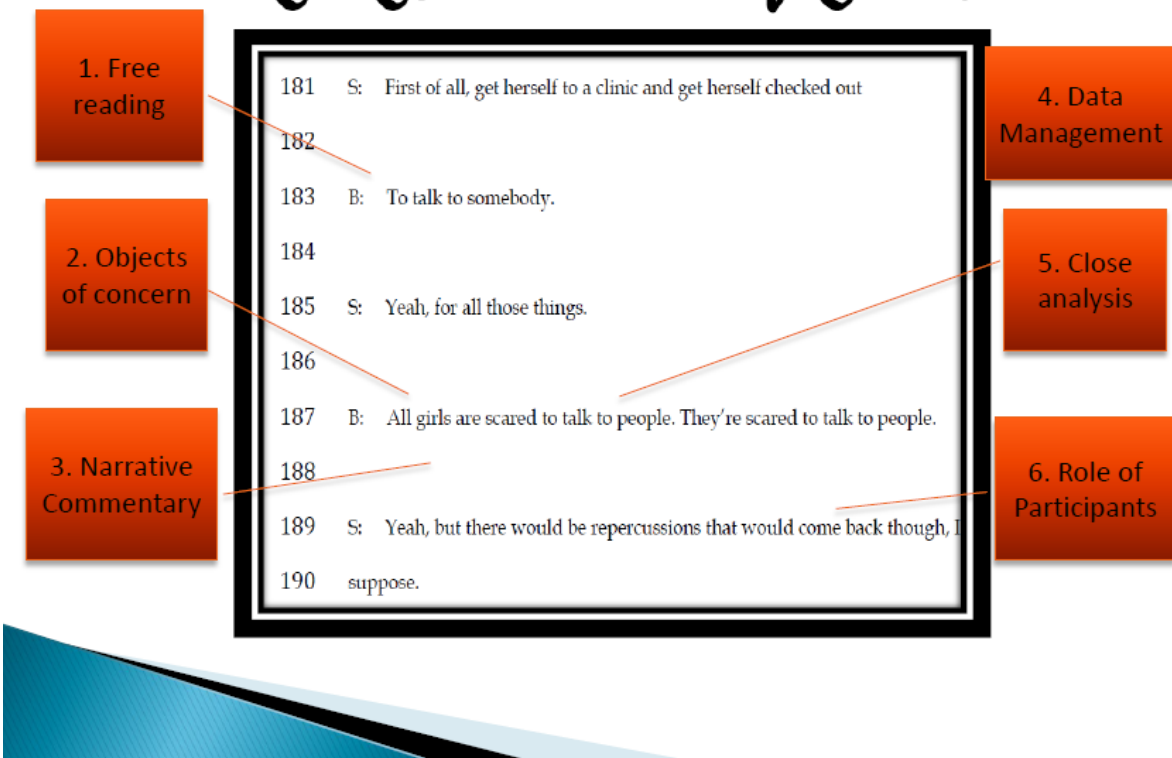
AIMS

1. **Develop** an **analytic strategy** for **focus group data** that incorporates a phenomenological and discursive approach
2. From a female perspective, **explore** the **social world** and **beliefs about sexual behaviour** of **street gangs** in the west midlands.



Slide 3. Placement Aims

ANALYTIC STRATEGY



Slide 4. Analytic Strategy applied to Focus Group Transcript

The two analyses that I used for the focus group transcript (IPA and FDA) are derived from two different epistemologies that when applied together, provide an extension of one another (Johnson, Burrows, & Williamson, 2004) to reveal both the intra and wider psychic experiences of individuals. IPA, rooted within idiography, phenomenology and hermeneutics, seeks to understand the lived experience of a given phenomena by an individual, whilst considering the researcher's interpretation (Smith, Flowers, & Larkin, 2009). IPA is less commonly used for focus group data given that focus groups have an experiential and interactional element that lends itself towards discursive analysis (Palmer, Larkin, De Visser, & Fadden, 2010). However, IPA can be applied to focus group data to provide a rich understanding of shared experiences that might not be revealed within a single interview or through using discursive analysis alone. Flexibility is needed from the idiographic nature of IPA in order to enable the exploration of experiences within a group of individuals. FDA is a constructivist approach which seeks to understand how meaning is implied from talk through discursive constructions (Willig, 2008). FDA adopts the notion that

language is tied within social and cultural practices, which should reveal in this case, the social world and beliefs about sexual behaviour from the perspective of females affiliated with street gangs. The analytic strategy which I employed (see Table 2.1) was adapted from Palmer, Larkin, De Visser, & Fadden (2010) which involved a broad analysis (what had been claimed) followed by a close analysis (how it was claimed):

Table 2.1

Analytic Strategy (adapted from Palmer, Larkin, De Visser & Fadden, 2010)

Analytic process		Description
Broad Analysis	Free-reading	Involved reading the transcript in full and acknowledging initial impressions.
	Objects of concern	Annotations were made in the margins regarding experiential claims that lead to the development of objects of concern. Notes were made on the discursive devices used to construct those objects.
	Narration	Attention was paid to the narrative within the transcript, making sure that local concerns were not over-looked. This process facilitated the navigation of claims through the transcript supporting the iterative process.
	Data Management	As objects began to emerge, they were placed onto a spread sheet with the relevant evidence from the transcript, along with my initial impressions. This helped to document new-emerging objects as they appeared, allowing the process to be more manageable.
Close analysis	Objects	Questions were asked of the data: <ul style="list-style-type: none"> - What is their nature and what do they represent i.e. a system, organisation, relationship, activity, subject? - What themes and positions emerge from these objects? - How are the themes described and what meaning and consequences do they have for the participant? - What positions are described? What actions and subject positions are revealed? What can this tell us about the nature of their environment? - Are there any contradictions? If so, what is their function? - What is understood by their consequences?

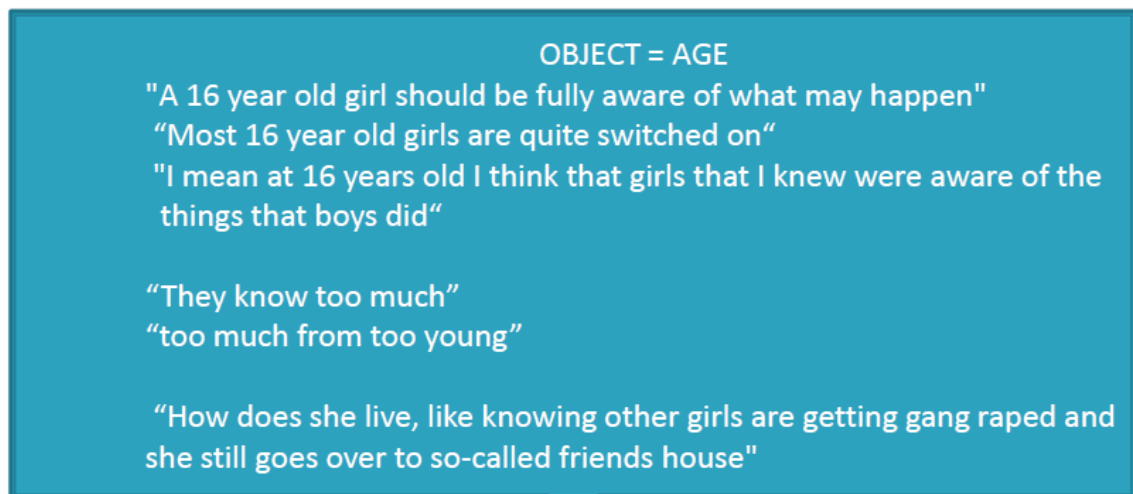
Table 2.1

Analytic Strategy (continued)

Analytic process		Description
Close analysis	Language	<p>Attention was paid to the use of language, metaphors, colloquialisms, euphemisms.</p> <p>Questions were asked of the data:</p> <ul style="list-style-type: none"> - What patterns develop within the language - what does this achieve? - What positions are created through language by both participants and facilitators and what actions are subsequently produced?
	Stories	Attention was paid to: how stories were facilitated, influenced and constrained by the conversation; their function; and what they achieve.
	Participants	<p>Questions were asked of the roles played by individuals within the group:</p> <ul style="list-style-type: none"> - Do roles change or stay consistent? - What does this reveal about the subject matter and the experience of the individual? - How might this inform individual interviews that have taken place alongside the focus group?

This strategy helped me to deconstruct the text, paying attention initially to the broad themes and then analysing local claims. The most difficult aspect of this strategy was keeping track of the role each participant was playing. Given that the research project was formed by a hybrid of interviews and focus groups, participants' roles and experiences are not the focus of this particular analysis. Once familiar with the transcript, objects of concern (something that the participants were talking about and had meaning) started to emerge. From here, themes started to emerge from the objects which lead to the development of superordinate and sub-themes (see Appendix F) often using evidence from a number of objects to form a single theme. The next slide demonstrates how I developed one theme from a single object.

From Objects to Themes – A Worked Example



Theme: The damaging consequences of lost innocence

Slide 5. The Process of Developing Themes

There are various claims made about this:

- Girls should know what's going on around them;
- Girls know too much;
- Too much from too young.

There are consequences for these claims:

- Girls that 'know' become subjected to victim blame

These findings created the theme shown on the slide.

I identified a number of risks with my analytic strategy at this stage:

1. Losing the context from which each statement was extracted;
2. Making statements 'fit' within a theme instead of allowing statements to be interesting in their own right;

3. Drifting from the transcript during the process of sense-making;
4. Failing to recognise that some discussions were not unique to this gang culture but had commonalities with young people and adolescent development in general.

Peer support, supervision and constant iterative referral to the text helped reduce these risks and encouraged a very dynamic analysis. Narrative commentary also kept the overall feel as well as local claims alive throughout the analysis.

Interesting Points

IPA

"When you want to get into a gang, you have to get battered... you have to beat someone up, kill someone or stab someone"

"he'll be recruiting, laughing, kicking a football"

"And that's where the gang comes in, the girls need to realise that you are nothing to them"

"if she was his girlfriend he wouldn't want anyone to touch her but him"

Boys will be boys

A pressured and desperate adolescence

Slide 6. Interesting Points Extracted from the Transcript

A number of themes were developed using IPA and included:

- Boys will be boys
- A pressured and desperate adolescence
- The allure of belonging;
- The consequence of belonging;
- Covering the irreversible damage caused by forced sex;
- The protective but damaging consequences of losing innocence.

I will discuss a couple of interesting statements and then two of above he themes: 'boys will be boys' and 'a pressured and desperate adolescence'. These themes have been selected because they highlight some key issues within the gang culture.

A number of statements (as shown on the slide) revealed some of social 'rules' within gang culture. In the first case, the girls within the focus group discuss male gang

affiliation. In one instance, this involves serious criminal threat and knife crime, whereas in the other, gang activities reflect those of adolescent behaviour.

The girls also make a clear distinction between girls affiliated with gangs and girlfriends of gang members. The girls in the focus group agree how girls associated with gangs are de-valued whereas girlfriends are the opposite – they are protected from other gang members and respected in a way that other girls are not.



Boys will be Boys

"these guys know how they can get out of it as well, that's why they're freely doing it"

"Maybe not all gang members are all that bad in one sense, maybe they're just born into it not knowin' [/knowing/] any better- their Dad, their Uncles, their Brothers and they don't know any better."



Slide 7. Boys have a Lack of Accountability

Boys are described as being free to do what they like. Consequently, it is the responsibility of the girl to protect herself from the things that boys do. Whilst boys do not take accountability for their actions they are also perceived as having learned their behaviour from male relatives. This appears to justify male perpetrator behaviour, revealing a sense of empathy from the girls within the focus group. It is perhaps this that encourages the girls to focus their discussions on the 'real' problem of sexual coercion i.e. the female victim.

A Pressured and Desperate Adolescence

Girls and boys are desperate

"These kids are too desperate to get in"

"It's they're- it's like they're – Boys in a gang, that's like something that's- like... not condoning it or anything, but there's reasons for the boy to be in a gang, but the girl she just wants- what does she want? She wants to be accepted she wants to feel some love. Like, look for it elsewhere. Why are you pushing yourself upon this gang life"

Compensating for a lost upbringing

"Really she's lost, got something missing in her life"

"You've got no love at home so you go searching for it elsewhere"

"They might they might want love and think that that's the way to get it. They should know that that's the wrong way."

Slide 8. Adolescence in Gang Life is Pressured and Desperate

Girls and boys are desperate. The focus group reflect upon the reasons why boys and girls become gang affiliated – there are more reasons for boys but it is less clear for girls commenting that they 'push' themselves on to gang life; girls have a choice, whereas boys do not. "she wants to be accepted, she wants to feel some love" and so girls engage in sexual behaviour in order to become accepted and feel love. This is consistent with Dorais and Corriveau (2009) who found that young women who become involved in sexual coercion/exploitation share a desperate desire to be liked.

Compensating for a lost upbringing. As a consequence of this behaviour, girls are deemed as having something 'missing' in their life. This is thought to be a result of their upbringing; girls are lost and looking for an alternative support network – a surrogate family (Ruble & Turner, 2000). The focus group reflect that there are 'right' and 'wrong' ways of finding love and gang life represents the 'wrong' way.

Foucauldian Discourse Analysis

Six stages of foucauldian discourse analysis were used (Willig, 2008): discursive objects, positions, action, subjectivity and practice implied from discourse.

This analysis revealed a number of discursive objects (something that was being constructed by the participants):

Sexual Coercion

Girls



Slide 9. Applying Foucauldian Discourse Analysis

I am only going to talk about two objects: girls and sexual coercion in order to present the different ways that girls are positioned and how sexual coercion and rape are constructed to reveal beliefs about sexual behaviour. Details of other objects that were identified from the data are presented in Appendix G.

Girls



"She's going to have a label"

Damaged goods

"Everyone is going to have an opinion of a girl who does something"

As a consequence, girls are **Scared**

"All girls are scared to talk to people. They're scared to talk to people"

"I think that's another reason why people are too afraid to say anything - They have forced you to do sexual acts so what else can they do".



Slide 10. Girls are Constructed as being Damaged

Object. Girls

Position. Damaged goods

Action. A girl having a label suggests that she is attached to the opinions and expectations created by others, regardless of whether they are true or not. In this case, the opinions suggest that her behaviour lead to her being forced or coerced into sex.

Practice. Rape myths are revealed through this labelling whereby "attitudes and beliefs that are generally false but widely and persistently held, and that serve to deny and justify male sexual aggression against women" (Lonsway & Fitzgerald, 1994, p.134). When these beliefs are attached to a female, she is no longer respected by males and females in (and outside) of the gang; she is perceived as a "drunge". Girls are unwilling to report the event due to the risk of being labelled and

because she is likely to know her perpetrator. Male behaviour is strengthened and sustained through avoidance of punishment (Boeringer, Shehan, & Akers, 1991), thereby perpetuating the culture.

Subjectivity. Rape myths provide an alternative understanding of how and why rape and coerced sex occur. The focus group assumed that female victims in the vignettes were either: willing to be involved or they brought the situation on themselves even when sex is forced. This reduces their empathy towards the victims in the vignettes and rape as a sexual violation and object of power is not identified.

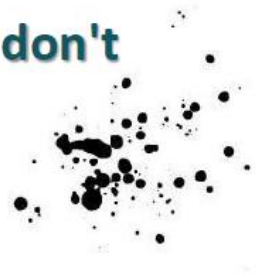
Sexual Coercion

Way of Life

“People around her who are used to doing it, so does she get upset and the forget about it because this is normally, what it's going to be like”

“Its just, you know it might not even be in this environment, sometimes you just do ting that you don't really want to do”

“Rape is rape, it's whatever, but I don't know”



Slide 11. Sexual Coercion is a Way of Life

Object. Sexual coercion

Position. Way of Life

Action. Girls within the gang environment have experienced situations of sexual coercion which is revealed by the above reflection “people around her who are used to doing it...” The girls attempt to understand why a girl might not become overly upset by the situation. In this case, they understand sexual coercion to be normalised through the actions of others.

Practice/Subjectivity. Girls and young women who are sexually exploited may not be able to perceive their situation as exploitation whereby they normalise it (Warrington, 2010). This can be seen from the statement “sometimes you just do ting that you don’t really want to do”. This is likely to explain why girls identify rape as rape whilst also identifying exceptions to the definition: “rape is rape but...”. As this culture

becomes normalised, the more likely gang members will positively define coerced or forced sexual behaviour. This will increase the likelihood that others will engage in the activity (Boeringer, Shehan, & Akers, 1991) whilst negative views will persist towards those who report against it.



Slide 12. Conclusions

Social experiences. Gang affiliation provides an alternative support network that provides a sense of acceptance and 'love' that is unattainable by conventional methods. Male behaviour is perceived as being acquired through the imitation of male caregivers within the family. Through avoidance of punishment, boys can freely do what they like - their behaviour is sustained through behavioural conditioning (Boeringer, Shehan & Akers, 1991). There are other social factors involved in gang affiliation that reflect elements of adolescent development and are key for intervention: peer pressure and gang-associated rewards e.g. status and money from illegal drugs.

Sexual beliefs. Girls do not identify sexual coercion as being forced but instead: "Sometimes you do things that you don't really want to do". Once a girl engages in group sex or sex with gang members it is likely that she will be labelled, reflecting the existence of traditional gender roles of sex within the culture. This

appears to justify rape and sexual coercion when it happens to a girl that has a label. These attitudes harvest rape myths and victim blame within the culture. Sexual exploitation and rape therefore go unreported by girls in fear of being labelled.

Given the few benefits that girls attain through gang affiliation, it remains unclear why gang affiliation remains attractive. There are limitations when exploring gang cultures in that girls are less likely to reveal their personal experiences in fear of persecution, whereas boys exaggerate their experience to increase their status (Burt, 1980). For purposes of intervention, it is important to understand the exact nature of gang sexual behaviour and beliefs in order to change attitudes and behaviour towards the acceptance and continuation of sexual exploitation.

► Supervision

- Supervision was an essential component for validating and developing the methodology. This was achieved by way of triangulation, which was also used to reflect upon and shape the development of my themes to accurately reflect the findings within the data.
- I found this process reassuring particularly for my application of IPA, of which is associated with a more personal interpretation of the data when compared with discourse analysis. Discourse analysis is embedded into social and cultural meanings, resulting in a interpretation that feels less personal and more valid.

► Analytic strategy

- My strategy may reflect a 'safe' approach whereby the broad analysis drove my initial interpretation of the data. I adopted this approach due to the quantity of the data and due to the lack of experiential claims made by participants.

Slide 13. Reflection

► **Analytic strategy (Continued)**

- The strategy is specific to this focus group and is likely to require adaptations for different focus groups especially where:
 - More experiential data is present
 - Interviewers have a more active role within the focus group
- The strategy helped to build my confidence with the analysis – an experience I found empowering as a novice qualitative researcher.

► **Gang culture**

- I have become more aware of how the media influence public understanding of gang culture in a way that does not accurately reflect the complexities of gang environments.
- Gang research should be presented to accurately reflect the culture in a way that does not attempt to bias audiences. This includes any imagery that is used to support the findings.

Slide 14. Reflection (*continued*)

Reflection

- ▶ I really enjoyed working in collaboration with other researchers on this project of whom gave me an insight into carrying out qualitative research in a 'real-world' context.
- ▶ I feel I have a better understanding of what is meant by the 'lived experience' – the core understanding of IPA:

The lived experience is about taking on the entire 'being' of the participant and as a researcher, one needs to decipher what and why responses are given in the way they are and not necessarily whether the experience was 'lived' or not.

Slide 15. Reflection (*continued*)

SECTION III

DEPRESSION AND SUICIDAL IDEATION IN PEOPLE WITH MULTIPLE SCLEROSIS AND ITS CORRELATION WITH DISABILITY

Abstract

Background and purpose. Multiple sclerosis (MS) is the leading neurological cause of disability amongst young adults affecting 1 in 400 people in the UK. MS is associated with the development of depression which significantly impacts on quality of life and unlike multiple sclerosis, can be prevented and is treatable. Depression is under-recognised in patients with MS and is the single best predictor for suicide ideation and suicide. Suicide rates are elevated in people with MS and are thought to be influenced by disability and depression. The present study investigates the relationship between disability, perceived disability, depression and suicide ideation in people with progressive MS.

Methods. Twenty-three participants with progressive MS completed four questionnaires: Guy's neurological disability scale (GNDS), the Multiple Sclerosis Impact Scale-29 (MSIS-29), Beck-depression inventory-II (BDI-II) and Beck Suicide Scale (BSS). Using a cross-sectional design, Pearson and Spearman correlation analyses were used to explore the relationship between disability and perceived disability in MS, with symptoms of depression and suicide ideation.

Results. A significant correlation was found between disability and depression. No significant relationship was found between: physical disability, perceived disability and suicidal ideation; and depression and suicide ideation. No significant relationship was found between total perceived disability scores and depression. MSIS-29 psychological items positively and significantly correlated with depression.

Conclusion. Symptoms of depression worsen with increasing disability in progressive MS. A lack of relationship between disability and perceived disability, depression and suicide ideation may be due to the limited variation and significant skew of scores on the BSS. The MSIS-29 may not be as sensitive to the impact of MS than the GNDS due to the choice of items included on the scale and therefore some items may be rated low as they do not apply. The small sample size in this study limits our understanding of the nature of other relationships. Further clarification is needed to determine the impact of disability on suicide ideation by way of a larger sample size and longitudinal design.

Introduction

Multiple Sclerosis is an immune-mediated, demyelinating disease of the central nervous system, affecting women twice as much as men (Royal College of Physicians, 2004). Diagnosis commonly occurs between the ages of 20 and 50 (National MS society, 2013) with an average age of 30 (NHS Choices, 2013). There are three common courses of the disease with 80% of patients initially presenting with a relapsing-remitting course, whereby exacerbation of the disease is followed by partial or full recovery (Feinstein, 1999). Relapses are usually associated with increased disability, which over time leads to gradual worsening where patients go on to develop secondary progressive MS. Primary progressive MS involves increasing disability over time from the onset of symptoms, with few periods of remission (see Figure 3.1; Feinstein, 1999). Presentation and severity of the disease, regardless of the disease course, vary dramatically with symptoms involving numbness, muscle stiffness, cognitive and visual dysfunctions (National MS society, 2013).

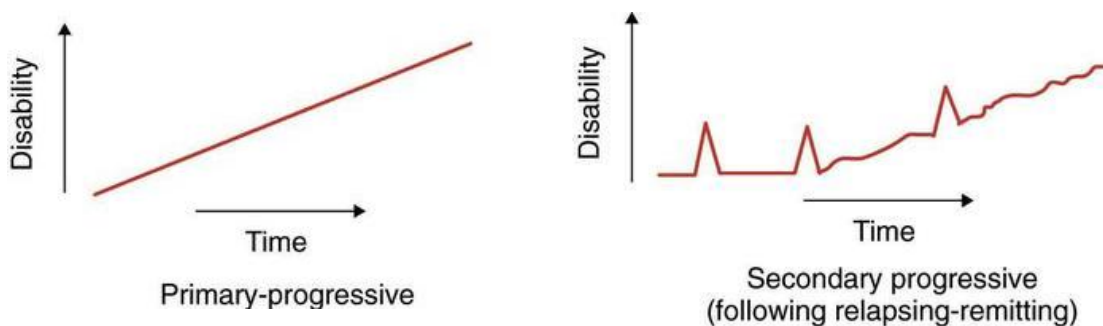


Figure 3.1. *Clinical Courses of Primary and Secondary Progressive MS (Lublin & Reingold, 1996).*

The prevalence of affective disorders in people with MS appears to vary between disease courses. Sarisoy, Terzi, Gümüş, & Pazvantoğlu (2012) found symptoms of depression to be significantly higher in patients with progressive MS than those with a relapsing-remitting course. Furthermore, Turner, Williams, Bowen, Kivlahan, & Haselkorn (2006) found suicide ideation to be significantly more likely in people with a progressive disease course (OR=1.67 95% CI, 1.08 –2.57). For this reason,

progressive MS is the diagnosis of interest in the present study. However, McCabe (2005) and Moore et al. (2012) found relapses during a relapsing-remitting disease course to be associated with heightened symptoms of depression. The observed differences are perhaps the result of the varying degrees of disability as oppose to the diagnosis per se. Alternatively, relapses during a relapsing-remitting disease course may lead to an increase in psychological distress as a result of the patient possibly becoming more aware of their transition towards a progressive course.

Depression and Suicide Ideation in MS

Up to 50% of people with MS develop major depression (José Sá, 2008), which significantly impacts on a person's quality of life, carer quality of life and treatment adherence (Paparrigopoulos, Ferentinos, Kouzoupis, Koutsis, & Papadimitiou, 2010). Depression is under-recognised in a third of patients (Feinstein, 2002 & 2011) despite their regular contact with medical services (Caine & Schwid, 2002); a reflection perhaps of the difficulty in discriminating symptoms of depression with those of MS (Wallin, Wilken, Turner, Williams, & Kane, 2006). Depression in MS is multi-factorial, arising from a combination of: psycho-social distress, functional changes, personality traits, coping styles, social changes and neurobiological factors (José Sá, 2008; Wallin et al., 2006). Having a previous history of depression and a recent stressful life event have also been found to predict depression in MS (Beal, Stuijbergen, Sands, & Brown, 2007; Chwastiak et al., 2002). When exploring depression against disease duration, Chwastiak et al. (2002) found participants within one year of diagnosis to have more symptoms of depression than those with more than five years since diagnosis. Although not statistically significant, Chwastiak et al. (2002) also found that overall a longer time since diagnosis (up to 12 years post-diagnosis) was associated with fewer symptoms of depression. Similarly, Hyphantis et al. (2008) reported an increased likelihood of having a psychiatric disorder to be 9 times greater in patients with recent onset MS when compared with patients with long-term disease.

Depression severity is reported to be the single-best predictor for suicide ideation in people with MS (Turner et al., 2006). Consistent with this finding, completed suicides are up to 7.5 times higher in people with MS than the general population (Sadovnick

et al., 1991). Suicide ideation involves the unusual preoccupation with thoughts and plans to commit suicide (Beck & Steer, 1993) and is therefore an important risk indicator for suicide itself (Turner et al., 2006). Similar to the patterns observed with depression in MS, Stenager et al. (1992) found 53 of 5525 MS patients committed suicide over a 30-year period, half of whom did so within the first 5 years following diagnosis. Furthermore, Brønnum-Hansen, Stenager, Stenager, & Koch-Henriksen, (2005) found that suicide risk over a 45-year period was overall twice as high in people with MS compared with an age/sex-matched population. Furthermore, an even higher risk was observed within the first five years of MS diagnosis (up to three times higher than an age/sex-matched population). Predictors of suicidal intent in MS were explored by Feinstein (2002) and included: living alone, male sex, young age (under 30 years) and having a history of alcohol abuse. The presence of these individual differences, consistent with predictive factors for depression, are likely to influence the extent to which a person with MS will develop depression and thoughts of suicide.

Our understanding of increased suicide risk in people with MS has been gained through studies exploring cause of death and incidence of suicide (e.g. Koch-Henriksen, Brønnum-Hansen, & Stenager, 1998; Lalmohamed et al., 2012). However, suicide rates are not an accurate indicator of the prevalence of suicide ideation as individuals with MS who express ideation may not be physically able to commit suicide. Exploring the presence of suicide ideation directly, potentially enables: identification and treatment leading to improved quality of life and possible prevention of suicide; improved understanding of the extent to which suicide ideation is expressed; and the opportunity to look at factors that increase its development. Feinstein (2011) suggests that over a quarter of MS patients experience suicide ideation.

The Impact of Disability in MS on Depression and Suicide Ideation

Numerous studies have found a significant relationship between disability and depression with increasing disability being a predictor of depression over the course of the disease. The strength of this relationship has been reported by Gay, Vrignaud, Garitte, & Meunier (2010) and Sarisoy et al. (2012) as being moderate ($r(113) = .27$

$p=.00$ and $r(74) = .39$ $p= .00$, respectively). Furthermore, Chwastiak et al. (2002) found symptoms of depression in people with moderate disability to be three times that of individuals with minimal disability (OR = 3.10 95% CL, 1.85–5.17).

Improvements in disability are also associated with elevated mood (Moore et al., 2012). The findings from the present study are therefore expected to support the relationship between increasing disability and increasing symptoms of depression.

Whilst there is evidence that disability in MS leads to increasing symptoms of depression, there is little evidence (e.g. Turner et al., 2006) specific to people with MS, that the same occurs with suicide ideation. The majority of evidence supporting the relationship between disability and suicide ideation can be found in studies based on findings within the general population. For example, a UK population survey exploring physical limitations and suicide ideation, found functional disability to be greatest in older adults (up to 74 years; Dennis et al., 2009). Consequently, older adults were found to express more suicide ideation than any other age group. In a more recent UK study, Meltzer et al. (2011) found that suicide ideation was four times greater in people with disabilities than those without, with disability having a direct impact on suicide ideation. The present study aims to establish whether a similar relationship exists in people with MS.

The development of affective disorders in people with MS may be influenced by changes in disability (Beal et al., 2007) as a result of gradual deterioration and the restrictions imposed upon functional activities (Voss et al., 2000). The impact disability in MS has on functional activities is likely to vary across age groups. For example, Dennis et al. (2009) found that disability affecting physical activity predicted suicide ideation in younger people, whereas disabilities impacting on financial and medical management were key predictors in adults. Disability in younger age groups may also lead to an increased sense of social stress and burden on others, leading to feelings of hopelessness and giving rise to negative affect (Russell, Turner, & Joiner, 2009). In support of this, whilst not specific to MS, Russell, Turner, & Joiner (2009) found younger people with a disability to express symptoms of depression four-times more so than their older counter-parts. In addition, the presence of certain types of disability are better able to predict depression and ideation than others, for example, bowel and bladder dysfunction (Dennis et al., 2009; Turner et al., 2006).

With consideration to these factors, increasing disability may not always share a linear relationship with the development of affective disorders.

Depression and suicide ideation therefore appear to occur both as an expression of distress at the time of diagnosis and as a response to worsening physical disability. This would explain why higher rates of depression and suicide ideation are observed in people with mild and severe disabilities as well as in younger and older people (potentially reflecting duration of the disease). Across the duration of the disease, we might expect to find two higher risk periods for the development of depression and suicide ideation: the time following the diagnosis, and periods of progressing disability (Turner et al., 2006). A phase of stability in-between the two might also be observed whereby a person's mood may remain low but stable, reflecting a period of adjustment to the disease.

Furthermore, it has been found in other health areas, that it is not actual disability but *perceived* disability that may be the best predictor of distress. For example, individuals who perceive the disabling effects from chronic pain to be greater, express more psychological distress regardless of their level of physical impairment (Severeijns, Vlaeyen, van den Hout, & Weber, 2001). The reason for this discrepancy is the impact of a person's beliefs and expectations of an illness, known as illness representations (Hagger & Orbell, 2010). These determine the way in which a person appraises an illness and are underpinned by both emotional and cognitive processing of that illness. For example, a diagnosis of cancer will have a greater emotional impact than a common cold due to the cognitive processes associated with understanding the identity, trajectory and consequences associated with cancer. Jopson & Moss-Morris (2003) found that patients' personal beliefs about their MS played a significant role in their adjustment to their condition (and therefore the expression of distress) even when the effects of disease severity were taken into account. For this reason, it is helpful to include a perceived disability measure alongside a measure of actual physical disability. Therefore, the multiple-sclerosis impact scale (MSIS-29; Hobart, Lamping, Fitzpatrick, Riazi, & Thompson, 2001) will be used to measure perceived disability in this study.

Disability, Depression and Suicide Ideation

The relationship between disability and depression is therefore well established. However, the role of depression in suicide ideation in people with MS is less clear. Depression has been found to mediate the effect between disability and suicide ideation (e.g. Meltzer et al., 2011; albeit within in a general population) and has been strongly associated with suicide ideation in people with MS (Turner et al., 2006). Conversely and more interestingly, Corna, Courtney, & Streiner, (2010) found two-thirds of primary-care patients reporting suicide ideation did not meet the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2000) criteria for depression, consistent also with findings of Goodwin et al. (2003). Ideation could be perceived here as providing a sense of mastery as a way to overcome a difficult and threatening situation (Seigel & Meyer, 1999) and as a result, a person develops a way of coping that reduces the likelihood of depression. However, this has not been explored in people with MS specifically.

Aims of the present study

In summary, there is a known link between diagnosis of MS and depression, and a fairly well established link between disability and depression in MS. However, little work has been carried out on the relationship between disability or perceived disability and suicidal ideation in MS. In addition, no work to date has looked at the relationship between all three variables with a view to establishing whether depression is a prerequisite for suicide ideation in this population. The aims of the present study are therefore:

1. To investigate whether the level of disability is associated with the level of depression in people with progressive MS (as suggested in current literature)?
2. To investigate whether there is a relationship between suicide ideation and disability in people with progressive MS (as suggested in the general population literature)?
3. To investigate whether there is a relationship between perceived disability, depression and suicide ideation in people with progressive MS?

4. To investigate the relationship between disability, depression and suicide ideation in people with progressive MS; does depression mediate the relationship between disability and suicide ideation?

During the conversations that took place whilst completing the questionnaires in this study, it was clear that a great deal of insight could be gained into the experience of people with MS and their thoughts surrounding suicide. Thus, although no data was collected using a formal qualitative method, as a final aim, it was felt to be very important to provide some of their insights as anecdotal evidence.

Method

A cross-sectional design was used to explore the relationship between disability and perceived disability, suicidal ideation and symptoms of depression in people with progressive MS. The study was approved by the National Research Ethic Service committee West Midlands - Solihul (Appendix H).

Participants. Participants were out-patients of a rehabilitation centre in Birmingham and were included based on having a) a diagnosis of progressive MS, determined by McDonald Criteria (the gold standard for MS diagnosis; Polman et al., 2010), b) able to give informed consent, c) aged 16 and over and d) had a diagnosis of MS for at least three years. The latter is to ensure the reliability of the diagnosis. Of 43 participants that were invited to take part: five declined to take part and 15 did not respond to the postal invitation. Details of non-responders were not available. A total of 23 participants were included in this study. Demographic information is given in Table 3.1a and 3.1b. Two of the 23 participants had made previous suicide attempts (one before diagnosis and the other after); both were male and had experienced episodes of depression around the time they attempted suicide. The participant who experienced suicide ideation and depression post-diagnosis also had a suicide event in his immediate family. Of the six participants who had previous symptoms of depression, depression occurred in two cases before diagnosis and four cases after diagnosis.

Recruitment. All patients were identified via an NHS database listing patient information. Participants were invited to take part by the MS therapy team, either during a regular clinic appointment, over the phone or via postal invite. In all cases, participants were given a research information leaflet (Appendix I) and an expression of interest letter (Appendix J). If an interest was expressed, the researcher would contact the patient 48 hours following initial contact to arrange an appointment (as per NHS ethical guidelines). All patients who were recruited to the project had been seen at least once by the MS team. Positive patient responses from each recruitment strategy were as follows: clinic = 11, postal = 6, telephone = 6. All data collection took place between July and August 2013.

Table 3.1a

Participant Characteristics

Participants Characteristics n=23	Frequencies
Sex	
Female	12
Male	11
Marital status	
Married	9
Divorced	3
Widowed	3
Single	8
Living status	
Alone	12
Co-inhabiting	11
Co-morbid disease	
Parkinson's disease	1
Employment status	
Employed	1
Volunteering	2
Unemployed	20
White British	23
Family history of depression	6
Family history of suicide	2
Lifetime Prevalence	
Previous diagnosis of depression	9
Alcohol abuse	1

Table 3.1b

Participant Characteristics (continued)

Participants Characteristics n=23	Mean (SD)	Range	Mode	Median
Age	55 (7.9)	41-71	56	56
Number of years of education				
< 12 years	12 (0.5)	10-17	11	11
12 years or more	11 (1.8)			
Age at diagnosis	37 (8.2)	24-54	31	36
Time since diagnosis (years)	17 (9.1)	5-55	20	20

Measures

Descriptive information. The descriptive information shown in Tables 3.1a and 3.1b was collected by the researcher at the start of each appointment.

Physical Disability. Guy's Neurological Disability Scale (GNDS) is a self-report measure of disability, developed to reflect the multi-dimensionality of disability in MS (Sharrack & Huges, 1999). It comprises 12 functional domains relevant to disability in MS, each graded from 0-5: 0 = normal status; 1 = symptoms causing no disability; 2 = mild disability; 3 = moderate disability; 4 = severe disability; 5 = total loss of function. Scores are added to give a minimum of 0 and maximum of 60 with higher scores indicating increasing disability. Internal consistency for the GNDS is good (Chronbach's alpha = 0.79; Sharrack & Hughes, 1999).

Perceived Disability. The Multiple Sclerosis Impact Scale (MSIS-29) is a 29-item self-report assessment measuring the physical (20 items) and psychological impact (9-items) of MS over the past two weeks. This will be used as a measure of perceived disability given that perceived, and not just disability alone, has an impact on emotional distress. Each item is assessed along a 5-point scale, asking users whether they are bothered by certain aspects of MS from "not at all", "a little", "moderately", "quite a bit" and "extremely". All items are added to produce a minimum score of 29 and a maximum score of 145, although individual physical (Max score = 100) and psychological scores (max score = 45) can be calculated separately to

produce two individual sub-scores (Hoogervorst, Zwemmer, Jelles, Polman, & Uitdehaag, 2004). Higher total scores indicate a greater degree of perceived impact of the disease. Internal consistency for the MSIS-29 is high (Chronbach's alpha = 0.91; Hobart et al., 2001).

Symptoms of depression. The Beck Depression Inventory-II (BDI-II; Beck, Steer, & Brown, 1996) is a measure of the presence and severity of depressive symptoms over the past two weeks. The BDI-II comprises 21 items with a 4-point scale from 0-3, giving a maximum score of 63. Clinical cut-off points according to the scale manual and based on a psychiatric out-patient sample are as follows: 0-13 = minimal; 14-19 = mild; 20-28 = moderate; 29-62 = severe (Beck, Steer, & Brown, 1996). The BDI-II is a reliable and valid, self-reported measure of depression for patients with MS whereby the inclusion of somatic items have been found to not falsely elevate total scores (Crawford & Webster, 2009). The BDI-II has high internal consistency (Chronbach's alpha = 0.91; Beck, Steer, & Brown, 1996).

Suicide ideation. The Beck Scale for Suicide Ideation (BSS; Beck & Steer, 1993) is used to detect and measure the severity of suicidal ideation in adults and adolescents over the past weeks. The BSS provides an indication of suicide risk as opposed to eventual suicide. The BSS is a self-report, 21-item scale with responses from 0-2. The last two items are not included in the total score and therefore the scores range between 0-38 based on the 19 remaining items. There are no specific clinical cut off-points with the BSS but increasing scores do reflect increases in suicidal risk. Positive responses on any items may reflect suicidal intention. The BSS has good internal consistency (Chronbach Alpha = .87 for outpatients; Beck & Steer, 1993).

Procedure

All recruitment approaches offered three appointment options to participants:

1. To meet following their next clinic appointment (if this fell within the months of July/August).
2. To meet at the West-Midlands Rehabilitation Centre at a time separate to their clinic appointment.

3. To be visited by the researcher within their own home.

The Lone-Working policy for Birmingham Community Healthcare NHS trust was followed in the event of option 3. In all cases, written informed consent (or verbal in cases where patients were unable to write) was sought at the start of each appointment (Appendix K), prior to the patient completing the scales. Descriptive data were collected at the start of the appointment followed by a brief explanation of each scale. Most often the scales were delivered verbally and completed by the researcher because patients were unable to write. Patients were given the scales in the following order: BSS, BDI, MSIS-29 and GDNS. The BSS was administered first in order to allow the researcher time to assess the patient for suicide risk. Trust procedures were followed where a suicide risk was identified; the Principal Investigator was notified who would carry out the referral process for counselling services. On occasions where suicide risk was high, time would be taken to allow the patient to openly discuss their feelings in an attempt to a) assess suicide risk more fully, b) to offer support through active listening. The researcher sought supervision and guidance from the Chief Investigator following each appointment.

Qualitative Data. Given that the scales were delivered verbally to the majority of participants, this initiated conversation around some of the items that were asked; participants were willing to discuss their emotions and experiences of living with MS in greater detail. This provided the researcher with a greater insight into the impact disability in MS has on a person's mood. The researcher made informal notes during these discussions and used the notes as the source of data. During analysis, particular attention was paid to common themes that arose as a result of participant experiences.

Analysis

SPSS (Version 20) was used to perform Pearson's and Spearman's correlation analysis; data from the BSS did not meet the assumptions of normality based on the Shapiro-Wilk test and therefore non-parametric analyses were used for BSS scores. Given that this study is investigating an area with limited previous research, a lack of data was found in which to base power calculations on. However, an estimate of

power was derived using Cohen's (1992) rule of thumb suggestions. For Pearson correlation coefficient, to achieve 80% power, a medium effect size (0.3) and an alpha of 0.05, Cohen (1992) suggests a minimum of 85 participants. Given that the participant numbers do not meet this requirement there is a risk of making both type 1 and type 2 errors from the conclusions drawn from this data. To reduce this error, an alpha level of $p = .01$ will be used as a measure of statistical significance.

Results

Descriptive statistics

Mean, median, range of scores and Chronbach's alpha for severity of disability (GNDS), perceived disability (MSIS-29), symptoms of depression (BDI-II) and suicidal ideation (BSS) are displayed in Table 3.2. The pattern of scores for each scale and the items therein are given in Figure 3.2. The item 'other' in Figure 3.2a refers to any other disability that impacts on the individual that isn't otherwise addressed in the scale. In 7 of 9 cases, 'other' refers to the patient's feelings of pain and two refer to feelings of dizziness. The remaining participants did not have any additional symptoms that weren't already described within the scale.

Table 3.2

Mean Scores of Measures

Measure	<i>M</i>	SD	Median	Range	Chronbach's Alpha
GNDS	26	9.7	26	8-49	.75
MSIS-29	94	20	94	60-129	.87
MSIS-29 Physical	71	16.5	72	35-96	.87
MSIS-29 Psychological	23	7.8	23	10-37	.78
BDI-II	13	6.9	13	0-29	.76
BSS	2.2	5.0	0	0-18	.92

Overall, participants had a mean physical disability score of 26 out of 60. Participants had greatest disability in areas of mobility and bladder dysfunction, followed by movement in arms and hands and bowel function (see Figure 3.2a). Participants had a mean perceived disability score (as measured by MSIS-29) of 94. Perceived disability was greatest for 'performing physically demanding tasks' (item 1), 'your body not doing what you want it to do' (item 11), 'depending on others to do things for you' (item 12), 'taking longer to do things' (item 18) and 'difficulty doing things spontaneously' (item 19; see Figure 3.2b). The mean depression score (as measured by the BDI-II) was 13 (falling within the minimal depression cut off; see Figure 3.2c). As can be seen in Figure 3.2d, higher scores were associated with somatic items - 'loss of energy' and 'fatigue or tiredness'; two presentations often seen in patients with MS as a result of neurological changes.

Suicide ideation (as measured by the BSS) was very positively skewed with a mean score of 2.2 with a range of 0-18. Fourteen participants had a total score of zero (see Figure 3.2e). Higher scores were associated with items: 2 'wish to die'; 3, 'reasons for living or dying'; 5, 'passive suicide attempt'; and 11 'reasons for attempt' (see Figure 3.2f).

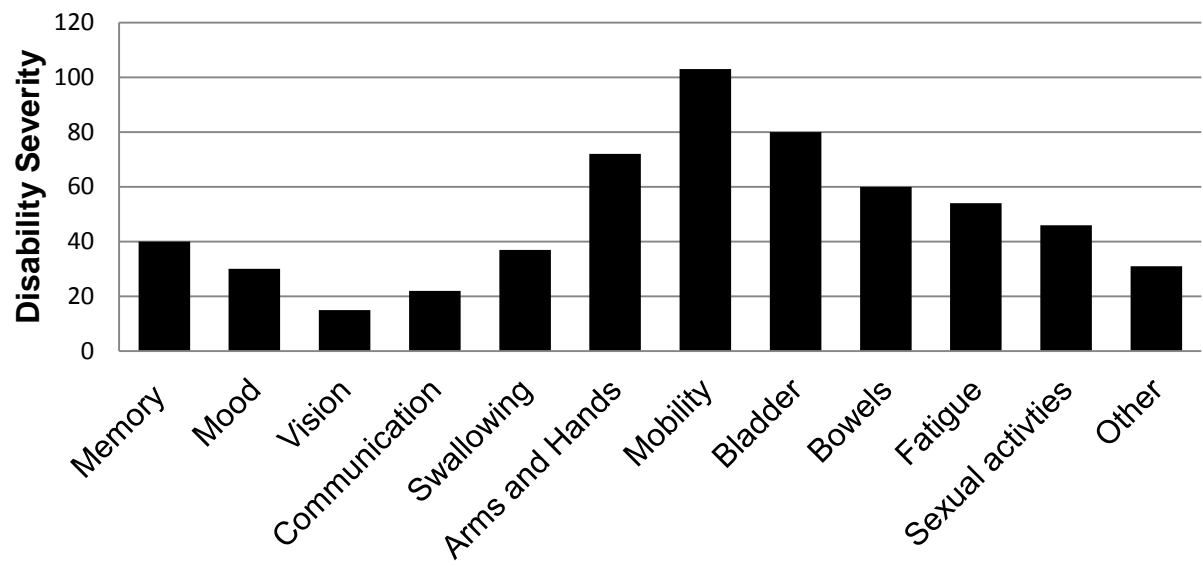


Figure 3.2a. *Pattern of Scores for Physical Disability using the GNDS*

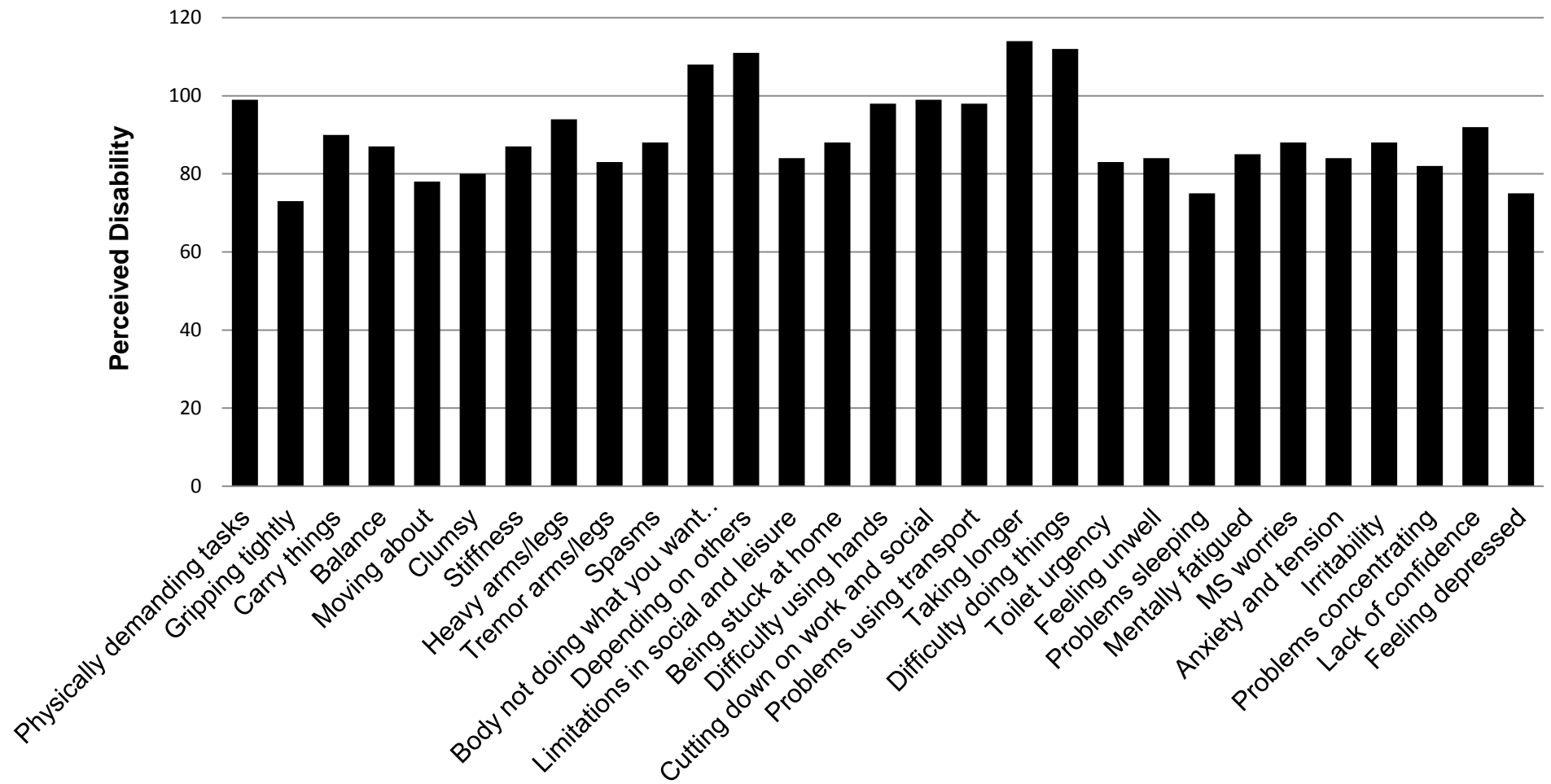


Figure 3.2b. Pattern of Scores for Perceived Disability using the MSIS-29

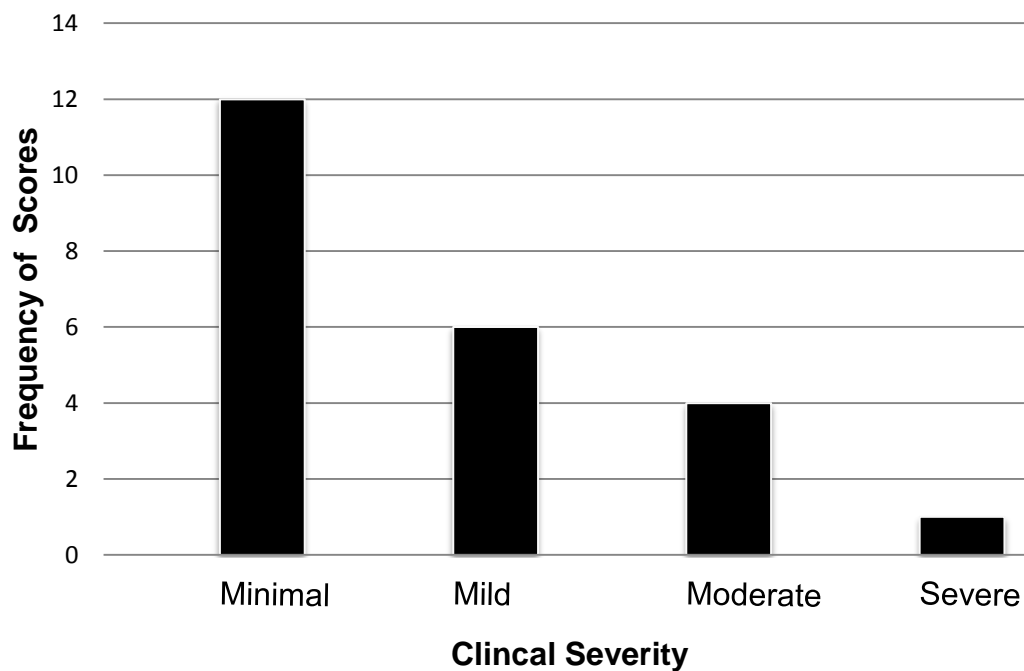


Figure 3.2c.

Frequency of Scores at each Clinical cut off for Symptoms of Depression (based on Beck, Steer & Brown, 1996).

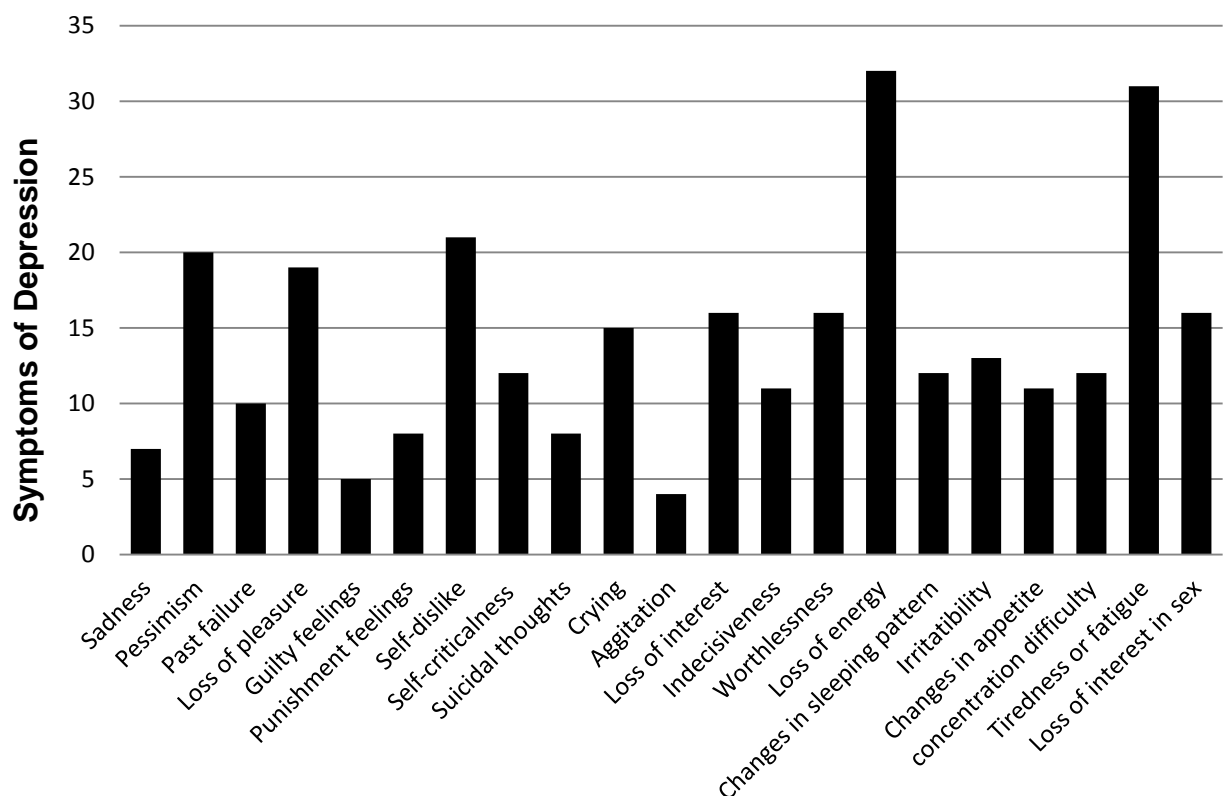


Figure 3.2d. *Pattern of Scores for Symptoms of Depression using the BDI-II*

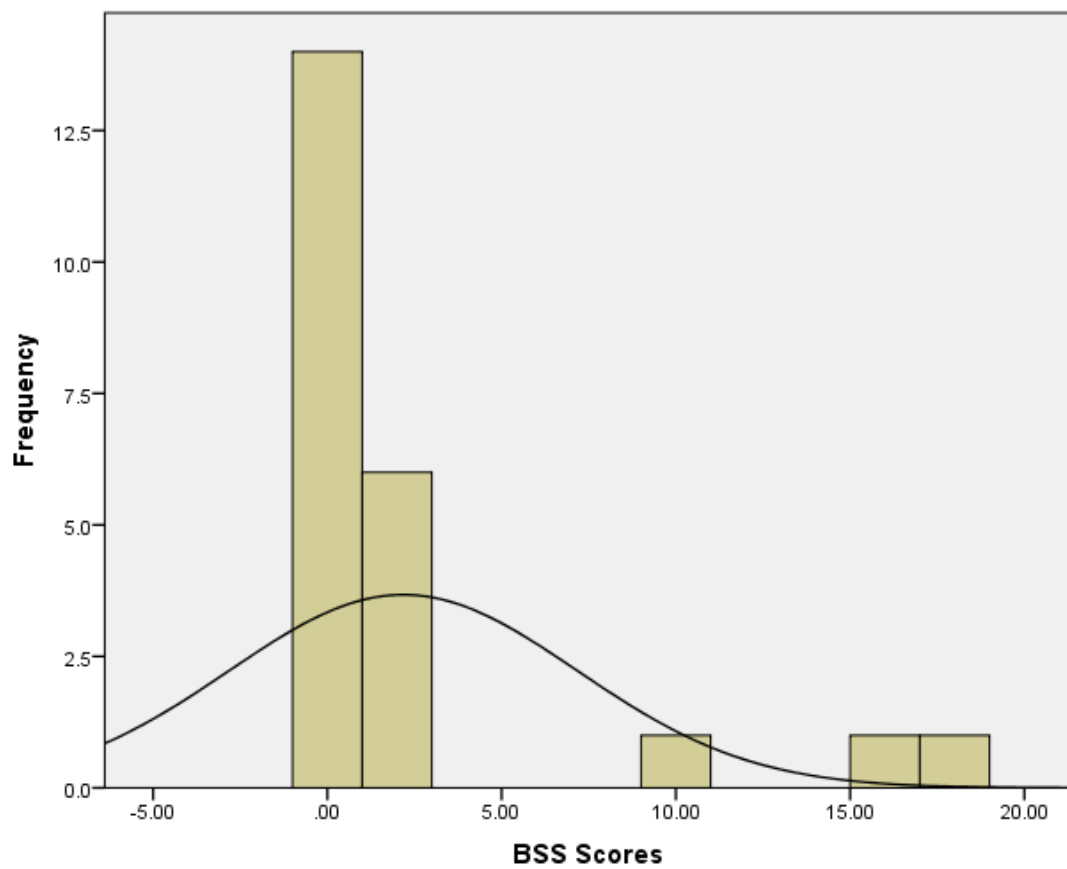


Figure 3.2e. Distribution plot of BSS scores. A highly positive skew was observed within the distribution of BSS scores.

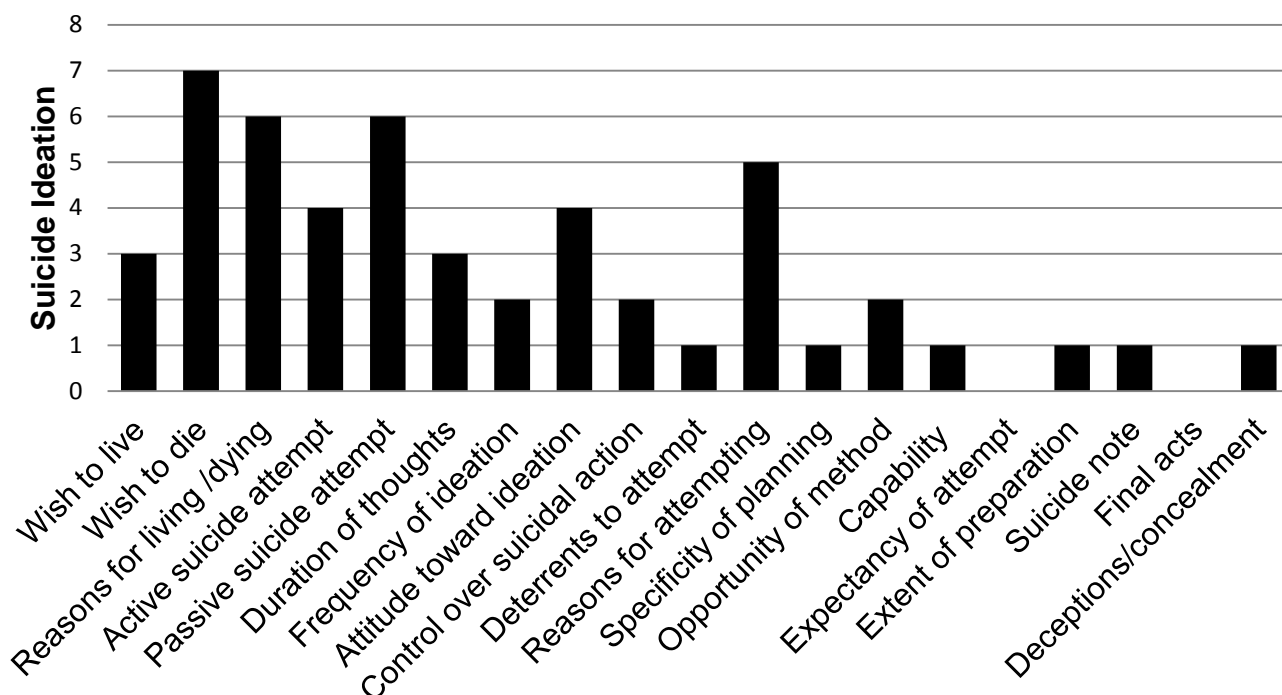


Figure 3.2f. *Pattern of Scores for Suicide Ideation using the BSS*

Is the level of disability associated with the level of depression in people with progressive MS?

Pearson correlation coefficient revealed a strong positive relationship between physical disability (as measured by the GNDS) and depression scores at a significant level of $p = .01$ (Table 3.3; $r(21) = .57$ $p = .01$). A strong positive correlation remained and was significant at $p = .01$ even when the two somatic items were removed from the BDI-II ($r(21) = 0.53$ $p = .01$). Therefore the level of disability appears to be associated with the level of depression.

Is there a relationship between suicide ideation and disability in people with progressive MS?

As presented in Table 3.3, no significant relationship was found between suicide ideation and disability when Spearman coefficient was calculated.

Is there a relationship between perceived disability, depression and suicide ideation in people with progressive MS?

Spearman and Pearson correlation was carried out to demine the relationship between: perceived disability and suicidal ideation; and perceived disability and depression respectively. Neither relationship was found to be statistically significant, although a positive trend in the predicted direction was observed in both cases (see Table 3.3). When the MSIS-29 scores were divided into its psychological and physical items, psychological but not physical items correlated with depression scores at significant level ($r(21) = .54$ $p = .01$; See Table 3.4).

What is the relationship between disability or perceived disability, depression and suicide ideation in people with progressive MS; does depression mediate the relationship between disability and suicide ideation?

Using Spearman correlation, no significant relationship was found between physical disability and perceived disability with depression *and* suicide ideation (see Tables 3.3 and 3.4). Based on the principles outlined by Baron & Kenny (1986), *all* three variables are required to significantly correlate in order to perform a mediation analysis; the role of depression as a mediator between disability and suicide ideation therefore could not be explored. Whilst a significant relationship has not been found between depression scores and suicide ideation, it should be noted that the three individuals who expressed a high degree of suicide ideation fell within the moderate range for symptoms of depression (scoring between 21-23 on the BDI-II).

Table 3.3

Correlations between Measures

Scale	GNDS	MSIS-29	BDI-II	BSS
GNDS	-			
MSIS-29	.23	-		
BDI-II	.57**	.31	-	
BSS ^a	.27	.30	.22	-

* $p < .05$ ** $p < .001$

Note. GNDS = Guy's Neurological Disability Scale; MSIS-29 = Multiple Sclerosis Impact Scale; BDI-II = Beck Depression Inventory 2; BSS = Beck Scale for Suicide Ideation.

^a Spearman correlation coefficient used with all correlations with BSS scores

Table 3.4

Correlations between Scale Scores with MSIS-29 Physical and Psychological Items

Scale	Physical Items (MSIS-29)	Psychological Items (MSIS-29)
BDI-II	.12	.54**
BSS ^a	.23	.29

** $p < .001$

^a Spearman correlation coefficient used with BSS scores.

Qualitative Feedback

Consistent with the final aim of this study, insights gained into the experience of people with MS and their thoughts surrounding suicide and feelings of depression are reported below.

Affective disorders are episodic. Expression of depression and suicide ideation clearly fluctuates overtime in people with MS. Participants would recall "I used to feel very low and depressed" or "I feel OK this week, but I was very different last week". These feelings appeared to be directly related to their disability status at the time. Two participants recalled having thoughts of suicide shortly following their diagnosis, resorting to excessive alcohol consumption and self-harm. One participant described how his mood fluctuates depending on whether he's recently fallen; he associated this with feeling hopeless.

Stressful life events. Six of the 23 participants described the sudden physical deterioration following a stressful life event (consistent with findings of Mohr, Hart, Julian, Cox & Pelletier, 2004). Life events usually involved the separation, divorce or death of a loved one. Two participants had made a suicide attempt following the breakdown of their marriage. In five of the six cases, the stressful life event occurred after diagnosis. The impact of an event, both emotionally and physically, is also likely to have contributed to a loss of social support in these cases. A loss of social support could have led to an existing sense of burden associated with a loss in functional ability, emphasising the presence of the disease (Russell, Turner & Joiner, 2009).

Impact on sexual intimacy. Sexual function and intimacy was an issue raised amongst most participants in response to item 11 on the GNDS. Problems associated with sexual ability were most often due to the limitations caused by their mobility and/or bowel and bladder dysfunction. For one couple, the lack of ability to have a sexual and intimate relationship appeared to severely impact their quality of life as a newly married couple; "we don't have sex, not because we don't want to but we can't". The couple agreed that they would not have felt comfortable raising this issue within a clinical context yet it appeared emotionally distressing for both of them. Although mood appeared to be influenced by disability, quality of life was not directly

impacted by a disability alone but by the restrictions it imposed, in this case, upon sexual intimacy.

Suicide ideation: providing the means for coping. During one interview, a participant expressed his desire to commit suicide. Initially, the participant felt he could not complete the scales due to the sensitivity of the questions. The participant described suicide as offering a source of hope; "It'd be harder to cope knowing I have no control of taking my own life" and described how the eventual total loss of function in his arms would motivate him to commit suicide, although he recognised he would need to do so before this occurred. This participant also had the means to commit suicide if he wished (although the risk was identified as being low) and knowing the method was available if he desired, provided him with a 'safety valve' (coined by Seigel & Meyer, 1999); a symbolic meaning of his ability to gain control. Suicide ideation was an important aspect of this person's coping and was likely indicative of his wish to relieve his emotional distress (Seigel & Meyer, 1999).

Suicide ideation and disability. Another participant who was severely physically disabled, expressed a high degree of suicide ideation (BSS = 18/38). The participant was physically unable to commit suicide as a result of her disabilities despite wishing to. The participant expressed a moderate degree of depression (BDI = 21) but clearly expressed that her wish to die was a result of her inability to lead a fulfilling life. Although the physical risk of suicide was low for this individual, the emotional impact of her disability was severe; highlighting the consequences when affective disorders are not identified and treated early enough. The participant refused any counselling support when it was offered by the clinical team; "counselling will not change the [physical] way I am" and therefore she perceived the same to be true regarding her psychological well-being.

Discussion

Is the level of disability associated with the level of depression in people with progressive MS?

Consistent with previous studies (Beal et al., 2007; Chwastiak et al., 2002; Gay et al., 2009; Martins da Silva, 2011; Sarisoy et al., 2013) there was a strong positive relationship between physical disability and depression. This study therefore supports that the level of disability is associated with the level of depression in people with progressive MS. However, the direction of causality remains unclear. For instance, disability in MS can influence a person's mood through its limiting effects upon social and vocational activities. Conversely, people with depression have also been found to make more assertions about their level of disability (Alschleier, Theisen-Goodvich, & Haig, 2008). Further research is required to establish how disability influences the development of depressive symptoms in progressive MS.

Is there a relationship between suicide ideation and disability in people with progressive MS?

No significant relationship was found between physical disability and suicide ideation. The most salient factor to have contributed to this finding was due to the highly skewed distribution of BSS scores (see Figure 3.2e) with the majority of participants scoring zero. Major depression is reported by Feinstein (2011) to be a significant predictor of suicide ideation in MS. Consequently, reported symptoms of depression are likely to have affected the distribution of BSS scores as most of the current sample (18 of 23 participants) reported minimal or mild depression. Therefore, the present population may not represent a typical population of people with MS in which the prevalence of major depression has been reported to be up to 50% (Feinstein, 2011). Other factors should also be considered as having contributed to this finding. Firstly, the sample comprised a minimum age of 41 and maximum of 71 with an average age of 55 years. Therefore, the findings from this study are unlikely to have accounted for the varied emotional impact of disability observed across different age groups. For example, Feinstein (2002) observed young age (under 30 years) to predict suicide ideation in MS. Secondly, given the time since diagnosis (mean time = 17 years), participants may have adjusted to their

disabilities and developed active ways of coping thereby reducing the likelihood of suicide ideation (Keskin & Engin, 2010). These findings are consistent with Turner et al. (2006) who found suicide ideation less likely in patients with a longer diagnosis. A larger sample size and a greater spread of ages are required in order to determine the nature of this relationship more fully.

Is there a relationship between perceived disability, depression and suicide ideation in people with progressive MS?

No significant relationship was found between total perceived disability scores and depression; and total perceived disability and suicide ideation. The latter finding may have occurred due to similar reasons as stated above. However, the relationship between perceived disability and depression was not expected given the significant association between physical disability and depression. These findings contrast with those of Ytterberg, Johansson, Holmqvist, & Koch (2008) who found more than 10 years since diagnosis of MS predicted an increased physical impact of the disease. Considering the time since diagnosis within the sample, a greater physical impact and in turn, symptoms of depression would have been expected.

Psychological but not physical items on the MSIS-29 significantly correlated with depression. This finding was likely due to the overlap of items between scales. However, the presence of depression and its influence on biased cognitive processing may have also contributed to this finding (Cole & Vaughan, 2005). This could explain why participants perceived the psychological and not physical impact of the disease to have a greater influence on their feelings of depression, despite the observed (and widely reported) relationship between physical disability and depression in MS. Alternatively, participants may have adapted practically to the physical aspects of the disease (given average time since diagnosis) but not the psychological aspects, contrasting with findings of Chwastiak et al. (2002). A lack of psychological adjustment may occur in people with MS due to a) therapists not being able to identify and therefore treat psychological distress, b) patients not being given the opportunity to discuss/not wishing to discuss psychological distress (Feinstein, 2002). The latter may occur if patients do not feel their psychological well-being is as important as managing the physical impact of the disease or if they do not feel an

effective solution will be offered (consistent with patient insights; Conner & Norman, 2005). Consequently, longer disease duration (and not just the time around diagnosis and periods of increasing disability) could present a risk factor for developing depression, consistent with findings by Beal et al. (2007).

However, the finding that psychological but not physical aspects of disease are associated with depression, may lie within the nature of the MSIS-29 physical items. For example, participant responses to the questions on the MSIS-29 indicated that they were not important to people with MS, or more specifically, people who have lived with the disease for longer and have been able to adapt to their limitations. For example, the majority of patients (20/23) were unemployed so when asked 'in the past two weeks, how much have you been bothered by having to cut down on the amount of time you spend on work or other daily activities' did not seem relevant to individuals who had been unemployed for a number of years. Unlike the GNDS, MSIS-29 physical items do not include the impact of bowel and bladder dysfunction specifically - two areas that were scored highly on the GNDS and have been found to predict depression in MS (Turner et al., 2006). Therefore, physical items on the MSIS-29 may not be as sensitive to the impact of MS that has been found associated with a decline in mood.

What is the relationship between disability or perceived disability, depression and suicide ideation in people with progressive MS; does depression mediate the relationship between disability and suicide ideation?

Disability and depression was the only relationship observed to be significant between the variables of interest. However, a trend in the expected direction between disability, depression and suicide ideation suggests that increasing disability may lead to an increase in suicide ideation (consistent with findings of Dennis et al., 2009), of which could be mediated by depression. Furthermore, despite the non-significant findings, the presence of depression is likely to be an important predictor of suicide ideation given that a) there is already established evidence that supports this relationship (e.g. Feinstein, 2002; Meltzer et al., 2011; Troister & Holden, 2010; Turner et al., 2006) and b) the three individuals who scored highest for suicide ideation (scoring 10, 15 and 18 on the BSS) all presented with moderate symptoms

of depression (scoring between 21-23 on the BDI-II). Therefore there is some evidence to support a mediation relationship between disability and suicide ideation in that both the independent (disability) and the outcome variable (suicide ideation) share an association with the mediator (depression) variable (Baron & Kenny, 1986). The fact that no relationship was observed between disability and suicide ideation; and depression and suicide ideation may have occurred on account of a) the distribution of BSS scores and b) the lack of presence of the mediator variable (participants had minimal depression overall). However, these findings are not reliable enough to reveal the true nature of this relationship and further clarification is needed by way of a larger sample size that could lead to significant findings and subsequent statistical analysis to test for a mediation relationship. Consequently, the outcomes of this study (regardless of sample size and BSS scores) may reveal that there is no overall association between depression and suicide ideation in progressive MS. For instance, three participants scoring 1 on the BSS had very few symptoms of depression (BDI-II score between 0-9). Although a score of 1 is low, Beck & Steer (1993) suggest that any response on the BSS could indicate the presence of suicide ideation. The occurrence of suicide ideation in absence of depression in previous studies is likely to have arisen due to the measure of depression - the Diagnostic and Statistical Manual of Mental Disorders criteria (DSM; Corna, Courtney, & Streiner, 2010; Goodwin et al., 2003). However "depression exists on a spectrum of severity, and need not meet full DSM criteria to be of clinical significance" (Goldman Consensus Group, 2005, p. 331) which still does not account for the findings of the present study or those of Turner et al. (2006).

A qualitative study from another health area may shed light on these findings. For example, Siegel & Meyer (1999) describe a paradox in suicidal thinking described 'suicidality to survival' whereby in one instance, suicide ideation can occur as a result of fear, which in MS, could apply to the time of diagnosis and/or fear of progressing disability. In another instance, suicide ideation could represent a process of coping that enables a person to imagine their worse fear i.e. death, whilst enabling them to gain control over it (Seigel & Meyer, 1999). The authors also describe how once this sense of control becomes rooted, it can be applied to other areas of life. In MS, this could lead to better disease management (including psychological well-being) and

engagement with health services (Conner & Norman, 2005). These findings may elucidate why suicide ideation could occur in the absence of depression; the extent to which this is true in progressive MS requires further exploration.

Methodological advantages

There are a number of methodological advantages in this study over other cross-sectional study designs in this field. Firstly, scales were delivered verbally in all cases but one. Collecting the data in this way increased item response by clarifying any ambiguous questions (eliminating errors associated with missing data); enabled control over the order in which the scales were completed; helped maintain participant motivation; and provided the opportunity to ask participants for further clarification regarding their responses (Bowling, 2005). Given that all but one interview took place within the participant's home, a better insight into a person's family life was gained, including their: social support, coping styles, recent stressful life events and personality traits. Although this study did not involve the measurement of these variables, they were relevant towards the understanding of how disability impacts the development of depression and suicide ideation.

Limitations

Limitations of this study arise from the small sample size and therefore conclusions drawn from the data are unlikely to represent the population of people with MS. This may have lead to the presence of type 1 and type 2 errors.

The recruitment process was also likely to present a number of biases. For example, participants who were recruited during their clinic appointment or over the phone may have felt more inclined to take part than those who were recruited via post. The very nature of the study may have deterred others from taking part.

Given the small sample size, participants with primary and secondary progressive MS could not be distinguished. People with secondary progressive MS may still experience sudden exacerbations and therefore could lead to increase periods of worsening disability which could bias the results to show more depression at one time point over another (Moore et al., 2012) thus undermining any linear relationship.

Somatic items on the BDI-II were likely to have been influenced by the impact of hot weather on the neurological condition at the time of data collection (Fraser, Clemmons, & Bennett, 2002). Whilst a number of studies (e.g. Crawford & Webster, 2009; Dalton & Heinrichs, 2005) have found somatic items on the BDI-II not to influence depression scores in MS, it is stated by Crawford & Webster (2009) that patient scores of fatigue and loss of energy could still overlap with neurological symptoms. Whilst this is not expected to impact the overall total score, clearly this was an issue in the present study given that somatic items were the most frequently endorsed items on the BDI-II. However, the relationship between disability and depression remained significant even when somatic items were removed.

Other limitations include one participant's recent diagnosis of Parkinson's disease (PD). Disability associated with both MS and PD, as well as the impact of a second diagnosis, may have increased her scores of depression at the time of data collection. Due to the nature of the cross-sectional design, limitations in regards to fluctuations in mood overtime would not have been accounted for. A longitudinal study would therefore provide a more reliable way of measuring the relationship between disability, depression and suicide ideation.

Conclusions and Clinical Implications

It is important that the relationship between disability, depression and suicide ideation is clarified given that most individuals with MS will develop a progressive form of the disease leading to gradual physical worsening and the possible development of depression. Furthermore, there is a known increased risk of suicide in this population that requires further exploration. If the findings of this study are not a statistical anomaly, then further research is required to determine what other factors are better able to predict suicide ideation in people with progressive MS. The role of hopelessness should be considered here. Hopelessness has a central role in suicide ideation independent from depression (Troister & Holden, 2010) and has been found more commonly in people with the progressive subtype (Patten & Metz, 2002). Higher scores on the MSIS-29 were found on items 'body not doing what you want it to', 'depending on others' and 'taking longer to do things'. These items could reflect loss of perceived control leading to feelings of hopelessness and despair

(Jopson & Moss-Morris, 2003), which would be expected to correlate with suicide ideation (Dennis et al., 2009). Unlike the BDI-II, other measures of depression used in MS studies (for example the Patient Health Questionnaire, PHQ-9), include an item for feelings of hopelessness. When using the PHQ-9, Turner et al. (2006) found a relationship between depression and suicide ideation. The role of hopelessness (and perceived control) as contributing to depression arising from disability leading to suicide ideation, has therefore not been accounted for in this study and requires further exploration.

Based on the findings of this study, the role of depression in suicide ideation remains inconclusive in people with progressive MS. Therapists should be aware then, that depression may not be a risk marker for suicide ideation or vice versa. Caution should be applied by therapists when exploring the nature of suicide ideation; a topic not to be avoided or for its expression to be discouraged as such thoughts may provide the foundations for coping, consistent with findings gained from patient insights in this study. Patients should be invited to openly discuss suicidal thoughts in order to allow therapists to explore alternative ways of coping that reduces suicide risk, whilst supporting the patient to acknowledge their desire for control. However, the role of suicide ideation in providing opportunities for coping in MS should be a future direction for research.

Findings from the relationship between MSIS-29 psychological and not physical items with symptoms of depression may have clinical implications in that people with MS may be disassociating their feelings of depression from the physical impact of the disease. Whether or not this occurs as a result of cognitive distortions associated with having depression, further research is required to explore why this disassociation occurs and how clinical practice can be used to help people with MS recognise the cause of their distress. However, these findings could reveal that the psychological impact of MS continues to occur across the disease course and not just as a response to diagnosis.

The relationship between disability and suicide ideation in progressive MS remains unclear and further exploration is required by way of a larger sample size. Increasing disability is likely to impact on symptoms of depression and therefore thorough assessment and the opportunity for patients to discuss the psychological impact of

the disease, especially at times of worsening disability, is essential. This will help alleviate emotional distress and improve the quality of life for people with MS.

Appendix A

Database Searches

Databases were dated back from 1946 and 1986 to November week 3 2012 for MEDLINE and PsycINFO respectively. It was not possible to refine the search further within the MEDLINE database without losing current publications. When synonyms were offered by the database that had not initially been identified they were added to the list of key words and the search was repeated until all possible keywords had been identified and searched. Conversely, if the keyword was not identified it would be removed from the list for that particular database, thereby tailor-making the search specific to each database. Database searches are as follows:

PsycINFO 1987-week 2 Nov 2012 carried out on 14.11.12

1. exp Brain Disorders/ or exp Traumatic Brain Injury/
2. exp Traumatic Brain Injury/
3. exp Brain Damage
4. exp Cerebral Haemorrhage/ or exp Cerebrovascular Accidents/ or exp Ischemia/
5. exp Ischemia/ or exp Brain Damage/ or exp Cerebral Ischemia
6. nervous system disorders
7. exp Cerebrovascular Accidents/
8. exp Subarachnoid Haemorrhage/
9. exp Head Injuries/
10. exp Meningitis
11. exp Anoxia
12. ABI.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests and measures]
13. TBI.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests and measures]
14. acquired brain injury.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests and measures]
15. traumatic brain injury.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests and measures]
16. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15
17. exp Employment Status/ or exp Employee Retention/ or exp Vocational Rehabilitation/
18. exp reemployment/ or exp Vocational rehabilitation/
19. exp Supported Employment/
20. exp Job Coach/
21. exp Sustaining Employment/
22. exp Natural Support/
23. exp Job re-entry
24. "Work Sampl*". mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests and measures]
25. "work tria*". mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests and measures]

26. "work retention". mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests and measures]
27. "job retention". mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests and measures]
28. "return to work". mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests and measures]
29. 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28
30. exp Treatment Outcomes/ or exp Occupational Therapy/ or exp Vocational Rehabilitation/
- 31.exp Rehabilitation Outcomes/
32. exp Interventions
33. exp treatment
- 34."outcome measures".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests and measures]
35. "intervention*" . mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests and measures]
36. 30 or 31 or 32 or 33 or 34 or 35
37. 16 and 29 and 36

Pubmed. Search carried out on 15.11.12

("acquired brain injury" OR "traumatic brain injury" OR "head injury" OR "multiple sclerosis" OR "bacterial infection" OR "stroke" OR "anoxia") AND ("vocational rehabilitation" OR "return to work" OR "employment outcom*" OR "employment" OR "rehabilitation" OR "work retention" OR "work re-entry" OR "work placement" OR "Job coach") AND ("outcome measure*s" OR "vocational outcomes")

AMED

- S1. Brain injury
- S2. traumatic brain injury
- S3. Stroke
- S4. Brain damage
- S5. S1 OR S2 OR S3 OR S4
- S6. Work retention
- S7. Job re-entry
- S8. Work placement
- S9. Work trial
- S10. Work sample
- S11. Supported employment
- S12. Job coach
- S13. Return to work
- S14. Vocational rehabilitation
- S15. Sustaining work
- S16. S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15
- S17. Outcome measures
- S18. Treatment

S19. Intervention

S20. S17 OR S18 OR S19

S21. S5 AND S16 AND S20.

Medline 1946-week 2 November 2012

1. Brain injuries/ or Brain damage/
2. Hypoxia-ischemia, brain/ or brain injuries/ or brain damage
3. Brain Ischemia/
4. subarachnoid haemorrhage/ or cerebral haemorrhage/
5. bacterial infections/or exp central nervous bacterial infections/ or exp central nervous system infections/ or exp virus diseases/
6. Virus diseases/ or central nervous system viral diseases/ or meningitis, viral.
7. Craniocerebral trauma/in [injuries]
8. Brain trauma.mp. or brain injuries/
9. Brain anoxia.mp or hypoxia, brain/
10. Stroke/
11. Acquired brain injury.mp. [mp=title, abstract, original title, name or substance word, subject heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]
12. Traumatic brain injury.mp. [mp=title, abstract, original title, name or substance word, subject heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]
13. Cerebrovascular trauma/ or Cerebrovascular disorders/
14. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 7 or 8 or 9 or 10 or 11 or 12 or 13
15. Occupational rehabilitation/
16. Employment/ed org, px [education, organisation & administration, psychology]
17. Supported employment.mp. or employment, supported/
18. Vocational rehabilitation.mp. or rehabilitation, vocational/
19. Work retention.mp. [mp=title, abstract, original title, name or substance word, subject heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]
20. Supported employment.mp. [mp=title, abstract, original title, name or substance word, subject heading word, protocol supplementary concept, rare disease supplementary concept, unique MH]
21. 15 or 16 or 17 or 18 or 19 or 20.
22. Outcome measures/
23. Intervention/
24. Vocational outcomes/
25. Outcome assessment (health care)/ or employment
26. 22 or 23 or 24 or 25
27. 14 and 21 and 25

CINAHL 1946-week 2 November

S1. (MH "brain injuries+") or (MH "head injuries+")

S2. (MH "central nervous system injuries+") OR (MH "nervous system diseases+")
 S3. (MH "central nervous system bacterial infections") or (MH "meningitis, bacterial+")
 S4. brain injury
 S5. traumatic brain injury
 S6. stroke
 S7. brain damage
 S8. S1 or S2 or S3 or S4 or S5 or S6 or S7
 S9. (MH "employment, supported") OR (MH "employment of disabled+")
 S10. (MH "rehabilitation, vocational+")
 S11. (MH "outcome assessment")
 S12. (MH "job re-entry")
 S13. work retention
 S14. job re-entry
 S15. work placement
 S16. work trial
 S17. work sample
 S18. supported employment
 S19. job coach
 S20. return to work
 S21. sustaining work
 S22. vocational rehabilitation
 S23. S9 or S10 or S11 or S12 or S13 or S14 or S15 or S16 or S17 or S18 or S19 or S20 or
 S21 or S22
 S24. intervention
 S25. outcome measures
 S26. treatment
 S27. vocational outcomes
 S28. S24 or S25 or S26 or S27
 S29. S8 and S23 and S28

Appendix B

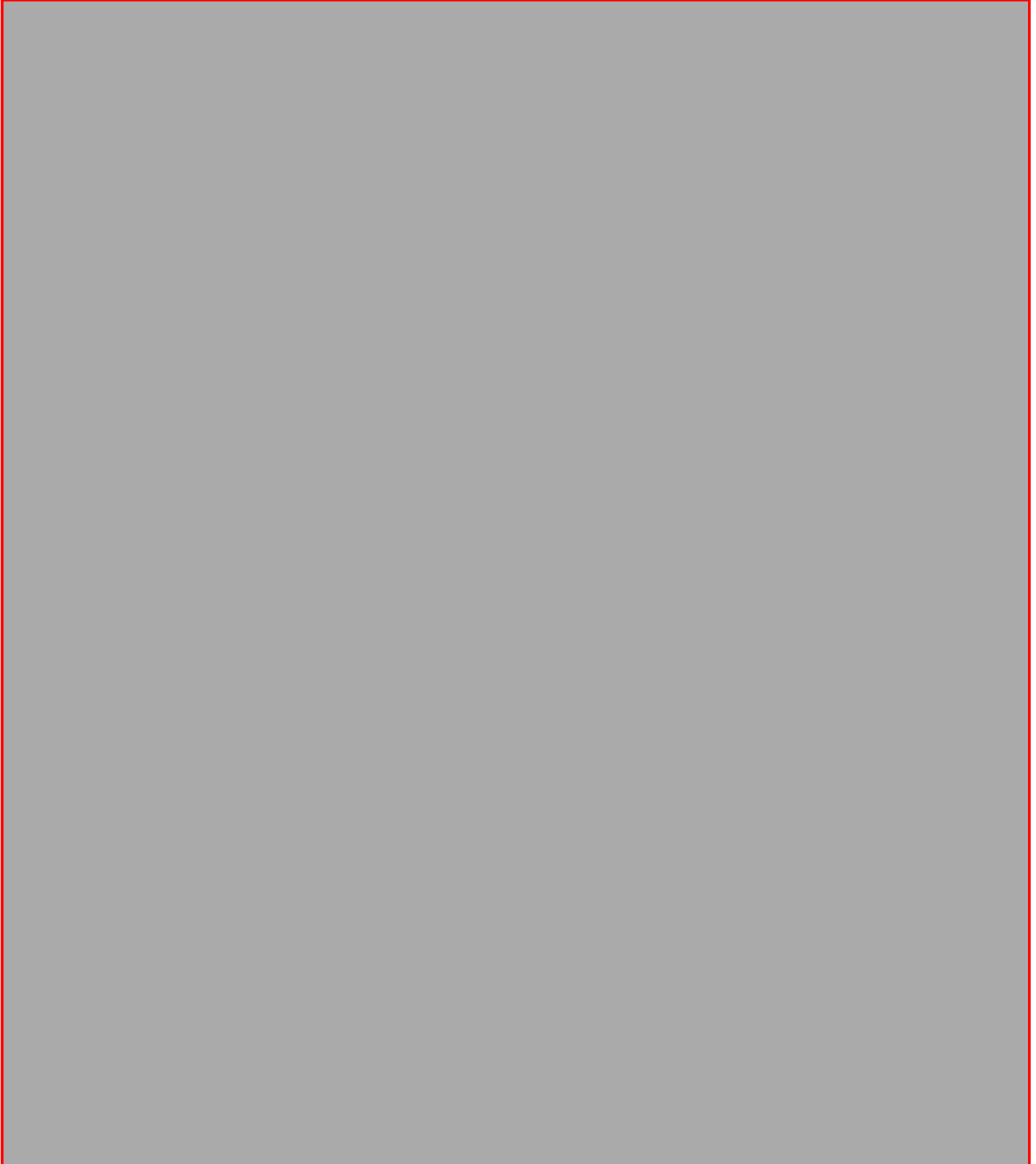
Down and Black's (1998) Checklist for Randomised and Non-Randomised Studies

Inter-rater reliability reported good ($r = 0.75$) for Down and Black's checklist.

Appendix C

Single Case Experimental Design (SCED) Quality Checklist by Tate et al. (2008)

Inter-rated reliability reported excellent (0.83) for the SCED.



Appendix E

Rehabilitation Programmes

Table E1

Programme Description

Author	Programme	Context	Length	Description
Haffey & Abrams (1991)	Work Re-entry Programme (WRP)	Specialist brain injury centre	60 hours	The work re-entry model is based upon the supported employment model but also contains a transitional employment element - a simulated employed environment supported by job coaches prior to achieving a competitive work placement. The programme was created to reduce employment barriers experienced by patients with ABI and involves a vocational assessment to determine desired work outcomes for individuals.
Malec & Moessner (2006)	Hospital-based Vocational Case Co-ordinator	Medical Centre	Not stated	Lead by a brain-injury specialist nurse and a vocational case coordinator (VCC) based within a medical centre. The VCC liaises with community-based services to attain vocational support for patients as well as contact previous employers. This relationship provides early identification of patients requiring vocational support, directing them to the appropriate services.
Murphy et al. (2006)	Rehab UK	Specialist brain injury centre	9-12 months	Comprise two elements; A and B. Element A provides pre-vocational and vocational support including: numeracy, literacy, IT skills and building self awareness and knowledge of brain injury. Element B is focused around in-situ work training involving placement support and a job coach. A work trial is sought with an employer with aim to secure a paid-work placement. The programme aims to offer maximum flexibility during the programme and following discharge.
Niemeier et al. (2010)	Vocational transitions programme (VTP)	Specialist brain injury centre	10 weeks	This programme was based in five different clubhouses, originally set up to support individuals with ABI transition from acute to community settings. The programme was designed based upon the clients' perceptions of the top 20 most important aspects of vocational rehabilitation. The programme is delivered within 20 sessions with 5-6 participants per group.

Table E1

Programme Descriptions (continued)

Author	Programme	Context	Length	Description
O'Brien (2007)	Commonwealth Rehabilitation Service Australia	Specialist brain injury centre	9 months	An Australian rehabilitation service that involves the use of up to 18 different return-to-work interventions that address methods of: job seeking; development of social, communication and cognitive skills; work placements; and graded return to work programmes.
Owensworth (2010)	Metacognition programme	Specialist brain injury centre	16 weeks	A specialist programme involving 5 components: group activities; individual activities to promote self-awareness and regulation; family involvement; disability service training; and a work trial followed by in-situ support.
Preston & Ulicny (1992)	Transitional job coaching model (TJC)	Post-acute Residential programme	Not stated	Involves participants in the Learning Services/Carolina Community-Based Rehabilitation Programme (LSC) that comprises an independent living skills programme (ILS) and a vocational programme to individuals with vocational goals. All clients within the vocational programme also take part in the ILS. The programme begins with a vocational assessment followed by work adjustment, job matching and supported employment.
Trexler et al. (2010)	Resource Facilitation (RF)	Telecommunication	10.5 hours	Individuals in the treatment group are allocated a resource facilitator who provides over-the-phone support to inform clients of relevant vocational services and/or get in contact with previous employers to facilitate return to work. Clients are encouraged to attend vocational rehabilitation with an external provider which is likely to include the use of job coaching and work placement support. A resource facilitator may also support clients to access other services such as counselling and financial support.

Appendix F

Interpretative Phenomenological Analysis

Objects of concern emerged from the text and were used to create superordinate and subthemes. The following table describes these themes along with their evidence drawn from the transcript. All evidence is taken verbatim from the transcript.

Table F1

Evidence and Descriptions of Superordinate and Sub-Themes

Superordinate themes	Sub themes	Evidence	Description
Boys will be boys	Lack of accountability	"A 16 year old should be fully aware of what may happen...so she doesn't have all the guys"	Ultimately it is the girl's responsibility for what happens to her. Girls should know what boys do.
		"I don't know if this fits in wiv [/with/] the discussion, because it's not really looking at the girl, but um like, maybe if we looked at the boys who were doin' [/doing/] it as well... Am I allowed to say, I know?"	It doesn't seem obvious to talk about the boy's role in the first vignette.
		"I know boys who have done things like this, and they don't think there is anything wrong wiv [/with/] it."	Girls feel that the boys do not see any harm in what they do. 'Things like this' avoidance of rape.
Gangs - a pressured and desperate adolescence	Compensating for a lost upbringing	"Maybe not all gang members are all that bad in one sense, maybe they're just born into it not knowin' [/knowing/] any better- their Dad, their Uncles, their Brothers and they don't know any better."	Male behaviour is reinforced by not getting punished - there are no consequences for what they do: "these guys know how they can get out of it as well, that's why they're freely doing it"
		"The ones that do get involved in it, there are obviously issues to the girls life"	Boys don't know any better - they have learnt it from their fathers, uncles etc... sympathy
		"You've got no love at home so you go searching for it elsewhere"	
		"It is how you are brought up again, isn't it?"	If a girl becomes involved with a gang then this is perceived to be a result of girls having issues in their life on account of their upbringing. Upbringing has a big influence on a girl's decision-making later on in life. Gives a sense of a desperate situation - the girl has no alternative.

Table F1

Evidence and Descriptions of Superordinate and Sub-Themes (continued)

Superordinate themes	Sub themes	Evidence	Description
Gangs - a pressured and desperate adolescence	Girls and boys are desperate	"These kids are too desperate to get in" "Desperate to be accepted" "Made her crave so much attention" "It's they're- it's like they're – Boys in a gang, that's like something that's- like... not condoning it or anything, but there's reasons for the boy to be in a gang, but the girl she just wants- what does she want? She wants to be accepted she wants to feel some love. Like, look for it elsewhere. Why are you pushing yourself upon this gang life?"	Girls and boys are desperate to get in - they crave the attention and gangs provide the attention. Boys do not appear to have a choice as to whether they want to be a part of a gang. Girls on the other hand do have a choice and if they make that choice then they are perceived as 'pushing' themselves into it. If they do this, then girls are likely to get involved with group sex with male gang members.
	Peer pressure	"Boys and girls get picked on all the time. Whateva, [/whatever/] at school, for different things, and you are going to get influenced. You are going to get peer pressure"	Peer pressure is inevitable and reflects adolescent development - It influences decisions including those to be affiliated with gangs. Everyone gets picked on - gang membership is a way of managing the inevitable of adolescence.
The Allure of Belonging	Acceptance	"Here it's just about acceptance and just being accepted" "She probably just wants to be accepted by anyone that's around her" "And then he comes under peer pressure, acceptance, you know and uh, just being part of something, while he reluctantly had sex with two girls."	Gangs provide a sense of acceptance Focus group girls attempt to understand why girls become involved - It's important to be accepted and group sex provides the means for acceptance. Girls and boys do things to be accepted. Girls justify the involvement of boys as a way of being accepted - this is a shared understanding amongst the girls and reveals a sense of empathy.
	Provides insurance - wealth, support, freedom, protection	"He's got the gift of the gab, good money, good car" "Big time man thought she could go anywhere at any time" Girlfriends: "you have a protectiveness over them" "They're all willing to back you up"	Gang provides money and good cars. Enables a sense a freedom - albeit a false one. Girlfriends are protected by boyfriends. Boys within gangs support one another and provide protection.

Table F1

Evidence and Descriptions of Superordinate and Sub-Themes (continued)

Superordinate themes	Sub themes	Evidence	Description
The Allure of Belonging	Rewarded	Boys: Money, cars, status "It's a status thing" Girls : "it's all a hype thing "He's got the biggest car. He's got the status. An' (and) you know, you're not gonna [/going to/] get touched. And so, that what I think- that's what half of the girls really like want though now-a-days. What happened to a good guy? I <i>do not</i> know." "It's not even that. I think that they just like that lifestyle. Not even that lifestyle. If you're man's gonna [/going to/] go and buy you some Gucci shoes yu-yu- Do you know what I mean?"	Boys and girls get different rewards Boys - status, girls, money and cars A girl's status is mediated by gang involvement. Girls enjoy it for the hype and material things: designer wear, cars etc.... Easier to get these things from boys associated with gangs - money is fast as oppose to boys that are educated and may have to borrow from parents. Desire for independence away from parents. Therefore relationships do not necessarily form on the basis of attraction but of desire for material things or things that cannot be attained by conventional methods.
The consequence of belonging	Girls - Scared	"All girls are scared to talk to people. They're scared to talk to people" "She might be too scared to say anything" "I think that's another reason why people are too afraid to say anything, because like if you- that them, them people have forced you and done sexual acts and whatever else, what's the next step in what they could do to yah? Do you know what I mean?" "What's he- what will they do to her if they find out that she was the one that told and she told the police things of what's happened?"	Girls are scared to talk to anyone. Girls are aware of the consequences of talking - if boys can force sex then what else can they do? Risk on a girl's safety and her street pride. There are repercussions for girls if they report experiences of rape and/or coercion.

Table F1

Evidence and Descriptions of Superordinate and Sub-Themes (continued)

Superordinate themes	Sub themes	Evidence	Description
The consequence of belonging	Girls -being labelled	"She's going to have a label" "Everyone is going to have an opinion of a girl who does..."	Girls get a label as a result of their sexual behaviours. A label means that girls get categorised. Because both girls and boys believe in these labels - once a girl does something that gives her a label, she is likely to believe it and act according to what is 'expected' from her as being part of that label. This also reveals victim blame and a way of understanding why rape happens. The girls assume that the female victims in the vignettes were 'asking' for it given their behaviour. Males escape blame.
The protective but damaging consequences of losing innocence	Age 16 and the requirement to 'know'	"A 16 year old girl should be fully aware of what may happen" "Most 16 year old girls are quite switched on" "I mean at 16 years old I think that girls that I knew were aware of the things that boys did" "At 16 you should know about some of these issues" "One thing about these girls thought - in these scenarios is they haven't got no sense or morals"	Girls need to be aware of what happens - this will ultimately protect them from adverse situations. Girls are expected to know what happens and so when they make a bad decision they are perceived as having no sense and being naive. The consequences for not knowing: Girl is perceived as naive "She probably just thought that the girls that did it, wanted to..."

Table F1

Evidence and Descriptions of Superordinate and Sub-Themes (continued)

Superordinate themes	Sub themes	Evidence	Description
	Age 16 and 'knowing too much'	<p>"They know too much"</p> <p>"Too much from too young"</p> <p>"How does she live, like knowing other girls are getting gang raped and she still goes over to so-called friends house"</p> <p>"There's girls out there that do it and they just carry on....the problem gets worse"</p>	<p>As a result of knowing what goes on in the environment, a 16 year old is no longer perceived as innocent. They have become exposed to too much which in itself can be damaging.</p> <p>Consequences for knowing too much: If girls are perceived as being aware then there are no excuses for their behaviour - leading to victim blame.</p> <p>Girls become perpetrators and it is assumed they know what they are getting themselves into.</p>
Sexual experiences - interesting points	Male sympathy	<p>"It used a bit strongly, like physically forced. I don't know that's like my experience".</p> <p>"When you read like um, so the sexual scenario, and then the girls is going along wiv [/with/] it and maybe like... Oh this is a bit too much. But, um when the intercourse started she says stop, but she's already actually gave her consent and then when it gets like taken out of the story it gets like, "Oh well, I didn't want to have sex wiv [/with/] them", and then that's classed as rape"</p>	<p>Suggests that sometimes you can be physically forced - but it is overused i.e. doesn't quite represent what is really happening - suggests that girls are wanting this and provoking it themselves? Forced - don't really want to. Suggests that girls are coerced but again this isn't clear.</p> <p>Reveals victim blame.</p>
	Victim blame	<p>"I mean obviously you've heard stories [looking at participants] of girls who go to someone's flat and they don't fully... Well they know exactly what they're going to get themselves into. They know...but not obviously girls being forced and raped at a certain age".</p>	<p>Rape happens as a result of the girl's behaviour If a girl is unaware then she needs to be careful - it will be her fault if anything happens. Sex isn't always physically forced. Perhaps because it is normalised, the girls cannot identify when sex is forced.</p>

Appendix G

Foucauldian Discourse Analysis

FDA was used to explore the ways in which objects were positioned in order to understand cultural practices in USGs. All evidence has been taken verbatim from the transcript.

Table G1

The Six Stages of Foucauldian Discourse Analysis

Object	Position	Discourse	Discursive constructs	Action	Practice	Subjectivity
Forced sexual acts	Way of life	"People around her who are used to doing it, so does she get upset and then forget about it because this is normally, what it's going to be like" "Sometimes you just do ting that you don't really want to do".	People are familiar with forced sexual behaviour and the more others engage in the behaviour the more it is reinforced.	Girls are reflecting on how forced sex is justified and hence why is continues within the culture. Girls use second and third person to reflect upon the issue, thereby putting themselves outside of the situation.	Forced sex continues because others reinforce the behaviour- it becomes normalised. Suggested by the girls that this normalisation takes time for new people in the culture to accept. This highlights how the behaviour may not be perceived as acceptable by others outside of the culture.	Perpetrators of forced sex are not punished; there is no law enforcement present that can reinforce the practice of consenting sex. The acts are not perceived to reflect violation or exploitation and so they go unreported and the problem perpetuates.
Women	Damaged goods	"Some men act like this maybe they've got female members of their mums who have been promiscuous" "One thing about these girls...they haven't got no sense or morals"	Women within the family are perceived to be the cause of male behaviour – men learn from promiscuous females. Girls have no morals as a result of engaging in sex with gang members.	Justification - almost serves to protect the men in the culture. Women are constructed as the perpetrators, which is likely to explain why there is female victim blame within the culture.	Allows girls to be able to understand their culture, which appears to be through the behaviour of other women and female family members. This may serve as a possible coping strategy in that rape and sexual coercion are always brought on by the females involved.	As a result of this coping strategy, girls have less empathy for girls and they develop their own culture of victim blame. Rape not perceived as a criminal act.

Table G1

The Six Stages of Foucauldian Discourse Analysis (continued)

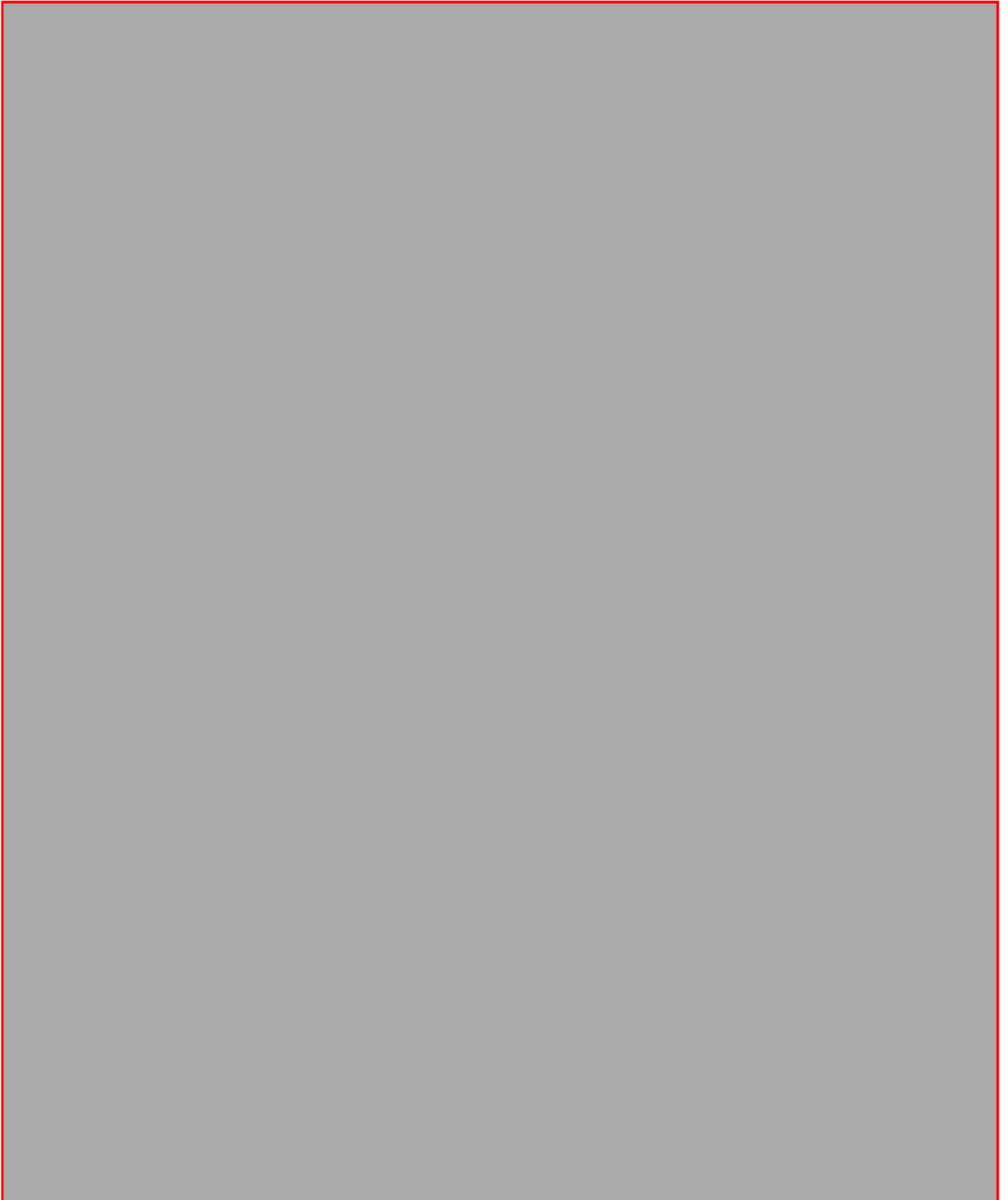
Object	Position	Discourse	Discursive constructs	Action	Practice	Subjectivity
Women	Naive	"She probably thought that she wasn't going to get involved" "She probably just thought that the girls that did it, wanted to..." "I think she's obviously just naive".	She probably thought = unsuspecting, naïve. Gives rise to victim blame – girl should know. Girls appear to make excuses to disguise the reality of the situation.	Girls perceived as naive - girls should know and be aware of what could happen. Note use of 'naive' and not 'innocent'. Naive has negative connotations. Ultimately there is no such thing as an innocent mistake within the gang culture. You do things for a reason, being naive won't protect you.	Allows victim blame even when the girls aren't aware of what goes on. It is the responsibility of the girl to make sure they know what goes on. So when they can no longer realistically justify rape or sexual coercion - i.e. in the case where girls don't know or aren't aware - it gives them an alternative way of explaining why it happens.	Allows girls to always explain why sex acts take place - the explanation of rape sounds too drastic.
	Scared	"All girls are scared to talk to people. They're scared to talk to people" "I think that's another reason why people are too afraid to say anything. - They have forced you to do sexual acts so what else can they do."	Girls are scared to talk to others because they know what the potential repercussions could be.	Said because being scared is a consequence of the repercussions girls are likely to face - justifies why girls don't talk even when they should.	Being scared - contains the culture - controls the culture in the way it exists and wants to continue to exist.	Girls are scared and feel as though they have less power which in turn if nothing is said, gives them less power than the men that drive the sex culture.
	lost	"You've got no love at home so you go searching for it somewhere else" "The ones that do get involved in it, there are obviously issues to the girls life" "She wants to be accepted she wants to feel some love."	The importance of love within family and the relationship with mother. Children and teens need love and attention at home.	Girls pushing on gang life - it's not a world for a girl - girls push themselves onto it if they want to get involved. Therefore if a girl gets raped then it is their fault.	Justifies the culture - gang provides an alternative up-bringing that isn't gained from home life. This gives importance to gang life which is why it is sustained and worth protecting.	Reflecting on their own thoughts towards themselves - no empathy for girls because of their own past experiences?

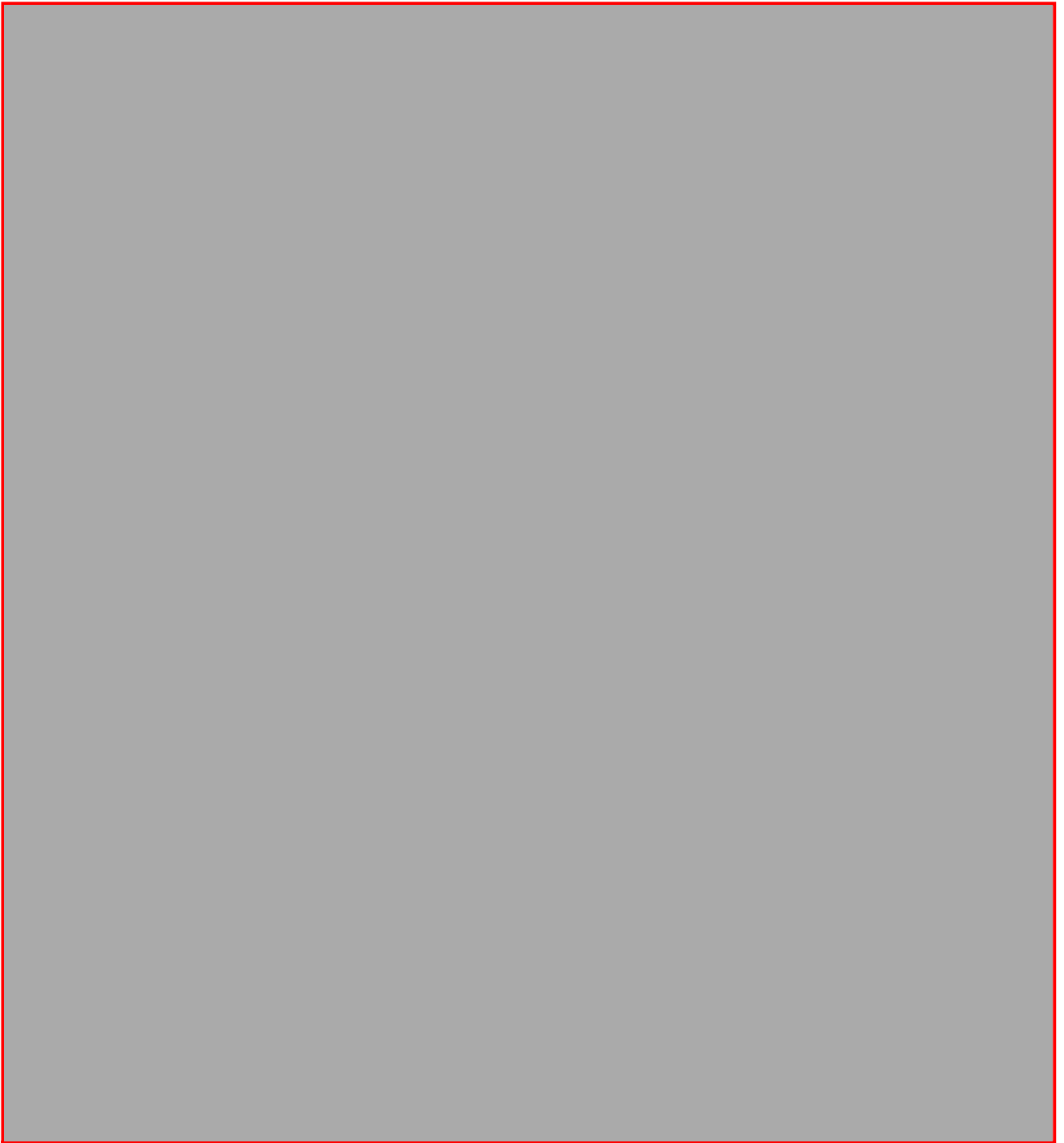
Table G1

The Six Stages of Foucauldian Discourse Analysis (continued)

Object	Position	Discourse	Discursive constructs	Action	Practice	Subjectivity
Gang	An alternative qualification	"When you want to get into a gang, you have to get battered... you have to beat someone up, kill someone or stab someone" "Now that not the test"	This is not a difficult subject to discuss. A test - an opportunity to prove oneself. Creating their own qualification - supports an alternative world for reward, recognition, identity against one that they could not succeed within.	Perpetrator empathy - boys have to do this - allows them to carry on doing it because they have no choice, they have to prove their worth one way or another.	Allows boys to qualify in an alternative way - gangs give a sense of purpose and identity where schools fail to?	At a time when identity and status appear to be most important it gives teenagers an alternative way of being. Gangs may appear as an opportunity.
	Peer pressure	"It's easier to go ahead and do it, then say 'I don't want to be a part of this gang'" "Gang have approached him. he's strong enough to say no"	Boys are pressured into gang life and there are consequences for not joining. You get picked on regardless as a young person but in the right environment this could lead to gang affiliation.	It's hard to resist against gang life so boys are sympathised with.	Importance of being accepted by one's peers. In practice, friends perpetuate the issue.	If girls perceive it to be more acceptable for boys - or boys have reasons then this is likely to facilitate the boy being in a gang.
Boys	Desperate	"He comes under peer pressure, acceptance"	Desperate to be accepted, under the influence of peer pressure.	Justifies the male being involved.	Gangs are strong forces and are likely to get bigger without intervention.	Boys will be determined and will do what it takes to join the gang and prove their worth - especially if they have lost out in school.
	Reward seeking	"He's got the gift of the gab, good money, good car" "He makes his money dealing death" "He's got the biggest car, he's got the status"	Joining a gang gives them access to the things they want within an alternative economy - strain theory.	Justification as to why girls go after these boys.	Why then would gang members go for the expected, law abiding route into business or employment when this way is much more accessible?	Once this is experienced, unlikely that gang members will want to find another way of getting the things they want. Leads to maintenance of gang affiliation.

Appendix H





Appendix I

Participant Information Sheet: Negative thoughts and feelings and disability in Multiple Sclerosis

We are inviting you to take part in a research study. Before you agree to participate, it is important that you understand the purpose and nature of the study.

What is the purpose of this study?

The purpose of this study is to examine whether the extent of impairment and disability in Multiple Sclerosis is related to feelings of depression and thoughts about harming oneself.


Why have I been chosen?

You have been asked to participate in this study as you have progressive multiple sclerosis which is the group of people we are interested in and you are a patient at the West Midlands Rehabilitation Centre.

Do I have to take part?

No. Participation is completely voluntary so you are under no obligation to take part. If you decide to participate, then you may keep this information and you will be asked to sign a consent form. If you do change your mind at any time during the study, you are able to withdraw your participation by contacting the researcher (see below). You can also withdraw from the study at any time within two weeks of completing the questionnaires. If for any reason you do choose to withdraw, any identifiable data will be destroyed and will not be used in the study.

What will happen to me if I take part?

If you are interested in taking part or finding out more about this study please post (in the stamped addressed envelope) or email () the expression of interest form enclosed within this letter. One of the researchers will telephone you to answer your questions or arrange a time to meet with you for 45-60 minutes at West Midlands Rehabilitation Centre. When you meet with the researcher you will be given the opportunity to ask any further questions and then asked to sign a consent form (to say that you agree to take part in the study). You will be given four questionnaires to fill in. One of the researchers will be there to help you if you need anything.

What are the possible disadvantages and risks of taking part?

As the study is looking at feelings of depression and negative thoughts, you will be asked to fill in a scale that asks you about thoughts you may have or had about harming yourself which you may find upsetting. If your questionnaires suggest that you are having thoughts

like this, then the researcher will let the clinical team know about this so that you can talk to them about it there and then. If you feel in any way distressed by the study after you have left however, then we suggest you call your MS nurse or the MS Society helpline on 0808 800 8000 (available 9am to 9pm, Monday to Friday) or the Samaritans on 08457 90 90 90 (available 24hrs and day 365 days a year).

What are the possible benefits of taking part?

There is no direct benefit to you in taking part. However, you will be assisting in furthering research into suicide and depression in multiple sclerosis, which could help to shape services in the future and raise awareness about this.

Will my taking part/performance in the study be kept confidential?

You will be allocated a participant reference number at the start of the study. From the point of [redacted] [redacted] questionnaires will be anonymous and identified by a participant reference number only. All data collected will be kept in a locked cabinet in a secure office. Once the raw data has been analysed, it will be deleted.

What will happen to the results of this study?

The results will be written up in a report within the University of Birmingham. If the study is found to be significant and add to the current research, it may be selected for publication in an academic journal. If this is the case, then the results will be available to be viewed by the general public.

Who is organising and funding the research?

This is a joint study which is being conducted by the University of Birmingham and the West Midlands Rehabilitation Centre.

Who has reviewed this study?

This study has been reviewed and approved by IRAS.

If you wish to seek advice about taking part in research in the NHS generally, please contact our patient advice and liaison service on [redacted].

Contact Details

For further details on this study, or to withdraw from the study, please e-mail the researchers, Katherine Alton, [redacted] or Vicky Lewis [redacted]k. Alternatively, if you have any concerns that you feel the researcher may not be able to address please contact Dr. Theresa Powell on [redacted].

Appendix J

Expression of Interest Letter: Negative thoughts and feelings and disability in Multiple Sclerosis

Expression of interest letter

This is a study examining whether the extent of impairment and disability in Multiple Sclerosis is related to feelings of depression and thoughts about harming oneself.

Participation in this study will involve meeting with a researcher and completing four questionnaires which will take approximately 45 - 60 minutes.

Information provided will be kept confidential.

The researchers carrying out this study are Katherine Alton [redacted] and Vicky Lewis V [redacted] who are both students at the University of Birmingham. The research is being supervised by Dr Chit KoKo at the West Midlands Rehabilitation Centre and Dr Theresa Powell [redacted] at the University of Birmingham. You may contact Dr Koko through his secretary, Lynn Humphrey on [redacted].

Please initial each box which applies

☐

I am unsure whether I would like to participate in this study and would like a researcher to telephone me with further information.

☐

I would like to participate in this study and meet with a researcher one hour before my clinic appointment (a researcher will telephone you to confirm)

Please provide a telephone number so that Katherine or Vicky can contact you:

Please return this form to West Midlands Rehabilitation Centre in the stamped address envelope provided or email it to [redacted]. Thank you for your consideration.

Appendix K

Consent Form: Negative thoughts and feelings and disability in Multiple Sclerosis

1. I,, confirm that I have read and understood the participant information sheet for this study. I have had the opportunity to ask any questions, and these questions have been answered satisfactorily.
2. I understand that my participation is entirely voluntary and that I am free to withdraw at any time in the study, without giving any reason.
3. I understand that any information I provide will be kept confidential.
4. I understand that the data will be treated according to the British Psychological Society Code of Ethics.
5. I understand that the information I provide will be used and analysed for research purposes. I also understand that these findings may be published in an academic journal.
6. I understand that I can withdraw from the study at any time, and up to two weeks after participating in the study, by contacting the researcher with my unique participant reference code. I have made a note of my participant reference code. I understand that if I do withdraw from this study, my data will be destroyed and will not be used in this study.
7. I understand that relevant sections of my data collected during the study, may be looked at by individuals from the University of Birmingham, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
8. By signing this consent form, I agree to participate in this study.

_____	_____	_____
Name of Participant	Signature	Date
_____	_____	_____
Name of researcher	Researcher's signature	Date

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