City Research Online

City St George's, University of London

Citation: Kennedy, S. (2016). Group based cognitive behavioural therapy programme for menstrual pain management in young women with intellectual disabilities: a mixed methods feasibility evaluation. (Unpublished Doctoral thesis, City, University of London)

This is the accepted version of the paper.

This version of the publication may differ from the final published version. To cite this item please consult the publisher's version.

Permanent repository link: https://openaccess.city.ac.uk/id/eprint/19796/

Copyright and Reuse: Copyright and Moral Rights remain with the author(s) and/or copyright holders. Copies of full items can be used for personal research or study, educational, or not-for-profit purposes without prior permission or charge, unless otherwise indicated, provided that the authors, title and full bibliographic details are credited, a hyperlink and/or URL is given for the original metadata page and the content is not changed in any way. For full details of reuse please refer to City Research Online policy.

City Research Online: http://openaccess.city.ac.uk/ publications@citystgeorges.ac.uk

Group based cognitive behavioural therapy programme for menstrual pain management in young women with intellectual disabilities: a mixed methods feasibility evaluation.

Susan Kennedy

Doctorate in Clinical Psychology (DPsych)

City University London

School of Arts and Social Sciences

October 2016

TABLE OF CONTENTS

Acknowledgements **18**

Declaration **20**

SECTION A: PREFACE **21**

SECTION B: RESEARCH **26**

Group based cognitive behavioural therapy programme for menstrual pain management in young women with intellectual disabilities: a mixed methods feasibility evaluation.

Abstract **27**

Chapter 1: Overview **28**

Chapter 2: The Concept of Intellectual Disability

2.1 Defining “Intellectual Disability” 30

2.2 The Prevalence of Intellectual Disability 32

Chapter 3: The Concept of Pain

3.1 Definitions of Pain 34

3.2 Prevalence of pain in the general population 35

3.3 Prevalence of pain in the intellectually disabled population 36

3.4 Theories and Models of Pain 43

3.4.1 Single Factor Models 43

3.4.2 Multidimensional Models 44

Chapter 4: Assessment of Pain

4.1 Assessment of pain 47

4.2 Assessment of pain intensity 49

4.3 Assessment of physical functioning 52

4.4. Assessment of emotional functioning 52

4.5 Assessment of symptoms and adverse events 55

4.6 Assessment of participant disposition 56

Chapter 5: Methodological issues in the assessment of pain in people with Intellectual Disabilities

5.1 Challenges and approaches to assessment 57

Chapter 6: Treatment of Pain

6.1 Overview of the Cognitive-Behavioural perspective 62

6.2 Components of a Cognitive-Behavioural therapy (CBT) approach to treatment 62

6.3 Uses and Effectiveness of CBT in the general population 64

6.4 CBT with individuals with an intellectual disability 64

6.5 CBT for pain management 67

6.6 CBT for pain management in individuals with an intellectual disability 69

Chapter 7: Menstrual pain

7.1 Definitions of menstrual pain 72

7.2 Prevalence of menstrual pain in the general population 73

7.3 Prevalence of menstrual pain in individuals with intellectual disabilities 74

7.4. Psychological processes in menstrual pain 76

7.5 Psychological interventions for menstrual pain 77

Chapter 8: Rationale for the current study

8.1 The present study 78

8.2 Study aims and objectives 78

8.3 Quantitative assessment 80

8.4 Qualitative assessment 80

8.5 Research questions 80

8.6 Research hypotheses 81

Chapter 9: Methodology

9.1 Study Design 83

9.2 Sample Size and Power Calculation 83

9.3 Participants 84

9.4 Recruitment Strategy 84

9.4.1 Inclusion Criteria 85

9.4.2 Exclusion Criteria 85

9.5 Treatment Allocation & Matching Process 86

9.5.1 Intervention Condition 86

9.5.2 Control Condition 87

9.6 Ethical Considerations 88

9.6.1 Informed Consent 88

9.6.2 Protection of privacy, anonymity and confidentiality of participants and, their data 89

9.6.3 Psychological well-being of participants 90

9.6.4 Dissemination of findings 91

9.7 Overview of psychological intervention 92

9.7.1 Programme development 92

9.7.2 Intervention programme 93

9.7.3 Pilot study 95

9.8 Outcome Assessment Strategy 95

9.8.1 Assessment measures 97

9.9 Statistics Strategy 103

9.9.1 Quantitative Analysis 103

9.9.2 Qualitative Analysis 104

Chapter 10: Quantitative Results

10.1 Descriptive statistics 105

10.2 Data distribution 111

10.3 Matching 115

10.4 Descriptive overview of the data 116

10.5 Correlation matrix 123

10.6 Cronbach's alpha 127

10.7 Summary of main findings 129

10.7.1 Hypothesis 1 129

10.7.2 Hypothesis 2 134

10.7.3 Hypothesis 3 140

10.7.4 Hypothesis 4 145

Chapter 11: Qualitative Results

11.1 Feedback from participants, parents and support staff 154

11.2 Participant evaluation of intervention 155

11.3 Staff evaluation of intervention 162

11.4 Parent evaluation of intervention 171

Chapter 12: Discussion & Recommendations

12.1 Overview 176

12.2 Summary of results from quantitative analysis 177

12.2.1 Pain Knowledge 177

12.2.2 Wellness-focused coping strategies 177

12.2.3 Pain Intensity 179

12.2.4 Pain Interference 180

12.2.5 Use of cognitive coping strategies 182

12.2.6 Use of behavioural coping strategies 183

12.2.7 Parental Pain Catastrophizing 185

12.2.8 Pain Self-Efficacy 186

12.3 Summary of results from qualitative analysis 189

12.4 Strengths and Limitations of the study 191

12.5 Recommendations for future research 198

12.6 Conclusion 199

References 202

Appendices 205

SECTION C: PROFESSIONAL PRACTICE

Menstrual pain and quality of life outcomes: Reflections on a behavioural approach to formulation and treatment 341

Chapter 1: Introduction 342

Chapter 2: Phase 1 344

2.1 The Referral and context for the work 344

2.2 Brief Profile of the service user 344

2.3 Background History 345

2.4 Therapeutic History 346

2.5 Presenting Problem 347

2.6 Clinical Assessment 348

2.7 Clinical Formulation 350

2.8 Theoretical Approach to Intervention 352

2.9 Therapeutic Intervention Plan and techniques employed 353

2.10 Progress of therapeutic intervention 355

2.11 Challenges to the intervention plan 356

2.12 The therapeutic ending and discharge 357

2.13 Evaluation and making use of supervision 358

2.14 Reflections and Reformulation 358

Chapter 3: Phase 2

3.1 Menstrual pain as a chronic pain condition 362

3.2 Biopsychosocial model of pain 362

3.3 Cognitive behaviour therapy approach to pain 363

3.4 Cognitive behaviour therapy for pain management in people with Intellectual disabilities 364

3.5 Case Reformulation 365

3.6 Summary of Reformulation 366

3.7 Summary of therapeutic intervention phase 2 366

3.8 Outcome of therapeutic intervention phase 2 368

3.9 Why a behavioural approach alone was insufficient 369

3.10 Conclusion 370

References **371**

SECTION D: SYSTEMATIC REVIEW OF LITERATURE

How effective are relationships and sexuality education programmes at addressing training needs, as identified by those with intellectual disabilities? 375

Abstract 376

Background 378

Literature Review Methodology 379

Results 383

Relationships and sexuality training needs, as identified by individuals with intellectual disabilities 383

Relationships and sexuality training programmes for individuals with intellectual disabilities 392

Conclusion 403

Strengths & Limitations 404

Recommendations 404

References **405**

List of Tables

Table 1:	Outcome measures and administration time points	96
Table 2:	Summary of demographic details	105
Table 3:	Summary of menstruation frequency and duration	106
Table 4:	Summary of menstruation impact	107
Table 5:	Summary of menstrual pain frequency	108
Table 6:	The most commonly reported locations of menstrual pain	108
Table 7:	Frequency of menstrual symptoms	109
Table 8:	Summary of medication details	111
Table 9:	Significance, skew and kurtosis of data distribution	112
Table 10:	Outcome variables compared at baseline	116
Table 11:	Means and Standard Deviations (SD) for primary and secondary outcome variables	116
Table 12:	Summary of correlations for primary and secondary outcome variables	126
Table 13:	Cronbach's Alpha values for study measures	127
Table 14:	Pain Knowledge scores for Intervention and Control groups across time periods	129
Table 15:	Wellness focused coping strategies used by the Intervention and Control groups across time periods	131

Table 16: Wellness focused coping strategies used by the Intervention and Control groups in real-life scenarios, across time periods 133

Table 17: Participant pain intensity scores for the Intervention and Control groups across time periods 134

Table 18: Participant pain interference scores for the Intervention and Control groups across time periods 136

Table 19: Parent ratings of participant pain intensity scores for the Intervention and Control groups across time periods 137

Table 20: Parent ratings of participant pain interference scores for the Intervention and Control groups across time periods 138

Table 21: Behavioural pain coping strategies used by the Intervention and Control groups across time periods 140

Table 22: Behavioural pain coping strategies used by the Intervention and Control groups in real life scenarios, across time periods 141

Table 23: Cognitive pain coping strategies used by the Intervention and Control groups across time periods 142

Table 24: Cognitive pain coping strategies used by the Intervention and Control groups in real life scenarios, across time periods 143

List of Graphs

Graph 1:	Total Wellness focused coping strategies used	120
Graph 2:	Total Illness focused coping strategies used	120
Graph 3:	Total Cognitive pain coping strategies used	120
Graph 4:	Total Behavioural pain coping strategies used	120
Graph 5:	Total Wellness focused coping strategies used during scenarios	120
Graph 6:	Total Illness focused coping strategies used during scenarios	120
Graph 7:	Total Cognitive focused coping strategies used during scenarios	120
Graph 8:	Total Behavioural focused coping strategies used during scenarios	120
Graph 9:	Pain Knowledge scores	121
Graph 10:	Pain Intensity – Participants	121
Graph 11:	Pain Intensity – Parents	121
Graph 12:	Pain Interference – Participants	121
Graph 13:	Pain Interference – Parents	121
Graph 14:	Pain Self-Efficacy	121

Graph 15: Parental Pain-Catastrophizing 121

List of Figures

Figure 1: Themes identified from qualitative analysis of Participants data. 157

Figure 2: Themes identified from qualitative analysis of Teachers data. 163

Figure 3: Themes identified from qualitative analysis of Parents data. 172

List of Appendices

Appendix 1:	Participant Information Letter (Parent Version).	238
Appendix 2:	Consent Form (Parent Version).	241
Appendix 3:	Participant Information Letter (Participant Version).	243
Appendix 4:	Consent Form (Participant Version).	247
Appendix 5:	Notification of ethical approval to complete research.	251
Appendix 6:	"Web of Ideas" for programme development	254
Appendix 7:	Session Summary Sheets	255
Appendix 8:	Certificate of Participation	271
Appendix 9:	The Pain Coping Strategies Questionnaire (McManus & McGuire, 2014).	272
Appendix 10:	The Pain Coping Scenarios Questionnaire (McManus & McGuire, 2014).	276
Appendix 11:	The Pain Management Knowledge Questionnaire (McManus & McGuire, 2014).	278
Appendix 12:	The Pain Intensity Scale (McGrath et al. 1996).	282
Appendix 13a:	Pain Impact Scale (Participant Version)	283
Appendix 13b:	Pain Impact Scale (Parent Version)	287

Appendix 13c:	Correspondence with Dr. Cleeland	291
Appendix 14:	Self-Efficacy Scale	292
Appendix 15:	Pain Catastrophizing Questionnaire (Parent version) (Goubert, Eccleston, Vervoort, Jordan & Crombez, 2006).	294
Appendix 16:	Background Information Questionnaire.	296
Appendix 17:	Transcript of Focus Group with participants.	300
Appendix 18:	Transcript of Focus Group with Teachers.	316
Appendix 19:	Notes from Focus Group with Parents.	331
Appendix 20:	Publications and Presentations	333
Appendix 21:	Fidelity Checklist	338

City, University of London
Northampton Square
London
EC1V 0HB
United Kingdom

T +44 (0)20 7040 5060

THE FOLLOWING PARTS OF THIS THESIS HAVE BEEN REDACTED FOR DATA PROTECTION REASONS:

Menstrual pain and quality of life outcomes: Reflections on a behavioural approach to formulation and treatment…….p.342-374

Acknowledgements

Firstly, I would like to say a huge thank you to my Supervisors, Dr. Brian McGuire, National University of Ireland, Galway (NUIG) and Professor Carla Willig, City University London. Brian, you very kindly agreed to provide external supervision to enable me to complete my research at home in Galway. This made my life so much easier so I greatly appreciate it. Thanks for all your support, helpful comments and direction with the thesis over the last few years. You also challenged me with lots of side projects along the way (which I hadn't anticipated!) but they certainly made the research journey memorable! Thanks so much for those great learning opportunities. A special word of thanks must go to Professor Carla Willig, both for her support and assistance as my internal Supervisor, and her help in organising my temporary withdrawal and return to study, following maternity leave. You made this process so easy at a busy time in my life and it was greatly appreciated. Thank-you.

I would also like to express my gratitude to my employers, the Brothers of Charity Services, Galway, and in particular, my line manager, Dr. Mary Davis, Head of Psychology Department, who facilitated me to complete this course by allowing me to take study leave and provided funding towards fees and conference attendance over the last few years. Without this support, the course would have been significantly more challenging to complete whilst continuing to work full-time, so I am extremely grateful for this assistance.

Special thanks must go to the young women, their families and support staff who so kindly agreed to participate in my research project. You gave freely of your time and were a joy to work with – thank you all so much for all you gave and taught me. A special mention to Dr. Kiran Sarma, Ronan Conway and Stephanie Haugh, who helped to refresh and expand my statistics knowledge! Thanks also to Dr. Siobhan O'Higgins who assisted with post-intervention data collection.

Finally, I would like to thank my family, friends and especially my husband, Cormac, for encouraging and supporting me to return to college to complete the top-up Doctorate. Despite the sacrifices involved over the last few years you have all been behind me all the way. I'm really looking forward to spending more time with you all, especially my husband and our wonderful daughter, Leila, now that I've finally finished studying!

Declaration

The author of this thesis has granted powers of discretion to the University Librarian to allow the thesis to be copied in whole or in part without reference to the author. This permission covers only single copies made for study purposes, subject to normal conditions of acknowledgement.

SECTION A: PREFACE

I am a Senior Clinical Psychologist and have worked in the area of Intellectual Disability for the last thirteen years, since completing my clinical training. During this time, I have worked with both children and adults with intellectual disabilities, but my particular area of interest and passion is in working with children. For the last eight years, I have worked on a community based team which provides multi-disciplinary support to children with intellectual disabilities. These children are aged 6 – 18 years and attend mainstream primary and secondary schools. The vision statement of the Brothers of Charity Services, Galway, the organisation with whom I work, states that "We support people to be valued citizens in their local community, to have ordinary life experiences and to be closely connected to family and friends". This ethos encapsulates my approach to clinical practice with this population and also informed my choices regarding the topics and issues I have chosen to present in each of sections of this research portfolio, as described below.

The research component of this portfolio (Section B) examines the efficacy of a cognitive-behavioural therapy approach to menstrual pain management with young women with intellectual disabilities. The aim of this research project was to pilot and evaluate a theory-based intervention programme applied to the issue of menstrual pain. It was my hope that this approach could expand the range of pro-active coping strategies offered to young women with intellectual disabilities within the service I work in, so that they could enjoy best possible physical and mental health and, quality of life. At a broader level, I recognised the scope, applicability and generalizability of the findings to the wider population of women with intellectual disabilities.

The professional practice element of the portfolio (Section C) is an in-depth exploration of my clinical experience with the young woman who was the inspiration for my decision to choose the issue of menstrual pain management as the topic for my research study. The case study outlines both her journey, and mine, through assessment, formulation and intervention. The case study proceeds to outline my reformulation of her presenting difficulties, and the therapeutic intervention approach which followed, when this issue was considered from an alternative theoretical framework as I proceeded through my Doctorate studies. The objective in presenting this case study is to highlight my skills as a reflexive practitioner. Often with the intellectually disabled population, a behavioural approach to intervention can be the first approach tried due to the challenges inherent in their understanding of other more cognitive focused therapeutic interventions. I was interested in seeing if a cognitive-behavioural therapy (CBT) approach could work for this young woman and if so, how and with what modifications. I feel that this case study is a good example of evidence based practice in action.

The systematic review of literature (Section D) examines the area of relationships and sexuality education for individuals with intellectual disabilities. This is an area of particular interest and relevance to me as a Psychologist in clinical practice as I receive a number of referrals each year from parents and schools, seeking support in addressing issues related to sexuality, with pre-pubescent children and adolescents with intellectual disabilities. The aims and objectives of this critical review of the literature on this topic were to familiarise myself with the most up-to-date research on this topic and enhance my critical thinking skills and objectivity in evaluating studies to inform my clinical practice.

The three distinct sections of the portfolio describe my efforts to expand the field of menstrual pain management for women with intellectual disabilities, demonstrate the application of the scientist-practitioner model to clinical practice informed by a clear theoretical base and, highlight 'gaps' in the literature on relationships and sexuality education for those with intellectual disabilities. The various components of this portfolio are inter-related by their common theme of seeking to support individuals with intellectual disabilities to better manage ordinary life experiences – the experience of menstrual pain, an issue faced by both women with and without intellectual disabilities and, the universal experience of sexual development and the issues and challenges associated with this. The three sections of this DPsych thesis are also connected by the fact that in different ways, they demonstrate the various forms of knowledge and skills required to work as a Psychologist in Clinical Practice.

My decision to return to University to complete the DPsych was both personally and professionally motivated. On a personal level, having worked in the same organisation and the same professional field for a number of years, I felt that I wanted a new "challenge" and what could be more challenging than returning to complete a Doctorate whilst continuing to work full-time! Since I qualified as a Clinical Psychologist, the training schemes in Ireland have developed such that all Clinical Psychologists now graduate with a Doctorate level qualification. I was also eager to update my qualifications to the current professional standard. From a practitioner's perspective, I was eager to refresh my research knowledge and skills and to explore an area which was meaningful and relevant to my work and which could have a direct and relevant impact for the service users with whom I work. The mixed methods research design employed in the research study presented opportunities to revise my

statistics skills and develop my knowledge of qualitative research methods. Completing this Doctorate programme has provided exposure to a myriad of new and exciting experiences, which I had not previously anticipated. These included opportunities to co-author research papers, to guest lecture on the topic of relationships and sexuality for those with intellectual disabilities at the National University of Ireland, Galway (NUIG), to present at international conferences and to make funding applications. Many of these experiences were new to me and proved both exciting and daunting in equal measure, at times. They were priceless in the opportunities they afforded me to develop my research skills and increase my professional knowledge and confidence.

Having completed my Doctorate portfolio, I now feel much more capable of critically evaluating research studies which I read to inform my clinical practice. I also feel more confident in my ability to design research studies to evaluate my own clinical work, with a view to writing papers for publication. I feel that the portfolio demonstrates my growth as a therapist and researcher over the course of my studies and has been a truly rewarding experience, both personally and professionally.

SECTION B: RESEARCH

Group based cognitive behavioural therapy programme for menstrual pain management in young women with intellectual disabilities: a mixed methods feasibility evaluation.

Abstract

Research on pain in individuals with intellectual disabilities has largely focused on identification of pain and medical management of pain symptoms. Pain management programmes have not routinely been offered to such individuals. In view of the ample evidence that Cognitive Behaviour Therapy (CBT) can be used for chronic pain management including the management of dysmenorrhea in the general population, and the preliminary evidence for its effectiveness in people with intellectual disability (McManus & McGuire, 2014), there is a rationale for evaluating a CBT-based pain management programme for menstrual pain in women with intellectual disabilities. The aim of this study was to develop and evaluate a theory-based cognitive behaviour therapy (CBT) programme for menstrual pain management in young women with intellectual disabilities. The programme was developed from the theory-based programme "Feeling Better" (McManus & McGuire, 2010). The study used a mixed methods design with the intervention delivered in group format, on a weekly basis, to those in the treatment condition. Those in the control condition received treatment as usual. Information was gathered throughout the process on a number of key pain variables including pain management knowledge, pain coping strategies, pain intensity and pain interference. Process evaluation was conducted with key stakeholders to examine which elements of the programme were most relevant in promoting change. Results suggest that participation in the menstrual pain management group had a positive impact in terms of increasing pain management knowledge over time, and increasing the use of wellness-focused coping strategies to manage pain in everyday situations. Findings suggest that a cognitive-behavioural therapy programme can be effectively used to support menstrual pain management amongst young women with intellectual disabilities.

CHAPTER 1: OVERVIEW

The aim of this study was to evaluate a group based cognitive behaviour therapy (CBT) programme for menstrual pain management in adolescent girls with intellectual disabilities. Process evaluation was also conducted with key stakeholders to assess the acceptability of the intervention, to explore their experiences including any suggestions they had to enhance the programme and to examine which elements of the programme appeared to be most relevant in promoting change for young women with intellectual disabilities who experience menstrual pain. Literature in the area of menstrual pain in intellectual disability focuses primarily on identification of pain and medical management. As pain management programmes are not routinely offered to individuals with an intellectual disability who experience chronic or recurrent acute pain, this study represented a new approach in supporting young women with intellectual disabilities to manage their menstrual pain.

In Chapter Two, the term "Intellectual Disability" is defined and the prevalence of this condition described. Chapter Three examines the concept of chronic pain and its prevalence in the general population and amongst those with intellectual disabilities. Theories and models of pain are also outlined.

Chapter Four outlines the various methods and measures for assessing pain. The challenges and approaches necessary for assessing pain in individuals with intellectual disabilities is addressed in Chapter Five. Pain management and treatment options are detailed in Chapter Six, with particular attention to Cognitive Behaviour Therapy

(CBT) as an evidence-based treatment option. This section describes the key components of this approach as well as the use of CBT for pain management both in the general population and individuals with intellectual disabilities. Menstrual pain in both the general population and individuals with an intellectual disability is explored in Chapter Seven as well as the use of CBT for menstrual pain management.

The rationale for the current study is described in Chapter Eight. Chapter Nine outlines the methodology employed in this research study. The results of the study are described in Chapter Ten (quantitative results) and Eleven (qualitative results) and discussed in Chapter Twelve, along with recommendations for future research and practice in this area.

CHAPTER 2: THE CONCEPT OF INTELLECTUAL DISABILITY

2.1 Defining "Intellectual Disability"

Blyth and Lee (2011) defined Intellectual Disability as a socially constructed term used to describe significant impairments in intellectual ability and adaptive functioning which impact learning, thinking and cognition. These impairments result in varying degrees of disability. Historically, the terms "learning disability", "mental retardation", "mental handicap" and "learning difficulty" have been used in different parts of the world to refer to the same concept and range of impairments. Parmenter (2001) gives an informative and detailed description of the evolution of the term "intellectual disability" within services, media, research and society in general.

Internationally, the two primary classification systems used to define intellectual disability are the Diagnostic and Statistical Manual of Mental Disorders (5th edition) (DSM-V) (American Psychiatric Association, 2013) and the International Classification of Diseases (10th edition) (ICD-10) (World Health Organization, 2010). The American Association on Intellectual and Developmental Disabilities (AAIDD; formerly the AAMR) also refine and update classification criteria, based on research developments and changes in clinical practice. Diagnosis of an intellectual disability is based on the presence of an Intelligence Quotient (I.Q.) score that is below a specific level, along with impairments in adaptive functioning (Gates & Wilberforce, 2002). The DSM5 and the AAIDD both specify that age of onset of impairment should be before 18 years of age and whilst this is not explicitly stated in the ICD10, it is generally accepted to also be the case.

All three classification systems define functional impairments as indicated by scores of 70 or below on standardised psychometric assessment tools which measure cognitive functioning and adaptive behaviour. There are a wide variety of psychometric instruments for the assessment of both cognitive functioning and adaptive behaviour and selection of the most appropriate tool is determined by factors such as the age of the individual, method of communication used and level of motor or sensory impairment. Carr (2006) provides a detailed outline of these instruments and the decision making processes involved in selecting the most appropriate and relevant tool to assess the abilities of a particular individual.

Levels of intellectual disability are typically classified by scores on cognitive and adaptive behaviour assessment. There are four categories used with the boundaries of categories usually spanning a range of approximately 15 - 20 points (depending on the classification system used) to account for the possibility of measurement error on testing. The categories can be defined as follows:

Mild: I.Q. = 50-55 to 70

Moderate: I.Q. = 35-40 to 50-55

Severe: I.Q. = 20-25 to 35-40

Profound: I.Q. = below 20-25

2.2 The Prevalence of Intellectual Disability

The prevalence of intellectual disability is generally accepted to be between 1% and 3% of the population using the criteria of an Intelligence Quotient (I.Q.) score below 70 and impaired adaptive behaviour (Volkmar & Dykens, 2002). Maulik, Mascarenhas, Mathers, Dua and Saxena (2011) conducted a meta-analysis of population based studies to estimate the prevalence of intellectual disability and found a prevalence rate of 10.37/1000 population across all studies. Carr (2006) stated that figures based on epidemiological community surveys indicate that of those with an intellectual disability, about 85% of people can be classified in the mild range, 10% in the moderate range, 3-4% in the severe range and 1-2% in the profound range.

Data on the prevalence of intellectual disability in the Republic of Ireland is available from the National Intellectual Disability Database (NIDD), a database managed by the Health Research Board (HRB) on behalf of the Department of Health and Children. The database provides information on the demographic profile of people with intellectual disabilities including gender, age and level of intellectual disability. Figures from the NIDD annual report for 2013 indicate the following prevalence rates for intellectual disability:

Level of Intellectual Disability	**Prevalence**
Not Verified	2277 (8%)
Mild	9190 (33%)
Moderate	11234 (41%)

Severe	4056 (15%)
Profound	934 (3%)

Whilst these figures vary somewhat for some categories compared with those reported by Carr (2006), it is important to note that consent is required to include an individual's details on the NIDD. In addition, those with a mild intellectual disability are not always registered with intellectual disability service providers who return data to the NIDD. These factors are likely to have impacted on the figures reported.

CHAPTER 3: THE CONCEPT OF PAIN

3.1 Definitions of Pain

The International Association for the Study of Pain (IASP) define pain as "an unpleasant experience that accompanies both sensory and emotional modalities; may or may not be accompanied by identifiable tissue damage; and is influenced by multiple factors including cognitive, affective and environmental factors" (Merskey & Bogduk, 1994, p. 210). Although definitions of what constitutes "chronic" pain vary, the IASP definition of pain lasting more than 3 months is widely accepted (IASP, 1986). Pain that persists for less than this is specified as "acute". Pain diagnoses and syndromes characterized by pain episodes that alternate with pain-free periods can be defined as *recurrent acute pain* or *intermittent chronic pain*.

Awareness of the prevalence and severity of pain is such that DSM-IV-TR (the previous version of the DSM) included the category of "Pain Disorder" which was defined as "pain in one or more anatomical sites which is the predominant focus of the clinical presentation and of sufficient severity to warrant clinical attention" (APA, 2000). Although this definition has been removed from the latest version of the DSM5, many of the individuals diagnosed with this disorder meet the criteria for the newly introduced Somatic Symptom Disorder (SSD). This disorder was introduced to eliminate overlap across the somatoform disorders and to better reflect the complex interactions between mental and physical health. SSD diagnosis requires that somatic symptoms must be significantly distressing or disruptive to daily life and be accompanied by excessive thoughts, feelings or behaviours. This is consistent with the

diagnostic criteria for the previously used condition of Pain Disorder, which stated that the pain must cause clinically significant distress or impairment in social, occupational or other important areas of functioning and acknowledged the important role played by psychological factors in the onset, severity, exacerbation and maintenance of the pain. It is important to note that pain may also be a physical symptom within a system of other signs and symptoms denoting a potential psychiatric disorder, as defined in DSM-5 or other classification systems.

3.2 Prevalence of pain in the general population

Turk (2003) stated that despite advances in understanding the anatomy, physiology and biochemistry of pain and the development of innovative pharmacological and surgical interventions, pain continues to be a significant problem for many people. Breivik, Collett, Ventafridda, Cohen and Gallagher (2006) examined this premise by conducting a European study of over 46,000 people to examine the prevalence of pain in the general population. They found that 19% of adult Europeans experience moderate to severe chronic pain that seriously affects their quality of life. The prevalence of chronic pain in Ireland was found to be approximately 13%. Whilst some community epidemiological studies of chronic pain have reported prevalence rates of over 30% in the Republic of Ireland (Raftery et al., 2011; Raftery et al., 2012) and over 50% in Sweden (Gerdle, Björk, Henriksson & Bengtsson, 2004) and the United Kingdom (Elliott, Fischer & Rennie, 1999), these differences in frequency are likely to reflect differing definitions of chronic pain and differing research methods employed in the various studies.

3.3 Prevalence of pain in the intellectually disabled population

Although early research in this area suggested that individuals with an intellectual disability may be insensitive to pain (Biersdorff, 1994), it is now acknowledged that the experience of pain for these individuals is no different from that of individuals in the general population (Gilbert-MacLeod, Craig, Rocha & Mathias, 2000).

Oberlander and Symons (2006) suggested that little was known about the nature, extent or impact of chronic pain in individuals with an intellectual disability with possible reasons for this including the challenges involved in accurately assessing pain in people who often have difficulties communicating and who may display idiosyncratic or unrecognised pain behaviours (Arvio & Sillanpaa, 2003; Breau, McGrath & Zabalia, 2006). Although some research attention has focused on methods for recognising acute pain in persons with limited ability to communicate (Lotan et al. 2009) only a few studies have examined the problem of chronic pain amongst those with intellectual disabilities (Jensen, Engel, Hoffman & Schwartz, 2004; Jones, 2003; Lewis, Bell & Gillanders, 2007; McGuire, Daly & Smyth, 2010; Walsh, Morrison & McGuire, 2011)**.**

As individuals with intellectual disabilities are more likely to experience both physical disabilities and medical conditions simultaneously, it has been suggested that they may be especially predisposed to suffering from chronic pain (Bottos & Chambers, 2006). One reason for this is the increased prevalence of musculoskeletal disorders in conditions which are known to be associated with intellectual disability, such as Down Syndrome, Fragile X Syndrome and Williams Syndrome. Schwartz, Engel and Jensen

(1999) found that chronic pain is highly prevalent amongst those with Cerebral Palsy (C.P.), a condition also associated with intellectual disability. Walsh, Morrison and McGuire (2011) investigated the prevalence, impact and health service use of adults with intellectual disability who experience chronic pain and summarised a number of risk factors for chronic pain in this population, which have also been identified by other researchers. These included the probability of increased pain sensitivity (Defrin, Pick, Peretz & Carmeli, 2004), physical inactivity (Robertson et al. 2000), greater chance of unintended harm (Sherrard, Tonge & Ozanne-Smith, 2001), lower rates of participation in decision making regarding health issues (McGuire, Daly & Smyth, 2007), more co-occurring physical conditions (Baldridge & Andrasik, 2010) and reduced use of pain management supports (McGuire et al., 2010). McGuire, Daly and Smith (2010) inferred from their findings that the issue of chronic pain in those with an intellectual disability warranted greater consideration.

In an overview of pain in people with an intellectual disability, Symons, Shinde and Gilles (2008) noted that pain does not appear to be routinely considered when providing care for this population and conditions that can cause chronic pain are often not identified for pain management. This is despite the increasing body of evidence indicating that pain is a common experience amongst those with intellectual disabilities. For example, in a study of chronic pain among people with Cerebral Palsy, many of whom have some level of intellectual disability in addition to physical limitations, Schwartz et al. (1999) found that 67% of adults in their study reported having chronic pain, with 56% indicating the pain was present on a daily basis. Turk, Geremski, Rosenbaum and Weber (1997) found that 84% of an adult female sample with Cerebral Palsy self-reported problems with pain. Studies of children with

Cerebral Palsy report a similarly high prevalence of chronic pain. Houlihan, O'Donnell, Conaway and Stevenson (2004) found that pain was present daily in 11% of their sample based on parental report and the presence and frequency of pain was positively correlated with the degree of physical disability. Tervo, Symons, Stout and Novacheck (2006) also found that pain was common among children with Cerebral Palsy and led to a high level of functional interference.

De Knegt and Scherder (2010) suggested that the lack of knowledge on the experience, assessment and treatment of pain in those with intellectual disabilities is remarkable because these individuals may suffer from more painful conditions than those without disabilities. In addition, the prevalence of age-related painful conditions such as arthritis, is increasing in this population due to increases in estimated life expectancy and the neuropathology of intellectual disability is now known to affect pain-related grey and white matter, which may alter pain experience.

McGuire et al., (2010) sought to examine the nature, prevalence and impact of chronic pain in adults with an intellectual disability and the pattern of treatment and health care which they received. Using a relatively small sample, results from carers indicated that 13% of participants had chronic pain. If this finding is considered accurate and extended to the wider population of individuals with an intellectual disability, it suggests that chronic pain may be a significant health problem in this population. Despite this, the authors concluded that chronic pain may be both under-recognised and under-treated in those with an intellectual disability relative to individuals without disabilities. The authors considered 13% a surprisingly low pain

prevalence rate when compared with prevalence rates of 19% to 58% in the general population (Elliott et al., 1999; Hoffman, Meier & Council, 2002; Smith, Elliott, Hannaford, Chambers & Smith, 2004; Breivik, Collett, Ventafridda, Cohen & Gallagher, 2006) and hypothesised that this figure was an underestimate of the true prevalence of chronic pain in this population. This hypothesis was made on the basis that the subsample with a mild intellectual disability was over-represented in the pain group and chronic pain was reported between 2 and 2.5 times more frequently in people with a mild intellectual disability than in people with more severe classifications of disability. The authors proposed that this finding reflected the fact that people with a mild intellectual disability can typically verbalise and articulate their pain experience so that their carers were aware of their pain problem. A further point supporting their hypothesis was the fact that no participant with Cerebral Palsy was described as experiencing chronic pain. This seems highly unlikely given that studies suggest that between 50 and 80% of people with Cerebral Palsy experience chronic pain (Turk, Geremski, Rosenbaum & Weber, 1997; Schwartz et al., 1999; Tervo, Symons, Stout & Novacheck, 2006). McGuire et al., (2010) proposed that those less able to communicate their pain were under-represented in the reports of chronic pain provided by carers in the study. The reason for this is unclear as studies have shown that people with limited ability to communicate verbally can express discernible pain behaviours (Haden & von Baeyer, 2002) or demonstrate recognisable deviations from their usual individual activity, responsiveness, mood and behaviour patterns (Tervo et al., 2006). McGuire et al., (2010) highlighted the problem of reliability of carer report and suggested that carers may not be aware of chronic pain amongst people with an intellectual disability. They concluded that carers of individuals with intellectual disabilities may require education and assistance in identifying the presence of chronic

pain in this population. Among those with an intellectual disability, the possible lack of recognition of pain amongst carers in addition to a reliance on others for health-related decision making (McGuire et al., 2007) means that those affected by pain may not receive adequate and appropriate opportunities for pain management.

The intensity of pain and degree of functional impairment associated with it were reported to be mild for the vast majority of participants in McGuire et al.'s (2010) study. These findings were in stark contrast to those of the study of chronic pain in Europe (Breivik et al., 2006) which found that almost one-third of participants had severe pain and functional limitations, as a consequence of pain, were reported to be common. Treatment uptake among McGuire at al.'s (2010) sample was reported to be relatively low with almost half receiving no treatment at all and only two individuals receiving Physiotherapy. The use of non-prescription analgesics was the primary form of pharmacological management used. This low treatment uptake is consistent with the sample experiencing a mild degree of pain but could also be considered an underestimate by carers of the true extent of pain severity in this sample, when compared with the findings of Breivik et al., (2006).

Walsh et al., (2011) conducted the first large-scale study of prevalence, severity, impact on physical and psychological functioning and treatment of chronic pain in persons with an intellectual disability in the Republic of Ireland. Using an informant-based approach, chronic pain was shown to be a significant health issue for those with an intellectual disability with a reported prevalence rate of 15.4%. This is consistent with prevalence rates reported in other pain studies e.g. Breivik et al., (2006); McGuire

et al., (2010), and supports the notion that chronic pain appears to affect individuals with an intellectual disability to at least the same extent as it does individuals in the general population. It has previously been suggested however, that this may be an under-estimate of the extent of the issue in those with intellectual disabilities, especially amongst those who are non-verbal or have a more severe level of disability (McGuire et al., 2010). Given that individuals with severe and profound intellectual disabilities are not always able to verbally communicate their pain, their pain experience may not always be recognised and reported. Whilst the use of proxy respondents can be beneficial in gathering information about the pain experience of those with significant intellectual disabilities and communication challenges, this method presents its own challenges such as the issue of reliability of carer report. This may actually underestimate the presence of pain. It is vital that caregivers are vigilant to the changes in behaviour that may reflect the onset of pain and that they are prepared to advocate on the individuals behalf for appropriate pain management. Other reliable and valid alternatives for recognizing and quantifying pain in people with an intellectual disability include structured behavioural observation and the use of more than one source of information, both of which increase the reliability of the information obtained (McGuire & Kennedy, 2013).

Walsh et al., (2011) found that those with chronic pain were reported to have experienced pain for an average of 6.3 years. Approximately 33% of individuals also experienced moderate to severe pain-related functional limitations and 25% had significantly reduced quality of life including reduced capacity for an independent lifestyle. Consistent with previous research, more females than males were reported to experience chronic pain and the majority of individuals who experienced pain

experienced a relatively mild degree of pain. The variables of age, communication skills and level of intellectual disability were not found to be associated with the presence of pain. The presence of pain was found to be associated with Cerebral Palsy, physical disability and reports of challenging behaviour. Many of the consequences of chronic pain reported in the general population were also found in this study. For example, a significant proportion of individuals with chronic pain also experienced limitations in several aspects of daily living and more than 78% of caregivers reported that the individual whom they cared for had become upset or distressed by pain. More than 80% of service users in the study were receiving some form of treatment for their pain with the primary form of pain management being medical management by a G.P. and the use of analgesics. Over 50% of individuals did not play a role in the decision-making process regarding treatment choice or when to take medication.

Previous studies have highlighted the impact of chronic pain on psychological health yet the percentage in Walsh et al.'s (2011) study who were reported to experience depression stemming from pain was less than the rate obtained in many other studies of the general population (Becker at al., 1997; Breivik et al., 2006). Caregivers also showed a lack of awareness of suicidal ideation amongst this population. These results suggest either that mental health problems as a result of pain may be less prevalent in persons with intellectual disabilities or that these problems may be under-recognised by carers for these individuals. If this is the case, it suggests a specific training need for caregivers and the need for greater attention to the accurate assessment of pain and its impact on mental health amongst those with intellectual disabilities. This stems from the finding by Tang and Crane (2006) that suicide risk is actually significantly higher amongst the general population with long-term pain.

As is evident from the studies outlined above, the experience of pain in those with an intellectual disability is likely to be as prevalent as it is amongst the general population, if not greater. These studies did not use multiple informants or structured behavioural observation which may explain the lower than expected prevalence rates for those with intellectual disabilities, despite the higher levels of co-occurring physical and musculoskeletal conditions associated with pain, in this population.

3.4 Theories and Models of Pain

3.4.1 Single Factor Models

Early theories of pain proposed single factor models to explain the concept. These models explained pain in terms of a particular cause. Examples included the biomedical model, the psychogenic model, the motivational model and behavioural models.

The biomedical model assumed that pain was related to a specific physical cause which if identified and treated, would eliminate pain. Kroenke and Mangelsdorff (1989) estimated that between 33% and 50% of all visits to G.P.'s are prompted by symptoms for which no biomedical causes can be found. This suggests that the biomedical model is insufficient to describe chronic pain. The psychogenic model of pain focuses on identifying the psychopathological tendencies or personality factors that instigate and maintain reported pain. Studies suggest that the emotional distress observed in those with chronic pain usually occurs in response to the persistence of pain and not as a causal agent of the pain (Okifuji, Turk & Sherman, 2000). It has been suggested that this emotional distress may resolve once pain is adequately treated

(Wallis, Lord & Bogduk, 1997). If this is the case, it casts doubt on this theoretical perspective.

The motivational model of pain suggests that reports of pain in the absence of, or in excess of physical pathology, are attributed to the individual's desire to obtain some benefit or secondary gain from their reported pain. Attention, time off from undesirable activities and financial compensation have been proposed as examples of such secondary gains. Mendelson (1982) reported little evidence of dramatic cure of pain following denial of disability payments thus rejecting support for this model. Behavioural models of pain describe the manner in which the main principles of learning – classical conditioning, operant conditioning and social learning – explain both the adaptive and dysfunctional behaviours associated with pain. Vlaeyen and Linton (2000) proposed a fear-avoidance model of pain to explain how emotional distress, physical limitations and disability develop from repeated avoidant behaviour motivated by fear of pain. This model has been further refined and developed in recent years and continues to be the subject of considerable research (Leeuw et al., 2007; Vlaeyen & Linton, 2012).

3.4.2 Multidimensional Models

Multidimensional models of pain began to emerge in the 1960's and attempted to explain the concept of pain by incorporating both the physical and psychological factors which influence an individual's experience of pain.

The Gate Control Theory of pain (GCT) (Melzack & Wall, 1965) proposed that three separate systems were involved in the processing of nociceptive stimulation, that these systems interacted with one another and contributed to the subjective experience of pain. These systems were identified as sensory-discriminative, motivational-affective and cognitive-evaluative. The model also emphasized the role of central nervous system activity in the experience of pain and provided a physiological basis for the role of psychological factors. Despite subsequent debate regarding some of the tenets of the model, the gate control theory marked a seminal development within the field of pain research as it explained the roles played by psychological processes such as cognitive state, appraisal, context and cultural values, in the experience of pain. This model laid the foundations for the development of subsequent multi-dimensional models such as the neuromatrix theory and the biopsychosocial conceptualisation of pain.

The Neuromatrix theory of pain (Melzack, Coderre, Katz & Vaccarino, 2001) represents an enhanced version of the Gate Control Theory and proposes that pain is a multidimensional experience produced by characteristic "neurosignature" patterns of nerve impulses generated by a widely distributed neural network - the "body-self neuromatrix"- in the brain. These neurosignature patterns may be triggered by sensory inputs, but they may also be generated independently of them. The neuromatrix theory of pain proposes that the output patterns of the body-self neuromatrix activate perceptual, homeostatic and behavioral programmes after injury, pathology, or chronic stress. According to this theory, pain is produced by the output of a widely distributed neural network in the brain rather than directly by sensory input evoked by injury, inflammation, or other pathology. The neuromatrix, which is genetically determined

and modified by sensory experience, is the primary mechanism that generates the neural pattern that produces pain. Its' output pattern is determined by multiple influences that converge on the neuromatrix, of which the somatic sensory input is only one part.

Modern conceptualisations of pain recognise that it is a complex multidimensional and biopsychosocial phenomenon and propose a model within which psychological factors can be understood and psychological interventions for pain have developed. The biopsychosocial model focuses primarily on the psychological and cognitive-behavioural elements of pain and views illness as a reciprocal interaction between biological, psychological and socio-cultural variables that shape the person's response to pain (Turk, 1996; Turk & Flor, 1999). This biopsychosocial model of pain assumes the existence of some form of physical change or pathology in the individual's muscles, joints or nerves which generates nociceptive input to the brain. Nociceptive fibres transmit sensations which may or may not be interpreted as pain. These sensations are not classified as pain until they undergo higher order psychological and mental processing that involves perception, appraisal and behaviour. Perception involves the interpretation of nociceptive input and identifies the type of pain. Meaning is then attributed to the pain and this influences the subsequent behaviour of the individual. This biopsychosocial model has been instrumental in the development of assessment and intervention strategies for chronic pain including cognitive-behavioural treatment approaches. These cognitive and affective factors associated with chronic pain provide the theoretical basis or framework for a cognitive-behavioural therapy approach to pain management.

CHAPTER 4: ASSESSMENT OF PAIN

4.1 Assessment of Pain

Completing a comprehensive history and physical examination is the first step in understanding and appropriately assessing and treating an individual whose primary symptom is pain. Because there is no 'pain thermometer' that can provide an objective quantification of the amount or severity of pain experienced by an individual, this can only be assessed indirectly, based on overt verbal and behavioural communication. However, even the availability of this information makes pain assessment difficult as pain is a complex subjective experience. It is comprised of a range of factors and is experienced in a unique manner by each individual.

Based on the multidimensional perspective, an adequate pain assessment needs to check not only for the physical source of the pain but also requires evaluation of the numerous psychosocial and behavioural factors that influence the subjective report and experience of pain. These include affective factors such as the individual's mood and fears, as well as cognitive factors such as their attitudes and beliefs, their coping efforts and resources, their expectations, thinking style, the responses of significant others and the impact of pain on their life. This evaluation process can be helpful in identifying how biomedical, psychosocial and behavioural factors interact to influence the nature, severity and persistence of pain.

In addition to interviews, a number of pain assessment instruments have been developed to evaluate these psychosocial and behavioural factors associated with pain. Standardized instruments have advantages over semi-structured and unstructured interviews as they are easy to administer, require less time, assess a wide range of behaviours and obtain information about behaviours that may be private or unobservable. In addition, they can be submitted to statistical analyses of their reliability and validity. Because variability in outcome measures across clinical trials hinders the evaluation of treatments, the Initiative on Methods, Measurement and Pain Assessment in Clinical Trials (IMMPACT) recommended that six core outcome domains should be considered when designing chronic pain clinical trials. These were defined as (1) pain intensity (2) physical functioning (3) emotional functioning (4) participant ratings of improvement and satisfaction with treatment (5) symptoms and adverse events and (6) participant disposition (Turk et al. 2006).

Studies on the affective and cognitive components of chronic pain have highlighted the reciprocal relationships which may impact on the experience of pain, the distress associated with it and the broader impact which pain may have on a person's life. These studies have identified several key directions for psychological interventions for chronic pain in the general population, but not as much direction, in the intellectually disabled population. In line with the IMMPACT guidelines, assessment of these variables is recommended prior to any intervention, and they are described here.

4.2. Assessment of pain intensity

Individuals display a broad range of pain behaviours that communicate to others that they are experiencing pain, distress and suffering. Some of these may be controllable by the person whereas others are not. Although there is no direct relationship between these pain behaviours and self-report of pain, they are at least modestly correlated.

A number of different observational procedures have been developed to quantify pain behaviours. Several investigators using the Pain Behaviour Checklist (e.g. Turk, Wack & Kerns, 1985) have found a significant association between these self-reports and behavioural observations. These scales can also be used by non-professionals such as family members. Healthcare providers can use observational methods to systematically quantify various pain behaviours and note the factors that increase or decrease them. Uses of the healthcare system and analgesic medication are other ways to assess pain behaviours e.g. clients can record the number of times they take medication over a specified interval. Diaries not only provide information about the frequency and quantity of medication usage but may also permit identification of the antecedent and consequent events associated with its use.

Behavioural measures of pain, including facial expression, can offer rich information about pain coping. However, behaviour is a broad category and there are good arguments for distinguishing behaviours with little or incomplete voluntary control, such as facial expression, from those resulting more from conscious decisions e.g. seeking help, taking analgesics or taking time off from work (Williams, 2003). Measures of pain behaviour are not without criticism, however, and issues have been

identified with their use in certain populations. For example, when using scales which include the observation of pain, one should realise that typical facial expressions shown spontaneously by some individuals with an intellectual disability might be confused with facial expressions of pain. Moreover, the level of intellectual disability of an individual can also affect pain behaviour. Dubois, Capdevila, Bringuier and Pry (2010) reported that nonverbal children who experience pain have more individualised and less generally recognised ways of communicating their pain. Non-verbal communication methods are more commonly used by those with a severe/profound intellectual disability.

Individuals close to the person who is experiencing pain may also be asked for their estimates and opinions on the effect of pain on function and quality of life, both for the individual, and for themselves (Walsh et al., 2011). It is important to recognize that a proxy respondent gives not an objective account but an alternative subjective account of the presence of pain. This is particularly relevant in assessing pain in those with intellectual disabilities as these individuals do not always have the verbal skills to be able to communicate their pain. Carer reports, whilst useful, have certain limitations and may actually underestimate the presence of pain (McGuire et al., 2010).

Self-report measures of pain often ask clients to quantify their pain by providing a single, general rating of pain: “Is your usual level of pain “Mild”, “Moderate” or “Severe”?” More accurate or specific information may be obtained by asking about current level of pain or pain over a defined period of time and by having clients

maintain regular diaries of pain intensity, with ratings recorded several times each day for several days or weeks. Jensen and Karoly (2001) recommend that an average of multiple recordings should be used whenever possible in preference to a single retrospective rating of average pain. Mean pain levels obscure systematic and potentially important differences between, for instance, pain at rest and during activities that may provoke pain, and so specifically sampling these activities can be informative. Retrospective ratings of pain differ from averaged diary ratings (Peters et al., 2000) and retrospective ratings of change are distinct from the difference between pre- and post-treatment pain ratings (Fischer et al., 1999).

A number of simple methods can be used to evaluate current pain intensity – numerical scales, descriptive rating scales and/or visual analogue scales. The visual analogue scale (VAS) (McGrath et al., 1996) remains one of the most popular measures despite the slightly superior reliability and greater practicality of the numerical rating scale (NRS) (Turk & Okifuji, 2003). It is particularly useful and commonly used with individuals with an intellectual disability.

LaChapelle, Hadjistavropoulos and Craig (1999) found that 65% of adults with an intellectual disability receiving intramuscular injections were able to report pain using a coloured visual analogue scale. When using visual analogue pain scales, however, it is important to take any visual impairments of the population into account (Evenhuis, Sjoukes, Koot & Kooijman, 2009).

Another commonly used general rating scale for pain is the McGill Pain Questionnaire (Melzack & Torgerson, 1971). Users select words from a series of lists, which best describe the quality and intensity of their pain experience. As is evident from the tools outlined above, methods for assessing pain intensity in those with intellectual disabilities has received some degree of research attention. However, these tools are somewhat dated and there has been little recent research attention to developing these tools further or creating new measures.

4.3 Assessment of physical functioning

Poor reliability and questionable validity of physical examination measures has led to the development of self-report measures that seek to quantify symptoms, function and behaviour directly, rather than inferring them. Self-report measures have been developed to assess peoples' reports of their ability to engage in a range of functional activities in the context of pain. An example of such a scale is the Brief Pain Inventory – Short Form (Cleeland & Ryan, 1994).

4.4 Assessment of emotional functioning

A number of measures have been developed for use specifically to measure coping in individuals who experience chronic pain. Instruments have been developed to assess psychological distress, the impact of pain on a person's life, feelings of control, coping behaviours and attitudes about pain (Turk & Melzack, 1992; 2001). These measures can be used to assess some of the core outcome domains recommended for consideration in the IMMPACT guidelines on designing chronic pain clinical trials (Turk et al., 2006).

Self-regulation of pain and its effects depends on the person's specific ways of dealing with pain, adjusting to pain and reducing or minimising pain and distress caused by pain i.e. their coping strategies (DeGood & Tait, 2001). Coping strategies act to alter both the perception of the intensity of pain and an individual's ability to manage or tolerate pain and to continue with everyday activities. Coping strategies can be assessed by both overt and covert behaviours. Overt behavioural coping strategies include rest, medication and use of relaxation techniques. Covert coping strategies include various means of distracting oneself from pain, reassuring oneself that the pain will diminish, seeking information and problem solving.

Studies have found active coping strategies (efforts to function in spite of pain or to distract oneself from pain) to be associated with adaptive functioning and passive coping strategies (depending on others for help with pain management, restricting activities, avoiding activities because of fear of pain/injury, self-medication, alcohol) to be related to greater pain and depression (Boothby, Thorn, Stroud & Jensen, 1999). Beyond this, there is no evidence supporting the greater effectiveness of any one active coping strategy compared to any other. It seems more likely that different strategies will be more effective for some people at some times but not necessarily for all people, all of the time. Regardless of the type of coping strategy, if clients are instructed in the use of adaptive coping strategies, their rating of intensity of pain decreases and tolerance of pain increases (Boothby et al., 1999). Coping with pain can also be classified into cognitive or behavioural techniques, as well as in terms of active or passive styles (Snow-Turek, Norris & Tan, 1996). Active coping involves using cognitive or problem-solving techniques to relieve or control pain. Passive coping generally involves avoiding activity and praying/hoping or relying on others to reduce

pain. Taking pain medication is often thought to be a passive coping strategy, particularly for chronic pain management (Gustafsson, Gaston-Johansson, Aschenbrenner & Merboth, 1999) and active coping is typically considered more adaptive than passive coping (Brown & Nicassio, 1987).

The Pain Coping Strategies Questionnaire (Rosenstiel & Keefe, 1983) is an example of one such questionnaire used to assess emotional functioning. It is predominantly composed of a list of coping responses that a person might use when they are experiencing pain and respondents are asked to indicate the extent to which they use each strategy. The subscales on this measure are diverting attention, reinterpreting the pain sensation, catastrophizing, ignoring sensations, praying or hoping, coping self-statements and increased behavioural activities. It is a useful scale in identifying individual coping strategies for pain, particularly catastrophizing.

Catastrophizing is the experience of negative thoughts about one's plight and interpreting even minor problems as major catastrophes. It appears to be a powerful way of thinking that greatly influences pain perception and associated disability and can contribute to the maintenance and exacerbation of pain (Turk & Rudy, 1986). It is generally thought to be predictive of poor pain coping. Research has indicated that catastrophizing and adaptive coping strategies are important in determining one's adjustment to pain and should be targeted in treatment intervention plans (Sullivan et al., 2001). Studies of both acute and chronic pain have found that people who spontaneously used more catastrophizing thoughts reported more pain than those who did not catastrophize. Goubert, Eccleston, Vervoort, Jordan and Crombez (2006)

found that parents' catastrophic thinking about their child's pain had a significant contribution in explaining the child's disability and school attendance.

4.5 Assessment of symptoms and adverse events

A significant amount of research has been directed toward identifying cognitive factors that contribute to pain. These studies have consistently demonstrated that the individual's coping resources as well as their attitudes and beliefs and their thinking style affect reports of pain, activity levels, disability and response to treatment. Studies have shown that clients who attribute their pain to a worsening of their underlying disease experience more pain despite comparable levels of disease progression (Spiegel & Bloom, 1983). Because behaviour and emotions are influenced by interpretations of events (rather than solely by objective characteristics of the event itself), when pain is interpreted as signifying ongoing tissue damage or a progressive disease, it is likely to produce considerably more suffering and behavioural dysfunction than if it is viewed as being the result of a stable problem that is expected to improve. Beliefs about the meaning of pain and one's ability to function despite discomfort are important aspects of expectations about pain. Once beliefs and expectations are formed, they tend to become stable and rigid and become difficult to modify. Pain sufferers tend to avoid experiences that could discredit their beliefs, even in situations where these beliefs are no longer valid. It is therefore important for people in pain to develop adaptive beliefs about the relationships between impairment, pain, suffering and disability. The reason for this is that results from numerous treatment outcome studies have shown that changes in pain level do not parallel changes in other

variables of interest including activity level, medication use, return to work, rated ability to cope with pain and pursuit of further treatment (Turk, 2002a).

4.6 Assessment of participant disposition

Self-efficacy is a personal expectation or conviction that one can successfully perform required behaviours to produce a desired outcome in a given situation (Bandura, 1977). Given sufficient motivation to engage in a behaviour, it is a person's self-efficacy beliefs that determine the choice of activities that he or she will initiate, the amount of effort that will be expended and how long the individual will persist in the face of obstacles and aversive experiences. In this way, self-efficacy plays an important role in the therapeutic change process and has implications for implementation of pain management strategies in effecting change.

The affective components of pain can include numerous emotions which are primarily negative in orientation e.g. depression, anxiety, fear and anger. It is important to be aware of the significant role of negative mood in those who experience pain because it is likely to affect treatment motivation and adherence to treatment recommendations. For example, participants who are depressed and who feel helpless may have little initiative to comply with treatment recommendations. Likewise, those who are anxious may fear engaging in what they perceive as demanding activities.

CHAPTER 5: METHODOLOGICAL ISSUES IN THE ASSESSMENT OF PAIN IN PEOPLE WITH AN INTELLECTUAL DISABILITY

5.1 Challenges and approaches to assessment

Until relatively recently, people with intellectual disabilities were rarely included in health research. Much of the research attention in this area has focused on carers as they play such a major role and influence on the health of individuals with intellectual disability and on the uptake of medical services (McGuire et al., 2007; Melville, 2005; Northway, Sardi, Mansell & Jenkins, 2006). The need to obtain the views of people with an intellectual disability has, however, become increasingly recognised. This trend has been informed by a philosophical change, in the last 20 years, towards empowering people with intellectual disabilities to make decisions about their lives and, by service user consultation (Finlay & Lyons, 2001). This is particularly important in the area of health if information is to be obtained on areas with inherent subjective and attitudinal components, such as the issue of pain.

Blyth and Lee (2011) reported that there are inherent challenges in conducting epidemiological studies in community settings with "difficult to sample" populations i.e. populations that are difficult to identify, find or interview. Typically, greater effort, less common sampling methods and therefore more resources are needed than is the case in conducting general population surveys. Conducting research with individuals with an intellectual disability is an example of this. Another issue relates to the difficulties associated with obtaining a large homogenous sample of participants with similar presenting problems, for the purposes of intervention research (Zhan &

Ottenbacher, 2001). For this reason, many researchers have used single case designs when evaluating interventions among people with intellectual disabilities and in studies of cognitive behaviour therapy and pain e.g. Glover, Shafran, Brown and Fairburn (2006).

One of the primary factors in the accurate identification of pain is the ability to communicate about pain to others. The definition of pain from the International Association for the Study of Pain (IASP) recognises that the inability to communicate verbally does not rule out the possibility that an individual is experiencing pain and is in need of appropriate pain-relieving treatment (Merskey & Bogduk, 2004). However, as there is no 'objective' measure of pain, clinicians and researchers usually rely on verbal self-report from the person affected by pain. In populations for whom the ability to communicate is impaired, verbal self-report may not be possible and alternative sources of information must be used. Individuals with an intellectual disability are one such example as they have cognitive and communication impairments that may make self-report difficult or unreliable (Hadjistavropoulos, von Baeyer & Craig, 2001; Bottos & Chambers, 2006). Several alternative communication systems have been developed including systems based on behavioural cues or facial expression (see Symons et al., (2008), for a review). Although such observational systems only point to a change in status of the person that suggests that distress is present and the observer must infer the cause of the distress (such as pain), there is growing evidence that such systems are reliable and valid and may even be sensitive to magnitude of pain (Symons et al., 2008). Several researchers have also used third-party reports (usually from carers) to gather data about pain and other aspects of health in people with an intellectual disability (Fanurik et al., 1999; Tervo et al., 2006; Breau, Camfield,

McGrath & Finley, 2007; McGuire et al., 2007). Because of their intimate knowledge of the person with an intellectual disability, carers are an important source of information on the experience of pain (Bottos & Chambers, 2006). To varying degrees, many people with an intellectual disability are also dependent on their carers for making the decision to access health services and for ongoing management of their health care needs (McGuire et al., 2007). As these important health management decisions frequently rest with carers, it is of great importance to investigate the carers' perceptions, views and understanding of the service users' chronic pain.

Historically, the self-reports of pain by people with learning disabilities have been considered to have only limited use (Balla & Zigler, 1979) because of the greater likelihood that factors such as social desirability (including acquiescence and dependency), memory problems, recency effects, anxiety and incomprehension threaten their validity. Any self-report measure is open to such criticisms (Anastasi, 1982) but researchers such as Sigelman, Budd, Winer, Schoenrock and Martin, (1982) found a significant correlation between levels of acquiescence and intelligence. It has been shown, however, that such pronounced effects can be overcome by applying a number of minor modifications in the construction of self-report materials for people with learning disabilities. For example, the use of pictorial materials instead of (or in addition to) auditory presentation of the assessment items can be used to aid understanding and memory (Kabzems, 1985). Open-ended, rather than closed (yes/no), questions can avoid acquiescence (Sigelman et al., 1982) and inserting a probe after each assessment item in order to elicit examples or further detail from the participant will establish whether the item has been understood and answered in a valid way.

Benson and Ivins (1992) concluded that people with learning disabilities can self-report on emotional states such as anger and depression when slightly modified questionnaires are used. Lindsey, Michie, Baty, Smith and Miller, (1994) presented people with mild and moderate learning disabilities with a battery of independent (but related) self-report measures and found a high degree of convergent validity in the responses, indicating a stable and reliable cognitive system related to emotion.

Even limited verbal communication with persons with intellectual disabilities, such as giving instructions for the use of visual analogue pain scales, requires a special conversation style. Open-ended questions and simple language should be used. To check whether the person understands the question, rephrasing the question by changing the sequence of words should lead to the same answer. The reason for this is that those with an intellectual disability tend to answer "yes" to every closed question and to repeat the final option in questions with multiple answers (Sigelman et al., 1982).

With regard to modifications to treatment approaches when working with this population, whilst Cognitive Behaviour Therapy (CBT) has been used successfully with people with an intellectual disability, this has been with individuals with a mild or moderate intellectual disability who are capable of understanding spoken language. In addition, a range of adaptations may be required. For example, simplification of language and intervention frameworks, the use of flexible methods and activities (non-verbal tools, pictures and drawings) and the inclusion of carers (Taylor, Novaco, Gillmer & Thorne, 2002; Whitehouse, Tudway, Look & Stenfert-Kroese, 2006).

From the studies outlined above, it would be fair to conclude that while there are certainly methodological challenges in assessing the experience of pain in individuals with intellectual disabilities, researchers are increasingly aware of these issues and adaptations and modifications to assessment and treatment approaches are becoming more common place.

CHAPTER 6: TREATMENT FOR PAIN

6.1 Overview of the Cognitive-Behavioural perspective

The Cognitive-Behavioural model incorporates psychological variables such as anticipation, avoidance and contingencies of reinforcement but suggests that cognitive factors rather than conditioning factors are of critical importance. This approach suggests that behaviours and emotions are influenced by interpretations of events and emphasis is placed on how people's attitudes and beliefs are influenced by physical, cognitive, affective and behavioural factors. It suggests that conditioned reactions are largely self-activated on the basis of learned expectations rather than automatically produced.

6.2 Components of a Cognitive-Behavioural therapy (CBT) approach to treatment

A cognitive-behavioural approach to treatment involves the use of a variety of cognitive, behavioural and environmental intervention strategies. Firstly, the client is assisted to redefine or 'reimagine' his or her problem within a framework which makes it open to change. Next, the individual is supported to develop skills which promote emotional, cognitive and behavioural change. The CBT approach then focuses on strengthening and generalizing these skills to support the maintenance of changes made.

One of the key principles of the CBT approach is facilitating the client to redefine his or her problem in a way that makes it amenable to change. Such an approach enables the client to consider an alternative perspective and a more solution-focused approach to treatment can then be applied to the problem. Cognitive restructuring is a technique used to develop awareness of how thoughts and emotions maintain problems. Clients are taught to identify their negative automatic thoughts, seek evidence for and challenge these thoughts and, replace these thoughts with positive coping statements.

Strategies such as training in deep breathing and progressive muscular relaxation as well as distraction techniques and problem solving, are used to support clients to change their thoughts, feelings and behaviour. Techniques such as in-session role-play and homework assignments are used to strengthen the skills taught during treatment sessions with a view to bringing about long-term behavioural and cognitive change.

Relapse prevention is a key element of the CBT approach. If treatment is to be successful in the long-term, clients need to be able to cope with setbacks on their own, once treatment has been completed. By addressing this issue in treatment, clients are made aware that setbacks can and do happen and are prepared to cope with them, if and when they occur. Clients are also taught problem-solving skills to support them to feel competent to deal with any issues which arise for them after treatment.

6.3 Uses and Effectiveness of Cognitive-Behaviour Therapy in the general population

Cognitive-behaviour therapy (CBT) has been recommended for the treatment of a range of conditions including anxiety and depression (Twomey, O'Reilly and Byrne, 2015), anger management (Sammut Henwood, Chou & Browne, 2015), insomnia (Taylor and Pruiksma, 2014), eating disorders (Vanderlinden, Adriaensen, Vancampfort, Pieters, Probst and Vansteelandt, 2012) and Post-Traumatic Stress Disorder (PTSD) (Wu, Li and Cho, 2014). CBT has also been used in the treatment of a range chronic medical conditions including cancer, diabetes, cardiac problems and chronic pain. White (2001), provided a comprehensive guide to the assessment and treatment issues which can arise during such treatment. Hofmann, Asnaani, Vonk, Sawyer and Fang (2012) conducted a review of 106 meta-analyses examining the efficacy of cognitive-behavioural therapy for a range of issues. They concluded that there is a strong evidence base for this treatment approach, particularly in the treatment of anxiety disorders, somatoform disorders, bulimia, anger control problems and general stress.

6.4 Cognitive-Behaviour Therapy with individuals with an Intellectual Disability

There has been some speculation as to the merits of the different components of the CBT approach, with individuals with intellectual disabilities. McGillivray and Kershaw (2015) explored this issue by comparing cognitive, behavioural and combined cognitive-behavioural strategies on depressed mood in individuals with intellectual disabilities. The findings supported the use of group based cognitive-behavioural interventions with this population and indicated the possible short-term

impact of behavioural strategies when compared with cognitive strategies and their potential for long-term effect.

A number of authors have described the use of modified CBT in the treatment of people with an intellectual disability. For example, CBT has been used successfully to treat depression (McCabe, Gillivray & Newton, 2006); anxiety (Lindsey, Neilson & Lawrensen, 1997) and anger problems in people with an intellectual disability (Willner, Jones, Tam & Green, 2002). In a recent overview of CBT for people with an intellectual disability, Jahoda, Dagnan, Stenfert-Kroese, Pert and Trower (2009) outline the potential use of this approach but also urge that further research is required. They suggested the inclusion of care providers as a means of tackling change at a broader social level and also the use of case series work to assist with evaluation of treatment in the context of limited opportunities for RCT's. Vereenooghe and Langdon (2013) conducted a systematic review and meta-analysis of psychological therapies for individuals with intellectual disabilities and found that CBT was efficacious for both anger and depression. Willner et al., (2013) evaluated the effectiveness of a group based CBT intervention for anger management delivered by care staff, to individuals with intellectual disabilities. They demonstrated that the intervention was effective in improving anger management in this population and that care staff could be trained and supervised to deliver such programmes, with reasonable fidelity to the treatment protocol. Taggart et al. (2015) developed a study protocol for a structured education programme for the self-management of type 2 diabetes in adults with intellectual disabilities. The rationale for such an approach was to improve psychological well-being, quality of life and promote a healthier lifestyle amongst this population, given the significant implications of this condition.

When conducting CBT with people who have an intellectual disability, certain adaptations are essential that take account of the constraints entailed by intellectual disability. Dagnan and Lindsey (2004) recommended the particular importance of planning the structure of therapy sessions. Beck (1995) identified a number of key components important for cognitive therapy including agenda setting, teaching the cognitive model, socializing clients into the cognitive model, identifying problems, setting goals, setting homework, obtaining feedback, providing a summary and reviewing sessions. Lindsey, Neilson and Lawrenson's (1997) followed this standard cognitive therapy structure in their successful approach to helping people with intellectual disabilities cope with anxiety and depression. Whilst the research studies referenced above support the organization of session structure according to identified principles, the flexibility necessary in using a CBT approach with people with intellectual disabilities was still achieved. This was addressed via other aspects of the therapy process such as the location, frequency and duration of sessions.

As we know, CBT relies heavily on understanding the interplay between thoughts, behaviours, actions and the body and this is primarily communicated in the therapeutic environment using spoken language. Participation in a CBT based pain management programme therefore necessitates a certain degree of proficiency both in terms of expressive and receptive language skills. As language is known to be a barrier to both pain assessment and pain reporting for some individuals with intellectual disabilities, it stands to reason that it may also be a barrier to participation in CBT approaches to pain management for this population. Whilst there is considerable research evidence supporting the use of a CBT approach with people with intellectual disabilities, the scope for the use of this approach is limited to a degree by an individuals means of

communication. Other limitations on the use of this approach with this population include the proficiency of the therapist in using alternative communication systems, if required, as well as their flexibility in adapting a CBT programme to meet the needs of participants. As is evident from the literature, CBT with those with intellectual disabilities lends itself more easily to use with individuals with a mild or moderate degree of intellectual disability. It is reasonable to conclude that CBT is not appropriate for use with those with a severe or profound intellectual and alternative assessment and treatment approaches are warranted for these individuals.

6.5 Cognitive-Behaviour Therapy for Pain Management

Several research studies have evaluated the effectiveness of behavioural and cognitive behavioural interventions for chronic pain. Cognitive-behavioural treatment protocols are effective for disease-related pain conditions such as arthritis (Keefe et al. 2002), cancer (Syrjala et al. 1995) and sickle cell disease (Gil, Abrams, Phillips & Keefe, 1989) as well as for non-malignant chronic pain conditions such as low back pain (Morley, Eccleston & Williams, 1999), tension headache and migraine headache (Compas et al. 1998). In studies of CBT for chronic pain in adolescents, pain intensity has traditionally been the most frequently assessed treatment outcome variable. Zagustin (2013) argued that emphasis should also be on measuring functional outcomes based on 'disability, quality of life, role functioning, and regular activity participation' (p.703).

Morley, Eccleston and Williams (1999) described the cognitive-behavioural perspective as the most generally accepted model for use in the psychological

treatment of individuals who experience chronic pain. Ostelo et al., (2007) reviewed behavioural treatment and cognitive behavioural treatments for chronic pain associated with low-back pain while Eccleston, Williams & Morley (2009) examined the results of several studies of psychological treatments for chronic pain. This study found that CBT has the strongest evidence base in the context of psychological interventions for chronic pain, resulting in improvements in functioning and psychological well-being. The goal of CBT is not to reduce pain per se, but to enhance the patient's adaptive coping and to resume a more productive, enjoyable life despite pain (Turk, 2003). In a study of pain-coping strategies in children with juvenile idiopathic arthritis, Thastum, Herlin, and Zachariae (2005) demonstrated that active coping strategies such as distraction, cognitive self-instruction and problem solving are considered optimal and may be the most helpful in the management of pain. Such strategies fall within the realm of CBT interventions.

Given the findings outlined above it is unsurprising that the British Pain Society's (2013) published guidelines for pain management programmes for adults state that pain management programmes "…based on cognitive behavioural principles have been identified as the treatment of choice for people with persistent pain which adversely affects their quality of life" (p.8). The guidelines state that there is good evidence for efficacy of cognitive behavioural pain management programmes as a package, in improving pain experience, mood, coping, negative outlook on pain and activity levels (Morley et al., 1999; Guzmán et al., 2001; Hoffman et al., 2007; Williams, Eccleston & Morley, 2012).

6.6 Cognitive-Behaviour Therapy for pain management in individuals with an Intellectual Disability

As outlined previously, a number of authors have described the use of modified CBT in the treatment of people with an intellectual disability e.g. McCabe et al., 2006; Lindsey et al., 1997 and Willner et al., 2002. CBT has also been successfully used to manage chronic pain both in the general population and with individuals with intellectual disabilities (McManus and McGuire, 2014; Lindsay et al. 1997). Review of the literature in this area suggests that this is a relatively recent area of focused attention as there has been limited research to date, on the use of cognitive behaviour therapy for pain management in those with intellectual disabilities.

Jahoda et al. (2009) in an overview of CBT for people with an intellectual disability outlines the potential utility of the approach and suggested the inclusion of carer's as a means of tackling change at a broader social level, as well as the use of case series studies to assist with the evaluation of treatment in the context of limited opportunities for randomised controlled trials with this population. McManus and McGuire (2014) examined the feasibility of CBT for pain management in a case series of individuals with intellectual disability. Results indicated that scores on pain management knowledge, wellness-focused coping and effectiveness of coping increased following the intervention, although these gains were not maintained at the follow-up measurement point. Using a case study approach, Lewis, Bell and Gillanders (2007) described a cognitive behavioural approach to managing pain in a woman with an intellectual disability and reported improvements in the level of pain intensity she

reported, the range of activities she took part in and her reported levels of depression and anxiety.

Consistent with issues regarding the assessment of individuals with intellectual disability, research on the use of CBT with this population suggests that many of the existing cognitive-behaviour techniques will need to be modified if they are to prove of optimum benefit for people with learning disabilities. From a theoretical perspective, there should be little difficulty in achieving this end as there is no gold standard which defines "pure" cognitive-behaviour therapy and no single accepted definition of exactly what constitutes cognitive-behaviour therapy (Williams, 1992).

Adaptations to cognitive procedures are actually quite common and much helpful guidance already exists. Scott (1992) discussed the changes in cognitive therapy techniques needed when working with people with chronic depression, suggesting that while the characteristically structured nature of this approach may help this group, creativity and flexibility on the part of the therapist are also necessary. Fowler, Garety and Kuipers (1995) suggested a number of adaptations to cognitive-behaviour therapy needed when working with people with psychosis, and Kendall and Braswell (1985) discussed changes relevant to work with impulsive children. It seems that not only is there a long tradition of adapting cognitive-behavioural interventions, but many of these suggestions are also appropriate in working with people with intellectual disabilities. Typical suggestions involve having shorter sessions and abandoning rigid agendas (Scott, 1992), breaking complex emotional information into simple and clear

components (Kendall & Braswell, 1985) and carefully controlling the induction of high emotional arousal (Fowler, Garety & Kuipers, 1995).

CHAPTER 7: MENSTRUAL PAIN

7.1 Definitions of menstrual pain

Premenstrual Syndrome or Premenstrual Stress (PMS) refers to a consistent pattern of emotional and physical symptoms occurring only before the onset of a menstrual period, that are of sufficient degree to restrict or hinder some aspects of everyday life (Dickerson, Mazyck and Hunter, 2003). These symptoms can include cramps/pain tiredness, irritability or moodiness, nausea, headache, lower back pain, vomiting, fainting, diarrhoea, weakness, leg pain, constipation, disorientation and hypersensitivity to light, sound, smell and touch.

In seeking to classify the nature of menstrual pain, Walsh, LeBlanc & McGrath (2003) described it as a unique sort of pain. It is not usually described as acute because for most women, it occurs on a regular but infrequent basis and it is not an isolated painful incident. It is not usually described as chronic either, because for most women, the pain only exists for a few days per month.

Dysmenorrhea, defined as pain during menstruation which is severe enough to impact or interfere with daily activities (American Congress of Obstetricians and Gynaecologists, 2011) has recently been the focus of brain-imaging studies. Results have shown that the brains of otherwise healthy women with moderate-to-severe dysmenorrhea show significant differences in brain structure and function, when compared with non-dysmenorrheic women (Tu, Niddam and colleagues 2009, 2010

and 2013). The differences identified include differences in cerebral metabolism and cerebral structure for those with dysmenorrhea and, between pain and pain-free states. Differences have also been found in neural activity induced by noxious skin stimulation when applied to areas at a distance from the pelvic/abdominal region, such as the arm (Vincent et al., 2011). An important aspect of these brain-imaging studies is that some of the differences in neural characteristics occurred chronically, throughout the menstrual cycle, even when dysmenorrheic women were not experiencing menstrual pain (Iacovides, Baker, Avidon & Bentley, 2013). Berkley (2013) suggests that the consistency of these findings of altered pain perception along with those from individuals with other chronic pain conditions provides a strong argument that dysmenorrhea should be considered a chronic pain condition.

7.2 Prevalence of menstrual pain in the general population

The prevalence rate for menstrual pain in the general population has been estimated at between 20% and 80% (Shye & Jaffe, 1991) with as many as 90% of menstruating female adolescents and 50% of adult women reporting that they experience pain which is severe enough to interfere with their usual lifestyle and participation in normal activities (Davis & Westoff, 2001; Eden, 1992). In a study of prevalence, impact and current knowledge of the issue of dysmenorrhea in adolescent females, De Sanctis et al. (2015) reported that only 6% of adolescent females receive treatment for dysmenorrhea but 70% use self-management strategies. Potur, Bilgin and Komurcu (2014) found that dysmenorrhea was highly prevalent amongst Turkish university students and was related to absenteeism from University as well as the ability to participate in and enjoy usual daily and social activities. Given the frequency with

which menstrual pain is experienced, it is unsurprising that its' perceived interference has been found to be a strong predictor of emotional distress associated with menstruation (Elliott & Harkins, 1992). Whilst this research was conducted some time ago, the findings remain consistent and pertinent today. Eryilmaz & Ozdemir (2009) evaluated approaches taken by Northeastern Turkish adolescents to cope with menstrual pain and examined the relationships among pain severity and duration of dysmenorrhea. The study concluded that teenage girls should be encouraged to consult a Doctor and should be prescribed medication in addition to non-pharmacological approaches, to alleviate menstrual pain and shorten its duration. A recommendation was also made that school curricula should be redesigned to address proper management strategies for adolescent problems. Review of the literature in the area of menstrual pain raises issues as to whether menstrual pain is part of a 'psychological disorder' or indeed associated with other physical conditions, such as endometriosis. These arguments warrant mentioning due to the potential for misdiagnosis and the potential impact on treatment approach and efficacy. Tang (2017) proposed a hybrid approach to the treatment of chronic pain conditions which could also be applied to the issue of menstrual pain. This approach acknowledges that complex conditions, such as menstrual pain, interact with co-occurring physical and mental comorbidities which in turn, can have an impact on pain management.

7.3 Prevalence of menstrual pain in individuals with intellectual disabilities

Kyrkou (2005) examined how menstrual pain and premenstrual stress presents in women with intellectual disabilities as there is anecdotal evidence of an increase in this condition in this population, but little research has been conducted in this area. In

one study, the parents of twenty-four women with Down Syndrome and Autism Spectrum Disorders were surveyed. The study found that two-thirds of the participants with Autism, three-quarters of those with Down Syndrome and all of the women with Aspergers Syndrome appeared to experience problematic period pain. These rates were higher than the 50% rate reported for women in the general population (Eden, 1992).

Kyrkou's findings support those of Taylor (1995) who suggested that premenstrual syndrome was a fairly common occurrence in girls with Autism and that even the most verbal young women with intellectual disabilities were often not able to explain how they felt. Due to the small sample size used in the study, however, caution is required in the interpretation of these findings. Quint, Elkins, Sorg and Kope (1999) examined the frequency of occurrence of cyclical behavioural changes in women with intellectual disabilities and found that it occurred in 18% of the sample. As 65% of individuals responded to non-steroidal anti-inflammatory drugs (NSAID's), they concluded that these behaviour changes may be related to menstrual pain. This hypothesis was further supported by the finding that birth control pills and Depot Medroxyprogesterone improved behaviour in 40 – 66% of those who did not respond to NSAID's.

Chou et al. (2008) conducted in-depth interviews with women with intellectual disabilities in Taiwan, to determine their perceptions and experiences of menstruation. Over seventy percent of these women reported experiencing menstrual pain. Walmsley et al. (2016) interviewed nineteen women with intellectual disabilities about

their experiences of making decisions about contraception. Several of these women reported using contraception to manage menstrual pain however there was no consistency reported in procedures for reviewing and checking that efficacy of this treatment approach.

Review of the literature on menstrual pain in women with intellectual disabilities firmly supports the conclusion that this condition is equally, if not more prevalent, amongst this population and warrants further consideration and investigation.

7.4. Psychological processes in menstrual pain

Psychological factors which affect chronic pain sufferers such as pain intensity, pain coping and pain catastrophizing, also appear to influence the experience of menstrual pain. Walsh et al., (2003) found that high pain catastrophizers, in comparison with low pain catastrophizers, reported greater menstrual pain intensity, greater impact on mood, greater variability in the use of pain coping strategies, lower perceived effectiveness of over-the-counter medications and nonmedical pain coping strategies and greater disability. In a study of menstrual pain coping flexibility, Kato (2016) reported that the ability to discontinue an ineffective coping strategy and replace it with a more effective alternative, was associated with reduced depressive symptoms during menstruation. Consistent with the negative impact of chronic pain on mood and emotional functioning, Alonso and Coe (2001) found that depression and anxiety were strongly associated with menstrual pain. Given the known impact of these psychological processes both on the experience of chronic pain and more recently, the experience of menstrual pain, further research attention appears warranted.

7.5 Psychological interventions for menstrual pain

Berkley (2013) conducted a comprehensive review of the issue of primary dysmenorrhea and concluded that it has received minimal scientific attention both in terms of pain research and research funding. This has impacted knowledge and understanding of the condition and, potentially beneficial and effective treatment options. In a systematic review of management options, Latthe and Champaneria (2011) reported nonsteroidal anti-inflammatory drugs (NSAIDs) as the only definitively effective treatment. As drug therapy is not always available to women, for various reasons, and because individuals are increasingly seeking alternatives to medical management of conditions, Proctor, Murphy, Pattison, Suckling and Farquhar (2011), reviewed the effectiveness of behavioural interventions with placebo or other interventions in women with dysmenorrhea. Only five randomised controlled trials (RCT's) met the criteria for inclusion in the review which found that behavioural interventions, which can include both behavioural and cognitive strategies (Denny and Gerrard, 1981; Lewis, Wasserman, Denny & Gerrad, 1983), may be effective in the treatment of this condition. The recency of this meta-analysis and the inclusion of a number of RCT's with robust research designs, lend strong and considerable support to the argument in favour of the use of cognitive behavioural strategies in the management of menstrual pain.

CHAPTER 8: RATIONALE FOR THE CURRENT STUDY

8.1 The present study

This study will be the first controlled clinical trial to address the issue of menstrual pain management with individuals with intellectual disabilities. Previous research on pain in individuals with intellectual disabilities has largely focused on identification of pain and medical management of pain symptoms. Pain management, including menstrual pain management, has largely been ignored and pain management programmes have not routinely been offered to such individuals.

Menstrual pain is proposed to afflict up to 80% of women in the general population and those with intellectual disabilities are thought to experience menstrual pain to at least the same degree. In view of the ample evidence that CBT can be used for chronic pain management including the management of dysmenorrhea in the general population, and the preliminary evidence for the effectiveness of CBT with people with intellectual disabilities (McManus & McGuire, 2014), there is a rationale for evaluating a CBT-based pain management programme for menstrual pain in women with intellectual disabilities.

8.2 Study aims and objectives

The main aims and objectives of this study are to:

1. Pilot a theory-based cognitive-behavioural therapy programme for menstrual pain management to refine the treatment delivery

2. Carry out a feasibility study specifically investigating the study protocol, success of recruitment at all sites, data collection and characteristics of the proposed outcome measures.

3. Carry out process evaluation regarding the delivery of the menstrual pain management programme and stakeholder views of the intervention.

The menstrual pain management programme was developed from the theory-based programme "Feeling Better – A manual for carers working with people who have intellectual disabilities and chronic pain". This manual, developed by McManus and McGuire (2010), comprises a comprehensive modularised programme to assist people with intellectual disabilities and chronic pain to manage their pain more effectively. The manual is designed to provide practical guidance to carers and health care employees who work with people with intellectual disabilities and chronic pain. Based on evidence-based cognitive behavioural principles, it provides a range of tools for teaching strategies to manage chronic pain more effectively. Each of the sessions are related to each other by their common purpose but they are also designed to be used as stand-alone modules. This approach was piloted in a case series study of cognitive behavioural therapy for chronic pain in people with an intellectual disability (McManus & McGuire, 2014). Results indicated that participant scores on pain management knowledge, wellness-focused coping and effectiveness of coping increased following the intervention.

8.3 Quantitative assessment

Review of the literature in the area of chronic pain identified a number of key variables which play a role in the experience of chronic pain. These include pain coping, pain knowledge, pain self-efficacy and pain-catastrophizing. These core outcome variables were measured in this study, however, it was necessary to modify existing assessment tools to adequately assess these constructs in individuals with intellectual disabilities.

8.4 Qualitative assessment

Process evaluation was conducted with key stakeholders to assess the acceptability of the intervention, to explore their experiences, including any suggestions they may have to enhance the programme and, to examine which elements of the programme appear to be most relevant in promoting change for young women with intellectual disabilities who experience menstrual pain.

8.5 Research questions

1. Does participation in the menstrual pain management group result in an increase in participants' pain management knowledge and use of wellness-focused pain coping strategies and is this maintained at follow-up?

2. Does participation in the menstrual pain management group result in a change in ratings of pain intensity and pain interference as rated by participants and their parents? If so, are these changes maintained at follow-up?

3. Does participation in the menstrual pain management group increase the use of behavioural pain coping strategies?

4. Do pain self-efficacy and parental pain-catastrophizing affect participants' ratings of pain intensity, pain interference, pain knowledge and pain coping strategies used?

8.6 *Research Hypotheses*

1. Participation in the menstrual pain management group will result in an increase in participants' pain management knowledge and use of wellness-focused pain coping strategies and, these changes will be maintained at follow-up.

2. Participation in the menstrual pain management group will reduce participants' ratings of pain interference but will have no effect on their ratings of pain intensity. Parental ratings of the same constructs will show a similar trend. These results will be unchanged at follow-up.

3. Participants in the menstrual pain management group will increase their use of behavioural coping strategies and use more behavioural than cognitive coping strategies to manage their menstrual pain. These findings will be unchanged at follow-up.

4. Participants' ratings of pain intensity, pain interference, pain management knowledge and pain coping strategies used at baseline, will be affected by ratings of pain self-efficacy and parental pain catastrophizing.

CHAPTER 9: METHODOLOGY

9.1 Study Design

The study used a mixed methods design involving both quantitative and qualitative analysis. The study design and methodology, based on the Medical Research Council's (MRC) Framework for Evaluating Complex Interventions (2008), was considered an exploratory clinical trial.

9.2 Sample size and power calculation

As this is a feasibility study, the target sample size was based on the recommendations for pilot and feasibility studies (Julious, 2005) and not on statistical power. There are a lack of well-conducted controlled trials and a lack of information about effect sizes of CBT with people with an intellectual disability within published research in this area. For this reason, the feasibility study by Hassiotis et al. (2011) was used as a guideline in calculating sample size requirement. The study by Hassiotis et al. (2011) proposed a total sample of 30 to be allocated across two conditions although there is currently discussion that feasibility trials ought to include up to 70 individuals in order to reduce the inaccuracy with regard to estimates of standard deviation (Teare et al. 2014). The sample size of n = 36 in this study was based on this paper and allowed for 20% attrition. The aim was to recruit 18 participants to each group. This permits assessment of the feasibility of a main trial including recruitment feasibility from different sites, suitability of outcome measures and estimation of variability in main outcome measures.

While initially it was intended to have a paired matched design, it was not possible to achieve N = 36 with equal numbers in each arm of the study. Instead, N = 32 was obtained with N = 18 in the experimental group and N = 14 in the control group. The control group was a comparison group with similar characteristics in terms of age, gender and level of cognitive ability. These individuals received treatment as usual during the study. This typically involved rest and medication, as required. On completion of the study, the comparison group will be offered the intervention.

9.3 Participants

Participants were females with a diagnosis of a mild or moderate intellectual disability who receive support services from a voluntary organisation which provides day programmes, residential and respite services, family and multi-disciplinary supports to individuals with intellectual disabilities and to their families, within a defined geographical catchment area in the west of Ireland. The Diagnostic and Statistical Manual (DSM) (APA, 2013) diagnostic framework was used for the diagnoses of intellectual disability and participants IQ scores were in the range 35 – 70.

9.4 Recruitment strategy

Potential participants who met the inclusion criteria for the study were identified by the Team Leaders for school age and adult services. These individuals have access to such information. The Parents/Guardians of potential participants were approached via a participant information letter and asked if they wished to take part in the study and if they consented to their daughter participating in the research. A consent form was provided for this purpose. Once consent was obtained from Parents/Guardians,

assent to participate in the research study was sought from the young women in question, via an accessible format participant information sheet and consent form. These forms included pictures to aid comprehension. A copy of these forms was provided to each potential participant and read out to them by the Researcher, at the same time. (Refer to Appendices 1 - 4 for samples of the parent and participant versions of the information letters and consent forms).

9.4.1 Inclusion criteria

- Females aged between 12 and 30 years of age. The upper age limit of 30 years was selected to avoid overlap with early menopausal symptoms based on Kyrkou (2005).
- Function in the mild or moderate range of intellectual disability.
- Use speech as the primary means of communication.
- Have a speech level consistent with, or greater than, their level of intellectual ability.
- Be in education or training, attending either a secondary school or an adult training centre.
- Have commenced menstruation.
- Have experienced pain symptoms with menstruation which impacted on daily functioning.

9.4.2 Exclusion criteria

- Females were not eligible to participate in the study if they did not have an intellectual disability.

- Research indicates that cognitive-behavioural strategies may be suitable for individuals with mild and moderate intellectual disabilities. For this reason, individuals with more significant degrees of cognitive impairment were excluded from the study as cognitively, they would not be able to participate.

Participants were not excluded from participating in the study on the basis of ethnicity, race, sexuality, religion or any other socio-cultural factors.

9.5 Treatment Allocation and Matching Process

9.5.1 Intervention Condition

Due to the logistics and practicalities of delivering an intervention group to individuals within a wide geographical sampling area, it was necessary to use a non-randomised process to assign participants to the intervention condition.

A list was compiled of all females attending special classes for students with a mild or moderate intellectual disability within mainstream schools, all females attending schools for students with mild or moderate intellectual disabilities and, adult day centres providing educational and training opportunities to young women with mild and moderate intellectual disabilities. All individuals also received support services from the organisation in question, within the defined geographical area. The Principals of five schools were contacted, informed of the research study and invited to participate in the study. Two schools expressed interest in participating and were assigned to the intervention group. Parents/Guardians of the relevant students were

then contacted, invited to participate in the study and consent was sought for their daughters to participate also. Once parental consent was obtained, the young women were approached and invited to take part in the study. Assent was obtained directly from them. The same approach was used to recruit participants attending adult day centres providing education and training opportunities to young women with mild and moderate intellectual disabilities, within the defined geographical area.

9.5.2 Control Condition

Individuals in the control condition were an equivalent comparison group matched by virtue of the fact that they were of the same cohort as the treatment group i.e. gender, age range and level of intellectual disability. Random allocation to conditions was not possible as the intervention programme was delivered during school/work hours within a large geographical region without adequate public transport links. Individuals in the control condition were from different schools and invited to participate in the research study in the same manner as intervention group participants. They were informed that they had been allocated to the control condition and what this meant. They received treatment as usual and were informed that they would be invited to participate in the intervention programme, once the study was completed.

The treatment allocation and matching process used in the study allowed for the delivery of the intervention during school/work hours, at the location where the young women received their day service. This approach minimised inconvenience and school/day centre absence by research participants and enabled the intervention to be delivered at an appropriate time within the school timetable/training programme e.g.

during Social, Personal and Health Education (SPHE) class. This minimised the potential impact on participants' overall education and training and helped to ensure consistent attendance.

9.6 Ethical Considerations

The research study protocol, participant information sheets, consent forms and assessment measures were granted ethical approval by the Senate Research Ethics Committee of City University London on 16/5/2012 (Ref: PSYETH 11/12 026).

As research participants were recruited from the catchment area of an organisation which provides support services to individuals with intellectual disabilities in County Galway, Republic of Ireland, ethical approval was also sought from the organisation's Research Ethics Committee. Ethical approval was granted on 25/6/2012. (see Appendix 5 for notification of ethical approval). Joint supervision of this research project was provided by the School of Arts and Social Sciences at City University London (internal supervision) and the School of Psychology at the National University of Ireland, Galway (NUIG) (external supervision).

A number of ethical issues were identified with conducting this research. These are outlined below along with details of how they were addressed.

9.6.1 Informed Consent

A participant information sheet was provided to the Parents/Guardians of all potential participants. This information sheet outlined the research proposal and what

participation in the study involved. This information sheet described the purpose of the study, risks and benefits of participating in the research study and how individuals would be informed regarding the findings of the study. Details were also included regarding the rights of participants to withdraw from the study at any point, if they wished, without prejudice to themselves and the service which they receive from their Disability Service Provider. Information was also included regarding how to seek additional information about the study, if required. If Parents/Guardians agreed to the participation of their daughter in the study, they were asked to sign and return a consent form.

Assent to participate in the study was subsequently sought from the individuals in question using a participant information sheet containing clear, concise information and pictures explaining what they were agreeing to when they consented to participate in the study. Potential participants were then provided with a consent form, again containing both pictures and text, to support them to provide informed consent to participate in the study. Participants were made aware that their participation was on a voluntary basis and their freedom to withdraw from the study at any time, without consequence, was clearly explained.

9.6.2 Protection of privacy, anonymity and confidentiality of participants and their data

All information provided by participants was considered confidential and was stored in a secure manner which protected their identity. Participants were assigned a number and all data was recorded with reference to this rather than the participant's name.

Details of this system were stored in a password protected computer file, with details known only to the main researcher. All consent forms and completed assessment measures were stored in a locked cabinet and a password protected and encrypted computer was used to store and analyse raw data.

With regard to the menstrual pain management intervention groups, ground rules were established for each treatment group including the participant's right to confidentiality. Participants were reminded of these ground rules at the beginning of each intervention session.

9.6.3 Psychological well-being of participants

Psychological discomfort in the form of social embarrassment could have been experienced by some participants in discussing the topic of menstrual pain in a group setting. The following precautions were taken to minimise any potential distress to participants:

- controlling the size/number of participants in each group (small groups)
- discussing the potential for embarrassment associated with participating in the group with participants and offering support in managing this, if required
- careful attention to establishing rapport between group participants through the use of "ice- breaker" techniques and a social "tea-break" at the end of each intervention session

- sensitive discussion of words/topics which some participants could have found discomforting
- informing participants that they were free to withdraw from the study at any stage and without consequence, if they wished, and that they did not have to give a reason for their decision

9.6.4 Dissemination of findings

Dissemination of research findings is an integral part of the research process and consideration was given to executing this in a manner which meets the needs of both the research participants, my Research Supervisors and the University. At the outset of this research study, it was envisaged that the research findings will be submitted for publication to a relevant academic journal to ensure the findings will be of benefit to practitioners within the fields of intellectual disability and pain research, as well as individuals who experience pain, their families and carers and service providers. Participants were informed of this from the outset.

Participants were asked if they would like to receive a summary of the results of the study following completion, and were asked to provide contact details, solely for this purpose, if they wished to receive this feedback. This will be presented in a manner which is accessible to all participants.

9.7 Overview of psychological intervention

The psychological intervention for menstrual pain management was developed from the "Feeling Better" programme for chronic pain management in people with intellectual disabilities (McManus & McGuire, 2010). This programme, based on evidence-based cognitive behavioural principles, provides a range of tools to enhance chronic pain management. Sessions are related but are also designed to be used as stand-alone sessions. Each treatment module includes key learning objectives, a rationale for the technique in relation to pain management, practical guidance on how to conduct the session, tips for making the intervention more effective, a case example and hand-outs for participants. McManus and McGuire (2014) piloted this programme in a case series study and found that participant scores on pain management knowledge, wellness-focused coping and effectiveness of coping increased following the intervention.

9.7.1 Programme Development

Prior to the main intervention, qualitative preparatory work was completed. Parents/Guardians were invited to take part in a focus group to inform the development of the intervention in order to best meet the needs of the participants.

The Participative Research Process (PRP) methodology was chosen for this aspect of the study as it facilitates people to present their views in a "more reflexive, interactive and flexible framework" (Rifkin, 1996). This approach facilitates participants to present their perspectives without filtering or censure by researchers. It allows varying

and sometimes unexpected perspectives to emerge as participants create, collate and present their own data.

Participants were provided with session outlines for the "Feeling Better" programme and asked to consider what should and should not be included in the menstrual pain management programme and, how this should be done. Parents were asked to respond to a single question: "If your daughter takes part in this group, what would it need to have to help her to cope with menstrual pain?" A "web of ideas" was created by parents outlining what they felt was suitable content and delivery methods for the intervention programme. (See Appendix 6).

9.7.2 Intervention Programme

The menstrual pain management intervention programme which was developed consisted of twelve sessions. These were as follows:

Session 1: Psycho-education

Session 2: Deep breathing

Session 3: Progressive muscular relaxation

Session 4: Guided visualisation

Session 5: Taking exercise

Session 6: Distraction techniques

Session 7: How your thoughts make you feel

Session 8: Challenging negative thoughts

Session 9: Using positive coping strategies

Session 10: Problem solving

Session 11: Medication

Session 12: Planning for the future

Each weekly session was approximately 45 minutes in duration and was conducted with a group of 5 - 7 young women. Sessions were completed at a time and in a location deemed appropriate by the School Principal and/or Adult Centre Team Leader. The session structure consisted of general information, examples related to the topic, group exercises and discussion, homework exercises and a session summary sheet. Each session began with a review of the previous session topic and feedback from participants on their use of the technique. At the end of each session, participants interacted during a snack break which afforded participants an opportunity for social interaction with group members and supported the development of group cohesiveness. A fidelity checklist was completed at the end of each session. This checklist detailed participant attendance, review of group rules, review of previous session topic including completion of homework, the extent to which the planned topic and session outline were adhered to, whether any changes or modifications to the session plan were necessary and if so, what these entailed and, if the session culminated with a snack break, to aid group cohesiveness. Bellg et al. (2004) identified delivery of treatment as one of five key areas in which researchers should strive for fidelity. The other areas are study design, training providers, receipt of treatment and enactment of treatment skills. The fidelity checklist used in this study drew on

elements of the MAnualized Group Intervention Check (MAGIC), a checklist developed and validated by Jahoda et al. (2013) for use in monitoring the delivery of a CBT intervention to groups of people with intellectual disabilities, by multiple therapists.

9.7.3 Pilot Study

The intervention was delivered initially in a pilot study with five participants and assessment measures were completed at key time points. The observations and experiences of the researchers during administration of the assessment measures underpinned modifications to some of the wording on some questionnaires to ensure that participants would understand what was being asked of them. Response options and scoring categories were also simplified on some assessment measures. Following this phase of the study, the parents/guardians of participants were invited to attend a focus group to provide feedback on their experiences and to suggest modifications to the study. Parents suggested that a picture be included on each weekly session outline to aid participants in remembering and applying the technique discussed that week. It was also recommended that participants be provided with a summary sheet at the end of the programme (see Appendix 7). The young women involved were asked for their feedback and they suggested that a certificate of participation be presented at the end of the intervention programme (see Appendix 8).

9.8 Outcome Assessment Strategy

The assessment strategy employed in the study involved the administration of specific pain outcome measures at defined time points during the study. The primary outcome

measures explored in this study were (1) strategies used to cope with pain and (2) pain management knowledge. Secondary outcome measures quantified pain intensity, pain interference, pain self-efficacy and pain catastrophizing. Following delivery of the intervention, qualitative evaluation was conducted with stakeholders including groups of participants, Parents/Guardians, Teachers and/or staff members at adult day centres to evaluate the programme and its impact and to determine which aspects of the intervention were most beneficial for this population. Table 1 provides a summary of the various assessment measures administered at each time point.

Measure	Questionnaire	T1: 0 weeks	T2: 5 weeks	T3: 10 weeks	T4: 12 weeks	T5: 24 weeks
Primary outcome measures	Pain Coping Strategies	X			x	x
	Pain Coping Scenarios	X	x	x	x	x
	Pain Management Knowledge	X	x	x	x	x
Secondary outcome measures	Pain Intensity Scale [McGrath,et al. 1996]	X	x	x	x	x
	Modified version of the Brief Pain Inventory – Short Form [Cleeland & Ryan, 1994]	X			x	x
Process variables	Modified version of the Self-Efficacy scale for child functioning despite chronic pain [Bursch, Tao, Meldrum & Zelter, 2006]	X			x	x
	Pain Catastrophizing Scale – Parent version (PCS-P) [Goubert, Eccleston, Vervoort, Jordan & Crombez, 2006]	X			x	x
Predictor variables	Background Information Questionnaire	X				

Table 1: Outcome measures and administration time points

9.8.1 Assessment Measures

As outlined in Chapter 4, a large number of pain-related assessment measures were reviewed during the design phase of this study. Many of these measures were not normed on individuals with intellectual disabilities and were therefore deemed unsuitable for use with this population, without modification. Modifications were also made to some measures previously used with individuals with intellectual disabilities. It is important to note that these measures remain to be validated and analysis of the internal consistency and validity of these modified measures was not conducted as part of this study.

Primary outcome measures

The Pain Coping Strategies Questionnaire (McManus & McGuire, 2014) and the Pain Coping Scenarios Questionnaire (modified from McManus & McGuire, 2014) were used to measure pain coping. These measures were previously compared pre-intervention, post-intervention and at 1-month follow-up, in a pilot study examining the feasibility and clinical utility of CBT for people with an intellectual disability (McManus & McGuire, 2014).

On the Pain Coping Strategies Questionnaire, participants were asked to name all the different things they do to deal with their menstrual pain. The use of open-ended questions was designed to elicit the participants' individualised pain coping strategies. This was deemed to be a more appropriate question format given that little is known about menstrual pain coping strategy use among people with an intellectual disability. Furthermore, this format can alleviate potential response bias such as acquiescence.

(see Appendix 9 for a copy of this measure). Participants' responses were coded as wellness-focused coping strategies or illness-focused coping strategies, based on the work of Jensen and Karoly (1992). Wellness-focused coping strategies included relaxation, physical exercise and distraction techniques. Illness-focused strategies included rest and use of medication. Coping strategies used were also coded as "behavioural" or "cognitive" in orientation based on session content, as outlined in the "Feeling Better" pain management programme handbook. The effectiveness of pain coping strategies was also assessed by asking participants to rate how well each of the strategies worked using three response options: "works very well", "works sometimes", "doesn't work at all".

The Pain Coping Scenarios Questionnaire (modified from McManus & McGuire, 2014) (Appendix 10) asked participants how they would cope with pain in four hypothetical situations i.e. during the night, at school/at their day programme, at home and during a social activity. This determined if participants could generalise techniques learnt during the intervention programme to situations in which they may experience menstrual pain. Again, coping strategies were coded as wellness-focused or illness-focused and as behavioural or cognitive in orientation.

The Pain Management Knowledge Questionnaire (McManus & McGuire, 2014) assessed knowledge of pain coping strategies using a seven item multiple choice questionnaire (Appendix 11). Response options were "yes", "no" and "don't know". The items on the scale reflect the core domains of the intervention e.g. relaxation, exercise, distraction, challenging negative thoughts. A clarifying question was asked

following each correct answer ("Can you give me an example?") to confirm that the participant had some knowledge related to their answer and was not demonstrating response bias. If the participant answered the question correctly but the supplementary information provided demonstrated inaccuracies in knowledge, the response was not credited as correct.

The three primary outcome measures were administered at T1: baseline (pre-intervention), T4: 12 weeks from baseline (post-intervention) and T5: 24 weeks from baseline (follow-up). Post intervention measures were administered by another researcher, independent of the research team, to minimise social desirability bias. The Pain Coping Scenarios Questionnaire and the Pain Management Knowledge Questionnaire were administered at two additional time points: T2: 5 weeks from baseline and T3: 10 weeks from baseline. These additional time point measures facilitated process evaluation to determine which elements of the intervention programme were most effective for this population, over time.

Secondary outcome measures

Pain, or pain intensity, is not the key target of the intervention in this study but rather, a secondary outcome measure. The goal of CBT-based pain management programmes is not to reduce pain but to enhance adaptive coping and support the individual to resume a more productive and enjoyable life despite pain (Turk, 2003). In a review of randomized controlled trials of CBT for chronic pain, Knoerl, Smith and Weisberg (2016) reported that CBT reduced pain intensity in 43% of trials. Lynch-Jordan et al. (2014) demonstrated that the rate of change of functional disability was significantly

more rapid than the change in pain intensity over the course of psychological treatment for children with chronic pain.

Participants rated pain intensity during their last menstrual period using a coloured Visual Analogue Scale (VAS) modified from the Pain Intensity Scale (McGrath et al. 1996). (Appendix 12). The scale used provided vivid gradations in colour and area so that participants could see concretely how different scale positions could reflect different values in their pain intensity. On this scale, 0 = no pain and 10 = lots of pain. Due to the challenges associated with using numerical rating scales with individuals with intellectual disabilities, proxy measures of pain intensity were also obtained from the parents of participants.

Pain interference was measured by a modified version of the Brief Pain Inventory – Short Form (Cleeland and Ryan, 1994) (Appendix 13). This questionnaire used a likert scale where 0 = did not interfere and 10 = completely interferes. The modified version of the Brief Pain Inventory – Short Form used in this study was specifically generated for the purpose of this research project. The specific modifications required included front and back female body outlines to enable participants to identify the areas of the body in which they experienced menstrual pain, omission of some questions e.g. questions regarding pain in the last 24 hours (participants may not have been menstruating at the time of administration of questionnaires), changes to the questions on categories assessed (wording changes and additional categories included) and modifications to the response categories by including the use of a visual analogue rating scale in conjunction with a numerical rating scale. Modifications to the original Brief Pain Inventory – Short Form were required to enable it to be understood by and

used with people with intellectual disabilities as well as to make it relevant to the assessment of menstrual pain, which is an intermittent rather than a constant type of pain.

Secondary outcome measures were administered to participants at T1: baseline (pre-intervention), T4:12 weeks from baseline (post-intervention) and T5: 24 weeks from baseline (follow-up). Secondary outcome measures were administered to parents/guardians at T1, T4 and T5. The pain intensity questionnaire was also administered to participants at T2: 5 weeks from baseline and T3: 10 weeks from baseline to determine the impact of the intervention on pain intensity, over time.

Process variables

Process variables are those which may lead to change in the outcome measures. Variables of interest included pain self-efficacy and pain catastrophizing. Pain self-efficacy refers to an individual's belief that they can perform certain tasks related to school, friends and family even when they are in pain. It is an important variable to consider given its potential impact on participants' willingness to implement strategies to cope with their pain. Participant pain self-efficacy was measured using a modified version of the Self-Efficacy Scale for Child Functioning despite Chronic Pain (Bursch, Tsao, Meldrum & Zelter, 2006) and was read to participants (Appendix 14). Modifications included reducing the response options to three (1 = Always, 2 = Sometimes and 3 = Never). One item related to "taking care of self" was omitted from the questionnaire as it was deemed unreliable given that many individuals with an

intellectual disability are reliant on family or staff for support with their basic care needs.

Pain catastrophizing is a negative cognitive-affective response to anticipated or actual pain and has been consistently associated with pain intensity and pain related activity interference (Quartana, Campbell & Edwards, 2009). Pain catastrophizing was assessed using the parent version of the Pain Catastrophizing Scale (PCS-P) (Goubert, Eccleston, Vervoort, Jordan & Crombez, 2006) (Appendix 15). This is a 13 item rating scale to assess parents' thoughts and feelings when their child is in pain. It looks at issues such as rumination, magnification and feelings of helplessness. The five response options are: not at all (disagree), mildly (agree), moderately (agree), severely (agree) and extremely (agree). Pain self-efficacy and pain-catastrophizing were assessed at the same time-points as the primary and secondary outcome variables i.e. T1: baseline (pre-intervention), T4:12 weeks from baseline (post-intervention) and T5: 24 weeks from baseline (follow-up).

Predictor Variables

There were a number of variables which may have moderated the impact of the outcome measures in this study. These included socio-demographic variables such as age and education as well as other variables such as level of cognitive ability, time since onset of menstruation; frequency and duration of menstruation; number and frequency of menstrual symptoms experienced and history, treatment and use of medication to manage gynaecological problems and other medical conditions. Information on these variables was gathered from administration of the background

information questionnaire (Appendix 16). Level of cognitive ability was confirmed by Team Leaders with reference to information recorded on the National Intellectual Disability Database (NIDD). The NIDD is a database of information about people who receive intellectual disability services in Ireland or who are in need of these services.

9.9 Statistics Strategy

9.9.1 Quantitative analysis

Research data was assessed using the following series of analyses. Firstly, the demographic data for participants will be presented using descriptive statistics. Variables were checked to see if they were normally distributed using the Kolmogorov-Smirnov (K-S) test and by checking the absolute values for skew and kurtosis. The principle of matching was considered to test for variation at baseline. This was done by comparing primary and secondary outcome variables at baseline across the control and the intervention conditions to see if there were significant differences between the groups. Next a descriptive overview of the data will be provided. This gives an indication of whether there were differences between the intervention and control conditions across each of the primary and secondary variables, at each of the time points assessed. It also gives an indication of whether data for the intervention group moved in the expected direction, for each of the variables. A correlation matrix was conducted to test whether variables that are conceptually linked were correlated, as would be expected. The internal consistency for each scale was then calculated using Cronbach's Alpha.

Parametric tests were used for statistical analysis as the variables were found to be distributed normally. Simple statistics were used for hypothesis testing as the capacity to conduct inferential statistics was somewhat limited by the small sample sizes in the data set. Mixed between-within subjects ANOVA's were used to check for change in the primary and secondary outcome variables from baseline (T1) to post-intervention (T4) and subsequently, to follow-up (T5). In light of the sample size, the overall impact of the intervention was examined first and then more complex effects were considered. Significant findings were tested using a three-way interaction between-within ANOVA. A Bonferroni correction was used to control the type I error rate, when running multiple tests. The alpha value was set at .05 and *p* values of less than .05 were considered significant. Moderator analyses were conducted using multiple regression, to examine the conditions under which process and predictor variables interacted with the intervention condition in the main effect analyses. These analyses were considered important to conduct in order to identify any trends which should be examined further in any future or larger scale studies.

9.9.2 Qualitative analysis

Focus groups were conducted with participants, parents and staff involved in the research study. Data was analysed using thematic analysis in order to identify key themes.

CHAPTER 10: QUANTITATIVE RESULTS

10.1. Descriptive Statistics

Demographics

Background Information

Thirty two participants took part in the research study, and were assigned to one of two treatment conditions. There were 18 participants in the intervention group and 14 in the control group condition. Three intervention groups were delivered. Participants were recruited from different schools and training centres and ranged in age from 12 – 30 years, with an overall mean age of 18 years, SD = 4.89. All participants were of Caucasian ethnicity and in full-time education or training. Twelve participants had Down Syndrome. The number of years of education reported by participants ranged from 6 – 23 years, with an overall mean of 13 years. The majority of participants (69%) reported that they lived in a rural, rather than an urban, setting.

	Intervention Group	**Control Group**
No. of participants	18	14
Mean Age	20	16
Mean years of education	15	10
Rural Residence	9	13
Urban Residence	9	1

Table 2: Summary of demographic details

Menstruation

The average age at which menstruation commenced was 12.25 years and ranged from 8 – 15 years. On average, participants menstruated every 31 days (although this ranged from 21 – 75 days) and each menstrual cycle lasted an average of 5 days (range from 3 – 10 days).

	Intervention Group	**Control Group**
Mean Age at First Menstruation	12	12
Mean Frequency of Menstruation (days)	31	30
Mean Duration of Menstrual Cycle (days)	5	5

Table 3: Summary of menstruation frequency and duration

Twenty-three (71.9%) participants reported that they experienced menstrual pain on a monthly basis with fifteen individuals (46.9%) reporting absence from school or their adult training centre in the previous three month period, due to menstrual pain. The average number of days missed in the previous three month period by both intervention and control group participants was one (1). The maximum number of days missed was nine (9). Twenty-two individuals (68.8%) reported that they used medication to manage their menstrual pain. Paracetemol (Panadol) and Ibuprofen (Feminax) were the most commonly used medications. The majority of participants (87.5%) reported no gynaecological problems. Of those who did experience such issues (4 individuals), painful and heavy periods were the two issues reported. Three

(3) participants had an intrauterine coil inserted to assist in managing their gynaecological issues and one (1) individual attended her G.P. for medical management of her condition.

	Intervention Group	Control
Monthly menstrual pain	13	10
Absence from school	9	6
Medication use	11	11
Paracetemol (Panadol)	5	3
Ibuprofen (Feminax)	3	2
Gynaecological Issues	2	2

Table 4: Summary of menstruation impact

Frequency of menstrual symptoms

Thirteen participants (40.6%) reported pain before menstruation each month. This figure increased to thirty individuals (93.8%) when participants were questioned about pain during menstruation. Similar figures were reported by parents, (40.6% and 90.6%, respectively). In each case, parental report related to parents reports on the experience of their daughter and in all cases, proxy reports were provided by the Mothers of participants.

	Intervention Group	Control Group
Pain before menstruation	6	7
Pain during menstruation	17	13
Cramps	16	13

Table 5: Summary of menstrual pain frequency

Participants were asked to identify which of the most commonly experienced menstrual symptoms they usually encountered with menstruation. Twenty-nine of the thirty-two participants (90.6%) reported having experienced cramps/pain with menstruation. The abdomen was the most commonly reported location for menstrual pain by both participants (75%) and their parents (78.1%). Other commonly reported pain locations are presented below, in table 6.

	Participant report			**Parental report**	
Location	**Intervention Group**	**Control Group**	**Location**	**Intervention Group**	**Control Group**
Abdomen	16	11	**Abdomen**	16	12
Back	7	8	**Back**	3	6
Legs	5	6	**Head**	5	2
Vagina	4	4	**Legs**	2	4
Head	5	3	**Breasts/Vagina**	2/1	1/2

Table 6: The most commonly reported locations of menstrual pain

Tiredness and irritability were the next most frequently reported symptoms experienced by participants, after menstrual cramps. These symptoms were experienced by twenty-six (81.3%) and twenty (62.5%) of the participants, respectively. Further details on the frequency of other menstrual symptoms are presented below, in table 7. Nine (28.1%) participants reported other less frequently occurring symptoms. These included bloated stomach, dizziness, pale complexion, tired/heavy eyes, a preference to be alone, confusion and feeling angry, upset and tearful.

Symptom	**Intervention group**	**Control Group**
Cramps/Pain	16	13
Tiredness	16	10
Irritability	12	8
Lower Back Pain	9	8
Headache	11	3
Weakness	9	5
Nausea	7	6
Leg Pain	6	5
Hypersensitivity	8	2
Other	6	3
Constipation	3	5
Disorientation	6	2

Vomiting	3	4
Diarrhoea	2	2
Fainting	0	1

Table 7: Frequency of menstrual symptoms

Additional Medical Needs

Twenty-five participants (78.1%) reported that they had a medical condition. Epilepsy was the most commonly occurring condition and was reported by 4 participants. This was followed by cardiac issues (3 participants) and underactive thyroid (2 participants). Other reported medical conditions were: Attention Deficit Hyperactivity Disorder (ADHD), Oppositional Defiant Disorder (ODD), Aspergers Syndrome and Hayfever (1); Allergy to penicillin (1); Asthma (1); Asthma, Alopecia and sleep apnoea (1); Blood pressure and diarrhoea (1): Cerebral palsy, epilepsy and constipation (1); Coeliac disease and cardiac condition (1); Constipation (1); Diabetes and epilepsy (1); Enuresis (1); Marfin syndrome, scoliosis, arthritis, reduced vision and cardiac issue (1); Migraine (1); Mood swings and Schizophrenia (1); Renal condition (1); Spina Bifida (1); Underactive thyroid and enlarged heart (1).

Nine individuals (28.1%) reported two or more medical conditions. With regard to treatment for medical conditions, 65.6% of participants reported receiving treatment. This typically involved review and support by relevant professionals (59.2%). Medication was used to manage a medical condition by 56.3% of participants. Eltroxin (for underactive thyroid) and Tegretol (for seizure management) were the most

commonly prescribed medications. Both drugs were reported to be used by three individuals (9.4%).

	Intervention Group	Control Group
Two or more medical conditions	5	4
Medical Treatment	14	7
Review & Support by relevant professionals	12	6
Medication Use	14	4
Use of Eltroxin	2	1
Use of Tegretol	2	1

Table 8: Summary of Medication details Table 8: Summary of Medication details

10.2 Data Distribution

The Kolmogorov-Smirnov (K-S) test was used to see if the distribution of scores for test data differed significantly from a comparable normal distribution. Separate descriptive statistics were obtained for each of the treatment conditions i.e. the intervention group and the control group. If the test is significant ($p < .05$) then the distribution in question is significantly different from a normal distribution. There are two key ways in which a distribution can deviate from normal and these are referred to as skew (a lack of symmetry) and kurtosis (the degree to which scores cluster at the ends of the distribution). Kline (2005) stated that although there are few clear-cut standards for interpreting the absolute values of skew and kurtosis, some guidelines

have been proposed. These are based on computer simulation studies of estimation methods which have been used by Structural Equation Modelling (SEM) computer programs such as those by Curran, West and Finch (1996). Variables with absolute values of skew > 3 can be described as "extremely" skewed. Where absolute kurtosis values are > 10 there is a problem, whilst values > 20 suggest "extreme" kurtosis. Using these guidelines, the data for each of the treatment conditions can be interpreted as being within acceptable limits for skew and kurtosis. Results for the K-S tests are presented in table 9, along with skew and kurtosis values.

	Treatment Condition	**Statistic**	**df**	**Sig.**	**Skew**	**Kurtosis**
Pain Coping Strategies – Wellness Focused	Control	.174	14	.200	.625	-.006
	Intervention	.240	15	.020	1.289	2.426
Pain Coping Strategies – Illness Focused	Control	.260	14	.011	-2.65	-.519
	Intervention	.204	15	.093	2.37	.046
Pain Coping Strategies – Cognitive Focused	Control	N/A	14	.0001	N/A	N/A
	Intervention	.514	15	.0001	2.405	4.349

Pain Coping Strategies – Behaviour Focused	Control	.293	14	.002	1.047	-.081
	Intervention	.225	15	.040	.414	-.887
	Treatment Condition	**Statistic**	**df**	**Sig.**	**Skew**	**Kurtosis**
Pain Coping Scenarios – Wellness Focused	Control	.226	14	.052	.544	1.952
Pain Coping Scenarios – Wellness Focused	Intervention	.192	15	.143	.538	-.509
Pain Coping Scenarios – Illness Focused	Control	.254	14	.015	.586	-1.116
	Intervention	.300	15	.001	2.388	7.088
Pain Coping Scenarios – Cognitive Focused	Control	N/A	14	N/A	N/A	N/A
	Intervention	.514	15	.0001	2.405	4.349
Pain Coping Scenarios –	Control	.222	14	.059	.280	-.586

Behaviour Focused						
	Intervention	.253	15	.011	.756	-.486
Pain Knowledge	Control	.203	14	.124	.308	-.694
	Treatment Condition	**Statistic**	**df**	**Sig.**	**Skew**	**Kurtosis**
Pain Knowledge	Intervention	.181	17	.140	.012	-1.044
Pain Intensity – Participant	Control	.144	14	.200	-.060	-1.452
	Intervention	.158	18	.200	.092	-1.386
Pain Intensity – Parent	Control	.128	14	.200	.029	-.931
	Intervention	.201	13	.155	-.025	.138
Pain Interference – Participant	Control	.220	14	.064	.930	-.091
	Intervention	.137	16	.200	.192	-1.249
Pain Interference - Parent	Control	.212	14	.088	.518	-.468
	Intervention	.236	17	.013	1.040	.043

Pain self-efficacy	Control	.189	14	.191	.405	-1.199
	Intervention	.145	15	.200	.166	-.137
Pain catastrophizing	Control	.209	14	.100	1.234	.721
	Intervention	.221	16	.036	1.703	2.777

Table 9: Significance, skew and kurtosis of data distribution

10.3 Matching

An ANOVA was used to check that there were no large differences between the intervention and control groups at baseline. The outcome variables compared are presented in table 10. The results were non-significant for all variables ($p > .05$) which means that there were no differences between the treatment groups at baseline. As intervention sessions were run in groups, group was treated as a factor in the analysis to determine if participants were influencing each other. The results were non-significant ($p > .05$).

Primary	Pain Coping Strategies
	Pain Coping Scenarios
	Pain Knowledge
Secondary	Pain Intensity
	Pain Interference

	Pain Self-Efficacy
	Parental Pain Catastrophizing

Table 10: Outcome variables compared at baseline

10.4 Descriptive overview of the data

Table 11 presents the mean and standard deviation for each of the primary and secondary outcome variables across the five assessed time points, for both treatment conditions. This table enables us to see if the data at each of the five time points is moving in the expected direction, based on the intervention. Graphs 1 – 15 provide a visual overview of the data.

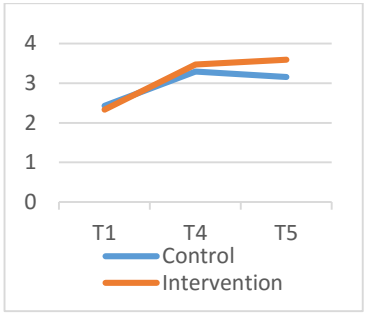
Primary Variables	**Cont.**	**Cont.**	**Cont.**	**Cont.**	**Cont.**	**Int.**	**Int.**	**Int.**	**Int.**	**Int.**
	T1	**T2**	**T3**	**T4**	**T5**	**T1**	**T2**	**T3**	**T4**	**T5**
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
Average Coping Strategy Effectiveness	1.56 (.37)	**N/A***	**N/A***	.94 (.43)	1.11 (.47)	1.45 (.40)	**N/A***	**N/A***	6.42 (23.11)	1.03 (.54)
Total Wellness Focused Coping Strategies Used	2.43 (1.65)	**N/A***	**N/A***	3.29 (1.94)	3.15 (1.91)	2.33 (1.80)	**N/A***	**N/A***	3.47 (1.81)	3.59 (2.03)

Total Illness Focused Coping Strategies Used	1.86 (1.23)	**N/A***	**N/A***	1.00 (1.11)	1.77 (1.24)	1.73 (1.10)	**N/A***	**N/A***	.94 (.97)	1.11 (.99)
Total Cognitive Coping Strategies Used	0 (0)	**N/A***	**N/A***	.07 (.27)	0.8 (.28)	.13 (.35)	**N/A***	**N/A***	.35 (.49)	.29 (.59)
Primary Variables	**Cont.**	**Cont.**	**Cont.**	**Cont.**	**Cont.**	**Int.**	**Int.**	**Int.**	**Int.**	**Int.**
	T1	**T2**	**T3**	**T4**	**T5**	**T1**	**T2**	**T3**	**T4**	**T5**
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
Total Behavioural Coping Strategies Used	4.29 (1.44)	**N/A***	**N/A***	4.21 (1.58)	4.85 (1.72)	3.93 (1.87)	**N/A***	**N/A***	4.06 (1.39)	4.41 (1.70)
Total Wellness Strategies Used during Scenarios	4.86 (2.14)	3.36 (1.55)	3.71 (2.33)	4.64 (1.82)	4.92 (3.01)	4.00 (2.45)	5.12 (2.89)	5.56 (2.90)	5.35 (2.21)	5.12 (2.42)
Total Illness Strategies	2.50 (1.60)	2.43 (2.03)	2.43 (1.40)	1.86 (1.10)	2.46 (1.81)	2.00 (2.24)	3.65 (2.98)	2.43 (1.40)	1.65 (1.90)	2.12 (1.76)

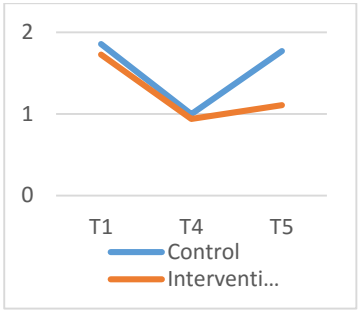
Used during Scenarios										
Total Cognitive Strategies Used during Scenarios	0 (0)	0 (0)	0 (0)	.57 (.65)	.38 (.51)	.13 (.35)	.47 (.87)	.69 (1.30)	.44 (.51)	.71 (1.16)
Total Behavioural Strategies	7.43 (2.14)	5.79 (2.15)	6.14 (2.51)	5.93 (1.69)	7.00 (2.92)	5.93 (2.37)	8.29 (3.41)	7.88 (2.28)	6.56 (2.03)	6.53 (2.00)
Primary Variables	**Cont.**	**Cont.**	**Cont.**	**Cont.**	**Cont.**	**Int.**	**Int.**	**Int.**	**Int.**	**Int.**
	T1	**T2**	**T3**	**T4**	**T5**	**T1**	**T2**	**T3**	**T4**	**T5**
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
Pain Knowledge Score	3.14 (.95)	2.07 (1.44)	2.36 (.84)	2.50 (1.40)	1.85 (1.62)	2.35 (1.66)	3.00 (1.90)	3.71 (1.40)	3.67 (1.78)	3.24 (1.75)
Secondary Variables										
Pain Intensity Participant	6.07 (2.89)	4.57 (2.65)	4.43 (2.31)	3.93 (3.45)	4.15 (3.65)	6.22 (2.37)	4.58 (2.57)	5.64 (2.50)	5.44 (3.51)	4.53 (3.57)
Pain Intensity Parent	5.29 (2.70)	**N/A***	**N/A***	3.92 (2.84)	4.38 (3.91)	4.38 (2.84)	**N/A***	**N/A***	3.25 (2.63)	3.54 (2.93)

Pain Interference Participant	20.29 (18.95)	**N/A***	**N/A***	9.43 (10.96)	10.00 (13.89)	26.44 (18.22)	**N/A***	**N/A***	23.94 (20.68)	16.47 (17.22)
Pain Interference Parent	20.29 (14.68)	**N/A***	**N/A***	25.07 (28.09)	13.77 (18.96)	25.24 (23.29)	**N/A***	**N/A***	25.50 (30.30)	17.2 (21.19)
Pain Self-efficacy	7.93 (2.73)	**N/A***	**N/A***	7.57 (1.50)	7.31 (1.93)	8.53 (2.17)	**N/A***	**N/A***	8.61 (2.57)	8.00 (2.45)
Pain Catastrophizing (Parent version)	4.79 (5.09)	**N/A***	**N/A***	5.62 (7.52)	4.31 (5.44)	8.00 (9.80)	**N/A***	**N/A***	11.13 (12.88)	8.80 (10.81)

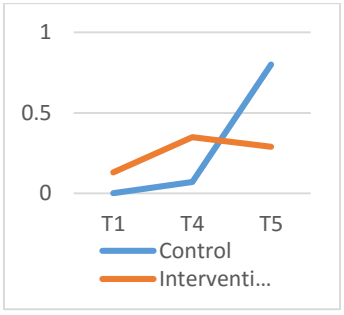
Table 11: Means and Standard Deviations (SD) for primary and secondary outcome variables * not administered at this time point



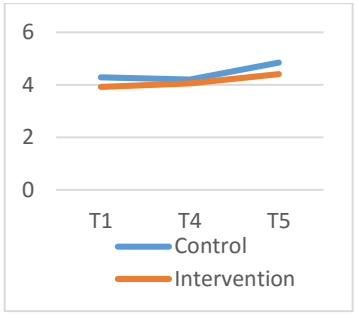
Graph 1: Total Wellness Focused Coping Strategies Used



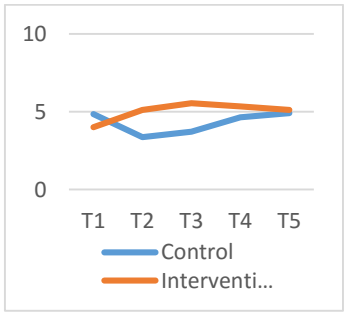
Graph 2: Total Illness Focused Coping Strategies Used



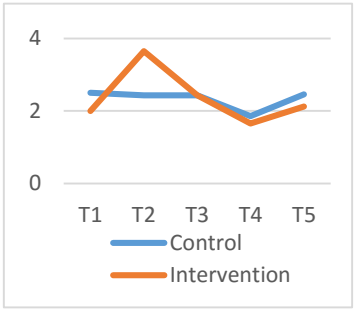
Graph 3: Total Cognitive Pain Coping Strategies Used



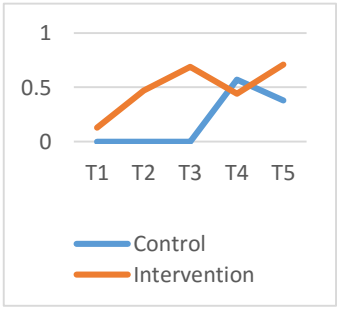
Graph 4: Total Behavioural Pain Coping Strategies Used



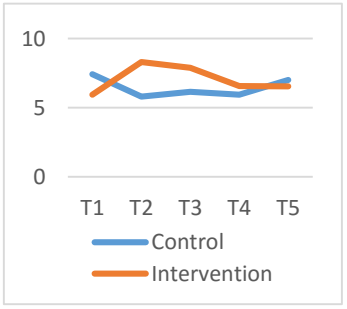
Graph 5: Total Wellness Focused Strategies Used during Scenarios



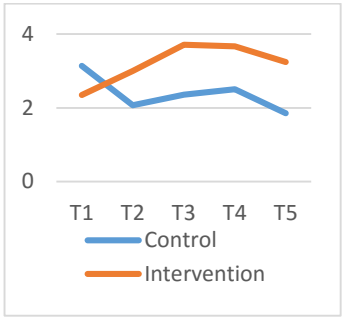
Graph 6: Total Illness Focused Strategies Used during Scenarios



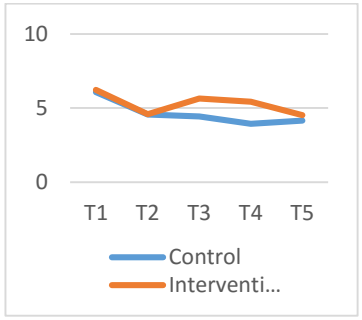
Graph 7: Total Cognitive Focused Strategies Used during Scenarios



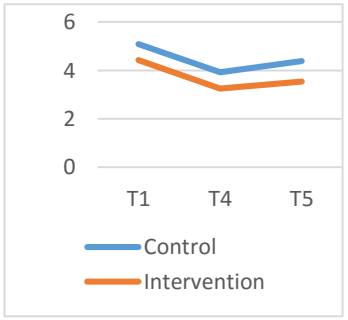
Graph 8: Total Behavioural Focused Strategies Used during Scenarios



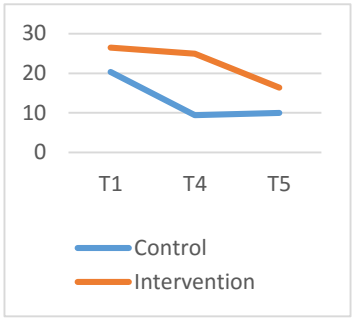
Graph 9: Pain Knowledge Scores



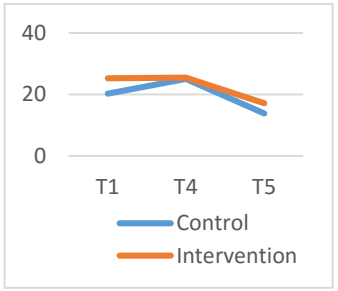
Graph 10: Pain Intensity – Participants



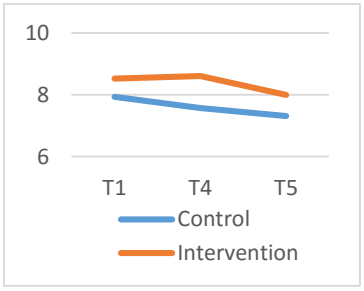
Graph 11: Pain Intensity – Parents



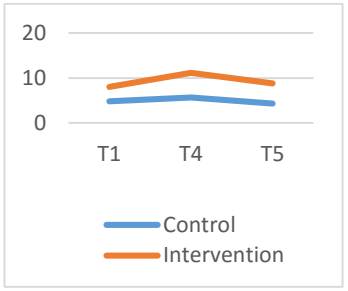
Graph 12: Pain Interference - Participants



Graph 13: Pain Interference – Parents



Graph 14: Pain Self-Efficacy



Graph 15: Parental Pain Catastrophizing

Looking firstly at the primary outcome variables, the mean number of wellness focused coping strategies used by both the control and intervention groups increased over time. The intervention group showed a continued small increase between post-intervention and follow-up while the control group showed a reduction. With regard to total illness focused coping strategies used, both groups showed a decrease in the number of strategies used, between baseline and post-intervention. Both groups showed an increase at follow-up although this was greater for the control group than for the intervention group. Both groups showed an increase in the total number of cognitive pain coping strategies used from baseline to post-intervention. The control group showed a further increase at follow-up although it should be noted that these values were negligible (< 1) and not clinically meaningful. Both groups showed a small increase in the number of behavioural pain coping strategies used over time.

The intervention group showed an increase in the number of wellness focused coping strategies used in everyday scenarios following delivery of the behavioural coping strategies component of the intervention programme (T2). A further increase was noted following delivery of the cognitive coping strategies component of the programme (T3). Scores for the control group declined over the course of the intervention programme. Participants in the intervention group showed an increase in the total number of illness focused coping strategies used in everyday scenarios, following the delivery of the behavioural strategies component of the intervention (T2). Participants in the intervention group used more cognitive coping strategies in everyday scenarios following delivery of the cognitive components of the intervention

programme (T3), than those in the control group. The intervention group showed an increase in the number of behavioural strategies used in everyday scenarios, relative to the control group, after delivery of the behavioural aspects of the intervention programme.

Participants in the intervention group showed a steady increase in their pain management knowledge scores following delivery of the behavioural and cognitive components of the intervention (T2 and T3). Those in the control group showed a steady decline in their pain management knowledge scores over time. Participants in both groups showed a decrease in their pain intensity scores over time. Parental ratings of this secondary outcome variable also declined over time, for both groups. Participants' ratings of pain interference also decreased over time. Parental ratings of participants' pain interference levels also showed a reduction over time. Participants in the intervention group showed a small increase in their ratings of pain self-efficacy, post-intervention, compared with those in the control group. Parental pain catastrophizing scores increased for both groups between baseline and post-intervention but returned to close to baseline levels by follow-up (T5).

10.5 Correlation Matrix

Variables that are conceptually linked should be correlated and this can be tested using a correlation matrix. Spearman's correlation coefficients were calculated for all variables in the study using the baseline sample. The intervention and control group

were grouped together and the rationale for this was that the groups were not significantly different from one another at baseline. The correlations are presented in table 12.

Looking at the relationships between variables, a number of significant correlations were observed. Specifically, significant positive correlations were observed between the number of behavioural and wellness-focused coping strategies used both generally and in specific everyday scenarios (rho = .73, n = 29, $p < .01$; rho = .63, n = 29, $p < .01$); between pain intensity (as rated by both participants and their parents) and the number of behavioural-focused coping strategies used generally (rho = .42, n = 29, $p < .05$; rho = .49, n = 25, $p < .05$) and between pain intensity as rated by participants and parents and their ratings of pain interference (rho = .42, n = 29, $p < .01$; rho = .67, n = 29, $p < .05$).

With regard to pain self-efficacy, positive correlations were observed with the number of illness-focused coping strategies used in everyday scenarios (rho = .37, n = 29, $p < .05$) and with pain interference as rated by both participants and parents (rho = .77, n = 29, $p < .01$; rho = .43, n = 29, $p < .05$).

Pain catastrophizing by parents was positively correlated with the number of illness-focused coping strategies used by participants in everyday scenarios (rho = .40, n = 28, $p < .05$) as well as parental ratings of their daughters pain intensity and pain

interference (rho = .44, n = 28, $p < .05$; rho = .43, n = 28, $p < .05$). Significant negative correlations were observed between the number of cognitive-focused pain coping strategies used generally and in specific everyday scenarios and, the number of illness-focused strategies used (rho = -.41, n = 29, $p < .05$; rho = -.41, n = 29, $p < .01$).

The relationships between pain knowledge and the pain coping variables were non-significant ($p > .05$) indicating that pain coping was not unduly influenced by pain knowledge.

	Variable	N =	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
1	**PCSU – E**	29	--															
2	**PCSU – W**	29	-.60**	--														
3	**PCSU – I**	29	.27	-.32	--													
4	**PCSU – C**	29	-.16	.22	-.41*	--												
5	**PCSU- B**	29	-.31	.73**	.34	-.08	--											
6	**PCS – W**	29	-.18	.44*	-.14	.08	.35	--										
7	**PCS – I**	29	.30	-.42*	.48**	-.08	-.11	-.35	---									
8	**PCS – C**	29	-.16	.22	-.41*	1.00**	-.08	.08	-.08	---								
9	**PCS - B**	29	.16	.02	.33	-.07	.26	.63**	.36	-.07	---							
10	**PK**	29	-.02	.06	.23	.15	.14	.29	-.17	.15	.03	---						
11	**PI – Participant**	29	.11	.17	.31	.10	.42*	-.10	.06	.10	.04	-.07	---					
12	**PI– Parent**	25	.08	.13	.47*	-.10	.49*	-.12	.36	-.10	.17	-.06	.61**	---				
13	**PInter – Participant**	29	-.24	.15	.20	.22	.31	-.09	.31	.22	.24	-.22	.42*	.36	---			
14	**PInter – Parent**	29	-.09	.11	.24	.02	.36	.04	.34	.02	.36	-.19	.34	.67**	.42*	---		
15	**PSE**	29	-.24	-.04	.11	.00	.05	-.14	.37*	.00	.23	-.30	.29	.15	.77**	.43*	---	
16	**PC**	28	-.22	.18	.10	.20	.15	-.24	.40*	.20	.00	-.14	.15	.44*	.33	.43*	.34	---

Note: PCSU - E = Pain Coping Strategy Effectiveness; PCSU – W = Pain Coping Strategies Used (Wellness Focused); PCSU – I = Pain Coping Strategies Used (Illness Focused); PCSU – C = Pain Coping Strategies Used (Cognitive); PCSU – B = Pain Coping Strategies Used (Behavioural); PCS – W = Pain Coping Scenarios (Wellness Focused Strategies Used); PCS – I = Pain Coping Scenarios (Illness Focused Strategies Used); PCS – C = Pain Coping Scenarios (Cognitive Strategies Used); PCS – B = Pain Coping Scenarios (Behavioural Strategies Used); PK = Pain Knowledge; PI – Participant = Pain Intensity (Participant); PI – Parent = Pain Intensity (Parent); PInter – Participant = Pain Interference (Participant); PInter – Parent = Pain Interference (Parent); PSE = Pain Self-Efficacy; PC = Pain Catastrophizing (Parent)

Statistical significance: * = $p < .05$; ** = $p < .01$ (2-tailed).

Table 12: Summary of correlations for primary and secondary outcome variables

10.6 Cronbach's Alpha

Table 13 contains the relevant Cronbach's Alpha values for scales used in the study. This is a measure of the internal consistency of these scales i.e. the extent to which test items are measuring the same underlying construct. Ideally, Cronbach's alpha should be above .7 (DeVellis, 2003) and in line with the published Cronbach's alpha for the scales used.

Outcome Measures	**Measure**	**Cronbach's Alpha**	**95% Confidence Interval (C.I.)**
Primary	Pain Coping Strategies Questionnaire	_	-
	Pain Coping Scenarios Questionnaire	_	-
	Pain Knowledge Questionnaire	.48	.13 - .72

Secondary	Pain Intensity Questionnaire	_	-
	Pain Interference Questionnaire (Participants)	.77	.63 - .88
	Pain Interference Questionnaire (Parents)	.83	.72 - .90
	Pain Self-Efficacy Questionnaire	.74	.56 - .87
	Parental Pain Catastrophizing Questionnaire	.90	.84 - .95

Table 13: Cronbach's Alpha values for study measures

Cronbach's Alpha could not be calculated for the Pain Intensity Questionnaire, the Pain Coping Strategies Questionnaire or the Pain Coping Scenarios Questionnaire as these questionnaires are not ordinal numerical scales. Ideally, test-retest reliability would be assessed by re-administering questionnaires to participants e.g. after one month, however this was not possible as the intervention took place between baseline (T1) and the second measurement point (T2), so a change was anticipated. Inter-rater reliability was ensured by having questionnaires administered by the same researcher across assessment time-points T1 (baseline) – T3 and T5 (follow-up). Assessment measures at T4 (post-intervention) were administered by a second researcher, familiar with the questionnaires and the study, to reduce the risk of socially desirable responding by participants.

There was strong internal consistency noted for the pain interference, pain self-efficacy and the pain-catastrophizing scales with all Cronbach's alpha values above .7. Published Cronbach's Alpha values were unavailable for the scales used in this study as no psychometric analyses were conducted in the study by McManus & McGuire (2014), which previously used these measures. The Cronbach's Alpha value for the pain knowledge questionnaire was .48 however this is likely to have been influenced by the small number of items on the scale (n = 7).

10.7 Summary of Main Findings

10.7.1 Hypothesis 1

Participation in the menstrual pain management group will result in an increase in participants' pain management knowledge and use of wellness-focused pain coping strategies. Changes will be maintained at follow-up.

		Intervention Group				**Control Group**		
Time period	**N**	**M**	**SD**	**95% C.I.**	**N**	**M**	**SD**	**95% C.I.**
Baseline (T1)	17	2.35	1.66	1.56 – 3.14	14	3.14	.95	2.64 - 3.64
T2	17	3.00	1.90	2.09 – 3.91	14	2.07	1.44	1.32 – 2.82
T3	17	3.71	1.40	3.04 – 4.38	14	2.36	.84	1.92 – 2.80

Post-intervention (T4)	18	3.67	1.78	2.85 – 4.49	14	2.50	1.40	1.77 – 3.23
Follow-up (T5)	17	3.24	1.75	2.41 – 4.07	13	1.85	1.62	.97 – 2.73

Table 14 - Pain knowledge scores for Intervention and Control Groups across time periods

Mixed between-within subjects analysis of variance (ANOVA) were conducted to assess the impact of participation in the menstrual pain management group on participants' scores on the pain management knowledge questionnaire and on wellness-focused pain coping strategies used, across time periods.

With regard to pain management knowledge, there was a significant interaction between group and time, Wilks' Lambda = .73, F (1, 29) = 10.89, p = .003, partial eta squared = .27. This indicates that the change in pain management knowledge over time was different for the two treatment groups (intervention and control). The intervention group showed an increase in their pain management knowledge over time whilst those in the control group showed a reduction in their scores, although in both cases these changes were small in size. There was no main effect for time, Wilks' Lambda = .96, F (1, 29) = 1.23, p = .276, partial eta squared = .04. The main effect comparing the groups was not significant, F (1, 29) = .147, p = .70, partial eta squared = .005. This was as a result of the control groups pain management knowledge scores starting

higher and ending lower than those of the intervention group so that averaged over time, both groups had the same mean.

Pain knowledge scores across the two treatment conditions were also compared between baseline and follow-up. An interaction effect was again found between programme type and time (Wilks' Lambda = .72, F (1, 27) = 10.68, p = .003, partial eta squared = .28) but no main effect was found for time or group (Wilks' Lambda = .96, F (1, 27) = 1.03, p = .319, partial eta squared = .04; F (1, 27) = .488, p = .49, partial eta squared = .018).

		Intervention Group				**Control Group**		
Time period	**N**	**M**	**SD**	**95% C.I.**	**N**	**M**	**SD**	**95% C.I.**
Baseline (T1)	15	2.33	1.80	1.42 – 3.24	14	2.43	1.65	1.57 – 3.29
Post-intervention (T4)	17	3.47	1.81	2.65 – 4.29	14	3.29	1.94	2.27 – 4.31
Follow-up (T5)	17	3.59	2.03	2.62 – 4.56	13	3.15	1.91	2.11 – 4.19

Table 15 – Wellness-focused coping strategies used by the Intervention and Control Groups across time periods

Looking at wellness-focused pain coping strategies used, there was no significant interaction between programme type and time between baseline (T1) and post-intervention (T4), Wilks' Lambda = .99, F (1, 27) = .15, p = .70, partial eta squared = .006. This indicates that there was the same change in the number of wellness-focused coping strategies used over time for the two groups (control and intervention). There was a small main effect for time, Wilks' Lambda = .78, F (1, 27) = 7.79, p = .01, partial eta squared = .22, with both groups showing an increase in the number of wellness-focused coping strategies used over time. The main effect comparing the groups was not significant, F (1, 27) = .006, p = .94, partial eta squared = 0. There was no difference in the effectiveness of the two approaches (participation in the menstrual pain management group versus treatment as usual) in increasing the use of wellness-focused coping strategies which participants reported that they used to cope with menstrual pain.

Wellness-focused coping strategies used across the two treatment conditions were also compared between baseline (T1) and follow-up (T5) and the results were unchanged (Wilks' Lambda for interaction effect = .98, F (1, 26) = .67, p = .42, partial eta squared = .03). Again, there was a small main effect for time (Wilks' Lambda = .86, F (1, 26) = 4.41, p = .05, partial eta squared = .15) but not for group (F (1, 26) = .13, p = .73, partial eta squared = .005).

		Intervention Group				Control Group		
Time period	**N**	**M**	**SD**	**95% C.I.**	**N**	**M**	**SD**	**95% C.I.**
Baseline (T1)	15	4.00	2.45	2.76 – 5.24	14	4.86	2.14	3.74 – 5.98
T2	17	5.12	2.89	3.74 – 6.48	14	3.36	1.55	2.55 – 4.17
T3	16	5.56	2.90	4.14 – 6.98	14	3.71	2.33	1.70 – 3.16
Post-intervention (T4)	17	5.35	2.21	4.30 – 6.40	14	4.64	1.82	3.68 – 5.60
Follow-up (T5)	17	5.12	2.42	3.97 – 6.27	13	4.92	3.01	3.28 – 6.56

Table 16 – Wellness-focused coping strategies used by the Intervention and Control Groups in real-life scenarios, across time periods

Looking at the total number of wellness-focused coping strategies used by participants in real-life scenarios in which they experience menstrual pain, there was no significant interaction between group and time, Wilks' Lambda = .88, F (1, 27) = 3.68, p = .07, partial eta squared = .12. There was no main effect for time, Wilks' Lambda = .93, F (1, 27) = 2.10, p = .16, partial eta squared = .07. The main effect comparing the groups was not significant, F (1, 27) = .001, p = .98, partial eta squared = 0, suggesting there was no overall difference in the effectiveness of the two approaches (participation in the menstrual pain management group versus treatment as usual) in increasing the

number of wellness-focused coping strategies which participants reported that they used to cope with menstrual pain in real-life scenarios.

Wellness-focused coping strategies used across the two treatment conditions were also compared between baseline (T1) and follow-up (T5) and the results were unchanged (Wilks' Lambda for interaction effect = .90, F (1, 26) = 3.00, p = .10, partial eta squared = .10; Wilks' Lambda for main effect of time = .94, F (1, 26) = 1.63, p = .21, partial eta squared = .06; Main effect for group F (1, 26) = .13, p = .73, partial eta squared = .005).

10.7.2 Hypothesis 2

Participants' self-ratings of pain intensity will be unchanged following participation in the menstrual pain management group. There will be no effect on parental ratings of this same construct. Participation in the menstrual pain management group will result in a reduction in participants' ratings of pain interference and parental ratings will show a similar trend. Results will be unchanged at follow up.

		Intervention Group				**Control Group**		
Time period	**N**	**M**	**SD**	**95% C.I.**	**N**	**M**	**SD**	**95% C.I.**
Baseline (T1)	18	6.22	2.37	5.13 – 7.31	14	6.07	2.89	4.55 – 7.59

T2	12	4.58	2.57	3.12 – 6.04	14	4.57	2.65	3.18 – 5.96
T3	11	5.64	2.50	4.16 – 7.12	14	4.43	2.31	3.22 – 5.64
Post-intervention (T4)	18	5.44	3.51	3.81 – 7.07	14	3.93	3.45	2.12 – 5.74
Follow-up (T5)	17	4.53	3.57	2.83 – 6.23	13	4.15	3.65	2.17 – 6.13

Table 17 – Participant pain intensity scores for the Intervention and Control Groups across time periods

Again, mixed between-within subjects analysis of variance (ANOVA's) were conducted to assess the impact of participation in the menstrual pain management group on participants' ratings of pain intensity and pain interference, between baseline (T1) and post-intervention (T4).

With regard to participants self-ratings of pain intensity, there was no significant interaction between programme type and time, Wilks' Lambda = .96, F (1, 30) = 1.35, p = .255, partial eta squared = .04. This indicates that there was no difference in the change in pain intensity scores over time for the two groups (control and intervention). There was a small main effect for time, Wilks' Lambda = .83, F (1, 30) = 6.17, p = .02, partial eta squared = .17, with both groups showing a reduction in pain intensity over time. The main effect comparing the groups was not significant, F (1, 30) = .81, p = .38, partial eta squared = .03 which suggests that there was no difference in the

effectiveness of the two approaches (participation in the menstrual pain management group versus treatment as usual) in reducing participants' pain intensity scores.

Participants pain intensity scores across the two treatment conditions were also compared between baseline (T1) and follow-up (T5) and the results were unchanged (Wilks' Lambda for interaction effect = 1.00, F (1, 28) = .003, p = .95, partial eta squared = .00; Wilks' Lambda for main effect of time = .81, F (1, 28) = 6.55, p = .02, partial eta squared = .19; Main effect for group F (1, 28) = .128, p = .72, partial eta squared = .005).

		Intervention Group				**Control Group**		
Time period	**N**	**M**	**SD**	**95% C.I.**	**N**	**M**	**SD**	**95% C.I.**
Baseline (T1)	17	26.44	18.22	17.52 – 35.36	13	20.29	18.95	10.36 – 30.22
Post-intervention (T4)	18	23.94	20.68	14.39 – 33.49	14	9.43	10.96	3.69 – 15.17
Follow-up (T5)	17	16.47	17.22	8.28 – 24.66	13	10.00	13.89	2.45 – 17.55

Table 18 – Participant pain interference scores for the Intervention and Control Groups across time periods

Looking at participants self-ratings of pain interference, again, there was no significant interaction between programme type and time, Wilks' Lambda = .90, F (1, 28) = 3.07, p = .09, partial eta squared = .10 i.e. there was no difference in the change in pain interference scores over time for the two groups (control and intervention). There was a small main effect for time, Wilks' Lambda = .84, F (1, 28) = 5.36, p = .03, partial eta squared = .16, with both groups showing a reduction in pain interference over time. The main effect comparing the groups was not significant, F (1, 28) = 3.23, p = .08, partial eta squared = .10. This suggests that there was no difference in the effectiveness of the two approaches (participation in the menstrual pain management group versus treatment as usual) in reducing participants' pain interference scores.

Participants pain interference scores across the two treatment conditions were also compared between baseline (T1) and follow-up (T5) and the results were unchanged (Wilks' Lambda for interaction effect = 1.00, F (1, 27) = .001, p = .97, partial eta squared = .00; Wilks' Lambda for main effect of time = .75, F (1, 27) = 9.00, p = .006, partial eta squared = .25; Main effect for group F (1, 27) = 1.24, p = .28, partial eta squared = .04).

		Intervention Group				**Control Group**		
Time period	**N**	**M**	**SD**	**95% C.I.**	**N**	**M**	**SD**	**95% C.I.**
Baseline (T1)	13	4.38	2.84	2.83 – 5.93	14	5.29	2.70	3.87 – 6.71

Post-intervention (T4)	12	3.25	2.63	1.76 – 4.74	13	3.92	2.84	2.38 – 5.46
Follow-up (T5)	15	3.54	2.93	1.95 – 5.13	13	4.38	3.91	2.26 – 6.50

Table 19 – Parent ratings of participant pain intensity scores for the Intervention and Control Groups across time periods

Parental ratings of their daughter's pain intensity and pain interference were also assessed between baseline (T1) and post-intervention (T4). In terms of pain intensity, there was no significant interaction between programme type and time, Wilks' Lambda = 1.00, F (1, 22) = .00, p = .99, partial eta squared = .00. This indicates that there was no difference in the change in parents' ratings of their daughter's pain intensity over time for the two groups (control and intervention). There was no main effect for time or group, Wilks' Lambda = .86, F (1, 22) = 3.62, p = .07, partial eta squared = .14; F (1, 22) = .51, p = .48, partial eta squared = .02. These results were unchanged at follow-up (Wilks' Lambda for interaction effect = .997, F (1, 22) = .069, p = .80, partial eta squared = .003; Wilks' Lambda for main effect of time = .94, F (1, 22) = 1.54, p = .23, partial eta squared = .07; Main effect for group F (1, 22) = .365, p = .55, partial eta squared = .016).

		Intervention Group				**Control Group**		
Time period	**N**	**M**	**SD**	**95% C.I.**	**N**	**M**	**SD**	**95% C.I.**

Baseline (T1)	17	25.24	23.29	14.17 – 36.31	14	20.29	20.29	12.60 – 27.98
Post-intervention (T4)	17	25.50	30.30	11.50 – 39.50	13	25.07	25.07	10.35 – 39.79
Follow-up (T5)	15	17.20	21.19	6.48 – 27.92	13	13.77	13.77	3.46 – 24.08

Table 20 – Parent ratings of participant pain interference scores for the Intervention and Control Groups across time periods

With regard to parent ratings of participants' pain interference, standard deviations were noted to be high due to the large degree of variability in responses. There was no significant interaction between programme type and time, Wilks' Lambda = .96, *F* (1, 29) = 1.29, *p* = .27, partial eta squared = .43, suggesting that there was no difference in the change in parents' ratings of participants pain interference over time for the two groups (control and intervention). There was no main effect for time or group, Wilks' Lambda = 1.00, *F* (1, 29) = .009, *p* = .93, partial eta squared = .00; *F* (1, 29) = .005, *p* = .94, partial eta squared = .00. These results were also unchanged at follow-up (Wilks' Lambda for interaction effect = 1.00, *F* (1, 26) = .002, *p* = .97, partial eta squared = .00; Wilks' Lambda for main effect of time = .90, *F* (1, 26) = 2.81 *p* = .11, partial eta squared = .10; Main effect for group *F* (1, 26) = .33, *p* = .57, partial eta squared = .013).

10.7.3 Hypothesis 3

Participation in the menstrual pain management group will result in an increase in the use of behavioural coping strategies and participants will use more behavioural, than cognitive, coping strategies to manage their menstrual pain. These findings will be unchanged at follow-up.

		Intervention Group				**Control Group**		
Time period	**N**	**M**	**SD**	**95% C.I.**	**N**	**M**	**SD**	**95% C.I.**
Baseline (T1)	15	3.93	1.87	2.98 – 4.88	14	4.29	1.44	3.54 – 5.04
Post-intervention (T4)	17	4.06	1.39	3.40 – 4.72	14	4.21	1.58	3.38 – 5.04
Follow-up (T5)	15	4.41	1.70	3.60 – 5.22	13	4.85	1.72	3.91 – 5.79

Table 21 – Behavioural pain coping strategies used by the Intervention and Control Groups across time periods

Mixed between-within subjects analysis of variance (ANOVA) were again conducted to assess the impact of participation in the menstrual pain management group on participants' use of cognitive and behavioural pain coping strategies between baseline (T1) and post-intervention (T4). Looking firstly at behavioural pain coping strategies used, there was no significant interaction between programme type and time, indicating no difference in the change in participants use of behavioural pain coping

strategies over time for the control and intervention groups (Wilks' Lambda = 1.00, F (1, 27) = .01, p = .92, partial eta squared = .00). There was no main effect for time or group (Wilks' Lambda = 1.00, F (1, 27) = .01, p = .92, partial eta squared = .00; F (1, 27) = .48, p = .50, partial eta squared = .02) and these results were unchanged at follow-up (Wilks' Lambda = 1.00, F (1, 26) = .00, p = .99, partial eta squared = .00; Wilks' Lambda = .96, F (1, 26) = 1.21, p = .28, partial eta squared = .04; F (1, 26) = .80, p = .38, partial eta squared = .03).

		Intervention Group				**Control Group**		
Time period	**N**	**M**	**SD**	**95% C.I.**	**N**	**M**	**SD**	**95% C.I.**
Baseline (T1)	15	5.93	2.37	4.73 – 7.13	14	7.43	2.14	6.31 – 8.55
T2	17	8.29	3.41	6.67 – 9.91	14	5.79	2.15	4.66 – 6.92
T3	16	7.88	2.28	6.76 – 9.00	14	6.14	2.51	4.83 – 7.45
Post-intervention (T4)	17	6.56	2.03	5.56 – 7.56	14	5.93	1.69	5.05 – 6.81
Follow-up (T5)	17	6.53	2.00	5.58 – 7.48	13	7.00	2.92	5.42 – 8.58

Table 22 – Behavioural pain coping strategies used by the Intervention and Control Groups in real-life scenarios, across time periods

With regard to participants' use of behavioural pain coping strategies in real-life scenarios in which they experience menstrual pain, there was a significant interaction between programme type and time; Wilks' Lambda = .79, F (1, 26) = 6.87, p = .01, partial eta squared = .21. Participants in the intervention condition showed an increase in their reported use of behavioural pain coping strategies in real-life scenarios over time whilst those in the control group showed a decrease. There were no main effects for time or group however, Wilks' Lambda = .98, F (1, 26) = .51, p = .48, partial eta squared = .02; F (1, 26) = 1.3, p = .27, partial eta squared = .05

There was no significant interaction effect at follow-up; Wilks' Lambda = .95, F (1,26) = 1.49, p = .23, partial eta squared = .05). The main effects for time and group were unchanged at follow-up (Wilks' Lambda = .99, F (1, 26) = .05, p = .83, partial eta squared = .002; F (1, 26) = 1.49, p = .23, partial eta squared = .05).

		Intervention Group			**Control Group**			
Time period	**N**	**M**	**SD**	**95% C.I.**	**N**	**M**	**SD**	**95% C.I.**
Baseline (T1)	15	.13	.35	-.05 - .31	14	0	0	0
Post-intervention (T4)	17	.35	.49	.12 - .58	14	.07	.27	-.07 - .21
Follow-up (T5)	17	.29	.59	.01 - .57	13	.08	.28	-.07 - .23

Table 23 - Cognitive pain coping strategies used by the Intervention and Control Groups across time periods

Looking at cognitive pain coping strategies, there was no significant interaction between programme type and time, Wilks' Lambda = .97, F (1, 27) = .97, p = .33, partial eta squared = .04. This indicates that there was no difference in the change in participants' use of cognitive coping strategies over time for the control and intervention groups. There was a large main effect for time, Wilks' Lambda = .86, F (1, 27) = 4.33, p = .047, partial eta squared = .14, with both groups showing an increase in the use of cognitive coping strategies over time. As can be seen from the table, these increases are not sufficiently large to be clinically meaningful. The main effect comparing the groups was not significant, F (1, 27) = 3.53, p = .07, partial eta squared = .12, suggesting no difference in the effectiveness of the two approaches (participation in the menstrual pain management group versus treatment as usual) in increasing the use of cognitive pain coping strategies.

Scores across the two treatment conditions were also compared between baseline and follow-up and results were unchanged. (Wilks' Lambda = .99, F (1, 26) = .38, p = .55, partial eta squared = .01; Wilks' Lambda = .93, F (1, 26) = 1.90, p = .18, partial eta squared = .07; F (1, 26) = 3.18, p = .09, partial eta squared = .11).

		Intervention Group				**Control Group**		
Time period	**N**	**M**	**SD**	**95% C.I.**	**N**	**M**	**SD**	**95% C.I.**
Baseline (T1)	15	.13	.35	-.05 - .31	14	0	0	0

T2	17	.47	.87	.05 - .86	14	0	0	0
T3	16	.69	1.30	.05 – 1.33	14	0	0	0
Post-intervention (T4)	17	.44	.51	.19 - .69	14	.57	.65	.23 - .91
Follow-up (T5)	17	.71	1.16	.16 – 1.26	13	.38	.51	.10 - .66

Table 24 – Cognitive pain coping strategies used by the Intervention and Control Groups in real-life scenarios, across time periods

Looking at participants use of cognitive pain coping strategies in real-life scenarios in which they experience menstrual pain, there was no significant interaction between programme type and time (baseline T1 and post-intervention T4); Wilks' Lambda = .96, F (1, 26) = .97, p = .34, partial eta squared = .04. There was a significant main effect for time; Wilks' Lambda = .59, F (1, 26) = 18.16, p = .00, partial eta squared = .41. Participants in both conditions showed an increase in their reported use of cognitive pain coping strategies in real-life scenarios, over time. Again, the increases in the number of cognitive strategies used were not sufficiently large to be clinically meaningful. There was no main effect for group, F (1, 26) = .07, p = .79, partial eta squared = .003 suggesting no overall difference in the effectiveness of the two conditions (participation in the menstrual pain management group versus treatment as usual) in increasing the reported use of cognitive coping strategies to manage menstrual pain in real-life scenarios.

These results were again unchanged at follow-up (Wilks' Lambda for interaction effect = .97, F (1, 26) = .71, p = .41, partial eta squared = .03; Wilks' Lambda for main effect of time = .73, F (1, 26) = 9.81, p = .004 partial eta squared = .27; Main effect for group F (1, 26) = 1.82, p = .19, partial eta squared = .07).

At baseline, participants in the intervention and control groups used more behavioural than cognitive coping strategies, both in general and in real-life scenarios. This trend remained unchanged over time.

10.7.4 Hypothesis 4

Participants' ratings of pain intensity, pain interference, pain knowledge and pain coping strategies used at baseline will be affected by parental pain-catastrophizing and participants pain self-efficacy scores.

a. Parental pain-catastrophizing

Hierarchical multiple regression was used to assess the conditions under which these process variables interacted with the intervention condition as predictors in the main effect analyses. Firstly, a correlation was conducted examining pain intensity and potential predictor variables including participants age, level of cognitive ability, age at onset of menstruation, frequency and duration of menstruation, frequency of menstrual symptoms, history of gynaecological problems and other medical

conditions and use of medication. As there were no significant correlations between pain intensity and these predictor variables, regression analysis was not conducted for this variable.

Correlations between the predictor variables and pain interference, pain knowledge and pain coping strategies used were also examined. Variables for which there was a significant correlation were subjected to hierarchical multiple regression with significant variables entered at step one and parental pain-catastrophizing entered at step two.

The ability of parental pain catastrophizing to predict pain interference (as rated by participants) after controlling for the influence of frequency of menstrual pain was examined first. Preliminary analyses were conducted to ensure no violation of the assumptions of normality, linearity, multi-collinearity and homoscedasticity. Frequency of menstrual pain was entered at step one, explaining 13% of the variance in participants' ratings of pain interference. After entry of parental pain-catastrophizing at step two the total variance explained by the model as a whole was 18.3%, F (2,26) = 2.90, p = .073. Parental pain catastrophizing explained an additional 5.5% of the variance in participants' ratings of pain interference, after controlling for frequency of menstrual pain, *R* squared change = .055, *F* change (1, 26) = 1.735, *p* = .199. In the final model, neither of the variables were statistically significant (*beta* = .24, *p* >.05). There was no evidence that parental pain-

catastrophizing had any influence on how frequency of pain affects ratings of pain interference.

Hierarchical multiple regression was also used to assess the ability of parental pain catastrophizing to predict parental ratings of participants' pain interference, after controlling for the number of days missed from school. Number of days missed in the previous three months was entered at step one and explained 13% of the variance in parents rating of participants' pain interference. After entry of parental pain-catastrophizing at step two, the total variance explained by the model as a whole was 40.1%, F (2, 27) = 9.05, p < .001. Parental pain catastrophizing explained an additional 27% of the variance, after controlling for number of days missed from school, *R* squared change = .272, *F* change (1, 27) = 12.27, $p < .002$. In the final model, parental pain-catastrophizing was statistically significant (*beta* = .53, $p < .005$) meaning that number of days missed in the previous three months does not predict as well as the two variables (number of days missed in the previous three months and parental pain-catastrophizing) together. For each one point increase in parental pain catastrophizing scores, parental ratings of participants' pain interference increased by .53 standard deviations.

The ability of parental pain catastrophizing to predict use of wellness-focused pain coping strategies was assessed after controlling for participants age at commencement of menstruation. The rationale for this enquiry was that a significant correlation was found between pain interference and age at commencement of

menstruation. Age at commencement of menstruation was entered at step one as a significant correlation was found. This explained 22% of the variance in wellness-focused pain coping strategies used. After entry of parental pain catastrophizing at step two, the total variance explained by the model as a whole was 24.2%, F (2,25) = 3.990, p = .031. Parental pain catastrophizing explained an additional 2.3% of the variance, after controlling for age at first menstruation, *R* squared change = .023, *F* change (1, 25) = .769, *p* = .389. In the final model, age at commencement of menstruation was statistically significant (*beta* = -.484, *p* = .011). For each one point increase in the age at commencement of menstruation, the use of wellness focused pain coping strategies decreased by .484 standard deviations.

The predicative impact of parental pain catastrophizing on the use of illness-focused pain coping strategies was assessed after controlling for frequency of menstrual pain and use of medication. Frequency of menstrual pain and use of medication were entered at step one and explained 17% of the variance in the use of illness focused pain coping strategies. After entry of parental pain catastrophizing at step two, the total variance explained by the model as a whole was 24.3%, F (3,24) = 2.571, p = .078. Parental pain catastrophizing explained an additional 6.9% of the variance, after controlling for frequency of menstrual pain, *R* squared change = .069, *F* change (1,24) = 2.197, *p* = .151. In the final model, none of the variables were statistically significant (*beta* = .382, *p* > .05).

Use of behavioural pain coping strategies predicted by parental pain catastrophizing was assessed after controlling for participants age. This variable was entered at step one (because a significant correlation was found) and explained 20% of the variance in the use of behavioural pain coping strategies. After entry of parental pain catastrophizing at step two, the total variance explained by the model as a whole was 27.1%, F (2,25) = 4.64, p = .019. Parental pain catastrophizing explained an additional 7.1% of the variance, after controlling for age, *R* squared change = .071, *F* change (1, 25) = 2.450, *p* = .130. In the final model, age was statistically significant (*beta* = -.415, *p* = .023). For each one point increase in participants' age, the use of behavioural pain coping strategies decreased by .415 standard deviations.

The predicative impact of parental pain catastrophizing on pain knowledge was assessed after controlling for average length of menstruation. Length of menstruation was entered at step one and explained 13% of the variance in pain knowledge scores. After parental pain catastrophizing was entered at step two, the total variance explained by the model was 13.2%, F (2.27) = 2.046, p = .149. Parental pain catastrophizing only explained an additional .04% of the variance after controlling for length of menstruation, *R* squared change = .004, *F* change (1, 27) = .123, *p* = .728. In the final model, neither of the variables was statistically significant (p > .05).

b. Pain self-efficacy

As with parental pain-catastrophizing, the same process was applied to analyse the effect of pain self-efficacy on participants ratings of pain intensity, pain interference, pain knowledge and pain coping strategies used. Variables for which there was a significant correlation were subjected to hierarchical multiple regression with significant variables entered at step one and pain self-efficacy entered at step two. As there were no significant correlations found between pain intensity and the predictor variables described previously, regression analysis was not conducted for this variable.

Hierarchical multiple regression was used to assess the ability of pain self-efficacy to predict pain interference (as rated by participants) after controlling for the influence of frequency of menstrual pain. Preliminary analyses were conducted to ensure no violation of the assumptions of normality, linearity, multi-collinearity and homoscedasticity. Frequency of menstrual pain was entered at step one, explaining 13% of the variance in participants' ratings of pain interference. After entry of pain self-efficacy at step two, the total variance explained by the model as a whole was 54.1%, F (2,26) = 15.302, p < .001. Pain self-efficacy explained an additional 40.7% of the variance in participants' ratings of pain interference, after controlling for frequency of menstrual pain, *R* squared change = .407, *F* change (1, 26) = 23.012, *p* = < .001. In the final model, pain self-efficacy was statistically significant (*beta* = .681, *p* < .001). As pain self-efficacy ratings increased, so too did participants pain interference scores.

Hierarchical multiple regression was also used to assess the ability of pain self-efficacy to predict parental ratings of participants' pain interference, after controlling for the number of days missed from school. Number of days missed in the previous three months was entered at step one and explained 8% of the variance in parents rating of participants' pain interference. After entry of pain self-efficacy at step two, the total variance explained by the model as a whole was 16.2%, F (2,26) = 2.515, p = 1.00. Pain self-efficacy explained an additional 7.8% of the variance, after controlling for number of days missed from school, *R* squared change = .078, *F* change (1, 26) = 2.431, *p* = .131 In the final model, neither of the variables was statistically significant (p > .05).

The ability of pain self-efficacy to predict use of wellness-focused pain coping strategies was assessed after controlling for participants age at commencement of menstruation. Age at commencement of menstruation was entered at step one as a significant correlation was found. This explained 21% of the variance in wellness-focused pain coping strategies used. After entry of pain self-efficacy at step two, there was no change in the total variance explained by the model, F (2,26) = 3.459 p = .047. In the final model, age at commencement of menstruation was statistically significant (*beta* = -2.620, *p* = .014). For every one point increase in the age at commencement of menstruation, participants' use of wellness focused pain coping strategies decreased by 2.620 standard deviations.

The predicative impact of pain self-efficacy on the use of illness-focused pain coping strategies was assessed after controlling for frequency of menstrual pain and use of medication. Frequency of menstrual pain and use of medication were entered at step one and explained 29% of the variance in the use of illness focused pain coping strategies. After entry of pain self-efficacy at step two, the total variance explained by the model as a whole remained unchanged, F (3,25) = 3.403, p = .033. Pain self-efficacy explained an additional .02% of the variance, after controlling for frequency of menstrual pain and medication use, *R* squared change = .002, *F* change (1,25) = .085, *p* = .773. In the final model, both frequency of menstrual pain and medication use were statistically significant (*beta* = -1.999, *p* = .057; *beta* = 2.182, *p* = .039). For every one point increase in the frequency of menstrual pain, use of illness focused coping strategies decreased by 1.999 standard deviations. If participants used medication to manage their menstrual pain, their use of illness focused pain coping strategies increased by 2.182 standard deviations.

Use of behavioural pain coping strategies predicted by pain self-efficacy was assessed after controlling for participants age. This variable was entered at step one (because a significant correlation was found) and explained 20% of the variance in the use of behavioural pain coping strategies. After entry of pain self-efficacy at step two, the total variance explained by the model as a whole was 25.9%, F (2,26) = 4.553, p = .020. Pain self-efficacy explained an additional 5.6% of the variance, after controlling for age, *R* squared change = .056, *F* change (1, 26) = 1.956, *p* = .174. In the final model, age was statistically significant (*beta* = -.548, *p* = .006). For every

additional year in the age of participants, the use of behavioural pain coping strategies decreased by .548 standard deviations.

The predicative impact of pain self-efficacy on pain knowledge was assessed after controlling for average length of menstruation, in days. Length of menstruation was entered at step one and explained 11% of the variance in pain knowledge scores. After pain self-efficacy was entered at step two, the total variance explained by the model was 18.1%, F (2.26) = 2.871, p =.075. Pain self-efficacy explained an additional 7.5% of the variance after controlling for length of menstruation, *R* squared change = .075, *F* change (1, 26) = 2.372, *p* = .136. In the final model, neither of the variables was statistically significant (p > .05).

CHAPTER 11: QUALITATIVE RESULTS

11.1 Feedback from participants, parents and support staff

Focus groups were conducted by the Principal Researcher with each of the three stakeholder groups involved in the research study (participants, parents and staff members). As the intervention was delivered to 18 participants spread across three groups, one group of participants was selected at random and invited to participate in a focus group. The same approach was applied to the three groups of parents and the three staff groups, who supported participants. The first focus group was conducted with parents, by the main researcher and an independent researcher. The focus groups conducted with study participants and with staff were conducted by the main researcher.

The data was analysed using thematic analysis to enable the identification, analysis and reporting of themes in the data (Braun and Clarke, 2012). A number of steps were followed in this process:

1. The first transcript of the data was read through a number of times with initial thoughts and possible codes noted.
2. The transcript was then examined more closely with themes noted, as they emerged.

3. When the complete transcript had been coded in his way, the codes were examined to see if there were ways in which they could be meaningfully grouped together.
4. This coding process was repeated for each transcript in turn, until clusters of themes were developed for each focus group.

This chapter provides an overview of the key themes identified from qualitative analysis, for each focus group. Each theme will be discussed with reference to supporting evidence from the information provided. The anonymity of participants has been maintained by the removal of any potentially identifying information.

11.2 Participant Evaluation of Intervention

The six women who took part in the third menstrual pain management group agreed to participate in the focus group for participants. Four over-arching themes were identified from the feedback which they provided. These themes and subthemes highlighted their experience of and the implications associated with participating in the intervention programme (see Figure 1).

The themes and subthemes identified were:

(1) Positive aspects of the intervention

   a. Topic

   b. Skills Taught

c. Session Summary Sheets

(2) Emotions triggered by the intervention

a. Anxiety

b. Enjoyment and Social Support

(3) Challenges of the intervention

a. Cognitive Strategies

(4) Empowerment

Participants identified the subject matter of the group, the topics covered and the provision of session summary sheets as positive aspects of the intervention. They reported feeling some initial anxiety but ultimately reported feelings of enjoyment and social support at participating in the group. Cognitive concepts were named as challenging components of the intervention but overall participants described feeling empowered as a result of their participation in the intervention programme.

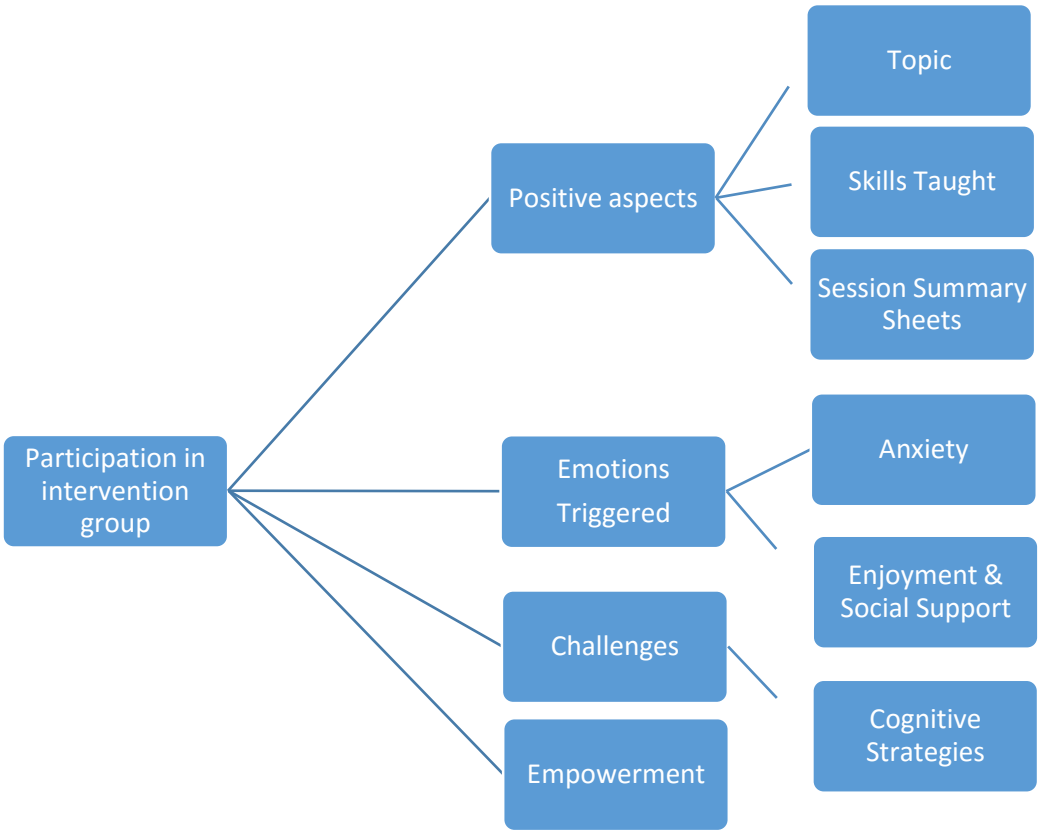


Figure 1: Themes identified from qualitative analysis of Participants data

Positive aspects of the intervention

Participants (referred to as P1 – P6, below) identified a number of positive aspects associated with the intervention:

Topic

Participants felt that the topic of the group (managing menstrual pain) was a good idea as it taught them "***how to deal with it (period pain) and what you're supposed to do***"

(P4, line 18, page 263; Appendix 17) as ***"we've no other way out of it"*** (P3, line 19, page 263; Appendix 17).

Skills taught during the intervention programme

Participants identified a preference for certain skills taught during the intervention programme and viewed these as positive and helpful to them in managing their menstrual pain. The preferred strategies included deep breathing, progressive muscular relaxation, visualisation, the use of physical exercise and, problem solving and management skills. Evidence for this is seen in comments such as: ***"I liked the exercises, I found that very good"*** (P2, line 22, page 264; Appendix 17); ***"I like breathing in and out (the breathing techniques)*** (P1, line 25, page 264; Appendix 17); ***"I enjoyed the relaxation"*** (P1, line 1, page 266; Appendix 17), and ***"I learnt how to be the manager of my period pain"*** (P6, line 32, page 264; Appendix 17).

With reference to learning problem solving skills, participants spoke favourably about the guided visualisation techniques taught: ***"When you closed your eyes and you were talking about the beach and you told us to imagine it … Yeah, that was good. Yeah, I liked that"*** (P2, lines 2 and 3; P5, line 6, page 268; Appendix 17).

When asked for their opinion on ways to improve the intervention programme, ***"more exercises"*** (deep breathing and relaxation exercises) were suggested by one participant (P2, line 16, page 273; Appendix 17). Other participants agreed with this suggestion.

Session Summary Sheets

At the end of each session, participants were provided with a one page summary sheet of what they had learned in the session. Information was provided in bullet point format and included a picture representing the topic discussed. Participants identified the summary sheets as ***"good"*** and ***"good information to have"*** (P3, line 13, page 265 and P2, line 19, page 266; Appendix 17) and described them as ***"very helpful"*** (P5, line 14, page 265; Appendix 1). This is evidenced by comments such as ***"Put them in my folder and take them out and read them, whenever I have my period"*** (P5, lines 16 - 18, page 265; Appendix 17). One participant reported that her Mum took out her sheets and folder and looked at them at home and that she talked to her Mum about them. Another participant described how she was asked about the group by a staff member so ***"… I showed her all the sheets and she said 'fair play to you'"*** (P2, lines 3, page 267; Appendix 17).

Emotions triggered by the intervention

Anxiety

One participant stated that ***"At the start I was shy. It was hard because I was nervous but I got over it"***. (P2, line 3, page 269; Appendix 17). This sentiment was echoed by another participant: ***"You weren't the only one who was nervous"*** (P3, line 4, page 269; Appendix 17). This emotional experience was related to talking in front of others that participants were less familiar with: ***"Normally I'd be at another centre with***

different people"; P3, line 11, page 269; Appendix 17) but these feelings dissipated as participants became more familiar and comfortable with one another.

Enjoyment and Social Support

Participants particularly enjoyed the social aspect of the group and the opportunity to come together with other females: ***"Being together. I like being together"*** (P2, line 7, page 267; Appendix 17). They reported that they would not usually have opportunities to meet together in this way, ***"Yeah, that would be the only time"*** (P2, line 12, page 267, Appendix 17) and were very positive in their praise for the opportunity the group provided to do this ***"I loved it"*** (P4, line 16, page 267; Appendix 17), and ***"I like doing this with the group"*** (P4, line 19, page 274; Appendix 17). Further evidence of participant's enjoyment of the social and supportive aspects of the intervention comes from the suggestion by one group member that ***"We should do it again and look at all the leaflets again"*** (P3, line 1, page 274; Appendix 17). Staff members within this particular service area also reported that this was a sentiment expressed by group members on a number of occasions.

Challenges of the intervention

Cognitive strategies

Some participants struggled to understand and apply cognitive strategies taught during the intervention programme, particularly the concept of challenging negative automatic thoughts. ***"I didn't understand what the negative/positive was"***; ***"Yeah it***

was hard"; ***"Yeah, me aswell"*** (P4, line 9; P3, line 14 and P2, line 15, page 270; Appendix 17); ***"Negative was hard"*** (P6, line 13, page 271; Appendix 17). Although participants did not elaborate on the specifics of why this concept was challenging, when questioned further they reported that this was not a topic they would usually talk about. However, they felt that the provision of examples had helped them to better understand the concept. ***"Yeah, that was good"*** (P2, line 4, page 271; Appendix 17).

Empowerment

A number of participants spoke about teaching others (such as siblings and cousins) the menstrual pain management strategies they learnt in the group and the feeling of empowerment which this gave them: ***"Some of the cousins are girls and they came down and I showed her them (gestured to summary sheets). She thought they were quite good"*** (P5, lines 3,4 and 6, page 275; Appendix 17). ***"It felt very good. She's younger than I am"***. (P5, line 13, page 275; Appendix 17). Other participants described similar experiences ***"I was telling her (my younger sister) just relax, take a deep breath and it'll be okay and to do the exercises as well"*** (P2, lines 1-2, page 276; Appendix 17). ***"Yeah, my sister D. She's older than me. I told her to take deep breaths"*** (P6, line 5, page 276; Appendix 17). Participants reported that ***"It felt weird"*** (P3 and P5, lines 9 and 10, page 276; Appendix 17) to teach others what they had learned but that it felt good to know that they were helping somebody else.

11.3 Staff Evaluation of Intervention

The three Class Teachers of the participants who took part in the second menstrual pain management group were invited and agreed to take part in a focus group to evaluate staff members' opinions of the intervention programme. The following six over-arching themes were identified from the data which they provided and are represented graphically in figure 2, below:

(1) Relevance of the intervention programme

(2) Normalization of the experience of menstrual pain

(3) Social support as a coping strategy

(4) Positive aspects of the intervention

   a. Social Aspect

   b. Programme Materials

   c. Empowerment and skill development

   d. Exercise Promotion

(5) Challenges posed by cognitive elements of the programme

(6) Greater parent and staff involvement

Staff members felt that the subject matter covered in the menstrual pain management group was highly relevant to participants as it helped to normalize the experience of menstruation and menstrual pain. It also offered the opportunity to avail of social support as a coping strategy for pain management. Teachers identified a number of positive elements to the intervention programme including the social aspect of the

group, the visual nature of the programme materials, the promotion of exercise as a coping strategy for pain management and the opportunity for empowerment and skill development afforded by participation in the group. The cognitive elements of the programme were again identified as challenging for this population. Teachers suggested greater parental and staff involvement in the programme to enhance learning and generalization of skills learnt.

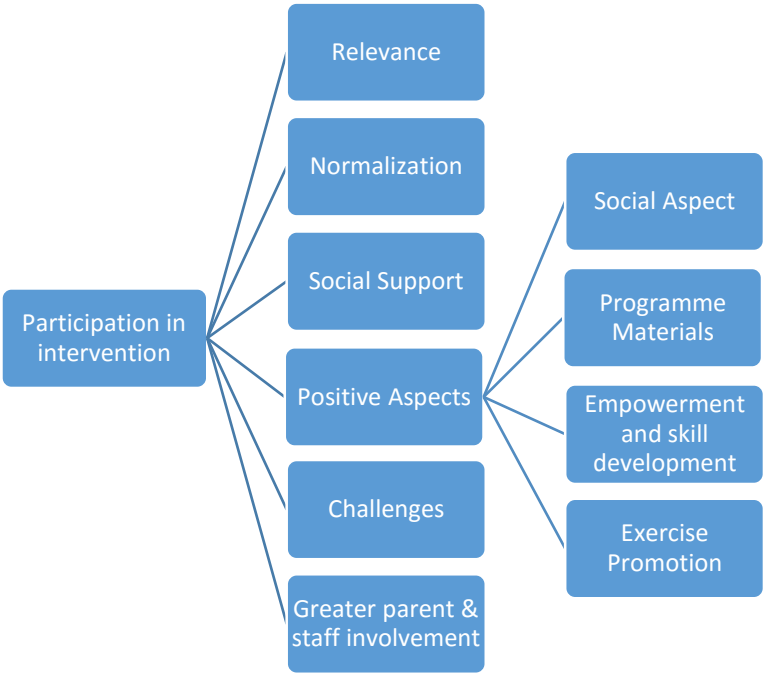


Figure 2: Themes identified from qualitative analysis of Teachers data

Relevance to the intervention programme

Teachers described the topic of the intervention programme as ***"very relevant for our group of students"*** as ***"it's something we would see symptoms of every month"*** (P1, lines 1 and 2, page 278; Appendix 18).

Normalization of the experience of menstrual pain

They referenced the therapeutic benefit gained from participating in the group stating that participants' experiences of menstrual pain were normalized by talking about it and learning that it was a common experience shared by others. ***"It allowed them to understand that it is a completely normal thing as well to go through every month, especially for those who might have felt a bit isolated if they were in severe pain every month from it"*** (P3, lines 8 - 10, page 278; Appendix 18).

Social support as a coping strategy

Staff members referenced the opportunity for social support which the intervention programme offered participants as evidenced by comments such as ***"It allowed them to talk to each other and maybe from doing it within the group with you it allowed them to have the confidence to talk to each other about it outside of the group, like at lunch-time maybe and when they got together"*** (P3, lines 12 - 14, page 278; Appendix 18). ***"I don't think they had an opportunity (to talk about menstruation and menstrual pain) because we're a mixed school and there aren't that many girls here, it's predominantly boys. So I don't think they ever really had that opportunity***

amongst themselves to do that, to have a conversation or to have a discussion" (P2, lines 23 – 24, page 278 and lines 1 – 2, page 279; Appendix 18).

Positive aspects of the intervention

Staff members identified a number of positive aspects and perceived benefits to participants as a result of participation in the intervention programme. These included the social aspect of the intervention programme, the programme materials and benefits in relation to empowerment and the development of a sense of independence in relation to pain management.

Social aspect

The social aspect of the intervention group was referenced by all staff members as being a particularly positive and important aspect of the programme. ***"They enjoyed the social aspect and looked forward to going to it. That's always a good sign because sometimes when you're pulling them out of class to go to something, they're missing a preferred activity as well depending on what time the group was. I know a particular student had to leave during DVD time on occasion because it was a Friday and our DVD was the first Friday of every month but she had no issue with that. Whereas if it was something else, an activity she didn't like going to and being pulled out of, she wouldn't have gone as cooperatively and that was a very positive thing"*** (P1, lines 6 - 12, page 280; Appendix 18). ***"They used to talk about getting a drink and a biscuit at the end but I know that's obviously not the main objective of***

it but that really that probably, they looked forward to it, it was like nearly a reward almost, we've learnt this now and now we're going to get this" (P2, lines 14 - 16, page 280; Appendix 18). ***"I think mine anyway just loved the fact that it was a girls club and the boys didn't know anything about it. This was something just for them because they'd always be saying it in the class and I'd have some of the boys saying 'why can't we have a boy's club'"*** (P3, lines 20 – 22, page 280; Appendix 18***). "I loved how it brought the girls together to be honest. I thought that was the best part of it. They absolutely loved going out every Friday, they really enjoyed it and it really made them happy. Like I know last year in my class there were two girls who would argue so much. They'd be best friends one day and they would kill each other the next day. Never when they were going down to the group would they be arguing. And certainly when they came back they'd be on great terms. I think it was just great to get the girls together, it was lovely for them"*** (P3, lines 8 - 13, page 5; Appendix 18).

Programme materials

Teachers judged the session summary sheets to be appropriately targeted to the ability levels and strengths of participants as evidenced by comments such as ***"I thought it was very good. The language used in them was appropriate. It was basic enough for them to understand it fully. It was good that they got to bring it home too because at least they got to look back on it and they got to show it to their parents so their parents knew exactly what they were doing within the group as well which they would have needed to know really in order to converse about it at home"*** (P3, lines

11 - 15, page 279; Appendix 18). ***"Simplistic in its format as well. It was structured well, pointed, there was a visual there also so it wasn't just all words. If you didn't understand some of the words for say the lower functioning students with a lower reading ability, you had a picture there to give them a quick reminder. That was good"*** (P2, lines 16 – 19, page 279; Appendix 18). The use of pictures from 'Boardmaker', which participants were familiar with was also seen as a positive aspect of the session summary sheets ***"And even the fact that the pictures are 'Boardmaker', which they would be familiar with seeing around the school"*** (P1, lines 22 and 23, page 279; Appendix 18).

Empowerment and skill development

Staff members noted a greater sense of independence amongst participants, in the management of their own menstrual pain symptoms, as a result of participating in the intervention programme. For example, one Teacher felt that ***"They were taking ownership of the management of their pain themselves"*** (P2, lines 6 - 7, page 282; Appendix 18). Another staff member gave an example of the change she had noted in one of her students. ***"One of my students used to be so reliant … on the hot water bottle. I only thought of it now. Towards the end of the year she never asked for it so obviously she must have been doing other things to cope with the pain"*** (P3, lines 4 – 7, page 282; Appendix 18). Her new Teacher commented: ***"And I've had her since September and she would never have asked me. But I would see her at the desk and she'd be breathing and sometimes I'd be looking down and thinking well what is she doing but obviously she's working through it and you'd know by her and she'd have***

her hand on her stomach and she's working through it. But she's very independent now at working through things unless she's very bad and she would ask to ring home. She has done once since September" (P1, lines 8 – 13, page 282; Appendix 18). Teachers also referenced the fact that students could independently implement some of the strategies they learnt, without staff support or the need for specialist equipment ***"It's something they can do, they didn't need any props, they didn't need to be in any special area they could sit at their desk or go out to the bathroom, breath in, breath out you know. It wasn't something that they had to run and get you know, a hot water bottle, special equipment, a blanket, a pillow"*** and ***"It wasn't staff dependent at all, it was great"*** (P2, lines 19 – 22, page 281 and P1, lines 2 – 3, page 3; Appendix 18).

Exercise Promotion

Exercise was viewed as a positive coping strategy by Teachers and it was felt that more should be done to promote this aspect, amongst students with disabilities: ***"I think encouraging and promoting the exercise even if it's only do five minutes and take a break or promoting that in the group as well"*** (P1, lines 15 - 17, page 284; Appendix 18); ***"… encouraging the physical activity side and that it's not negative and that you don't have to be hiding away somewhere, that it might actually help your pain"*** (P1, lines 20 – 22, page 284; Appendix 18); ***"So really promoting that exercise is positive and it can be. I know there are some days they just might not be able for it but letting them know it is a very good option because it is used as an excuse, overly used as an excuse I think"*** (P1, lines 2 - 4, page 285; Appendix 18).

Challenges posed by cognitive elements of the programme

Teachers spoke about the challenges posed by cognitive elements of the programme such as visualisation and challenging negative automatic thoughts. One Teacher commented that ***"It's harder for them to conceptualise it and to think about it whereas a visual, something that they can see, that's very concrete"***. (P2, lines 12 - 13, page 281; Appendix 18). ***"And they can see the others doing it (for example, deep breathing) which makes it easier, you can't see what anyone else is visualising unless they are representing it on paper or something"*** (P1, lines 14 and 15, page 281; Appendix 18). They were in agreement that the behavioural aspects of the programme appeared to have been more beneficial to participants. ***"For A., I would say the very practical stuff, the breathing and she mentioned yoga, you know the exercise movements, that seemed to work better for her. I wouldn't have heard her refer to the visualisation or the more cognitive aspects of it. The behavioural side absolutely worked for her and she would refer to it every once in a while and I would hear from her Mother as well the echo of it, she would do some of the positions at home. But the cognitive side for A. I'm not sure of because of her autism, I don't know how beneficial it was for her but again that's just my hypothesis on it". "But even with the students with a mild learning difficulty without the autism definitely I often heard them on about the more behavioural stuff like the breathing so that they were definitely more aware of that rather than the cognitive behavioural stuff"*** (P1, lines 1 – 7, page 281; P2, lines 8 – 10, page 281Appendix 18).

Greater parental and staff involvement

Teachers suggested the need for greater parental involvement in the programme ***("For parents to be on board with it as well"*** (P2, line 5, page 284, Appendix 18) to support participants to implement the strategies learnt, within the home environment ***("Even if the parents have to sign the sheet that you send home so that you can see that they did actually see it"*** (P3, lines 6 and 7, page 284; Appendix 18).

They identified gaps in their own knowledge of the content and structure of the intervention programme and expressed the opinion that if they themselves had more knowledge of the programme, they could better support the students. This was evident from comments such as ***"I think I've only really learnt the whole concept, like I knew it was menstrual pain but I really wasn't aware let's say of all the different themes and topics you were doing. I think if I had known then I might have been more engaging with them as to what was going on"*** (P2, lines 17 - 19, page 285; Appendix 18). ***"I think now that I'm more informed I'd be more equipped to comment on what did you do this week, what's the topics, just to remind them, just to give them a reminder"*** (P2, lines 23, page 285 and lines 1 – 2, page 286; Appendix 18). It was also suggested that Teachers could encourage participants to complete a reflective activity (involving words, pictures or both) after each session, in order to reinforce learning. ***"… ask them was there one thing they took away from today and getting them to write that down"*** (P1, lines 3 – 4, page 286; Appendix 18).

11.4 Parent Evaluation of Intervention

The parents of the five participants who took part in the first menstrual pain management group were invited to take part in a focus group to evaluate their opinions of the intervention. Notes were taken of the content of the discussion as one parent did not wish for the discussion to be audio-recorded. The following four key themes were identified from the discussion and are represented in figure 3:

(1) Parents perceptions of the perceived benefits of the intervention
    a. Education and associated challenges
    b. Skills generalisation
(2) Aspects of the intervention valued by participants
    a. "Tea-break"
    b. Session summary sheets
(3) The challenges posed by the cognitive elements of the programme
(4) Use of visual aids to support learning

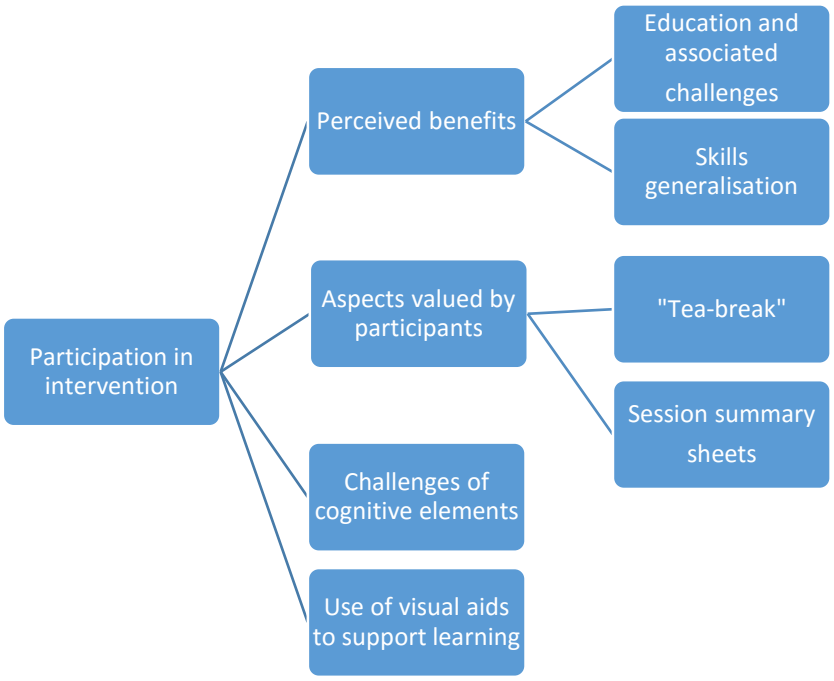


Figure 3: Themes identified from qualitative analysis of Parents data

Parents perceptions of the perceived benefits of the intervention

Education and the challenges posed by this

The role of the intervention group in educating participants about menstrual pain was identified as a beneficial aspect of the programme. Parents felt that their daughters had a ***"better understanding of period pain"*** after taking part in ***"group discussion"*** (P1, line 6, page 290; Appendix 19) about the issue at school, compared with their previous knowledge and understanding from discussion with parents at home. One parent commented that ***"what was most important was that the area was addressed, that they learnt that its' (menstrual pain and pain management) for everybody"*** (P1, line 11, page 290; Appendix 19).

The challenges which can be associated with educating young women with disabilities about how to manage their menstrual pain were also discussed. One parent expressed concern about teaching her daughter to use a calendar to keep track of her period and plan around it. She said that her daughter might want to take time off from school in anticipation of getting her period, if she saw it marked on a calendar. Another parent explained how her daughter does not want to take medication for menstrual pain now that she knows what it is for. She stated that her daughter knows that if she has no pain, she can not take time off from school.

Skills generalisation

Parents gave examples of observing their daughters use deep breathing and relaxation skills to support them in other situations at home. One parent recounted how her daughter uses deep breathing techniques to help her to calm down when she argues with her brother about what to watch on television.

Aspects of the intervention valued by participants

"Tea-break"

Parents identified the ***"tea-break"*** (P2, line 2, page 291; Appendix 19) after each intervention session as something that their daughters looked forward to. Parents viewed this social element to the intervention group (designed to promote group cohesion and build rapport amongst participants) as a reward for participation in the

intervention programme and felt that it helped to encourage attendance and participation.

Folders and Session Summary Sheets

At the start of the intervention programme, each participant was provided with a folder in which to keep their session summary sheets. Parents talked about their daughters wanting to ***"share her folder every week and let me see what she did"*** (P1, line 4, page 291; Appendix 19). One parent described this as ***"very important to her (daughter)"*** (P2, line 4 and 5, page 291, Appendix 19). Parents stated that they found the session summary sheets particularly helpful as it could be used as a tool to prompt discussion and ask questions to assess learning and understanding. ***"It was very good to have them (as) she wouldn't tell me (what was discussed)"*** (P3, line 9, page 291; Appendix 19).

The challenges posed by the cognitive elements of the programme

Parents stated that it was ***"hard to know"*** (P2, line 6, page 290; Appendix 19) how much their daughters understood and took from intervention sessions focused on cognitive pain management strategies such as challenging negative automatic thoughts and using positive coping statements to manage their menstrual pain. Similar concerns were raised regarding the visualisation techniques: ***"… don't know about visualisation"*** (P1, line 19, page 290; Appendix 19).

Use of visual aids to support learning

Parents identified several practical changes which could be made to enhance the learning of the participants. These included greater use of visual aids throughout the programme and, providing a one page laminated summary sheet listing each of the strategies taught during the intervention programme, along with a picture representing the topic. It was suggested that the weekly session summary sheets include a picture representing the topic discussed that week. Pictures were also suggested for use at the beginning of each session, to revise the previous week's topic. Parents also suggested that if a summary sheet was provided at the end of the intervention programme, this could be kept or displayed in their daughter's bedroom and referred to in order to promote the use of the strategies they had learnt during the programme.

CHAPTER 12: DISCUSSION & RECOMMENDATIONS

12.1 Overview

In this chapter, a summary of the key findings from both the quantitative and qualitative aspects of the research study will be presented. Findings will be considered in the context of previous research and current knowledge regarding pain management and the use of cognitive behaviour therapy approaches with individuals with intellectual disabilities. The researcher's own reflections on the findings will also be provided. These will be psychologically informed, based on observations made throughout the research study and qualitative feedback from participants, parents and staff members.

Strengths and limitations of the study will be outlined and recommendations presented with regard to directions for future research in this area. In the conclusion, a synopsis will be provided of the current position with regard to menstrual pain management for individuals with intellectual disabilities and the viability of the proposed intervention programme as a recommended treatment approach, for this population.

12.2 Summary of results from quantitative analysis

12.2.1 Pain Knowledge

Results from quantitative analysis indicated that there was a change in pain management knowledge scores over time for the two groups (control and intervention) and the change was different for both groups. Participants in the intervention group showed a slight increase in their pain management knowledge scores over time whilst those in the control group showed a reduction in their scores. This finding was consistent with McManus & McGuire (2014), who found an increase in pain management knowledge amongst individuals with intellectual disabilities following participation in a pain management intervention programme.

12.2.2 Wellness-focused coping strategies

Participants in both the menstrual pain management intervention group and the control group (treatment as usual) showed a small increase in the number of wellness-focused coping strategies used to cope with menstrual pain, over time. No difference was found in the effectiveness of the two approaches in increasing the use of wellness-focused coping strategies and results were unchanged at follow-up (24 weeks post baseline).

Participants in both the intervention and control groups reported using just one additional wellness-focused coping strategy over time, moving from naming two strategies at baseline to three strategies at post-intervention. As post-intervention questionnaires were completed by another researcher, a possible explanation for the

reported increases by the control group as well as the intervention group, was that participants were simply given more time by the second researcher, to list the coping strategies which they used.

The increase in the use of wellness-focused pain coping strategies by the treatment group was not very large and this may be due to characteristics inherent in the nature and experience of menstrual pain. Unlike other forms of chronic pain, menstrual pain is not experienced on a day-to-day basis but rather, for a number of days each time the individual menstruates. For this reason, the opportunity and need to implement pain coping strategies, including wellness-focused pain coping strategies, is much less frequent than for other forms of chronic pain. Given that the average length of participants' menstrual cycle was 31 days, participants may have only had two points during the course of the intervention programme when they could have implemented the pain coping strategies taught. With limited opportunity to practice new skills taught during the intervention programme, this may explain why the expected increase in wellness-focused pain coping strategies was not greater, for those in the intervention group.

With regard to the four real-life scenarios in which participants were asked to describe how they would cope with menstrual pain, although participants in the intervention group showed a small increase in the number of wellness-focused strategies used from baseline (four strategies) to post-intervention (five strategies), this finding was not

statistically significant. Results were unchanged between post-intervention and follow-up (five strategies also used). There was no difference in the overall effectiveness of the two approaches (intervention versus treatment as usual) with regard to the use of wellness-focused pain coping strategies in real-life scenarios. Again, these results may have been influenced by limited opportunity for skills implementation for those who participated in the intervention programme.

It is worth noting that both groups reported the use of a greater number of wellness-focused pain coping strategies in the four hypothetical real-life scenarios (pain coping scenarios questionnaire) compared with their responses when asked to name all of the different strategies they used to cope with menstrual pain (pain coping strategies questionnaire). Whilst the use of open-ended questions is recommended for use with individuals with intellectual disabilities to reduce socially desirable responding (Sigelman et al. 1982), it is possible that the use of this technique on the pain coping strategies questionnaire meant that as a measurement tool, it was not specific and sensitive enough to elicit the full extent of wellness-focused pain coping strategies used by participants.

12.2.3 Pain intensity

Participants in the intervention group showed a small reduction in their pain intensity ratings over time, however this was not clinically significant. A clinically significant change in pain intensity is two points on a Visual Analogue Scale, according to

IMPPACT guidelines. No overall difference was found between the two treatment approaches in reducing pain intensity scores. Parental ratings of participants' pain intensity showed a similar trend. These findings were as hypothesised and consistent with previous research in relation to pain intensity. As proposed by Turk (2003), the main aim of cognitive behavioural approaches to pain management is not to reduce pain intensity, but to develop the individual's adaptive coping skills to support them to lead as productive and enjoyable a life as possible, despite pain.

12.2.4 Pain Interference

In keeping with the primary objective of CBT approaches to pain management which is to enhance the individual's adaptive coping skills, several studies have reported improvements in psychological well-being and participation in activities following cognitive behavioural treatment for pain management (Lewis, Bell & Gillanders, 2007; Eccleston, Williams & Morley, 2009). It was hypothesised, therefore, that participation in this study would result in a decrease in both participants' self-ratings and parental ratings of participants' pain interference levels. This hypothesis was supported in that participants in the intervention group did show a decrease in their pain interference scores over time. Participants in the control group also showed a reduction on this measure, however, with no significant difference found in the effectiveness of the two approaches in reducing participants' pain interference scores and enhancing their participation in activities. These findings were somewhat surprising given the strong clinical evidence for the effect of a CBT approach in

enhancing participation in activities. A possible reason for the findings in this study may be the sensitivity of the tool used to assess pain interference.

Pain interference was assessed using a modified version of the Brief Pain Inventory – Short Form (Cleeland and Ryan, 1994). This modified questionnaire was specifically generated for the purpose of this research project and included changes to the wording of questions on categories assessed by the original scale, as well as the inclusion of additional categories. Given that this measure has not been used previously with individuals with intellectual disabilities, it is possible that it may not have been specific and sensitive enough to detect changes in pain interference for this population. Review of the questionnaire highlighted that the inclusion of questions regarding attendance at school/day centre, ability to participate in school/day centre activities and complete homework (where relevant), ability to complete jobs at home and to participate in exercise, may have impacted on overall pain interference scores. Individuals with intellectual disabilities are more likely to miss time from school, work, social or recreational activities due to menstrual pain (Kyrkou, 2005). Qualitative feedback from participants, parents and staff members indicated that expectations regarding participation in activities may be different for this population compared to their same age peers without a disability, when they are menstruating. For example, a number of participants and parents referenced the fact that these women could not go swimming when they were menstruating and therefore their ability to participate in exercise was greatly compromised as a result. Only one staff member made reference to the possibility that these young women could be taught to use tampons for personal care

during menstruation, if they wished to go swimming. On the contrary, the use of tampons is a commonly used personal care practice amongst women without intellectual disabilities which supports continued participation in exercise during menstruation and has a positive effect on pain interference.

Parental ratings of participants' pain interference reduced over time for those in the intervention group. Scores increased slightly post-intervention, before reducing again at follow-up, for those in the control group. There was no significant difference, however, in the effectiveness of the intervention programme compared with the control condition, based on parental ratings of participants' pain interference.

12.2.5 Use of cognitive coping strategies

Participants in the intervention and control groups both showed an increase in the use of cognitive coping strategies to manage their menstrual pain, on both the pain coping strategies questionnaire and the pain coping scenarios questionnaire. These increases were not clinically meaningful, however, as the average number of cognitive strategies used was less than one, in each case.

Participation in the menstrual pain management group was not expected to have an effect on the use of cognitive pain coping strategies as research in this field indicates that individuals with intellectual disabilities can experience difficulties in understanding and applying the cognitive elements of intervention programmes. For

example, Willner, Jones, Tam and Green (2002) described the use of a CBT approach to anger management in individuals with intellectual disabilities and reported that participants repeatedly struggled with the cognitive restructuring element of the programme. No significant difficulties were noted, however, in their understanding of the behavioural aspects of the intervention approach. Willner's findings were replicated in this study as the cognitive component of the menstrual pain management group was identified as the most challenging element of the programme by all three groups of stakeholders (participants, parents and staff members) during the qualitative focus groups.

The findings from this study were as expected and in line with those of Turner, Mancl and Aaron (2006) and McManus & McGuire (2014), who found a notable absence in the reported use of cognitive pain coping strategies in their case series study of a CBT approach to chronic pain management in individuals with intellectual disabilities.

12.2.6 Use of behavioural coping strategies

There was no change noted in the use of behavioural coping strategies for either group, over time, on the pain coping strategies questionnaire. However, those in the intervention group showed an increase over time in their use of behavioural coping strategies in real-life scenarios, as reported on the pain coping scenarios questionnaire. As with the use of wellness focused pain coping strategies, both groups reported the use of a greater number of behavioural coping strategies in the four hypothetical real-

life scenarios (pain coping scenarios questionnaire) compared with their responses when asked to name all of the different strategies they used to cope with menstrual pain (pain coping strategies questionnaire). As previously discussed, it is possible that the open-ended question format of the pain coping strategies questionnaire impacted participants' responses on this measure.

Participants in both the intervention and the control groups used more behavioural than cognitive pain management strategies with deep breathing, relaxation, exercise and distraction techniques (such as watching television), the most commonly cited strategies used. In the qualitative feedback provided by participants, parents and staff members, deep breathing and progressive muscular relaxation techniques were specifically identified as being enjoyable and beneficial aspects of the intervention programme. As behavioural strategies such as these can be practiced within the therapeutic intervention session, participants may find it easier to learn, remember and use these techniques, compared with cognitive coping strategies such as challenging negative automatic thoughts.

The preference for behavioural pain management strategies, as evidenced in this study, is consistent with findings by Turner et al. (2006) who reported increased use of behavioural pain coping strategies and negligible use of cognitive coping strategies, following a CBT based intervention for pain management. McManus et al. (2014) also

found that relaxation and exercise were the behavioural coping strategies most likely to be used by participants in their study.

12.2.7 Parental pain catastrophizing

The study also examined the predictive effect of parental pain-catastrophizing on the primary and secondary outcome variables. Looking firstly at the primary outcome measure of pain coping strategies used, participant age and age at commencement of menstruation were of significance. The greater the age of study participants, the fewer behavioural pain coping strategies they reported using. With increasing age, it is possible that participants' menstrual pain intensity has reduced, thereby necessitating the use of fewer behavioural pain coping strategies. This would be consistent with studies which have found that whilst up to 90% of adolescent females experience dysmenorrhea, this figure drops to 50% or more, amongst menstruating women (Davis & Westhoff, 2001; Durain, 2004; Ortiz, Rangel-Flores, Carrillo-Alarcon & Veras-Godoy, 2009). Alternatively, by virtue of their age, older participants may have had more opportunities to try a range of behavioural pain coping strategies to manage their menstrual pain and have now identified which ones are most effective for them. As a result, they may be using a smaller number of pain management strategies than younger participants. Younger study participants may be using a larger number of behavioural pain coping strategies in order to identify which ones are most effective for their pain management and because their pain intensity requires a broader suite of tools from which to choose, depending on the intensity of the pain on any given day or during any given menstrual cycle.

The study also found that the older a participant was when they first began to menstruate, the fewer wellness focused pain coping strategies they reported using. It is possible that participants who were older when they first began to menstruate may have fewer years of experience of menstruation, relative to participants who began menstruating at an earlier age. Consequently, their experience of dysmenorrhea may still be at its' most intensive thereby necessitating the use of more illness focused pain coping strategies to manage their menstrual pain, such as rest and medication use, rather than wellness focused pain coping strategies.

In relation to the secondary outcome variables, no significant relationship was found between pain intensity and parental pain catastrophizing. This was somewhat surprising given previous findings that high pain catastopshizers have reported greater menstrual pain intensity and greater pain interference from menstruation (Walsh, LeBlanc & McGrath, 2003). It may, however, be related to the sample size of the study. Parental pain catastrophizing was, however, found to be predictive of parental ratings of participants' pain interference. There was a commensurate increase in parental ratings of participants' pain interference, as parental pain catastrophizing scores increased.

12.2.8 Pain self-efficacy

Surprisingly, pain self-efficacy was not found to predict the use of wellness-focused pain coping strategies. As with parental pain catastrophizing, the older a participant

was at the time of first menstruation, the fewer wellness focused pain coping strategies they used. If participants who were older when they first began to menstruate have less experience of menstruation, relative to participants who began menstruating at an earlier age, their experience of menstrual pain may still be at its' most severe. As a result, they may feel the need to use fewer wellness focused and more illness focused pain coping strategies, such as rest and medication use, to manage their menstrual pain at this time.

It is worth considering whether there may have been another variable at work here. Specifically, if there was a difference in menstrual pain intensity of those who were older at first menstruation, compared with those who commence menstruation at an earlier age. Those who were older at first menstruation may be using more illness focused pain coping strategies (such as rest and medication) and fewer wellness focused pain coping strategies, which could explain the findings.

If participants used medication to manage their menstrual pain, they also used more illness focused pain coping strategies. This was a strong finding. Use of medication is an illness focused pain coping strategy and it is likely that participants who used this strategy or were supported or encouraged to do so by parents or guardians, considered the experience of menstrual pain and pain management from a medical or illness-focused perspective, rather than a biopsychosocial or wellness-focused approach. The more frequently that participants experienced menstrual pain, the fewer illness focused

pain coping strategies they used. With greater experience of menstrual pain, participants may have identified the specific pain coping strategies which were most effective for them, resulting in the use of fewer illness focused pain coping strategies and greater pain self-efficacy.

With regard to the use of behavioural pain coping strategies, for every additional year in age, there was a reduction in participants' use of behavioural pain coping strategies. As with pain catastrophizing, it is possible that participants' menstrual pain intensity decreased with increasing age and as a result, the number of behavioural pain coping strategies used also decreased.

Looking at the predictive effect of pain self-efficacy on the secondary outcome variables of pain intensity and pain interference, no relationship was found with pain intensity. Although Brister, Turner, Aaron and Mancl (2006) reported that greater pain self-efficacy was associated with lower levels of pain, this finding was not replicated in this study. A possible explanation for this was the different populations (intellectually disabled v. non-disabled) with whom the research studies were conducted. This study found that for every unit increase in participants' ratings of pain self-efficacy there was also an increase in their rating of pain interference. Parental ratings of participants' pain interference showed a similar trend. This finding was contrary to what was expected as participants would have been predicted to report less pain interference the stronger their belief in their ability to continue with tasks and

activities, despite the experience of pain. A probable reason for this was the specificity and sensitivity of the assessment measures used. The pain self-efficacy scale looks at five areas, only four of which are included in the eleven items assessed by the pain interference scale. The relationship between pain self-efficacy and pain interference may have been influenced to an unknown degree, therefore, by the other items on the pain interference questionnaire.

12.3 Summary of results from qualitative analysis

A qualitative element was incorporated into this research study with the inclusion of focus groups with participants, parents and staff members. The purpose of this aspect of the study was to elicit the views of stakeholders on the content of the programme and seek suggestions for how it could be further developed and enhanced to best meet the needs of individuals with intellectual disabilities. A number of key issues emerged from the data following thematic analysis.

Participants described feeling empowered by their participation in the menstrual pain management group and identified the subject matter of the group, the skills taught and the session summary sheets as positive aspects of the programme. These themes were also identified by staff members. Taylor, Novaco, Gillmer and Thorne (2002) advocated for the use of flexible methods such as the use of pictures and drawings when conducting CBT with individuals with intellectual disabilities. This recommendation was taken into consideration when developing the session summary

sheets which included ‘Boardmaker’ pictures as visual aids to learning. ‘Boardmaker’ is a tool commonly used to create accessible materials for individuals with intellectual disabilities. The positive feedback on the session summary sheets, provided by all stakeholders, supported the use of this technique and lends further support to the evidence base supporting the ability of those with intellectual disabilities to engage with mainstream assessment and treatment approaches, once appropriate adaptations are applied.

Participants expressed feelings of enjoyment and spoke of the social support they experienced with taking part in the menstrual pain management programme. They reported experiencing some anxiety in the initial stages of the intervention programme as they acclimatised to the group situation and the experience of discussing a sensitive topic in front of unfamiliar individuals. This anxiety quickly dissipated, however, as delivery of the programme progressed.

Participants, parents and staff members all identified the cognitive elements of the programme as challenging, which was not unexpected given previously outlined findings on this issue. Staff members described the menstrual pain management group as highly relevant for individuals with intellectual disabilities as it helped to normalize the experience of menstrual pain for them. They also identified the role of exercise promotion as an important aspect in the pain management programme. This is significant and supports current thinking in the field of pain management given that

low levels of physical activity and exercise has been identified as a risk factor for chronic pain amongst individuals with intellectual disabilities (Robertson et al., 2000).

A key recommendation by staff members was the suggestion that future pain management programmes should consider greater parental and staff involvement in programme delivery. This echoes the recommendations for future research of McManus & McGuire (2014) who suggested that pain management programmes with this population could be enhanced by routinely including staff and family support for participants as well as in-session participation.

Similar to the participants and staff members, parents also identified the social element of the group and the use of session summary sheets and visual aids as positive aspects of the menstrual pain management programme. They also highlighted the role of group participation in education and skills generalisation for this population but spoke of specific challenges associated with this, which warrant consideration in the delivery of future pain management programmes.

12.4 Strengths and limitations of the study

This research study had a number of key strengths which should be acknowledged. First and foremost, this study was highly innovative and as such, has a significant contribution to make to opening up the area of menstrual pain management in women with intellectual disabilities to greater consideration, debate and research support. It

was a controlled trial, the first of its kind to evaluate a menstrual pain management programme for women with intellectual disabilities. The programme delivered was theory based and manualised, which ensured that there was a sound theoretical basis for teaching the different elements of the intervention programme and all groups received the same information, in the same order. In addition, the programme was designed to meet the specific learning needs of individuals with intellectual disabilities such as the inclusion of visual aids to learning, shorter sessions, breaks during intervention sessions (if needed) and delivery of the programme to small groups of participants. This tailoring of the intervention programme to meet the needs of the target population is consistent with research on strategies to support the participation of those with intellectual disabilities in therapeutic interventions (Taylor et al., 2002; Whitehouse, Tudway, Look & Stenfert-Kroese, 2006).

The delivery of the intervention programme during the hours in which participants attended school or an adult training centre was a significant strength in the research design. This approach minimised non-attendance issues associated with transport, hobbies and other commitments which typically occur when programmes are offered in the evening or on weekends. Supporting participants to attend the intervention on a regular basis aided group cohesion and group dynamics and provided participants with the best possible chance to develop new skills to independently manage their menstrual pain.

The length of each intervention session was deliberately kept to a maximum of 45 minutes in order to maintain participant interest in the subject matter and minimise the likelihood of participants becoming bored or distracted during intervention sessions. It was felt that such an approach would support participants' to maintain interest in and willingness to attend all 12 therapeutic intervention sessions, thereby minimising drop-out and non-attendance rates. This aspect of the research design was supported by Scott's (1992) recommendation, that cognitive behavioural interventions for individuals with intellectual disabilities should involve shorter sessions than those typically provided to those without disabilities. A further argument in favour of this approach was the mixed abilities of group participants. As all three intervention groups included a mix of individuals with mild and moderate intellectual disabilities as well as some individuals with additional learning needs associated with conditions such as Down syndrome and Autism, brief, focused intervention sessions were deemed to be most appropriate.

The consideration given to the sequence in which modules were presented during the intervention programme was a further positive aspect of the study. Behavioural pain coping strategies were taught before cognitive strategies and the rationale for this was manifold. As individuals with intellectual disabilities typically experience greater difficulty with the cognitive elements of intervention programmes, it was felt that presenting the behavioural strategies first would support participants to become comfortable in the group before presenting the most demanding aspects of the programme. In this way it was also hoped that non-attendance and participant drop-

out rates could be minimised. Participation rates for individuals in all three intervention groups were extremely high, with the majority of participants attending all 12 sessions and a small number of individuals missing no more than two sessions in total. In each of these cases, non-attendance was due to other factors such as illness or attendance at appointments, and deemed to be unrelated to the planned subject matter of the particular session. The drop-out rate of study participants was zero percent – all participants who commenced the intervention programme attended throughout the 12 week programme. These findings support the attention given to the sequencing of the intervention modules.

The inclusion of modules on deep breathing, progressive muscular relaxation and the use of distraction techniques as effective strategies to aid menstrual pain management can be viewed as positive features of the intervention programme. These strategies have been consistently identified as beneficial in terms of pain management both for those with and without intellectual disabilities. Inclusion was further vindicated by their identification by focus group stakeholders, as being the most beneficial and frequently used pain management strategies, taught within the group. The strengths as outlined above, support the applicability and generalizability of this research to the wider population of women with intellectual disabilities.

As with all research, there were some limitations inherent in the study and consideration should be given to these issues when reflecting on the results. With

regard to the research design, the sample size (N=18 intervention group, N=14 control group) was small which impacts on the ability to provide meaningful statistical results and generalize from the quantitative findings. The researcher was very aware of this issue from the inception of the study and considerable efforts were made to recruit more participants across a wide catchment area. The sample size was ultimately impacted by challenges associated with recruitment including the large geographical area in which the study was conducted, the largely rural nature of this geographical area and transport issues associated with this for potential participants.

A further limitation with regard to study design was the use of non-standardised assessment measures which remain to be validated. Although the researcher had little choice but to use these measures due to the lack of appropriate standardised measures for use with this population, it should be acknowledged that this may have impacted on research findings. These measurement tools should be subjected to assessment of their validity, reliability and sensitivity to change before they are used again with this population.

Previous research in this area has recommended the inclusion of family members and relevant care staff in the delivery of therapeutic intervention programmes e.g. McManus & McGuire, (2014). Given that this suggestion was also made by staff members in the focus groups conducted following the delivery of the intervention programme, the decision not to incorporate such support within the study could be

viewed as a methodological flaw. Consideration was in fact given to this issue in the initial stages of study design but given the difficulties inherent in the recruitment process, it was deemed necessary to deliver the intervention programme during working hours to maximise participant attendance. As a result, it was deemed unlikely that parent/carer attendance could also be achieved at this time. Given that this study was the first of its kind to evaluate a menstrual pain management programme for women with intellectual disabilities, the researcher deemed it of greatest importance to maximise participant numbers, on this occasion. Parental and staff participation in programme delivery should undoubtedly be evaluated in any future programmes of this nature.

Whilst participants' level of cognitive functioning was ascertained for the purposes of this research study, information was not obtained on their level of adaptive functioning. Adaptive functioning refers to a person's ability to complete everyday activities such as washing, dressing and feeding themselves as well as completing general domestic tasks. Given that the pain interference questionnaire assessed change in some of these areas, knowledge of participants' baseline level of adaptive functioning may have been beneficial to determine if this had an effect on the pain interference outcome measure.

Consideration must be given to omission of assessment measures to assess for changes in participants' mood, over the course of the study. The Initiative on Methods,

Measurement and Pain Assessment in Clinical Trials (IMMPACT) identified participant disposition as one of six core outcome domains that should be considered when designing chronic pain trials (Turk et al. 2006). Assessment of affective factors such as depression, anxiety, fear and anger is important when considering the experiences of those who suffer pain, given the known interplay between feelings, thoughts and behaviour, as defined in cognitive behavioural therapy models. Negative emotions may have impacted on participants' thoughts about the intervention and their willingness to try recommended coping strategies.

On reflection, the intervention programme may have needed to be longer or to have included fewer topics to enable greater focus on each concept in order to support greater change. The programme covered 12 different topics in as many weeks, which may have been too much content for this population. Given that participants menstruated on average only two times over the course of the intervention programme, this provided a small number of occasions during which to practice implementing a large number of strategies taught.

With regard to the methods of statistical analysis used in this study, it must be acknowledged that there can be issues with multiple testing when multiple mixed between-within subjects ANOVA's are used. Although this approach was selected because of the small sample size of the study, a MANOVA could also have been used as it offers protection from multiple testing problems.

12.5 Recommendations for future research

As this was an initial exploratory study, the results obtained are suggestive rather than conclusive in nature. The findings from both quantitative and qualitative analysis indicate that there is certainly a case for further training for women with intellectual disabilities to support them to better manage their menstrual pain. A number of key recommendations can be identified for future research in this area.

Firstly, consideration should be given to delivering the programme again to a larger sample of individuals and to a more homogenous group of participants. Burkitt, Breau and Zabalia (2011) demonstrated that it is greater developmental level which is associated with the use of more cognitively demanding strategies. As such strategies are generally used in CBT, it may be worthwhile evaluating the programme with only individuals with a mild intellectual disability.

In light of the feedback from qualitative analysis, there is a strong case to be made for evaluating the delivery of the intervention programme with the participation of parents and/or staff members during therapeutic intervention sessions. Other suggestions for further research include modifying the programme by removing the cognitive modules and focusing only on behavioural therapy techniques as these are the strategies most frequently used and best understood by those with intellectual disabilities. Consideration should also be given to evaluating the programme after condensing it into fewer sessions delivered more intensively over a shorter period of intervention or

delivering it over a significantly longer period of time than the 12 week schedule evaluated in this study.

Undoubtedly, assessment of the reliability and validity of the measurement tools used in this study is warranted before further use with individuals with intellectual disabilities. It is imperative to determine the ability of these measures to accurately assess the constructs they are purported to evaluate, if there is to be confidence in the findings of studies which may use these measures in the future. Furthermore, measures to assess participants' mood should also be included as part of baseline assessment in future studies, in line with IMMPACT recommendations (Turk et al. 2006) and current knowledge of the influence of such variables on key outcomes in pain research such as pain coping strategies used.

12.6 Conclusion

In summary, this research study found that participation in a menstrual pain management group increased participants' knowledge of pain management strategies which could be used to cope with menstrual pain. Participants showed a small increase in their use of wellness-focused coping strategies, as predicted, although this was not statistically significant. Participation also resulted in small reductions in participants' self-ratings of pain intensity and pain interference as well as parental ratings of these constructs, as experienced by participants. Small increases in the use of both cognitive

and behavioural pain coping strategies were noted, with participants favouring behavioural over cognitive pain coping strategies, as was predicted.

Pain catastrophizing was found to be a predictor of parental ratings of participants' pain interference, the use of wellness-focused pain coping strategies and the use of behavioural pain coping strategies. Pain self-efficacy predicted the use of wellness-focused, illness-focused and behavioural pain coping strategies. It was also predictive of participants' pain interference scores. The results of this study are preliminary and should be interpreted with caution due to the small sample size involved.

Focus groups conducted with relevant stakeholders identified a number of important themes and suggestions for both programme modification and further research. The development and delivery of a menstrual pain management programme for young women with intellectual disabilities was considered highly relevant and pivotal in helping to educate this population and to normalize the experience of menstrual pain. The behavioural coping strategies and the highly visual nature of the session summary sheets were singled out for praise. The programme was reported to have generated a sense of empowerment amongst participants and provided opportunities for much needed and enjoyed social interaction and support, as well as encouraging skills generalisation. Whilst all stakeholders questioned the inclusion of cognitive pain coping strategies within the intervention programme due to the challenges which such approaches present for individuals with intellectual disabilities, the overall feedback

was overwhelmingly positive and supportive. There was strong support for such training with other women with intellectual disabilities as well as calls from participants and staff members for ‘revision courses’ and booster sessions with those who took part in this first programme.

Further research in this area is undoubtedly warranted and several ideas have been outlined above, with regard to proposed directions for future research and investigations warranted. Individuals with intellectual disabilities are increasingly participating in research as well as developing and informing society’s knowledge and understanding of their needs. Consideration of issues related to menstrual pain management for women with intellectual disabilities is very much in its infancy but it is hoped that this study has demonstrated the wide ranging scope and generalizability of the findings and has helped to open the topic to greater consideration, debate and further advancement.

REFERENCES:

American Psychiatric Association. (2000). *Diagnostic and Statistical Manual of Mental Disorders-IV-Text Revision.* Washington, DC: American Psychiatric Association.

American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental Disorders – Fifth Edition.* Washington, DC: American Psychiatric Association.

American Congress of Obstetricians and Gynaecologists. (2011). *Dysmenorrhea.* Patient Education Pamphlet.

Alonso, C. & Coe, C.L. (2001). Disruptions of social relationships accentuate the association between emotional distress and menstrual pain in young women. *Health Psychology, 20, p. 411 – 416.*

Anastasi, A. (1982). *Psychological Testing* (5th Edition). New York: Macmillan Publishing Company.

Arvio, M. & Sillanpaa, M. (2003). Prevalence, aetiology and comorbidity of severe and profound intellectual disability in Finland. *Journal of Intellectual Disability Research*, 47, p.108–112.

Balla, D. & Zigler, E. (1979). Personality development in retarded persons. In N.R. Ellis (Ed.), *Handbook of Mental Deficiency: Psychological Theory and Research* (2nd Edition). Hillsdale, New York: Laurence Erlbaum.

Baldridge, K.H. & Andrasik, F. (2010). Pain assessment in people with intellectual or developmental disabilities. *American Journal of Nursing*, 110, p. 28–35.

Bandura, A. (1977). *Social Learning Theory*. Englewood Cliffs, New Jersey: Prentice Hall.

Beck, J.S. (1995). *Cognitive Therapy: Basics and Beyond*. New York: Guilford Press.

Becker, N.A., Bondegaard, T.A., Olsen, A.K. et al. (1997). Pain epidemiology and health related quality of life in chronic non-malignant pain patients referred to a Danish multidisciplinary pain center. *Pain*, 73, p. 393-400.

Bellg, A.J., Borreeli, B., Resnick, B., Hecht, J., Minicucci, D.S., Ory, M. et al. (2004). Enhancing treatment fidelity in health behaviour change studies: Best practices and recommendations from the NIH Behaviour Change Consortium. *Helath Psychology,* 23, p. 443-451.

Benson, B.A. & Ivins, J. (1992). Anger, depression and self-concept in adults with mental retardation. *Journal of Intellectual Disability Research,* 36, p. 169–175.

Berkley, K.J. (2013). Primary Dysmenorrhea: An Urgent Mandate. *Pain,* XXI (3): p. 1–8. Clinical Updates.

Biersdorff, K.K. (1994). Incidence of significantly altered pain experience among individuals with developmental disabilities. American Journal of Mental Retardation, 98, p. 619–631.

Blyth, F.M. & Lee, L. (2011). Commentary: Giving a voice to the vulnerable. *Pain,* 152(9), p. 1937. doi:10.1016/j.pain.2011.03.014

Boothby, J.L., Thorn, B.E., Stroud, M.W. & Jensen, M.P. (1999). In: Gatchel, R.J., Turk, D.C. (Eds.). *Psychosocial Factors in Pain: Critical Perspectives* (p. 343–359). New York: Guilford Press.

Bottos, S. & Chambers, C.T. (2006). The epidemiology of pain in developmental disabilities. In: T. Oberlander & F. Symons (Eds.) *Pain in children and adults with developmental disabilities* (p. 67–87). Baltimore: Paul H. Brookes.

Braun, V. & Clarke, V. (2012). Thematic analysis. In H. Cooper (Ed.), *Handbook of Research Methods in Psychology* (Vol 2: Research Designs, p. 57-71). Washington Dc: APA books.

Breau, L.M., McGrath, P.J. & Zabalia, M. (2006). Assessing paediatric pain and developmental disabilities. In: F. Symons & T. Oberlander (Eds.) *Pain in individuals with developmental disabilities* (p. 67–87). Baltimore: Paul H. Brookes.

Breau, L.M., Camfield, C.S., McGrath, P.J. & Finley, G.A. (2007). Pain's impact on adaptive functioning. *Journal of Intellectual Disability Research*; 51, p.125–134.

Breivik, H., Collett, B., Ventafridda, V., Cohen, R. & Gallagher, D. (2006). Survey of chronic pain in Europe: Prevalance, impact on daily life and treatment. *European Journal of Pain, 10(4), p. 287–333.*

Brister, H., Turner, J.A., Aaron, L.A. & Mancl, L. (2006). Self-efficacy is associated with pain, functioning and coping in patients with chronic temporomandibular disorder pain. *Journal of Orofacial Pain, 20(2),* p. 115–124.

Brown, G.K. & Nicassio, P.M. (1987). Development of a questionnaire for the assessment of active and passive coping strategies in chronic pain patients. *Pain, 31,* p. 53–64.

Burkitt, C.C., Breau, L.M. & Zabalia, M. (2011). Parental assessment of pain coping in individuals with intellectual and developmental disabilities. *Research on Developmental Disabilities,* 32, p. 1564–1571.

Bursch, B., Tao, J.C.I., Meldrum, M. & Zelter, L.J. (2006). Preliminary validation of a self-efficacy scale for child functioning despite chronic pain (child and parent versions). *Pain,* 125(1 – 2), p. 35–42.

Carr, A. (2006). *The handbook of child and adolescent clinical psychology: A contextual approach* (2nd Ed.). London: Routledge, Taylor & Francis Group.

Chou, Y., Lu, Z.J., Wang, F. T. Y.; Lan, C. & Lin, L. (2008). Meanings and experiences of menstruation: Perceptions of institutionalized women with an

intellectual disability. *Journal of Applied Research in Intellectual Disabilities,* Vol. 21(6), p. 575-584.

Cleeland, C.S. & Ryan, K.M. (1994). Pain assessment: global use of the Brief Pain Inventory. *Annals of Academic Medicine Singapore,* 23(2), p. 129–138.

Compas, B.E., Haaga, D.A., Keefe, F.J., Leinternberg, H. & Willimas, D.A. (1998). Sampling of empirically supported psychological treatments from health psychology: Smoking, chronic pain, cancer and bulimia nervosa. *Journal of Consulting & Clinical Psychology,* 66, p. 89-112.

Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I. & Petticrew, M. (2008). Developing and evaluating complex interventions: the new Medical research Council Guidance. *British Medical Journal,* 337, p. 979-983.

Curran, P.J., West, S.G. & Finch, J.F. (1996). The robustness of test statistics to nonnormality and specification error in confirmatory factor analysis. *Psychological Methods,* Vol 1(1), Mar, p. 16–29.

Dagnan, D. & Lindsay, W.R. (2004). Cognitive therapy with people with learning disabilities. In E. Emerson, C. Hatton, T. Parmenter & T. Thompson (Eds.),

International Handbook of Research and Evaluation in Intellectual Disabilities. Chichester: J. Wiley & Sons.

Davis, A.R. & Westoff, C.L. (2001). Primary dysmenorrhea in adolescent girls and treatment with oral contraceptives. *Journal of Paediatric and Adolescent Gynaecology*, 14, p. 3–8.

DeGood, D.E. & Tait, R.C. (2001). Assessment of pain beliefs and coping. In: S.B. McMahon & M. Koltzenburg (Eds.), *Wall and Melzack's textbook of pain* (5th ed.). New York: Elsevier.

Defrin, R., Pick, C.G., Peretz, C. & Carmeli, E. (2004). A quantitative somatosensory testing of pain threshold in individuals with mental retardation, *Pain*, 108, p. 58–66.

Denny, D.R. & Gerrard, M. (1981). Behavioural treatments for primary dysmenorrhea: A review. *Behavioural Research and Therapy*, 19, p. 303-312.

De Knegt, N. & Scherder, E. (2010). Pain in adults with intellectual disabilities. Pain, 152, p. 971–974. Doi: 10.1016/j.pain.2010.11.001.

De Sanctis, V., Soliman, A., Bernasconi, S., Bianchin, L., Bona, G., Bozzola, M., Buzi, F., De Sanctis, C., Tonini, G., Rigon, F., Perissinotto, E. (2015). Primary Dysmenorrhea in Adolescents: prevalence, Impact and Recent Knowledge. *Paediatric Endocrinology Review,* 13(2); p. 512-520.

DeVellis, R.F. (2003). *Scale development: Theory and applications* (2nd Ed.). Thousand Oaks, California: Sage.

Dickerson, L.M., Mazyck, P.J. & Hunter, M.H. (2003). Premenstrual Syndrome. *American Family Physician,* 67(8), p. 1743–1752.

Dubois, A., Capderila, X., Bringuier, S. & Pry, R. (2010). Pain expression in children with an intellectual disability. *European Journal of Pain,* Jul; 14(6), p. 654-660. doi: 10.1016/j.ejpain.2009.10.013 Epub2009 Dec 5.

Durain, D. Primary dysmenorrhea: assessment and management update. *Journal of Midwifery and Womens Health, 49,* p. 520–28.

Eccleston, C., Williams, A.C.de C. & Morley, S. (2009). Psychological therapies for the management of chronic pain (excluding headache) in adults. *Cochrane Database of Systematic Reviews, Art. 4. CD007407.* doi: 10.1002/14651858.CD007407.

Eden, J.A. (1992). Dysmenorrhoea and premenstrual syndrome. In F.N. Hacker & J.G. Moore *(Eds.). Essentials of Obstetrics and Gynaecology, (*2nd Ed.), p. 332–337. Philadelphia, PA: W.B. Saunders.

Elliott, T.R. & Harkins, S.W. (1992). Emotional distress and the perceived interference of menstruation. *Journal of Psychology & Behavioural Assessment,* 14, p. 293–306.

Elliott, R., Fischer, C.T. & Rennie, D.L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, 38, p. 215–229.

Eryilmaz, G. & Ozdemir, F. (2009). Evaluation of menstrual pain management approaches by Northeastern Anatolian adolescents. *Pain Management Nursing,* 10(1), p. 40–47.

Evenhuis, H.M., Sjoukes, L., Koot, H.M. & Kooijman, A.C. (2009). Does visual impairment lead to additional disability in adults with intellectual disabilities? *Journal of Intellectual Disability Research,* 53, p. 19–28.

Fanurik, D., Koh, J.L., Schmitz, M.L. et al. (1999). Children with cognitive impairment: parent report of pain and coping. *Journal of Developmental & Behavioural Pediatrics*, 20, p. 228–234.

Finlay, W.M.L. & Lyons, E. (2001). Methodological issues in interviewing and using self-report questionnaires with people with mental retardation. *Psychological Assessment*, 13, p. 319–335.

Fischer, D., Stewart, A.L., Bloch, D.A., Lorig, K., Laurent, D. & Holman, H. (1999). Capturing the patient's view of change as a clinical outcome measure. *Journal of the American Medical Association*, Vol. 282(12), Sep, p. 1157–1162.

Fowler, D., Garety, P. & Kuipers, E. (1995). *Cognitive Behaviour Therapy for Psychosis: Theory and Practice.* Wiley Series in Clinical Psychology. Chichester: John Wiley.

Gates, B. & Wilberforce, D. (2002). The nature of learning disabilities. In: B. Gates (Ed.), *Learning disabilities: toward inclusion* (p. 1-19). London: Churchill Livingstone.

Gerdle, B., Björk, J., Henriksson, C. & Bengtsson, A. (2004). Prevalence of current and chronic pain and their influences upon work and healthcare-seeking: population study. *Journal of Rheumatology*, 31(7), p. 1399–1406.

Gil, K.M., Abrams, M.R., Phillips, G. & Keefe, F.J. (1989). Sickle cell disease pain: relation of coping strategies to adjustment. *Journal of Consulting & Clinical Psychology*, 57(6), p. 725-731.

Gilbert-MacLeod, C.A., Craig, K.D., Rocha, E.M. & Mathias, M.D. (2000). Everyday pain responses in children with and without developmental delays. *Journal of Pediatric Psychology*, 25, p. 301–308.

Glover, D.S., Shafran, R., Brown, G.P., & Fairburn, C.G. (2006). A preliminary evaluation of CBT for clinical perfectionism: a case series. *British Journal of Clinical Psychology*, 46(1), p. 85–94.

Goubert, L., Eccleston, C., Vervoort, T., Jordan, A. & Crombez, G. (2006). Parental catastrophizing about their child's pain. The parent version of the Pain Catastrophizing Scale (PCS-P): A preliminary validation. *Pain*, 123, p. 254–263.

Gustafsson, M., Gaston-Johansson, F., Aschenbrenner, D. & Merboth, M. (1999). Pain, coping and analgesic medication usage in rheumatoid arthritis patients. *Patient Education Counselling, 37, p. 33–41.*

Guzmán, J., Esmail, R., Karjalainen, K., Malmivaara, A., Irvin, E., Bombardier, C. (2001). Multidisciplinary rehabilitation for chronic low back pain: systematic review. *British Medical Journal,* 322, p. 1511-1516.

Hadden, K.L. & von Baeyer, C.L. (2002). Pain in children with cerebral palsy: common triggers and expressive behaviours. *Pain,* 99(1-2), p. 281–288.

Hadjistavropoulos, T., von Baeyer, C. & Craig, K.D. (2001). Pain assessment in persons with limited ability to communicate. *In D.C.* Turk & R. Melzack (Eds), *Handbook of pain assessment* (2nd Ed.), p. 134-149. New York: Guilford Press.

Hassiotis, A., Serfaty, M., Azam, K., Strydom, A., Martin, S., Parkes, C., Blizard, R. & King, M. (2011). Cognitive behaviour therapy (CBT) for anxiety and depression in adults with mild intellectual disabilities (ID): a pilot randomised controlled trial. *Trials*, 12, p. 95–101.

Hassiotis, A., Serfaty, M., Azam, K., Strydom, A., Blizard, R., Romeo, R., Martin, S., King, M. (2013). Manualised Individual Cognitive Behavioural Therapy for mood disorders in people with mild to moderate intellectual disability: a feasibility randomised controlled trial. *Journal of Affective Disorders,* 151(1); p. 186- 195. doi: 10.1016/j.ad.2013.05.076. Epub 2013 Jul 1.

Hoffman, P.K., Meier, B.P. and Council, F.R. (2002). A comparison of chronic pain between an urban and rural population. *Journal of Community Health Nursing, 19, p. 213–224.*

Hoffman, B.M., Papas, R.K., Chatkoff, D.K. & Kerns, R.D. (2007). Meta-analysis of psychological interventions for chronic low back pain. *Health Psychology,* 26, p. 1-9.

Houlihan, C.M., O'Donnell, M., Conaway, M. & Stevenson, R.D. (2004). Bodily pain and health-related quality of life in children with cerebral palsy. *Developmental Medicine and Child Neurology, Vol 46(5), May, p. 305–310.*

Iacovides, S., Baker, F.C., Avidon, I. & Bentley, A. (2013). Women with dysmenorrhea are hypersensitive to experimental deep muscle pain across the menstrual cycle. *Journal of Pain*, Epub Jun 12.

International Association for the Study of Pain. (1986). International Association for the Study of Pain: classification of chronic pain. *Pain,* 24, p. 1–226.

Jahoda, A., Dagnan, D., Stenfert Kroese, B., Pert, C. & Trower, P. (2009). Cognitive behavioural therapy: From face to face interaction to a broader contextual understanding of change. *Journal of Intellectual Disability Research,* 53, p. 759-771.

Jahoda, A., Willner, P., Rose, J., Kroese, B.S., Lammie, C., Shead, J., Woodgate, C., Gillespie, D., Townson, J., Felce, D., Stimpson, A., Rose, N., MacMahon, P., Nuttall, J., Hood, K. (2013). Development of a scale to measure fidelity to manualised group-based cognitive behavioural interventions for people with intellectual disabilities. *Research in Developmental Disabilities,* 34(11); p.4210-4221. doi: 10.1016/j.ridd.2013.09.

Jensen, M.P., Engel, J.M., Hoffman, A.J. & Schwartz, L. (2004). Natural history of chronic pain and pain treatment in adults with cerebral palsy. *American Journal of Physical Medicine & Rehabilitation,* 83, p. 439–445.

Jensen, M.P. & Karoly, P. (1992). Self-report scales and procedures for assessing pain in adults. In: D.C Turk & R. Melzack (Eds.), *Handbook of Pain Assessment,* (p. 135-151). New York: Guilford Press.

Jensen M.P. & Karoly, P. (2001). Self-report scales and procedures for assessing pain in adults. In: D.C. Turk and R. Melzack, (Eds), *Handbook of pain assessment* (2nd Ed.), (p. 15–34). New York: Guilford Press. .

Jones, D. (2003). Pain management and people with learning disabilities: a complex challenge. *Journal of Learning Disabilities,* 7, p. 291–295.

Julious, S.A. (2005). Sample size of 12 per group rule of thumb for a pilot study. *Pharmaceutical Statistics,* 4, p. 287 – 291.

Kabzems, V. (1985). The use of self-report measures with mentally retarded individuals. *The Mental Retardation and Learning Disability Bulletin, 13,* p. 106–114.

Kato, T. (2016). Effects of flexibility in coping with menstrual pain on depressive symptoms. *Pain Practice: The Official Journal of the World Institute of Pain. doi: 10.1111/papr.12412.*

Keefe, F.J., Buffington, A.L.H., Gibson, J., Studts, J.L. & Caldwell, D.S. (2002). Recent advances and future directions in the biopsychsocial assessment and treatment of arthritis. *Journal of Consulting & Clinical Psychology*, 70, p. 640-655.

Kendall, P.C., & Braswell, L. (1985). *Cognitive-Behavioural Therapy for Impulsive Children.* New York: Guilford Press.

Kline, T.J.B. (2005). *Psychological testing: A practical approach to design and evaluation.* Thousand Oaks, California: Sage.

Knoerl, R., Lavoie Smith, E.M., Weisberg, J. (2016). *Western Journal of Nursing Research*, 38(5): p. 596-628. doi: 10.1177/0193945915615869. Epub 2015 Nov 24. Review.

Kroenke, K. & Mangelsdorff, A.D. (1989). Common symptoms in ambulatory care: incidence, evaluation, therapy and outcome. *The American Journal of Medicine,* Vol. 86(3), p.262–266.

Kyrkou, M. (2005). Health issues and quality of life in women with intellectual disability. *Journal of Intellectual Disability Research,* 49(10), p. 770–772.

LaChapelle, D.L., Hadjistavropoulos, T. & Craig, K.D. (1999). Pain measurement in persons with intellectual disabilities. *Clinical Journal of Pain*, 15, p. 13–23.

Latthe, P.M. & Champaneria, R. (2011). Dysmenorrhoea. *British Medical Journal of Clinical Evidence.* Epub Feb 21.

Leeuw, M., Goossens, M.E.J.B., Linton, S.J., Crombez, G., Boersma, K. & Vlaeyen, J.W.S. (2007). The Fear-Avoidance Model of Musculoskeletal Pain: Current State of Scientific Evidence. *Journal of Behavioral Medicine,* Vol. 30, No. 1, February.

Lewis, S., Bell, D. & Gillanders, D. (2007). Managing chronic pain in people with learning disabilities: A case study. *British Journal of Learning Disabilities,* 35, p. 93–98.

Lewis, R.J., Wasserman, E., Denny, N.W. & Gerrad, M. (1983). The etiology and treatment of primary dysmenorrhoea: A review. *Clinical Psychology Review,* 3, p. 371-389.

Lindsay, W.R., Michie, A.M., Baty, F.J., Smith, A.H.W. & Miller, S. (1994). The consistency of reports about feelings and emotions from people with intellectual disability. *Journal of Intellectual Disability Research,* 38, p. 61-66.

Lindsay, W.R., Neilson, C. & Lawrensen, H. (1997). Cognitive-behaviour therapy for anxiety in people with learning disabilities. In: B. Stenfert-Kroese, D. Dagnan & K.

Loumidis (Eds.) *Cognitive Behaviour Therapy for people with Learning Disabilities.* (p. 110–123). London: Routledge.

Lotan, M., Ljunggren, E.A., Johnsen, T.B., Defrin, R., Pick, C.G. & Strand, L.I. (2009). A modified version of the Non-Communicating Children Pain Checklist – Revised, adapted to adults with intellectual and developmental disabilities: sensitivity to pain and internal consistency. *Journal of Pain,* 10, p. 398–407.

Lynch-Jordan, A.M., Sil, S., Peugh, J., Cunningham, N., Kahikar-Zuck, S. & Goldschneider, K.R. (2014). Differential changes in functional disability and pain intensity over the course of psychological treatment for children with chronic pain. *Pain*, 155(10), Oct., p. 1955-1961. doi: 10.1016/j.pain.2014.06.008.

Maulik, P.K., Mascarenhas, M.N., Mathers, C.D., Dua, T. & Saxena, S. (2011). Prevalence of intellectual disability: a meta-analysis of population-based studies. *Research in Developmental Disabilities, 32(2),* Mar-Apr, p. 419–436.

McCabe, M.P., Gillivray, J.A., & Newton, D.C. (2006). Effectiveness of treatment programmes for depression among adults with mild/moderate intellectual disability. *Journal of Intellectual Disability Research,* 50, p. 239–247.

McGillivray, J.A., Kershaw, M. (2015). Do we need both cognitive and behavioural components in interventions for depressed mood in people with mild intellectual disabilities? *Journal of Intellectual Disability Research,* 59(2); p. 105-115. doi: 10.1111/jir.12110. Epub 2013 Dec 27.

McGrath, P.A., Seifert, C.E., Speechley, K.N., Booth, J.E., Stitt, L. & Gibson, M.E. (1996). A new analogue scale for assessing children's pain: an initial validation study. *Pain*, 64, p. 435–443.

McGuire, B.E., Daly, P. & Smyth, F. (2007). Lifestyle and health behaviours of adults with an intellectual disability. *Journal of Intellectual Disability Research*, 51, p. 497–510.

McGuire, B.E., Daly, P & Smyth, F. (2010). Chronic pain among people with an intellectual disability: Under-recognised and under-treated? *Journal of Intellectual Disability Research*, 54, p. 240–245.

McGuire, B.E. & Kennedy, S. (2013). Pain in people with an intellectual disability. *Current Opinion in Psychiatry*, 26, *p.* 270–275.

McManus, S. & McGuire, B.E. (2010). *Feeling Better – A manual for carers working with people who have intellectual disabilities and chronic pain.* Brighton: Pavilion Publishing Ltd.

McManus, S. & McGuire, B.E. (2014). Cognitive behavioural therapy for chronic pain in people with an intellectual disability: a case series using components of the *Feeling Better* programme. *Journal of Intellectual Disability Research*, 58(3), p. 296–306. doi: 10.1111/jir.12018.

Melville, C. (2005). Discrimination and health inequalities experienced by disabled people. *Medical Education*, 39, p. 122–129.

Melzack, R., Coderre, T.J., Katz, J. & Vaccarino, A.L. (2001). Central neuroplasticity and pathological pain. *Annals of the New York Academy of Sciences*, 933, p. 157–174.

Melzack, R. & Torgerson, W.S. (1971). On the language of pain. *Anesthesiology*, 34, p. 50-59.

Melzack, R. & Wall, P.D. (1965). Pain mechanisms: A new theory. Science, 150, p. 971–979.

Mendelson, G. (1982). Alexithymia and chronic pain: Prevalence, correlates and treatment results. *Psychotherapy and Psychosomatics,* 37(3), Nov, p. 154–164.

Merskey, H. & Bogduk, N. (1994). *Classification of Chronic Pain: Description of Chronic Pain Syndromes and Definition of Pain Terms* (2nd Ed.), (p. 210.). Seattle: IASP Press.

Merskey, H. & Bogduk, N. (2004). *Classification of Chronic Pain* (2nd Ed.). Washington: IASP Press.

Morley, S., Eccleston, C . & Williams, A. (1999). Systematic review and meta-analysis of randomised controlled trials of cognitive behaviour therapy and behaviour therapy for chronic pain in adults, excluding headache. *Pain,* 80, p. 1-13.

Northway, R., Sardi, I., Mansell, I. & Jenkins, R. (2006). Hopes and fears concerning service developments. A focus group study of parents and family carers of people with learning disabilities. *Journal of Applied Research in Intellectual Disabilities*, 19, p. 240.

Oberlander, T.F. & Symons, F.J. (2006). An introduction to the problem of pain in developmental disability. In: T.F. Oberlander & F.J. Symons (Eds.). *Pain in children*

& adults with developmental disabilities. (p. 1–4). Baltimore: Paul H Brookes Publishing.

Okifuji, A., Turk, D.C. & Sherman, J.J. (2000). Evaluation of the relationship between depression and fibromyalgia syndrome: why aren't all patients depressed. *Journal of Rheumatology*, 27(1), p. 212–219.

Ortiz, M.I., Rangel-Flores, E., Carrillo-Alarcón, L.C. & Veras-Godoy, H.A. (2009). Prevalence and impact of primary dysmenorrhea among Mexican high school students. *International Journal of Gynaecology and Obstetrics*, 107(3), Dec., p. 240–243.

Ostelo, R.W.J.G., van Tulder, H.W., Vlaeyen, J.W.S., Linton, S.J., Morley, S.J. & Assendelft, W.J.J. (2007). Behavioural treatment for chronic low-back pain. *Cochrane Database of Systematic Reviews*, Cochrane AN: CD002014.

Parmenter, T.R. (2001). The contribution of science in facilitating the inclusion of people with intellectual disability into the community. *Journal of Intellectual Disability Research*, Vol 45(3), Jun, p. 183-193.

Peters, M.L., Sorbi, M.J., Kruise, D.A., et al. (2000). Electronic diary assessment of pain, disability and psychological adaptation in patients differing in duration of pain. *Pain*, 84, p. 181–192.

Potur, D.C., Bilgin, N.C. & Komurcu, N. (2014). Prevalence of dysmenorrhea in university students in Turkey: Effect on daily activities and evaluation of different pain management methods. *Pain Management Nursing*, 15(4), Dec, p. 768-777.

Proctor, M., Murphy, P.A., Pattison, H.M., Suckling, J.A. & Farquhar, C. (2011). Behavioural interventions for dysmenorrhoea (Review). *Cochrane Database of Systematic Reviews*, Issue 10, Art. No. CD002248. Doi: 10.1002/14651858. CD002248.pub3.

Quartana, P.J., Campbell, C.M. & Edwards, R.R. (2009). Pain catastrophizing: a critical review. Expert Review of Neurotherapeutics, 9(5), p. 745–758.

Quint, E.H., Elkins, T.E., Sorg, C.A. & Kope, S. (1999). The treatment of cyclical behavioural changes in women with mental disabilities. *Journal of Paediatric and Adolescent Gynaecology*, Vol. 12(3), p. 139-142.

Raftery, M., Murphy, A.M., Normand, C., De la Harpe, D., Sarma, K., McGuire, B.E. (2011). Chronic pain in the Republic of Ireland – community prevalence, psychosocial profile and predictors of pain-related disability: Results from the *PRIME* study, Part 1. *Pain*, 152, p. 1096-1113.

Raftery, M., Ryan, P., Normand, C., Murphy, A.W., De la Harpe, D., McGuire, B.E. (2012). The economic cost of chronic non-cancer pain in Ireland: Results from the *PRIME* study, Part 2. *Journal of Pain*, 13, p. 139-145.

Rifkin, S.B. (1996). Rapid Rural Appraisal: its use and value for health planners and managers. Public Administration, 74(3), p. 509–526.

Robertson, J., Emerson, E., Gregory, N., Hatto, Turner, Kessissoglo & Hallam (2000). Lifestyle related risk factors for poor health in residential settings for people with intellectual disabilities. *Research in Developmental Disabilities*, 21, p. 469–486.

Rosenstiel, A.K. & Keefe, F.J. (1983). The use of coping strategies in chronic low back pain patients: relationship to patient characteristics and current adjustment. *Pain*, 17, p. 33–44.

Sammut Henwood, K., Chou, S. & Browne, K.D. (2015). A systematic review and meta-analysis on the effectiveness of CBT informed anger management. *Aggression and Violent Behaviour,* 25B, p. 280-292.

Schwartz, L., Engel, J.M., & Jensen, M.P. (1999). Pain in persons with cerebral palsy. Archives of Physical Medicine & Rehabilitation, 80(10), p. 1243–1246.

Scott, J. (1992). Chronic depression: can cognitive therapy succeed when other treatments fail? *Behavioural Psychotherapy*, 20, p. 25-36.

Sherrard, J., Tonge, B.J. & Ozanne-Smith, J. (2001). Injury in young people with intellectual disability: descriptive epidemiology. *Injury Prevention,* 7, p. 56–61.

Shye, D. & Jaffe, B. (1991). Prevalence and correlates of perimenstrual symptoms: A study of Israeli teenage girls. *Journal of Adolescent Health,* 12, p. 217–224.

Sigelman, C.K., Budd, E.C., Winer, J.L., Schoenrock, C.J. & Martin, P.W. (1982). Evaluating alternative techniques of questioning mentally retarded persons. *American Journal of Mental Deficiency,* 86, p. 511-518.

Smith, B.H., Elliott, A.M., Hannaford, P.C., Chambers, W.A. & Smith, W.C. (2004). Factors related to the onset and persistence of chronic back pain in the community: results from a general population follow-up study. *Spine,* 29, p. 1032–1040.

Spiegel, D. & Bloom, J.R. (1983). Pain in metastatic breast cancer. *Cancer*, 52(2), p. 341–345.

Snow-Turek, A.L., Norris, M.P. & Tan, G. (1996). Active and passive coping strategies in chronic pain patients. *Pain,* 64, p. 455–462.

Sullivan, M.J.L., Thorn, B.E., Haythornthwait, J., Keefe, F.J., Martin, M., Bradley, L., Lefebvre, J.C. (2001). Theoretical perspectives on the relation between catastrophizing and pain. *Clinical Journal of Pain,* 17, p. 53–64.

Symons, F.J., Shinde, S.K. & Gilles, E. (2008). Perspectives on pain and intellectual disability. *Journal of Intellectual Disability Research,* 52(4), p. 275–286.

Syrjala, K.L., Donaldson, G.W., Davis, M.W., Kippes, M.E. & Carr, J.E. (1995). Relaxation and imagery and cognitive-behavioural training to reduce pain during cancer treatment: A controlled clinical trial. *Pain,* 63(2), p. 189-198.

Taggart, L., Coates, V., Clarke, M., Bunting, B., Davies, M., Carey, M., Northway, R., Brown, M., Truesdale-Kennedy, M., Martin-Stacey, L., Scott, G., Karatzias, T. (2015). A study protocol for a pilot randomised trial of a structured education programme for the self-management of type 2 diabetes for adults with intellectual disabilities. *Trials,* 10(16); p. 148. doi: 10.1186/s13063-015-0644-y.

Tang, N.K. & Cran, C. (2006). Suicidality in chronic pain: a review of the prevalence, risk factors and psychological links. *Psychological Medicine,* 36, p. 575–586.

Tang, N.K. (2017). Cognitive behavioural therapy in pain and psychological disorders: Towards a hybrid future. *Progress in neuro-psychopharmacology & biological psychiatry,* pii: s0278-5846(17)30083-0. doi: 10.1016/j.pnpbp.2017.02.023.

Taylor, G. (1995). Adolescence and early adulthood: the needs of the more able young adult. In: K. Ellis (Ed.) *Autism. Professional Perspectives and Practice* (p. 47–65). London: Chapman & Hall.

Taylor, J.L., Novaco, R.W., Gillmer, B. & Thorne, I. (2002). Cognitive-behaviour treatment of anger intensity among offenders with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities,* 15, p. 151–165.

Taylor, D.J. & Pruiksma, K.E. (2014). Cognitive and behavioural therapy for insomnia (CBT-I) in psychiatric populations: a systematic review. *International Review of Psychiatry,* 26, p. 205-213.

Teare, M.D., Dimairo, M., Shephard, N., Hayman, A., Whitehead, A. & Walters, S.J. (2014). Sample size requirements to estimate key design parameters from external pilot randomised controlled trials: a simulation study. *Trials,* 3(15), p. 264. doi: 10.1186/1745-6215-15-264.

Tervo, R.C., Symons, F., Stout, J. & Novacheck, T. (2006). Parental report of pain and associated limitations in ambulatory children with cerebral palsy. *Archives of Physical Medicine & Rehabilitation,* 87, p. 928–934.

Thastum, M., Herlin, T. and Zachariae, R. (2005). Relationship of pain-coping strategies and pain-specific beliefs to pain experience in children with juvenile idiopathic arthiritis. *Arthritis and Rheumatism*, 53(2), p. 178–184.

The British Pain Society (2013). *Guidelines for Pain Management Programmes for adults. An evidence-based review prepared on behalf of the British Pain Society.* London: the British Pain Society.

Tu, C.H., Niddam, D.M., Chao, H.T., Chen, Y.S., Wu, Y.T., Yeh, T.C., Lirng, J.F., Hsieh, J.C. (2010). Brain morphological changes associated with cyclic menstrual pain. *Pain*, 150, p. 463–468.

Tu, C.H., Niddam, D.M., Chao, H.T., Liu, R.S., Hwang, R.J., Yeh, T.C., Hsieh, J.C. (2009). Abnormal cerebral metabolism during menstrual pain in primary dysmenorrhea. *Neuroimage*, 47, p. 28–35.

Tu, C.H., Niddam, D.M., Yeh, T.C., Lirng, J.F., Cheng, C.M., Chou, C.C., Chao, H.T., Hsieh, J.C. (2013). Menstrual pain is associated with rapid structural alterations in the brain. *Pain.* Epub, May 18.

Turk, D.C. (1996). Biopsychosocial perspective on chronic pain. In: R.J. Gatchal & D.C. Turk (Eds.). *Psychological approaches to pain management: a practitioner's handbook.* (p. 3-32). New York, US*:* Guilford Press.

Turk, D.C. (2002). Clinical effectiveness and cost-effectiveness of treatments for patients with chronic pain. *Clinical Journal of Pain*, 18, p. 355–365.

Turk, D.C. (2003). Cognitive-behavioural approach to the treatment of chronic pain patients. *Regional Anesthesia and Pain Medicine*, 28(6), p. 573–579.

Turk, D.C. & Flor, H. (1999). Chronic pain: a biobehavioural perspective. In: R.J. Gatchel & D.C. Turk DC (Eds.). *Psychosocial Factors in Pain: Critical Perspectives*. (p. 18-34). New York: Guilford Press.

Turk, D.C. & Okifuji, A. (2003). A cognitive-behavioural approach to pain management In: P.Melzack & P.D. Wall (Eds.). *Handbook of pain management: A clinical companion to Wall and Melzack's textbook of pain* (p. 533-542). Philadelphia: Churchill Livingstone.

Turk, D.C. & Melzack, R. (Eds.) (1992). *Handbook of pain assessment*. New York: Guilford Press: xv, 491.

Turk, D.C. & Melzack, R. (Ed.s) (2001). *Handbook of pain assessment* (2nd Ed.). Guilford Press: xix, 760.

Turk, D.C. & Rudy, T.E. (1986). Assessment of cognitive factors in chronic pain: A worthwhile enterprise? *Journal of Consulting and Clinical Psychology,* Vol. 54(6), p. 760–768.

Turk, D.C., Wack, J.T. & Kerns, R.D. (1985). An empirical examination of the "pain behaviour" construct. *Journal of Behavioural Medicine,* 8, p. 119-130.

Turk, M.A., Geremeski, C.A., Rosenbaum, P.F. and Weber, R.J. (1997). The health status of women with cerebral palsy. *Archives of Physical Medicine and Rehabilitation*, Supplement 5, 78(12), S10-7. (1p).

Turk, D.C., Dworkin, R.H., Burke, L.B., Gershon R., Rothman M., Scott, J., Allen, R.R., Atkinson, J.H., Chandler, J., Cleeland, C., Cown, P., Dimitrova, R., Dionne, R., Farrar, J.T., Haythornthwaite, J.A., Hertz, S., Jadad, A.R., Jensen, M.P., Kellstein, D., Kerns, R.D., Manning, D.C., Martin, S., Max, M.B., McDermott, M.P., McGrath, P., Moulin, D.E., Nurmikko, T., Quessy, S., Raja, S., Rappaport, B.A., Rauschkolb, C., Robinson, J.P., Royal, M.A., Simon, L., Stauffer, J.W., Stucki, G., Tollett, J., von Strin, T., Wallace, M.S., Wernicke, J., White, R.E., Williams, A.C., Witter, J., Wyrwich, K.W. (2006). Developing patient-reported outcome measures for pain clinical trials: IMMPACT recommendations. *Pain,* 125, p. 208 – 215. doi:10.1016/j.pain.2006.09.028

Turner, J.A. & Clancy, S. (1986). Strategies for coping with chronic low back pain: Relationship to pain and disability. *Pain*, 24, p. 355–364.

Turner, J.A., Mancl, & Aaron, L.A. (2006). Short- and long-term efficacy of brief cognitive-behavioural therapy for patients with chronic temporomandibular disorder pain: A randomized controlled trial. *Pain*, 121(3), p. 181-194.

Twomey, C., O'Reilly, G. & Byrne, M. (2015). Effectiveness of cognitive behavioural therapy for anxiety and depression in primary care: A meta-analysis. *Family Practice,* 32(1), p. 3-15.

Vanderlinden, J., Adriaensen, A., Vancampfort, D., Pieters, G., Probst, M. & Vansteelandt, K. (2012). A cognitive-behavioural therapeutic program for patients with obesity and binge eating disorder: short and long-term follow up data of a prospective study. *Behaviour Modification,* 36(5), p. 670-686.

Vereenooghe, L. & Langdon, P.E. (2013). Psychological therapies for people with intellectual disabilities: a systematic review and meta-analysis. *Research in Developmental Disabilities,* 34(11), p. 4085-4102.

Vincent, K., Warnaby, C., Stagg, C.J., Moore, J., Kennedy, S. & Tracey, I. (2011). Dysmenorrhea is associated with central changes in otherwise healthy women. *Pain*, 152, p. 1966–1975.

Vlaeyen, J.W.S. & Linton, S.J. (2012). Fear-Avoidance model of chronic musculoskeletal pain: 12 years on. *Pain*, 153(6), p. 1144–1147.

Volkmar, F.R. & Dykens, E. (2002). Mental Retardation. In: M. Lewis (Ed.) *Child and adolescent psychiatry: A comprehensive textbook* (3rd Ed.). p. 587–937; Philadelphia, PA, US: Lippincott Williams & Wilkins Publishers; xxiv, 1495.

Wallis, B.J., Lord, S.M. & Bogduk, N. (1997). Resolution of psychological distress of whiplash patients following treatment by radiofrequency neurotomy: A randomised, double-blind, placebo-controlled trial. *Pain,* Vol 73(1), Oct, p. 15–22.

Walmsley, J., Earle, S., Tilley, E., Chapman, R., Ledger, S. & Townson, L. (2016). Contraceptive choices for women with learning disabilities. *Learning Disability Practice,* Vol. 19(2), p.32-34.

Walsh, M., Morrison, T.G. and McGuire, B.E. (2011). Chronic pain in adults with an intellectual disability: prevalence, impact and health service use based on carer report. *Pain*, 152, p. 1951–1957. doi:10.1016/j.pain.2011.02.031

Walsh, T.M., LeBlanc, L. & McGrath, P.J. (2003). Menstrual Pain Intensity, Coping and Disability: The Role of Pain Catastrophizing. *Pain Medicine,* Vol.4, Issue: 4, p. 352-361.

White, C.A. (2001). Cognitive behavioural principles in managing chronic disease. *Western Journal of Medicine,* Vol. 175(5), p. 338-342.

Whitehouse, Tudway, Look & Stenfert-Kroese (2006). Adapting individuals psychotherapy for adults with intellectual disabilities; a comparative review of the cognitive-behavioural and psychodynamic literature. *Journal of Applied Research in Intellectual Disabilities,* 19, p. 55-65.

Williams, J.M.G. (1992). *The Psychological Treatment of Depression: A Guide to the Theory and Practice of Cognitive Behaviour Therapy.* London: Routledge.

Williams, W.H. (2003). Brain injury and emotion: An overview to a special issue on biopsychosocial approaches in neurorehabilitation. *Neuropsychological Rehabilitation,* 13, Issue: No. 1–2, p. 1–11.

Williams, A.C. de C., Eccleston, C. & Morley, S. (2012). Psychological therapies for the management of chronic pain (excluding headache) in adults. *Cochrane Database of Systematic Reviews,* Issue 11, Art. No.: CD007407. Doi: 10/1002/14651858.cd007407. pub3.

Willner, P., Jones, J., Tam, R. & Green, G. (2002). A randomised controlled trial of a cognitive behavioural anger management group for clients with learning disabilities. *Journal of Applied Research in Intellectual Disabilities,* 15, p. 224–235.

Willner, P., Rose, J., Jahoda, A., Stenfert Kroese, B., Felce, D., MacMahon, P., Stimpson, A., Rose, N., Gillespie, D., Shead, J., Lammie, C., Woodgate, C., Townson, JK., Nuttall, J., Cohen, D., Hood, K. (2013). Group-based cognitive-behavioural anger management for people with mild to moderate intellectual disabilities: cluster randomised controlled trial. *British Journal of Psychiatry*, 203(3); p. 288-296. doi: 10.1192/bjp.bp.112.124529. Epub 2013 Mar 21.

World Health Organization. (2010). *The ICD-10 classification of mental and behavioural disorders: Clinical descriptions and diagnostic guidelines*. Geneva: World Health Organization.

Wu, K.K., Li, F.W. & Cho, V.W. (2014). A randomized controlled trial of the effectiveness of brief-CBT for patients with symptoms of posttraumatic stress following a motor vehicle crash. *Behavioural and Cognitive Psychotherapy*, 42(1), p. 31-47.

Zagustin, T.K. (2013). The role of cognitive behavioural therapy for chronic pain in adolescents. *PM&R: the journal of injury, function and rehabilitation,* 5(8); p. 697-704. doi: 10.1016/j.pmrj.2013.05.009.

Zhan, S. & Ottenbacher, K.J. (2001). Single-subject research designs for disability research. *Disability and Rehabilitation,* 23(1), p. 1-8.

Appendix 1: Information Letter for Parents/Guardians of potential participants.

PSYETH 11/12 026

Seeking Participants for Research

Evaluation of a menstrual pain management programme for adolescent girls with intellectual disabilities.

Dear Parent(s),

My name is Susan Kennedy and I am a Senior Clinical Psychologist with the Brothers of Charity Services, Galway. I am conducting research with teenage girls with learning disabilities about managing their period pain and would like to invite you and your daughter to participate. This research is part of a doctoral thesis I am completing at City University London.

What is the research about?

The aim of the research is to evaluate a cognitive behaviour therapy (CBT) based pain management programme for period pain in teenage girls with learning disabilities. Cognitive behaviour therapy is an approach used to treat a variety of problems. It aims to change people's behaviour and feelings by changing the way they think about a situation. You and your daughter are being asked to participate in this study because you can provide important information about this issue.

What does it involve?

If you would like to take part in this research you will be asked to answer some questions about the effect of period pain on your daughter's life, how she usually copes with the pain and other things you think could help her to cope with the pain. The information which you provide will be analysed.

What will happen to the information I provide?

Your information will be stored in a locked filing cabinet during the research. It will be confidential and no identifying information e.g. name, address etc. will be included

on it. You will be given a number so your name will not be on the information you provide. The information which you provide will be published in journal articles and presented at conferences. It will be kept for five years, in line with data retention policies, and it will then be shredded.

What if I change my mind?

If you change your mind about taking part you can end the discussion at any point without explanation. This will not affect you or your daughter.

What does the pain management group involve?

If you would like your daughter to take part in the research, she will be invited to attend a twelve week period pain management group. This will take place on a weekly basis at school, for approximately forty minutes. There will be 6 – 8 girls in the group and she will learn different ways to manage her period pain e.g. relaxation techniques, taking exercise, how to challenge negative thoughts, ways to think more positively and ways to take her mind off her pain. The group will only talk about coping with period pain. It will not include information on other topics such as sexual intercourse or contraception.

What will happen to the information my daughter provides?

Your daughter's information will be confidential and no identifying information will be included in the research. She will also be given a number so her name will not be on the information she provides. Her information will be kept in a locked filing cabinet during the research and shredded afterwards, in line with data retention policies.

What will happen if my daughter changes her mind about taking part?

If your daughter changes her mind about taking part in the group she can leave without explanation. This will not affect her.

How do I get more information?

If you have any questions on this research or want more information, you can contact me on 087 2724221. You can also contact my Research Supervisor, Dr Brian McGuire, at NUI Galway on 091 492954.

How do I participate?

If you would like to take part in the study and would like your daughter to take part in the period pain management group, please complete the attached consent form and return it to me in the stamped addressed envelope provided. I will then arrange to meet with you and your daughter to explain the group to her and seek her consent to take part.

Comments, concerns or observations procedure:

This project has been approved by the Research and Ethics Committee of the Department of Psychology of City University London (project approval number **PSYETH 11/12 026).**

If you have any comments, concerns or observations about the conduct of the study or your experiences as a participant, please contact the Secretary to the Committee Mr Peter Aggar, quoting the above project approval number.

Telephone: +44 (0)20 70404566

Email: peter.aggar.1@city.ac.uk

Postal Address: Mr Peter Aggar

Secretary to Psychology Department

Research & Ethics Committee

School Office

Schools of Arts & Sciences

City University

Northhampton Square

London EC1V 0HB

Yours sincerely,

_____

Susan Kennedy

Senior Clinical Psychologist

Appendix 2: Consent form for Parents/Guardians.

PSYETH 11/12 026

Evaluation of a menstrual pain management programme for adolescent girls with intellectual disabilities.

1.	I have read and understand the participant information sheet provided. The research has been explained to me and I have had the opportunity to ask questions, if I wish.	☐
2.	I understand that my participation is voluntary and that I can withdraw at any time. This will not affect me or my daughter.	☐
3.	I understand that the information which I provide will be analyzed.	☐
4.	My information is confidential and will be stored in a safe manner. It will be shredded when the research has been completed. It will be presented at conferences and published in journal articles but I will not be identified.	☐
5.	I agree to participate in the research project.	☐
6.	I give permission for my daughter to participate in the period pain management group.	☐
7.	I would like to receive information on the results of the study, when it is completed (If so, please provide an address or email address).	☐

_____

Name:

_____

BLOCK CAPITALS

Signature:

_____

Phone Number:

_____

Date:

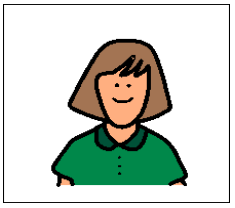
_____

Appendix 3: Participant Information Sheet.

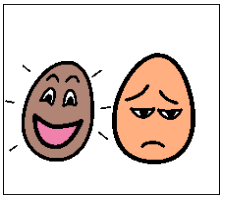
PSYETH 11/12 026

Dear _____

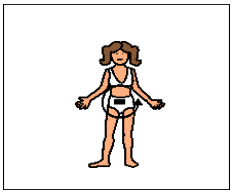
My name is Susan Kennedy. I am a Psychologist.



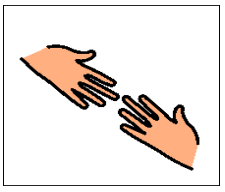
I work with men and women and help them to talk about their feelings.



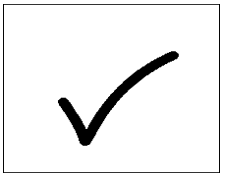
I am doing a group about period pain.



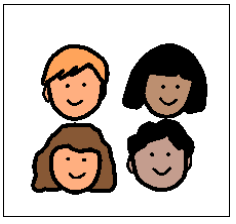
I want you to help me with my group.



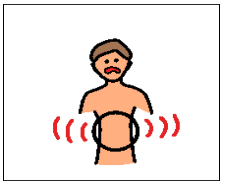
If you say yes



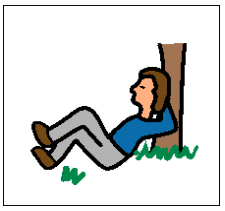
You will take part in a group every week for 12 weeks with other women.



We will talk about how to deal with the pain you get each month when you have your period.

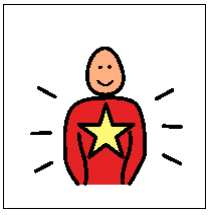


If you get tired, we can take a break.



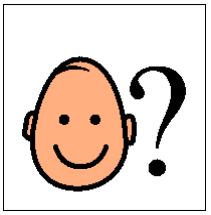
You can leave the group whenever you like.

You will not get into trouble if you leave the group.

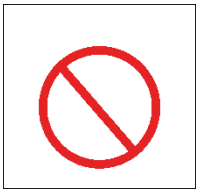


Your information is private but if you tell me something that makes me worried I may need to talk to someone else about it.

I will write about the group for my college course but I won't use your name.



You do not have to take part in the group if you don't want to.



If you have any questions you can contact me at:

Susan Kennedy

4 Rathbawn Road, Creagh, Ballinasloe, Co. Galway

Ph: 087 2724221

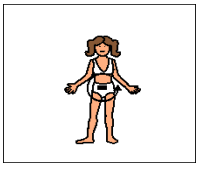
Thank you

Appendix 4: Participant Consent Form.

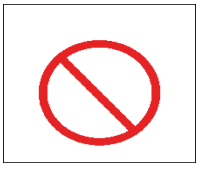
PSYETH 11/12 026

I understand that …

This is a group about period pain

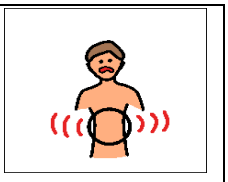


I do not have to take part in this group



If I want to take part …

We will talk about how to deal with the pain I get each month when I get my period

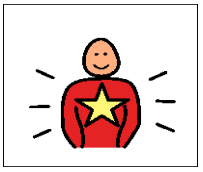


I understand that …

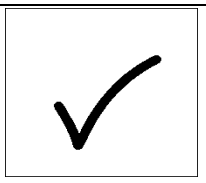
All my information will be private

I can leave the group whenever I like

I will not get into trouble if I leave the group

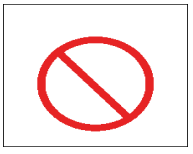


Yes I want to take part in this study



OR

No I do not want to take part in this study



Name of Participant: _____

Signature of Participant: _____

Date: _____

I have read the consent form with the potential participant and they have had the opportunity to ask questions about the study. I confirm that consent has been freely given to participate in this study.

Name of Researcher: _____

Signature of Researcher: _____

Name of Parent: _____

Signature of Parent: _____

Date: _____

Appendix 5: Notification of Ethics Approval.

From: **Aggar, Peter** <Peter.Aggar.1@city.ac.uk>
Date: Mon, Apr 23, 2012 at 2:26 PM
Subject: PSYETH 11/12 026 Susan Kennedy
To: Susan Kennedy <susankennedy2007@gmail.com>

Dear Susan,

Approval reference: PSYETH 11/12 026

The unique approval reference number **'PSYETH 11/12 026'** should be included on the top of all information and consent forms, and in all future correspondence about your ethical approval for ease of reference.

The Psychology Department Research & Ethics committee has made the following comments regarding your application:

"This looks like a very useful intervention and study.

I could do with a bit more information on how the intervention and control groups will be allocated, and how this will be communicated. For example, how will the questionnaires be explained to those in the matched control (TAU) group? Could the controls be offered the same intervention at a later date? What if some in the focus group like the sound of the intervention, but are then excluded (e.g., because of low pain etc)?

Also, location is not yet set. If it does take place in school, will the participants be pulled out of their classes to attend the training? If so, might there be a risk of stigmatisation? The researchers clearly have a lot of experience in this area, but I would like to see a bit more information about how they manage such issues.

In sum, I would be very grateful if the researchers could provide the following info:

How will the control group be matched?

What info will the control group receive?

Is randomisation out of the question (perhaps with half randomly allocated to a waiting list for the training)?

Will the intervention take place in school time? If so, will other pupils know where the participants are going? How will the research team minimise the risk of participants being

judged by those who were not eligible to participate? What info will the unselected pupils/ parents receive?"

On the Info sheet and the Consent form, please also include the following text:

"Comments, concerns or observations procedure:

This project has been approved by the Research and Ethics Committee of the Department of Psychology of City University London (project approval number **PSYETH 11/12 026**).

If you have any comments, concerns or observations about the conduct of the study or your experiences as a participant, please contact the Secretary to the Committee Mr Peter Aggar, quoting the above project approval number:

Telephone: +44 (0)20 7040 4566.

Email: peter.aggar.1@city.ac.uk

Postal Address: Mr Peter Aggar

Secretary to Psychology Department Research and Ethics Committee

School Office

Schools of Arts and Social Sciences

City University

Northampton Square

London

EC1V 0HB"

Could you please send me your response for the committee to consider?

Do not hesitate to contact me should you have any questions or require further clarification

Kind regards,

Peter

WOODLANDS CENTRE
Renmore, Galway, Ireland

Brothers of Charity Services,
Woodlands Centre,
Renmore,
Galway.

25 June 2012

Ms. Susan Kennedy,
Senior Clinical Psychologist,
C/o Brothers of Charity,
10 Church Hill,
Ballinasloe,
Co . Galway

Dear Susan,

Thank you for your submission to the Ethics Committee of the Brothers of Charity Services Galway. I wish to commend you on your well presented submission and in particular the committee would like to commend you on your 'easy to read' Participant Information sheet.

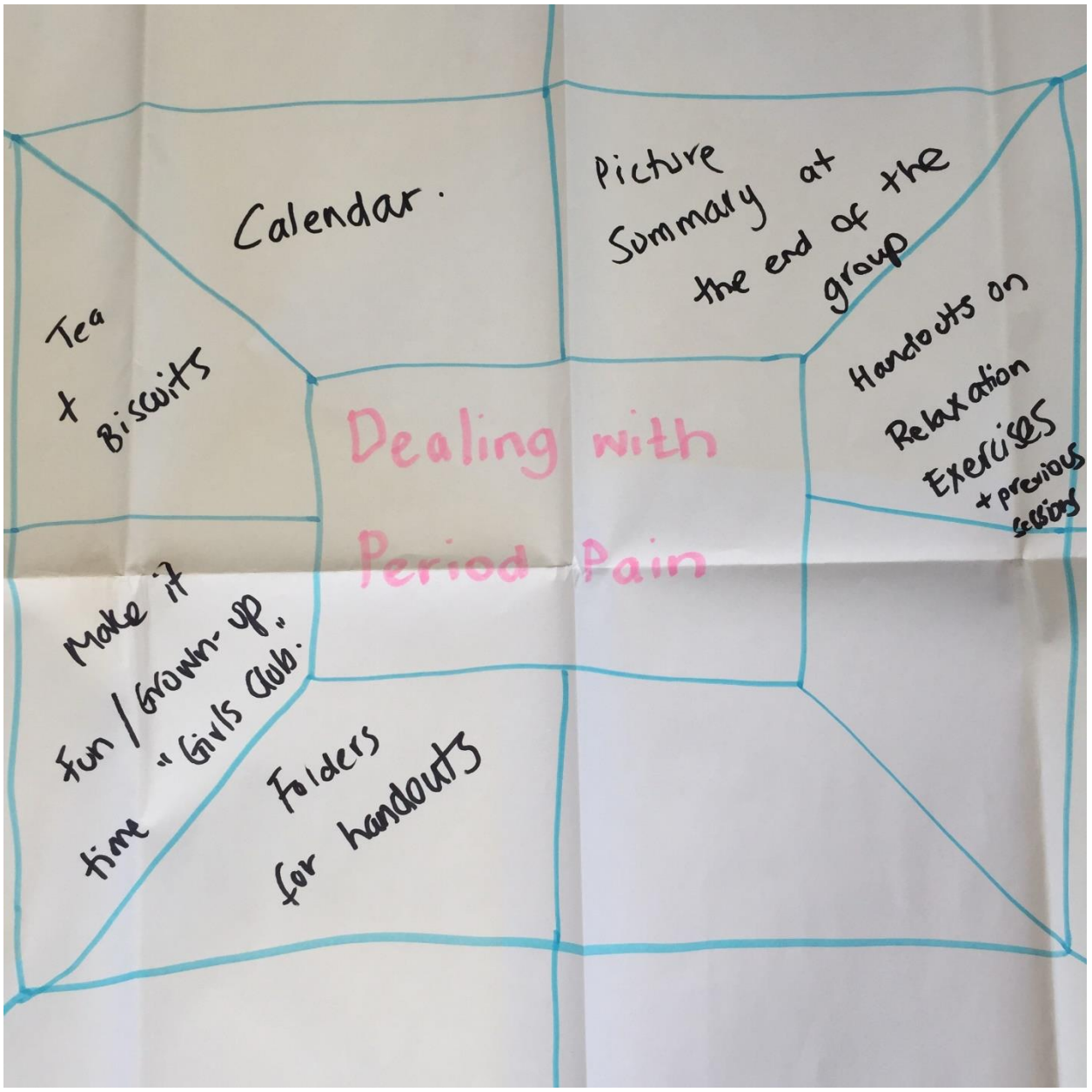
I wish to confirm approval for your Ethics Submission and to wish you well with your work..

Yours sincerely,

Joe Murphy
Acting Chairperson,
Research Ethics Committee

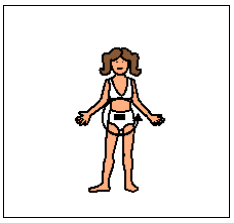
Joseph Murphy

Appendix 6: 'Web of Ideas' created during Parent Focus Group



Appendix 7: Session Summary Sheets

Session 1 – Understanding Period Pain



Today I learnt that ….

- Period pain is the pain that women get before or during their period.

- Period Pain is normal - many girls and women get it.

- Women can get period pain at different times, in different parts of their body and for different lengths of time.

- Pain is affected by many things like mood, thoughts and feelings.

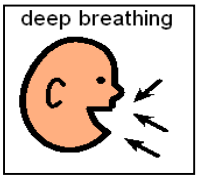
- It is okay to talk about period pain – I don't have to be embarrassed or ashamed to talk about it.

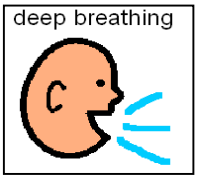
- "Self-management" is thinking of and doing things that will make the pain better.

Next Week I will learn ….

- Ways to relax to help me manage my pain.

Session 2: Relaxation – Deep Breathing





Today I learnt that ….

- Our normal response to pain is to tense our bodies.
- Tensing our bodies against pain for long periods of time can lead to increased levels of pain and physical tension.
- Relaxation helps to avoid the effects of tension.
- Relaxation can help put our minds and bodies in a calm and relaxed state.
- How to practice deep breathing.

Next Week I will learn ….

- Ways to relax my body.

Session 3: Progressive Muscle Relaxation

Step-by-step Guide

- **Deep Breathing:** Take 6 long, slow deep breaths

- **Hands and lower arms:** Make a tight fist and pull up your wrists. Feel the tension in your hands, knuckles and lower arms. Relax and repeat.

- **Upper arms:** Bend your arms at the elbows. Make fists and pull up your fists towards your chin while squeezing your fists tightly. Feel the tension in the back of your arms, shoulders and back. Relax and repeat.

- **Neck:** Touch your chin to your chest. Feel the pull in the back of your neck as it spreads into your head. Relax and repeat.

- **Shoulders:** Pull your shoulders up toward your ears. Feel the tension in your shoulders, head, neck and upper back. Relax and repeat.

- **Chest, shoulders and upper back:** Pull your shoulders back as if you're trying to make your shoulder blades touch. Relax and repeat.

- **Stomach:** Pull your stomach towards your back, tightening your stomach muscles. Relax and repeat.

- **Upper legs:** Squeeze your knees together and lift your legs up. Feel the tension in your thighs. Relax and repeat.

- **Lower legs:** Raise your feet toward the ceiling while pointing your toes toward your body. Feel the tension in your calves. Relax and repeat.

- **Feet:** Turn your feet toward inward and curl your toes up and out. Relax and repeat.

- **Upper part of your face:** Lift your eyebrows toward the ceiling. Feel the tension in your forehead and scalp. Relax and repeat.

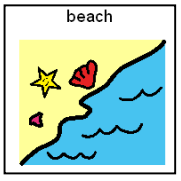
- **Central part of your face:** Squint your eyes together and wrinkle your nose and mouth. Feel the tension in your face. Relax and repeat.

- **Lower part of your face:** Clench your teeth and pull back the corners of your mouth toward your ears. Show your teeth like a snarling dog. Relax and repeat.

Next Week I will learn ….

- How to use my imagination to help me to relax

Session 4: Relaxation – Visualisation



Today …

- I learnt that using my imagination (visualisation) can help me to better manage menstrual pain.

- I completed a visualisation exercise and used my imagination to think of a relaxing place.

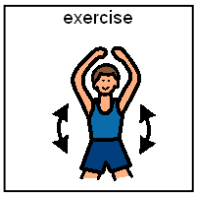
- I can use this with deep breathing and the other relaxation skills I learnt.

- I should practice this skill every day to get better at it.

Next week I will learn …

- How exercise helps me when I have pain.

Session 5: Physical Exercise



Today …

- I learnt that Exercise is important in managing pain.

- I learnt that Exercise stops painful areas becoming more painful.

- I learnt that being fit and strong helps me to cope with pain.

- I learnt that Exercise makes me feel happier.

- I discussed different types of exercise and made an exercise plan for when I have my period.

My exercise plan

When I have my period I will

……
……
……
……

Next week I will learn …

- To pace my activities

Session 6: Attention Management – Taking your mind off your pain

---

Today …

- I learnt different things that I can do to try to take my mind off my pain when I have my period.

- These skills can be used to distract yourself from pain no matter where you are and what time of the day it is.

- These skills include:

- Looking – looking at all of the items in the room, describing them and putting them into groups.

- Listening – listening to all the sounds in the room and outside the room and trying to name the sounds.

- Remembering – remembering the names of people in your favourite TV programme or Teachers in your school.

Next week I will learn …

- How your thoughts make you feel

Session 7: How your thoughts make you feel

Today ….

- I completed exercises that looked at how you think and feel about pain.

- Sometimes the thoughts and feelings happen so quickly you can miss them.

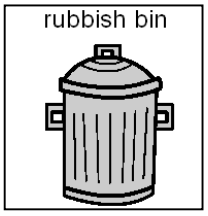
- With practice, I can become more familiar with my thoughts and feelings.

- I can learn to change negative thoughts to positive thoughts.

Next week I will learn …

- To challenge negative thoughts

Session 8: Challenging negative thoughts



Today ….

- I learnt to spot the physical signs of stress in my body and how it affects me by making me angry or irritated. It is very helpful if I know what things can make me stressed.

- I learnt how to check my stress levels by thinking about my life and physical signs of stress.

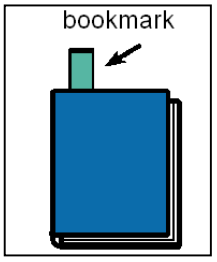
- I learnt to check if my thoughts are true or false and to “bin” negative thought and “bank” positive thoughts about period pain.

- I learnt to try to challenge negative thoughts – it is important not to just accept them and let them make you me feel bad.

Next Week I will learn ….

- Positive thinking and coping.

Session 9: Positive Thinking and Coping Self-Talk



Today …

- I learnt a new skill called “coping self-talk”.

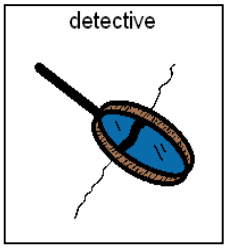
- I learnt things that I can say to myself when I have negative thoughts or feelings. This will help me to feel better and to continue what I am doing.

- I made a book mark with a “coping statement” on it. I can use this to help me when I am doing my work.

Next Week I will learn ….

- How to solve problems.

Session 10: Problem-Solving



Today I learnt …

- that when I have a problem, I should think of as many different ways to solve it as I can.
- I can then pick the solution I think will work best.
- The solution I choose may not work but now I know how to go back and start to solve a problem again.

Next Week I will learn about ….

- Medication.

Session 11: Medication

Today I learnt …

- That medication can help some people to feel better when they are in pain

- That some medication can have side effects and I should always tell an adult if I feel unwell after taking a new medication

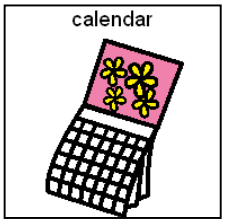
- That medication is one form of pain management but not the only one

---

Next Week I will learn ….

- how I can be the “Manager” of my own pain

Session 12: Self-Management



Today I learnt …

- I have many skills that I can use to help me when I am in pain.

- It is important to keep practicing these skills so that they can be used quickly and easily when I need them.

- I can be my own “Manager” and be in charge of managing my period pain.

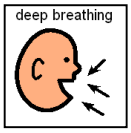
- I need to decide when to use the skills I have learnt to manage my period pain.

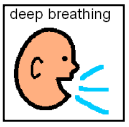
Appendix 8: Certificate of Participation

Certificate of Achievement

…….. successfully completed a 12 week pain management programme to help her manage her period pain.

The skills she learnt to manage are …

- Deep Breathing 

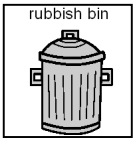


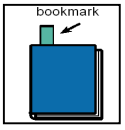
- Full body relaxation

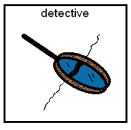
- Visualising a happy time

- Taking exercise

- Distracting myself through looking, listening and remembering other things

- Questioning negative thoughts 

- Using positive statements to encourage me to keep going 

- Problem-solving 

- Using medication

- Planning ahead using my calendar

Appendix 9: Pain Coping Strategies Questionnaire

Researcher: Please tell me about all of the different things that you do to deal with your pain?

Instructions:

A. If the participant lists many different strategies to manage pain add these into the various strategy slots from 1 – 7.
B. Next, return to each strategy individually and rate its effectiveness with the participant. A visual aid is provided, if required.
C. To rate effectiveness of strategy ask "How well do you think X works to manage pain? (Barry et al., 2004).
D. If the participant provides only one answer put this in slot 1. Next rate effectiveness of this strategy. To rate effectiveness ask "How well do you think X works to manage pain?
E. If one answer is provided at a time, after effectiveness rating ask "Do you use any other methods to cope with pain? This can be asked up to a maximum of seven times.

Using the Visual Aid:

This page shows you that there are three different answers to choose from. The biggest line shows that you think that this works very well. As the line gets smaller it means that it works only sometimes, right down to the smallest line which means that this does not work at all.

The participant can point to the item on the visual aid or respond verbally.

Strategy 1: _____

Effectiveness: Works very well (2)

Works sometimes (1)

Doesn't work at all (0)

Strategy 2: _____

Effectiveness: Works very well (2)
Works sometimes (1)
Doesn't work at all (0)

Strategy 3: _____

Effectiveness: Works very well (2)
Works sometimes (1)
Doesn't work at all (0)

Strategy 4: _____

Effectiveness: Works very well (2)
Works sometimes (1)
Doesn't work at all (0)

Strategy 5: _____

Effectiveness: Works very well (2)
Works sometimes (1)
Doesn't work at all (0)

Strategy 6: _____

Effectiveness: Works very well (2)

Works sometimes (1)

Doesn't work at all (0)

Strategy 7: _____

Effectiveness: Works very well (2)

Works sometimes (1)

Doesn't work at all (0)

Scoring:

Number of pain coping strategies listed _____

Total effectiveness score _____

Visual Aid

Works Very Well

Works Sometimes

Doesn’t Work At All

Appendix 10: Pain Coping Scenarios Questionnaire

1. What would you do if you had pain during the night?

_____

_____

_____

_____

2. What would you do if you had pain at school?

_____

_____

_____

_____

3. What would you do if you had pain at home?

_____

_____

_____

_____

4. What would you do if you had pain when you were out somewhere or during an activity e.g. bowling, shopping?

_____

_____

_____

_____

Appendix 11: Pain Knowledge Questionnaire

Instructions:

I am going to ask you some questions about how you manage your pain. You can answer "yes", "no" or "don't know" to these questions. I will also ask you to give me more information and examples for some questions. Don't worry if you don't know the answers.

a. I am usually able to manage my pain on my own.

Yes ☐

No ☐

Don't know ☐

If yes, how do you manage your pain?

_____

_____

b. Relaxing my muscles can help me to cope with my pain.

Yes ☐

No ☐

Don't know ☐

If yes, what muscles would you relax and how?

_____

_____

c. My thoughts can make my pain feel better or worse.

Yes ☐

No ☐

Don't know ☐

If yes, can you give me an example?

_____

_____

d. If I try to distract myself it can help me to manage my pain.

Yes ☐

No ☐

Don't know ☐

If yes, what do you do to distract yourself?

_____

_____

e. The way I am feeling can make my pain feel better or worse.

Yes ☐

No ☐

Don't know ☐

If yes, can you give me an example?

_____

_____

f. Deep breathing can help my pain.

Yes ☐

No ☐

Don't know ☐

If yes, can you tell me how you would do deep breathing?

_____

_____

g. Tablets are the only thing that can help my pain.

Yes ☐

No ☐

Don't know ☐

If no, what other things can help?

_____

_____

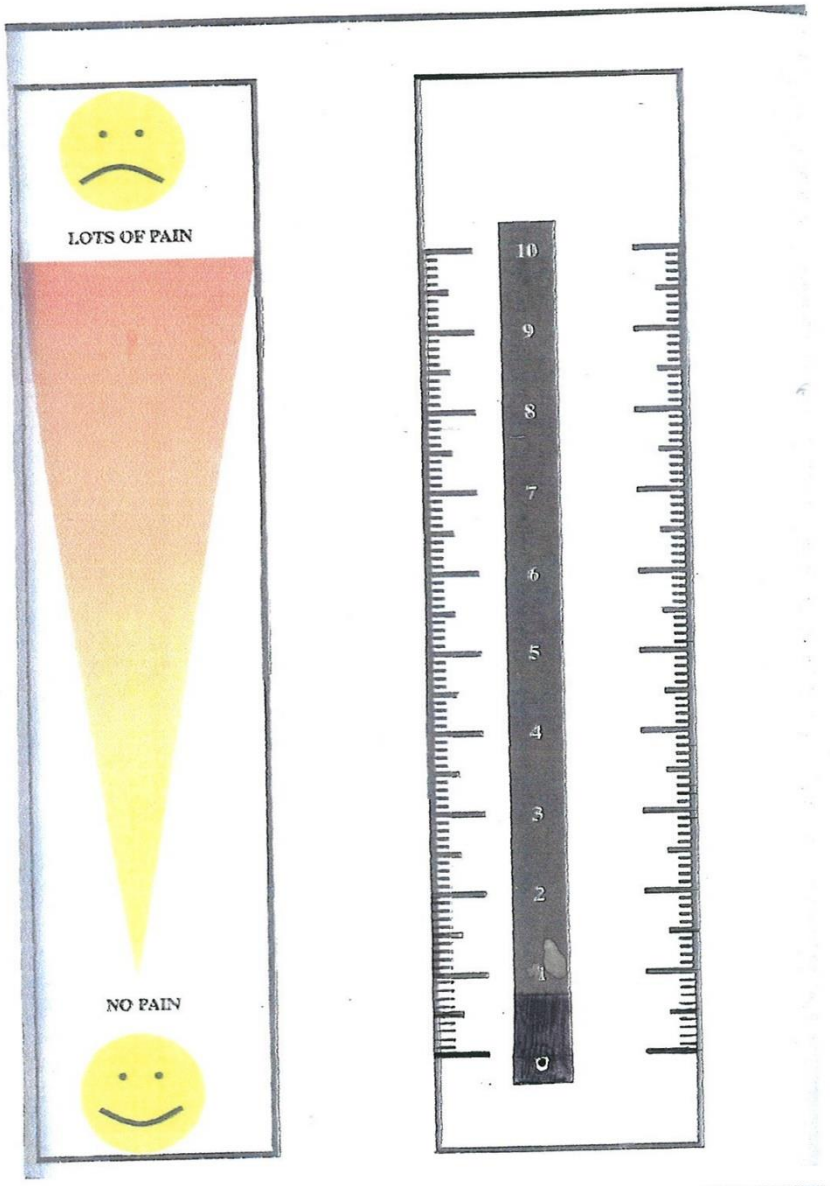
Scoring:

Valid answers must also be provided to the probing questions to receive credit.

Maximum score = 7

Score: _____

Appendix 12: The Pain Intensity Scale (McGrath et al. 1996)



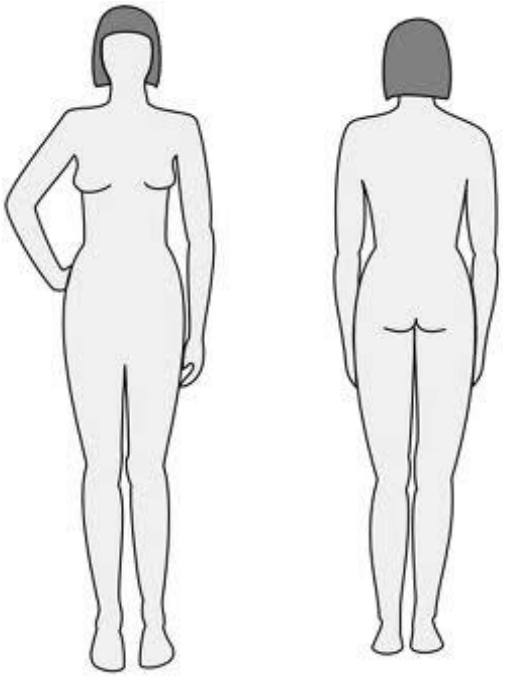
Appendix 13a: Pain Impact Scale - Participant Version.

(Modified from the Brief Pain Inventory – Short Form; Cleeeland & Ryan, 1994)

1. Most people have pain sometimes like a headache or a toothache. Have you had any other kind of pain?

☐ Yes ☐ No

2. On the picture, colour the areas where you feel pain. Put an X where it hurts the most.



3. Have you had pain before your period?

☐ Yes ☐ No

Have you had pain during your period?

Yes ☐ No ☐

4. During your last period did pain affect your:

Sleep

0	1	2	3	4	5	6	7	8	9	10
Did Not Interfere										Completely Interferes

School Attendance

0	1	2	3	4	5	6	7	8	9	10
Did Not Interfere										Completely Interferes

Schoolwork

0	1	2	3	4	5	6	7	8	9	10
Did Not Interfere										Completely Interferes

Friendships

0	1	2	3	4	5	6	7	8	9	10
Did Not Interfere										Completely Interferes

Homework

0	1	2	3	4	5	6	7	8	9	10
Did Not										Completely

Interfere Interferes

Feelings

0 1 2 3 4 5 6 7 8 9 10

Did Not Completely

Interfere Interferes

Ability to do jobs at home

0 1 2 3 4 5 6 7 8 9 10

Did Not Completely

Interfere Interferes

Free time

0 1 2 3 4 5 6 7 8 9 10

Did Not Completely

Interfere Interferes

Self-care

0 1 2 3 4 5 6 7 8 9 10

Did Not Completely

Interfere Interferes

Ability to participate in exercise

0 1 2 3 4 5 6 7 8 9 10

Did Not Completely

Interfere Interferes

Enjoyment of life										
0	1	2	3	4	5	6	7	8	9	10
Did Not Interfere										Completely Interferes

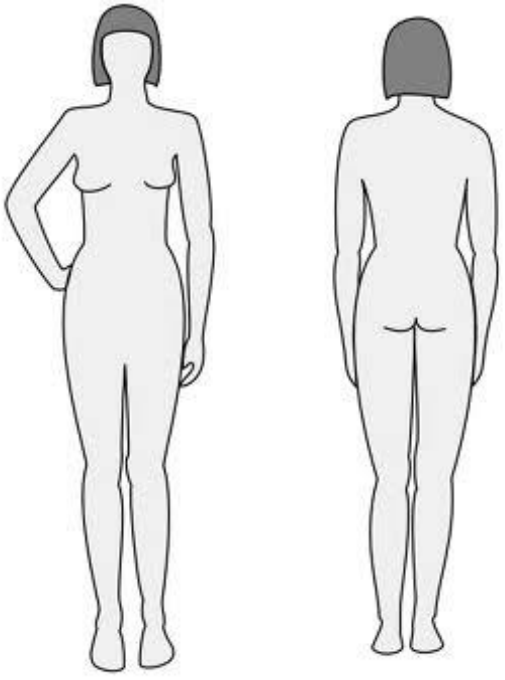
Appendix 13b: Pain Impact Scale – Parent Version

(Modified from the Brief Pain Inventory – Short Form; Cleeland & Ryan, 1994)

1. Most people have pain sometimes like a headache or a toothache. Has your daughter had any other kind of pain?

Yes ☐ No ☐

2. On the picture, colour the areas where she feels pain. Put an X where it hurts the most.



3. Has your daughter had pain before your period?

Yes ☐ No ☐

Has your daughter had pain during your period?

Yes ☐ No ☐

4. During her last period did pain affect her:

Sleep

0	1	2	3	4	5	6	7	8	9	10
Did Not Interfere										Completely Interferes

School Attendance

0	1	2	3	4	5	6	7	8	9	10
Did Not Interfere										Completely Interferes

Schoolwork

0	1	2	3	4	5	6	7	8	9	10
Did Not Interfere										Completely Interferes

Friendships

0	1	2	3	4	5	6	7	8	9	10
Did Not Interfere										Completely Interferes

Homework

0	1	2	3	4	5	6	7	8	9	10
Did Not Interfere										Completely Interferes

Feelings

0	1	2	3	4	5	6	7	8	9	10
Did Not Interfere										Completely Interferes

Ability to do jobs at home

0	1	2	3	4	5	6	7	8	9	10
Did Not Interfere										Completely Interferes

Free time

0	1	2	3	4	5	6	7	8	9	10
Did Not Interfere										Completely Interferes

Self-care

0	1	2	3	4	5	6	7	8	9	10
Did Not Interfere										Completely Interferes

Ability to participate in exercise

0	1	2	3	4	5	6	7	8	9	10
Did Not Interfere										Completely Interferes

Enjoyment of life

0	1	2	3	4	5	6	7	8	9	10
Did Not Interfere										Completely Interferes

Appendix 13c: Correspondence with Dr. Cleeland

Susan Kennedy <susankennedy2007@gmail.com> 7/6/12

to ccleeland

Dear Dr Cleeland,

My name is Susan Kennedy and I am a Senior Clinical Psychologist working in the area of Intellectual Disability in Ireland. I contacted you recently regarding research which I am completing for a DPsych in Clinical Psychology from City University London. The title of my research project is “Evaluation of a menstrual pain management programme for adolescent girls with intellectual disabilities”. This research is being supervised by Dr Brian McGuire, National University of Ireland, Galway (NUIG). Dr McGuire is also Joint Director of the Centre for Pain Research at University College Hospital Galway (UCHG).

As part of my research study, I would like to use a modified version of the Brief Pain Inventory and am attaching a copy for your information.

An epidemiological study of pain in children is currently being conducted by the Centre for Pain Research and it is proposed that the Brief Pain Inventory be validated with children in the general population, as part of this study. I would greatly appreciate your consideration of these requests and am happy to provide any additional information which you may require to do so.

Yours sincerely,

Susan Kennedy, BSc., MSc. App.Psy., DPP (Clin.)

Senior Clinical Psychologist

Appendix 14: Pain Self-Efficacy Scale

(Modified from the Pain Self-Efficacy Scale for Children; Bursch, Tsao, Meldrum & Zelter, 2006).

Some people are able to do different things even when they have pain. Some people are not able to do things when they have pain.

The next questions are about your ability to do things when in pain.

1. When you are in pain, can you make it through a day at school?

(1) *Always*
(2) *Almost Always*
(3) *Sometimes*
(4) *Occasionally*
(5) *Never*

2. When you are in pain, can you be with friends?

(1) *Always*

(2) *Almost Always*

(3) *Sometimes*

(4) *Occasionally*

(5) *Never*

3. When you are in pain, can you do your schoolwork?

(1) *Always*

(2) *Almost Always*

(3) *Sometimes*

(4) *Occasionally*

(5) *Never*

4. When you are in pain, can you do jobs around the house?

(1) *Always*

(2) *Almost Always*

(3) *Sometimes*

(4) *Occasionally*

(5) *Never*

5. When you are in pain, can you do fun things with your family e.g. go bowling or shopping?

(1) *Always*

(2) *Almost Always*

(3) *Sometimes*

(4) *Occasionally*

(5) *Never*

Appendix 15: Pain Catastrophizing Scale – Parent Version (PCS-P)

Thoughts and feelings when your child is in pain

We are interested in the thoughts and feelings you have when your child is in pain. Below are 13 sentences of different thoughts and feelings. Please put a circle around the word or phrase under each sentence that best reflects how strongly you have each thought when your child is in pain.

1. When my child is in pain, I worry all the time about whether the pain will end.

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

2. When my child is in pain, I feel I can't go on like this much longer.

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

3. When my child is in pain, it's terrible and I think it's never going to get better.

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

4. When my child is in pain, it's awful and I feel that it overwhelms me

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

5. When my child is in pain, I can't stand it anymore

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

6. When my child is in pain, I become afraid that the pain will get worse

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

7. When my child is in pain, I keep thinking of other painful events

NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

8. When my child is in pain, I want the pain to go away
NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

9. When my child is in pain, I can't keep it out of my mind
NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

10. When my child is in pain, I keep thinking about how much he/she is suffering
NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

11. When my child is in pain, I keep thinking about how much I want the pain to stop
NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

12. When my child is in pain, there is nothing I can do to stop the pain.
NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

13. When my child is in pain, I wonder whether something serious may happen
NOT AT ALL MILDLY MODERATELY SEVERELY EXTREMELY

Appendix 16: Background Information Questionnaire

PSYETH 11/12026

Code: _____

Date of Birth: _____

Age: _____

School: _____

Year: _____

Ethnic/Racial Origin: _____

Location: Urban □ Rural □

1. At what age did your daughter first get her period?

_____

2. How often does your daughter get her period?

_____

3. How long does her period usually last?

_____

4. Does your daughter experience any of the following symptoms before or during her period:

Tiredness	☐
Irritability or moodiness	☐
Cramps/pain	☐
Nausea	☐
Headache	☐
Lower back pain	☐
Vomiting	☐
Fainting	☐
Diarrhoea	☐
Weakness	☐
Leg pain	☐
Constipation	☐
Disorientation	☐

Hypersensitivity to sound, light, smell, touch ☐

Please list any other symptoms which she experiences:
_____

_____

5. How often does your daughter experience menstrual pain?

Never ☐ Monthly ☐ Every 2 - 3 months ☐

Every 3 – 6 months ☐ Every 6 -12 months ☐

6. Has your daughter missed days from school due to period pain?

Yes ☐ No ☐

If yes, approximately how many days has she missed in the last 3 months? _____

7. Does she have a history of any gynaecological problems? If so, please give details:
_____

_____

8. Does she take any medication to manage her period pain? If so, please give details:

_____

_____

9. Does your daughter receive any treatment for her period pain? If so, please give details:

_____

_____

10. Does your daughter have any other medical condition(s)? If so, please give details:

_____

_____

11. Does your daughter take any medication to manage her medical condition(s)? If so, please give details:

_____

_____

12. Does your daughter receive any treatment for her medical condition(s)? If so, please give details:

_____

_____

Appendix 17 – Transcript of Focus Group with Participants

Researcher: Good morning everybody and you're very welcome to today's focus group and what we're going to do today is that I'm going to ask you some questions about your opinions and your ideas about the pain management programme that you took part in. Please feel free to say whatever you want okay?

Now I'm going to start by asking you what you thought about the topic of the group and what we covered. So the topic of the group was managing our period pain. What did you think about that? Did you think it was a good idea, not such a good idea?

P1: Good idea, yeah.

Researcher: Anybody else, what did you think about it?

P2: A very good idea.

P4: I liked it. I thought it was a good idea.

Researcher: What was good about it? What you did in the group?

P2: Learning how you manage your own pain was good.

Researcher: Okay, anything else that people liked about the group and what you learned in it over the 12 weeks.

P4: How to deal with it (period pain) yeah and what you're supposed to do

P3: We've no other way out of it.

Researcher: And what about the different topics that you did every week. So we had 12 weeks and we did a different thing every week.

P2: I liked the exercises, I found that very good.

Researcher: In what way was that good?

P2: Learning how to do it yourself.

P1: I like breathing in an out (the breathing techniques).

Researcher: And did you do that at home?

P1: Yes.

Researcher: And did you find it helpful?

P1: Yes.

Researcher: Okay, good. Anybody else, what did you think about what you learned in the group?

P6: I learnt how to be the manager of my period pain.

Researcher: Okay, you liked being the manager, taking control and having a plan of what to do.

P6: Yes.

P5: Exercises and making an exercise plan for myself.

P4: I liked being the detective.

Researcher: Okay, you liked being the detective and solving your problems, coming up with ideas to solve your problems.

P2: I liked doing ?

Researcher: Will you tell me a little about that?

P2: There was a list of stuff on the board and we picked a topic. I picked "Relax and take a deep breath and it will be okay".

Researcher: Okay, so that was a positive coping statement wasn't it?

P2: Yes

Researcher: So you liked making a bookmark with your positive coping statement. And what do you do with your bookmark?

P2: You take it out whenever … (Participant became shy and was encouraged by others to continue)

P4: … Whenever you feel like it and read it.

Researcher: Okay, the next question I want to ask you is about the information sheets, you know the handout that you got at the end of every week. What did you think about the sheets?

P3: Good.

P5: They were very helpful.

Researcher: What did you do with them that you found them helpful?

P5: Put them in my folder and take them out and read them.

Researcher: And when would you do that?

P5: Whenever I had my period

Researcher: Okay, very good. What about other people, what did you think about the sheets?

P1: I thought they were good.

Researcher: And where did you keep your sheets?

P1: In my workroom.

Researcher: Did you use them here or did you bring them home.

P1: No, I didn't bring them home.

Researcher: So did you use the sheets when you had your period here in the centre?

P1: Yeah.

Researcher: What about other people? Did anybody bring their folder home?

P6: I did.

P3: I'm bringing my folder home this week.

Researcher: Where did you keep your folder at home?

P6: My bag

Researcher: And did you take out the sheets and the folder and look at them at home?

P6: My Mum did.

Researcher: Did you talk to your Mum about what was on the sheets then?

P6: Yes, to manage my own period.

Researcher: Did Mum help you by reminding you to do those things when you had your period?

P6: Yeah.

Researcher: What about anyone else, what did you think about the sheets?

P2: It was good information to have.

Researcher: Was it good to have something to look at to remind yourself of what we had talked about?

P2: H.E. asked me how I got on and I showed her all the sheets and she said "fair play to you".

Researcher: Okay, yes because sometimes it can be hard to remember everything that was done so the sheet then helps you because you have something to look back at and talk about.

Researcher: What did you think worked well in the group?

P2: Being together. I liked being together.

Researcher: And would you normally get to all come together the six of you together or was that the only chance you had?

P3: Not really.

Researcher: Would that be the only time that would happen?

P2: Yeah, that would be the only time.

Researcher: Okay, and what did other people think about that? Did you like it? Was it a good idea?

P4 and **P5:** Yeah.

P4: I loved it.

P5: I did.

Researcher: What else did you like about it? What worked well?

P6: I liked it. I liked being the Manager (one of the techniques taught in the group).

Researcher: What about the whole group, what part did you like that worked well?

P6: That everyone can be the Manager, that everyone can do what I do.

P1: I enjoyed the relaxation.

P2: When you closed your eyes and you were talking about the beach and you told us to imagine it.

Researcher: Yes, the visualisation of the beach scene.

P2: Yeah, that was good.

P5: Yeah, I liked that.

Researcher: Do you think was there anything that didn't work that wasn't a good idea?

P2: They all worked.

Researcher: Okay, you felt that everything that we did worked but was there anything that anybody didn't like or didn't enjoy or didn't think was a good idea? Now is the time to tell me so I can learn for the next group of girls.

P6: I felt worried about going swimming with your period.

Researcher: That's often something that women worry about and unfortunately sometimes people have to take that week off from swimming when they have their period if they are worried about it.

P6: It's not a nice thing to happen.

P3: No it's not.

Researcher: But we did learn that it's a part of life for women

P5: It's all part of growing up

Researcher: And we learnt that it doesn't have to take over your life and that by doing the things that we learnt in the group, those strategies, you can learn to live with your period so that it doesn't affect you as much. Isn't that right? So was there anything that people didn't think worked well, that they didn't like about the group?

P2: At the start I was shy. It was hard because I was nervous but I got over it.

P3: You weren't the only one who was nervous.

Researcher: So L., was that something that at the start you didn't like, that you had to talk out in front of other people?

P2: Yeah, but I got over it.

Researcher: Okay and also was that because as you said you don't get to meet all these women together very often but as you got to know them you got more comfortable talking out, was it?

P2: Yeah.

P3: Normally I'd be at another centre with different people.

P4: At the very beginning I was a bit worried.

Researcher: Okay and what were you worried about?

P4: I didn't like it … I was worried when my period started for the first time.

Researcher: And what about taking part in the group, was there anything you were worried about that?

P4: No, that was fine.

Researcher: What about you AI, was there anything that you didn't like or didn't think was worth doing?

P5: No it was fine.

Researcher: What about you C.?

P1: No, I liked it.

Researcher: Okay, did you think we shouldn't have done that, there was no point in doing that, I wouldn't use that again?

P2: No

P3: Can't think of anything anyway

P6: I just liked being the Manager and being the Detective and solving problems

Researcher: Was there anything that was hard, anything that we did that you found hard? Any of the things that I talked about, was any of it hard to understand or follow?

P4: One or two things. I didn't understand what the negative/positive was.

P3: What does that mean anyway?

Researcher: Okay, was that at the start when we started talking about them or after we talked about them?

P4: Before and after.

P3: Yeah it was hard.

P2: Yeah, me aswell.

Researcher: Okay, so people found it hard to understand the difference between positive and negative.

P3: What is negative, I never heard of it.

Researcher: Negative is something that's not very nice or something that's not working very well.

P5: Positive is good.

Researcher: Yes, exactly. After we talked about it and we did the examples did that help it to make more sense to you?

P4: Yeah, it did.

P2: Yeah, that was good.

Researcher: Was it hard at the start because it wouldn't be something you'd usually talk about?

P2: Yeah. Sorry.

Researcher: No, this is great. This is exactly what I want to find out so that for the next group of women that I do this with I can give more examples to make sure that's something that they do understand if it is something that people usually find hard. So thanks, that's a great suggestion.

What about everyone else? Did everyone find the same thing that it was a hard thing to understand, the positive and the negative thoughts?

P6: Negative was hard.

Researcher: So was there anything that people didn't like about it? Was it on too early, was it on too long?

P6: Being late on the bus.

Researcher: You didn't like being late for it on the bus.

P6: No. Not good.

P3: That happens.

Researcher: We understood Aoife that that wasn't your fault that sometimes the bus was delayed.

P3: Yeah, it was the busdrivers fault.

Researcher: Was there anything else that people didn't like?

P3: I can't think of anything.

Researcher: If I was to ask everyone what their favourite thing was, what would you say?

P2: Exercise.

P3: Well the first class that we did was hard to do.

Researcher: When we talked about what period pain was.

P3: Yes.

Researcher: Was that something that you didn't like and found hard?

P3: Yes.

Researcher: Okay, and was there something that you really liked?

P3: Exercise

P6: Relaxing

Researcher: Was there anything that you didn't like Aoife, besides being late on the bus?

P6: Not on time.

Researcher: You like to be on time. C., what about you. What was your favourite thing and the thing you didn't like?

P1: Exercises.

Researcher: And what was the thing you didn't like?

P1: The leg exercises.

Researcher: Were they hard to do?

P1: Yeah, to stretch out my leg.

Researcher: AI., what about you?

P5: The exercises.

Researcher: What was the hardest part?

P5: There was nothing I found hard.

P4: Some things I did like

Researcher: But you can't remember now?

P4: No.

P3: I can't either

P4: Oh yeah, problem solving, I liked that.

Researcher: When you pretended to be the detective when we were solving the problems.

P4: yeah.

Researcher: Is there anything that you think I should change or do differently the next time I run it with another group of women.

P2: More exercises.

Researcher: Is it the deep breathing and relaxation exercises?

P2: Yes.

Researcher: Do other people think the same thing?

P6 and **P5:** Yeah.

P3: We should do it again and look at all the leaflets again.

Researcher: H.E. will run it with you again in a little bit of time. Is there any other suggestions that people have of what I should do differently next time?

P6: Be the Manager of your period.

Researcher: Okay, you think that's an important one to keep in A.O., along with deep breathing and relaxation.

P6: Yeah, I liked the deep breathing.

Researcher: Okay, anything that was missing that you think I could put in as well, that would be an important thing to talk about?

Researcher: Is there anything else that people would like to say about the group?

P6: I liked the group cos I learnt things.

P3: It was hard when we started.

Researcher: Okay and what was it about it that was hard at the start?

P2: I think it was coming every day to the centre.

Researcher: okay, actually getting here every day to take part in the group was hard. Was that because you had to come a long way?

P3: I didn't mind too much.

Researcher: Was there anything else that people wanted to say about the group?

P4: I like doing this with the group.

Researcher: Okay, so if there's nothing else that anyone wants to say about it I'll say thank you very much to everyone.

P2: We would like to say thank you to you Researcher for coming every week to support us. We're going to miss you.

P5: Some of the cousins are girls and they came down and I showed her there (gestures to information sheets)

Researcher: Very good. And what did she think about them?

P5: She thought they were quite good.

Researcher: And does she have period pain as well?

P5: yeah, yeah, yeah.

Researcher: So were you able to teach her things and tell her things that she didn't know she could do?

P5: Yeah.

Researcher: And how did that feel?

P5: It felt very good. She's younger than I am.

Researcher: So that must have felt good to be able to help her out and to teach her?

P5: Yeah.

Researcher: Brilliant, well done. Has that happened for anyone else?

P2: yeah. My sister.

Researcher: So you were able to tell your sister. And is your sister younger or older than you?

P2: Younger.

Researcher: And what were you telling her?

P2: I was telling her just relax, take a deep breath and it'll be okay and to do the exercises aswell.

P6: My sister does that too.

Researcher: Did you tell your sister to do it?

P6: Yeah, my sister Deirdre. She's older than me. I told her to take deep breaths.

P3: I told that to my sister but she doesn't listen to me at times.

Researcher: Well it sounds like some of you have been able to take what you learned and be Teachers to other people. How did it feel to be the Teacher?

P3: It's weird.

P5: It felt weird.

Researcher: Did it feel good though to know that you're helping somebody else.

P5 and **P2:** Yeah.

Researcher: Well done that's great.

P3: Well it can be weird sometimes.

Researcher: That's just because you're not used to it but the more you do it and the more practice you get, the more comfortable you become with it. But that's fantastic that you're able to take the information that you've learned and help others. That's very good and thank you all very much for taking part.

Appendix 18 - Focus Group with Teachers

Researcher: You're very welcome and thank you for agreeing to take part in the focus group which is to explore the opinions of Teachers on the menstrual pain management group that the students took part in. I'm interested in finding out what aspects of the programme worked well or didn't work for this population of young women with intellectual disabilities. Maybe we could just begin by you stating your name and where you work if that's okay.

P3: I'm ST, currently working in (identifier removed) and last year when you did the programme I was down in M. (Class).

P1: LT working in (identifier removed) and had A., one student last year.

P2: SH working in the Senior end of (identifier removed) and I had most of the girls in the group in my class.

Researcher: Okay, thanks a lot. I'll just explain a little bit about what we're going to do today. I'd like to ask you some questions about your opinions on the programme and any impact which you feel it may have had. Please speak freely and give your opinions and any ideas that could be used to enhance the programme for other students. The focus group will take the form of a discussion in which I'll ask some general questions which I'd like you to discuss. It'll last about 20 – 30 minutes and it's going to be audio recorded to allow me to gather as much information as possible. So the first question I'd like to ask you today is what you thought of the topic for the group

and the content contained in it. So what did you think of the topic of menstrual pain management for young women with intellectual disabilities?

P1: I thought it was very relevant for our group of students and it's something we would see symptoms of every month and something we would not know outside of medication with parents administering it at home, I would just say relax, breath but nothing specific so it's great the students have their own specific strategies within the group formulating it themselves, that's relevant to them.

P2: More independent, rather than led by somebody else, either a Teacher or an SNA, that they were taking ownership of the management of their pain themselves.

P3: And it allowed them to understand that it is a completely normal thing as well to go through every month those who might have felt a bit isolated if they were in severe pain every month from it so that was very good as well.

Researcher: So by coming together with their peers they realised

P3: It allowed them to talk to each other and maybe from doing it within the group with you it allowed them to have the confidence to talk to each other about it outside of the group like at lunch-time maybe and when they got to together.

P1: And hopefully to translate that home aswell and not to be afraid to say to Mom look it I'm going to try my breathing this time instead of tablets or something like that which is very beneficial for them.

P2: And I think even the vocabulary even "I have my things" and pointing to their tummy You know this kind of thing rather than saying I have my period. You know that sort of thing. Using certain vocabulary to express. Generally what I found was that

they were fine saying it to an adult, the one's that were good vocally, that had good verbal skills. And then the one's who didn't were fine saying I have my things but I don't know if they conversed with each other about it and what words they used when they were conversing with one another. I don't think they had an opportunity because we're a mixed school and there aren't that many girls here it's predominantly boys. So I don't think they ever really had that opportunity amongst themselves to do that, to have a conversation or to have a discussion.

Researcher: Because they mentioned several times about the girls group

P3: Oh mine loved it … Girls club.

P2: That's over 4 or 5 years.

Researcher: And they really seemed to still miss that because they mentioned it several times and made a lot of comparisons, this is like girls club and we miss girls club, and it was such fun so I think they liked coming together as a group.

Researcher: Okay, what did you think of the session information sheets that they got. You would have been given a copy of those at the end. What did you think of the content of those?

P3: I thought it was very good. The language used in them was appropriate. It was basic enough for them to understand it fully. It was good that they got to bring it home too because at least they got to look back on it and they got to show it to their parents so their parents knew exactly what they were doing within the group as well which they would have needed to know really in order to converse about it at home.

P2: Simplistic in its format as well. It was structured well, pointed, there was a visual there also so it wasn't just all words. If you didn't understand some of the words for say the lower functioning students with a lower reading ability you had a picture there to give them a quick reminder. That was good, I thought it kind of covered, differentiated between a higher functioning mild student and a lower functioning moderate student which is sometimes the case here.

P1: And even the fact that the pictures are Boardmaker which they would be familiar with seeing around the school especially A. being part of the autism unit. She would have been very familiar with PECS and Boardmaker symbols and as I said earlier, she would tend to compartmentalize things and even bringing the sheet back would help her associate with I can use these things in the classroom. Kindof reinforce that for her.

Researcher: What do you think worked well in the group? Did you think or did you notice anything that the participants benefitted from?

P1: They enjoyed the social aspect and looked forward to going to it. That's always a good sign because sometimes when you're pulling them out of class to go to something they're missing a preferred activity as well depending on what time the group was. I know A. had to leave during DVD time on occasion because it was a Friday and our DVD was the first Friday of every month but she had no issue with that. Whereas if it was something else an activity she didn't like going to and being pulled out of, she wouldn't have gone as cooperatively and that was a very positive thing and that's half the battle really and obviously she enjoyed the content of it and even the social aspect of just being there with the other girls, she enjoyed that.

P2: They used to talk about getting a drink and a biscuit at the end but I know that's obviously not the main objective of it but that really that probably, they looked forward to it, it was like nearly a reward almost, we've learnt this now and now we're going to get this. I often heard them on about that, oh we got biscuits today and Susan brought … so you know it was saying something that they really enjoyed that so someone difficult to participate in something a nice motivator.

P3: I think mine anyway just loved the fact that it was a girls club and the boys didn't know anything about it. This was something just for them because they'd always be saying it in the class and I'd have some of the boys saying why can't we have a boys club.

Researcher: And do you think there were any aspects of the group that didn't work or didn't work as well? If so, what were they?

P1: For A. I would say the very practical stuff, the breathing and she mentioned yoga you know, the exercise movements, that seemed to work better for her. I wouldn't have heard her refer to the visualisation or the more cognitive aspects of it. The behavioural side absolutely worked for her and she would refer to it every once in a while and I would hear from her Mother as well the echo of it, she would do some of those positions at home. But the cognitive side for A. I'm not sure of because of her autism, I don't know how beneficial it was for her but again that's just my hypothesis on it.

P2: But even with the students with a mild learning difficulty without the autism definitely I often heard them on about the more behavioural stuff like the breathing so that they were definitely more aware of that rather than cognitive behavioural stuff

Researcher: That is more challenging for them

P2: It's harder for them to conceptualise it and to think about it whereas a visual, something that they can see, that's very concrete

P1: And they can see the others doing it which makes it easier, you can't see what anyone else is visualising unless they are representing it on paper or something. I think even for A. sometimes she would have limited understanding of what's going on in a group, if she saw that N. was breathing or P. was breathing, then she'd mimic that. So that was easier for her to comprehend and to follow.

P2: It's something they can do, they didn't need any props, they didn't need to be in any special area they could sit at their desk or go out to the bathroom, breath in, breath out you know. It wasn't something that they had to run and get you know, a hot water bottle, special equipment, a blanket, a pillow or

P1: Staff dependent either … you know, I have to go out here and there's no staff available and you're going to have to wait 20 minutes now until they're back from their break. It wasn't staff dependent at all, it was great.

P3: I know one of my students used to be so reliant, S. used to be so reliant on the hot water bottle. Do you remember I used to be going out looking for it but towards the end, I only thought of it now, towards the end of the year she never asked for it so obviously she must have been doing other things to cope with the pain

P1: And I've had her since September and she would never have asked me but I would see her at the desk and she'd be breathing and sometimes I'd be looking down and thinking well what is she doing but obviously she's working through it and you'd know

by her and she'd have her hand on her stomach and she's working through it but she's very independent now at working through things unless she's very bad and she would ask to ring home. She has done once since September.

P2: That's funny because she was always sick last year and it wasn't just to do with her period. She was constantly sick. Do you remember … always had the flu or a pain. And she'd always mimic the sign for pain and you weren't really sure and I think her Mum sometimes said she wasn't sure if she was really actually sick but you know she'd have had some kind of pain and wasn't able to cope with it at all.

P3: She must be managing it herself which is brilliant. Yeah I only thought of that now actually.

P2: Or the level of pain. What is considered enough pain to warrant you to be ill enough to go home. Or is it just a pain, a normal pain that you're focusing on and maybe that could be the cognitive work working, the distraction techniques. You know if she thinks it's not high enough now you know or it's not maybe a 9, it's only a 1 so maybe I shouldn't be focusing on it. You know I'm distracted if I'm doing my work or I'm distracted if I'm playing or I'm eating I'm distracted or I can work through it.

P1: Cos there's only been one incident since September where her Mother rang me before school and said listen this is the way she's feeling, I've given her this and you know see how she is but she probably will ask to come home. And she said if she does, that's fine. So I had to ring home you know. And I said to her what is the pain and can you handle it any more are you trying your different things and she just had to go home

at that stage. Her Mother was fine with it so I wasn't going to argue with it. That was only the once which was great.

Researcher: Was there anything that you think there … you mentioned the cognitive elements, was there anything else that you think they found particularly challenging or would that be the key piece?

P1: For me that's the only thing from what I know about the group and from observing A. and I only had the one student to observe so I didn't get lots of feedback. But from that one student I would say that the cognitive aspect was the most difficult because the attendance was good, she liked the participation, she liked the social aspect and she liked the techniques, the physical techniques used so that's the only thing that I could see that she didn't respond a 100% too.

P2: Maybe with one or two now, if they have a poor working memory, one in particular, just trying to remember what to do and to use the strategies and if they weren't being brought home you know let's say the . If I was to do it again now, If I knew then what I know now, I would have a folder for them and let's say one for here and one for home and I think definitely parents need to be on board or guardians, they need to know okay, the blanket and the couch and the television cos they would take a day off and you know could we try these and sometimes it could go into a bag and it could get lost in translation or it could get thrown somewhere and it mightn't necessarily you know,

P3: Because in school they're not going to be sitting on, wrapped up in a blanket. It's at home all that happens. So if they're in school, they're doing their work, they're

going out for lunch, they're doing PE. It's at home they're in danger of just crawling into bed.

P2: Yeah, you offer a blanket to me and the couch and I think, yeah, I think I'll take that. So for that you know, just for parents to be on board with it as well. Sometimes they might get

P3: Even if the parents have to sign the sheet that you send home so that you can see that they did actually see it. You know, something like that.

Researcher: That's a good suggestion. Would there be anything else that you would suggest, any changes to it that would be beneficial to run the programme with other people?

P1: I think that I do the PE on a Wednesday and the senior girls would use their period as an excuse to sit out of PE and I would always say to them it's part of your programme and it's one of the benefits. Now there's obviously days when they're not going to, you're going to know by looking at them, that they're not going to be able and there's days when A. will just pan out on the bench and there's no moving her but a lot of the other senior girls will try and opt or use it as an excuse and try and see how far they'll get with it. But I think encouraging and promoting the exercise even if it's only do 5 minutes and take a break or promoting that in the group as well and let them know. I remember years ago I saw it on one of the packets of Always (sanitary pads) you have the most energy the first two or three days of your period and that just stuck with me so I don't use it as an excuse that I wouldn't exercise. And I do find that even last week I had more energy for the first few days so encouraging the physical activity

side and that it's not negative and that you don't have to be hiding away somewhere that it might actually help your pain or it might actually help because I know in secondary school it would be very relevant. You would have a double PE class which could be an hour, an hour and a half, and they would try and sit out of that and I suppose a lot of the instructors in Secondary Schools would probably be male and probably if they said they were having their period they probably wouldn't argue with it. And I know the male Teacher here, he'd probably do the same. So really promoting that exercise is positive and it can be. I know there are some days they just might not be able for it but letting them know it is a very good option because it is used as an excuse, overly used as an excuse I think.

Researcher: Was there anything that you particularly liked or didn't like, that you had a strong feeling on, either way, in relation to the group?

P3: I loved how it brought the girls together to be honest. I thought that was the best part of it. They absolutely loved going out every Friday, they really enjoyed it and it really made them happy. Like I know last year in my class there were two girls who would argue so much. They'd be best friends one day and they would kill each other the next day but never when they were going down to the group would they be arguing. And certainly when they came back they'd be on great terms. I think it was just great to get the girls together, it was lovely for them.

Researcher: So do you think that was one way they benefited?

P3: Oh yeah definitely, definitely yeah.

Researcher: Did you notice anything else in that way?

P2: I think I've only really learnt the whole concept, like I knew it was menstrual pain but I really wasn't aware let's say of all the different themes and topics you were doing. I think if I had known then I might have been more engaging with them as to what was going on, you know you'd ask what was going on but to be quite honest it's so, you know, snowballs all day with work. I think you know if I had have known I might have given them a bit more attention but I definitely knew what it was about or if they had shown me the sheet, even though I do know you used to give me a sheet towards the end but I think now that I'm more informed I'd be more equipped to comment on what did you do this week, what's the topic, just to remind them, just to give them a reminder.

P1: Yeah and to ask them was there one thing they took away from today and getting them to write that down. Today the one thing that really stuck for me is negative thoughts or positive thoughts or whatever it is. The calendar I think, now knowing that it's there. A. might not be as beneficial because she wouldn't have as much control around preparing events and things like that but I know definitely for some of the senior girls it's very beneficial for them and going up through life now the ones that are more able to organise themselves will definitely, I would say, find that useful. And I know I used to do it, Mam used to get me to do it, when I first started getting them to see were they regular even and just so they can start realising even oh well it's always 5 days or it's always 2 days or a week or whatever it is.

P2: Yeah, or it's always the 14th of the month or whatever.

P1: Because the concept I would imagine, especially for those just beginning with their period, of how long it's going to last would be very very difficult and I know especially

for students with autism we have visual and social stories and stuff we would have done with them and I know A. before I had her, had done lots of preparation work on that with a previous Teacher but I know girls coming in now, we would start that kind of work pretty early and the concept of, it's only going to last for a certain number of days and it's going to be gone for most of the month again, that's a concept that for a lot of them, especially the one's with autism, that's a concept that a lot of them would find very very difficult. So the visualisation of the plan on the calendar, the mapping of it even if they did them on little charts or any sort of visual representation for them was really really good.

Researcher: And I think you're suggesting then that the handouts coming weekly to the staff, to the Teachers, then as well. You think that would be helpful.

P2: Yeah, I do. I think it would just give me … You know yourselves, we're so busy all the time, especially when you have the boys in front of you, they're quite demanding of your attention, to be honest, and if you just had something that you could kind of look at, it wouldn't be a whole programme of events of anything, I wouldn't want that or anything, if they came down and handed you a handout and we'd have a look and a folder for them so they can put it in or maybe two sheets so they can send one home and get Mum to sign it that comes back and keep it here and one for home.

Researcher: Now it sounds like you may not have actually known that they did get a folder. I gave them each a folder at the start to put their handouts into but that went home but maybe a second one for here

P2: Yeah, that way we could look at it as well because that can be a bit of a barrier that we find especially with any child with special needs or mild general learning difficulty is that they don't relay information. You might get it later on, you might get it again, you might get it at a different time or you know sometimes we don't … you even the parents, we find that we don't get the information because

P3: Yeah, because school is school home is home and the group with you is the group with you and you don't need to tell everyone else in those three settings what was going on in the each of the others and what the others were saying. There was no connection.

P2: Like I have a child myself and sometimes I'd have to pull the information out of her you know that kind of way so you know but that's only cos I know to do that you know did you do English, did you do this … I mean things could happen here and parents are like, well I never knew, I never heard it, we could have a table quiz and none of them would know. You know they would never think to share the information, yeah exactly.

P1: If it's appropriate, let's say for A. when she was going to another therapy, when she would come back to try and link it and the other therapist and myself worked together. She would do a reflection sheet with me on "Today I did this", "This was my favourite thing today" and here are six pictures of what I did. That helped her translate it up, ok what I do with him in the other room, I should really be showing Teacher. Obviously there's different therapies and you wouldn't be disclosing what's in certain therapies but for him and for her, this worked to communicate with me. It was very visual, a one page thing. It was a kind of a reflection and it didn't seem homework or

extra work it was a positive thing and she would take 10, 15, 20 minutes and spend in detail on the pictures because the pictures was the most important thing for her. She didn't really care about the sentences, she'd fill them out but when it came to the pictures she'd draw her representations of what happened in her head while she was there for that half hour or whatever it was and it really really worked. So I don't know if it's appropriate in these therapies but if it was appropriate for some of the students going forward, I think some kind of reflective activity like that. It can be private, they can sit at their work station and do it and maybe just hand it up to the Teacher then rather than you know, some of them may not like to converse about it again outside of the group.

P2: The pictures are great and you know like a word. There'd be one's that are Moderate or high functioning, drawing wouldn't be a strong point or they wouldn't be able to draw. And then you'd have higher functioning that would be able to verbalize it or they could actually write down exactly, the 6 things they did learn. Generally I would actually say for a high functioning person I would go down the route of visuals but for the actual person I'm thinking about, they wouldn't actually draw. They wouldn't actually physically have the ability to draw. If you had a word, they'd actually be more inclined to do word association than pictures.

Researcher: Ok, and as you said, make it individual.

P3: Yeah, whatever the abilities of the individual, it will have to come down to the abilities of the actual child.

P2: You could team up with the Teacher or whoever is in charge of their education and they would know what they're able for.

Researcher: So we've talked there about any changes or suggestions to improve it and you've given me lots of ideas there, do you have any other comments that you'd like to make about the topic about the group, how you feel group members benefited from taking part in it. Any other comments in relation to it?

Ok if there aren't any more comments or any more suggestions I'd like to thank you very much now for all your help. It was a great assistance to me and I'll have lots of typing to do!

Appendix 19 - Notes of Focus Group with Parents

What worked?

- Deep breathing and relaxation. This has transferred to other situations at home e.g. arguments re: TV
- "hard to know" (**P2**) how much she got from session such as positive thinking
- Worked. "Made no fuss" during last period (on mid-term) (**P1**)
- "Better understanding of period pain" (**P1**). Different having a "group discussion" about the issue at school (**P1**)
- Using distraction techniques already (TV).
- Medication works but doesn't want to take it now as pain stops and wouldn't get time off school.
- "What was most important was that the area was addressed". "That it's for everybody". (**P1**)

What didn't work?

- Sessions on cognitive strategies didn't work.
- Calendar – might want to take days off before period arrives if she saw it marked on a calendar.
- "Don't know about visualisation" (**P1**).

What did the students like?

- "Tea-break"! (**P2**)
- Deep breathing
- "Wanted to share her folder every week and let me see what she did" (**P1**). Folder "very important to her". (**P2**)

What did you think of the session summary sheets?

- Fine.
- "Very good to have them, she wouldn't tell me". (**P3**)
- Use as a tool to prompt discussion and questions.

Suggested changes?

- 1 page laminated sheet (with pictures) summarizing topics at end of group.
- Pictures on weekly handouts.
- Pictures at beginning of each session to revise topics.
- Lots of drawings/visual aids.

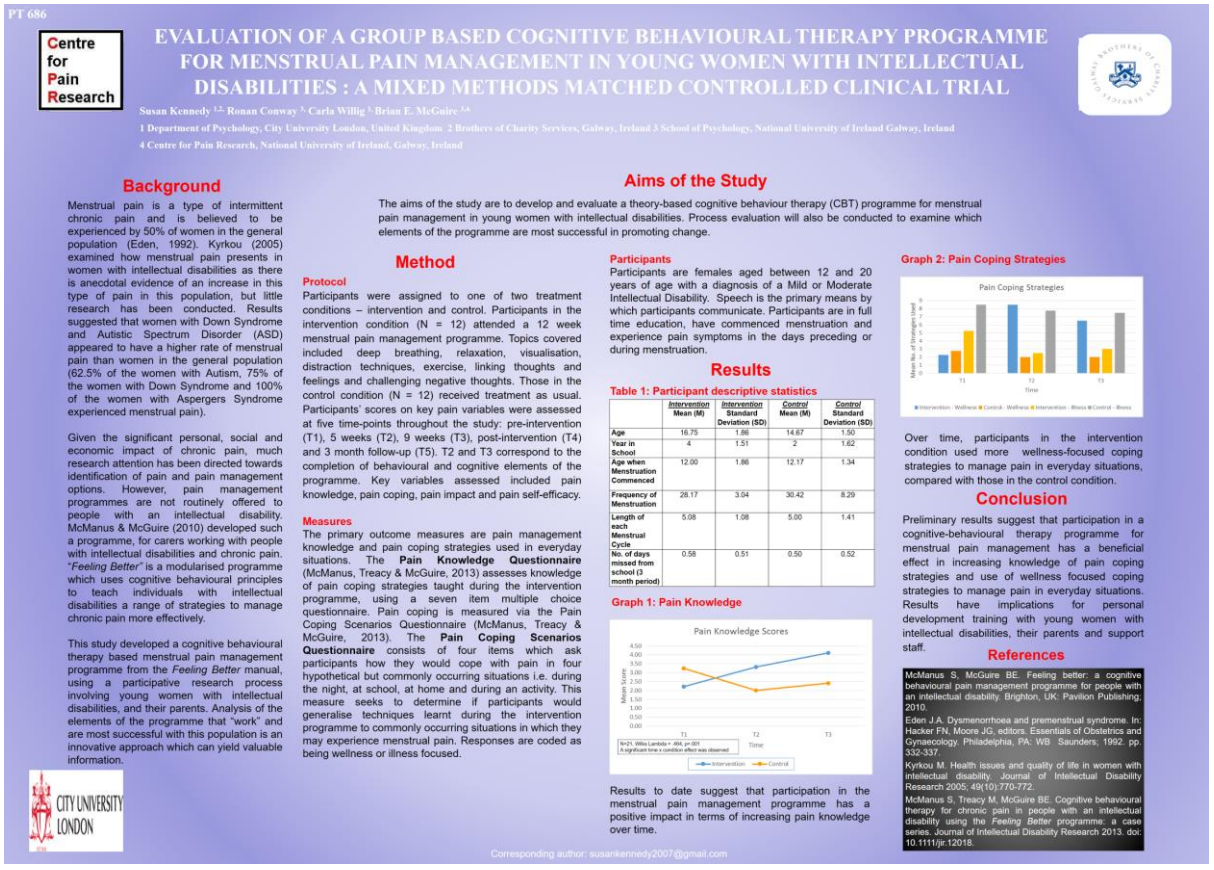
Appendix 20 – Publications and Presentations

Professional and academic work completed:

- embarked on doctorate level research which set out to pilot and evaluate a menstrual pain management programme for young women with intellectual disabilities developed from the "Feeling Better" pain management programme for carers of individuals with intellectual disabilities and chronic pain (McManus and McGuire, 2010).
- conducted significant reading on the topic of pain management and intellectual disability
- co-authored a journal article on the topic of chronic pain and intellectual disability (McGuire & Kennedy, 2013).
- attended and presented a poster at the European Federation of IASP Chapters conference on "Chronic Pain", held in Florence, Italy in October 2013.
- published a study protocol manuscript in the Biomedical Central journal, "Women's Health" (Kennedy, O'Higgins, Sarma, Willig and McGuire, 2014).
- attended and presented as part of a symposium on "The burden of chronic pain in children and adolescents across the lifespan" at the European Health Psychology Society (EHPS) 2014 conference in Innsbruck, Austria in August 2014. The title of the conference was "Beyond prevention and intervention: increasing well-being".

- delivered three menstrual pain management groups to young women with intellectual disabilities within the intellectual disability service I work for.

Poster presentation at the European Federation of IASP Chapters (EFIC) Conference, Florence, October 2013



PT 686

Centre for Pain Research

EVALUATION OF A GROUP BASED COGNITIVE BEHAVIOURAL THERAPY PROGRAMME FOR MENSTRUAL PAIN MANAGEMENT IN YOUNG WOMEN WITH INTELLECTUAL DISABILITIES : A MIXED METHODS MATCHED CONTROLLED CLINICAL TRIAL

Susan Kennedy [1,2], Ronan Conway [3], Carla Willig [1], Brian E. McGuire [3,4]

1 Department of Psychology, City University London, United Kingdom 2 Brothers of Charity Services, Galway, Ireland 3 School of Psychology, National University of Ireland Galway, Ireland

4 Centre for Pain Research, National University of Ireland, Galway, Ireland

Background

Menstrual pain is a type of intermittent chronic pain and is believed to be experienced by 50% of women in the general population (Eden, 1992). Kyrkou (2005) examined how menstrual pain presents in women with intellectual disabilities as there is anecdotal evidence of an increase in this type of pain in this population, but little research has been conducted. Results suggested that women with Down Syndrome and Autistic Spectrum Disorder (ASD) appeared to have a higher rate of menstrual pain than women in the general population (62.5% of the women with Autism, 75% of the women with Down Syndrome and 100% of the women with Aspergers Syndrome experienced menstrual pain).

Given the significant personal, social and economic impact of chronic pain, much research attention has been directed towards identification of pain and pain management options. However, pain management programmes are not routinely offered to people with an intellectual disability. McManus & McGuire (2010) developed such a programme, for carers working with people with intellectual disabilities and chronic pain. "*Feeling Better*" is a modularised programme which uses cognitive behavioural principles to teach individuals with intellectual disabilities a range of strategies to manage chronic pain more effectively.

This study developed a cognitive behavioural therapy based menstrual pain management programme from the *Feeling Better* manual, using a participative research process involving young women with intellectual disabilities, and their parents. Analysis of the elements of the programme that "work" and are most successful with this population is an innovative approach which can yield valuable information.

City University London

Aims of the Study

The aims of the study are to develop and evaluate a theory-based cognitive behaviour therapy (CBT) programme for menstrual pain management in young women with intellectual disabilities. Process evaluation will also be conducted to examine which elements of the programme are most successful in promoting change.

Method

Protocol

Participants were assigned to one of two treatment conditions – intervention and control. Participants in the intervention condition (N = 12) attended a 12 week menstrual pain management programme. Topics covered included deep breathing, relaxation, visualisation, distraction techniques, exercise, linking thoughts and feelings and challenging negative thoughts. Those in the control condition (N = 12) received treatment as usual. Participants' scores on key pain variables were assessed at five time-points throughout the study: pre-intervention (T1), 5 weeks (T2), 9 weeks (T3), post-intervention (T4) and 3 month follow-up (T5). T2 and T3 correspond to the completion of behavioural and cognitive elements of the programme. Key variables assessed included pain knowledge, pain coping, pain impact and pain self-efficacy.

Measures

The primary outcome measures are pain management knowledge and pain coping strategies used in everyday situations. The **Pain Knowledge Questionnaire** (McManus, Treacy & McGuire, 2013) assesses knowledge of pain coping strategies taught during the intervention programme, using a seven item multiple choice questionnaire. Pain coping is measured via the Pain Coping Scenarios Questionnaire (McManus, Treacy & McGuire, 2013). The **Pain Coping Scenarios Questionnaire** consists of four items which ask participants how they would cope with pain in four hypothetical but commonly occurring situations i.e. during the night, at school, at home and during an activity. This measure seeks to determine if participants would generalise techniques learnt during the intervention programme to commonly occurring situations in which they may experience menstrual pain. Responses are coded as being wellness or illness focused.

Participants

Participants are females aged between 12 and 20 years of age with a diagnosis of a Mild or Moderate Intellectual Disability. Speech is the primary means by which participants communicate. Participants are in full time education, have commenced menstruation and experience pain symptoms in the days preceding or during menstruation.

Results

Table 1: Participant descriptive statistics

	Intervention Mean (M)	*Intervention* Standard Deviation (SD)	*Control* Mean (M)	*Control* Standard Deviation (SD)
Age	16.75	1.86	14.67	1.50
Year in School	4	1.51	2	1.62
Age when Menstruation Commenced	12.00	1.86	12.17	1.34
Frequency of Menstruation	28.17	3.04	30.42	8.29
Length of each Menstrual Cycle	5.08	1.08	5.00	1.41
No. of days missed from school (3 month period)	0.58	0.51	0.50	0.52

Graph 1: Pain Knowledge

Results to date suggest that participation in the menstrual pain management programme has a positive impact in terms of increasing pain knowledge over time.

Graph 2: Pain Coping Strategies

Over time, participants in the intervention condition used more wellness-focused coping strategies to manage pain in everyday situations, compared with those in the control condition.

Conclusion

Preliminary results suggest that participation in a cognitive-behavioural therapy programme for menstrual pain management has a beneficial effect in increasing knowledge of pain coping strategies and use of wellness focused coping strategies to manage pain in everyday situations. Results have implications for personal development training with young women with intellectual disabilities, their parents and support staff.

References

McManus S, McGuire BE. Feeling better: a cognitive behavioural pain management programme for people with an intellectual disability. Brighton, UK: Pavilion Publishing; 2010.

Eden J.A. Dysmenorrhoea and premenstrual syndrome. In: Hacker FN, Moore JG, editors. Essentials of Obstetrics and Gynaecology. Philadelphia, PA: WB Saunders; 1992. pp. 332-337.

Kyrkou M. Health issues and quality of life in women with intellectual disability. Journal of Intellectual Disability Research 2005; 49(10):770-772.

McManus S, Treacy M, McGuire BE. Cognitive behavioural therapy for chronic pain in people with an intellectual disability using the *Feeling Better* programme: a case series. Journal of Intellectual Disability Research 2013. doi: 10.1111/jir.12018.

Corresponding author: susankennedy2007@gmail.com

Abstract submitted to the European Health Psychology Conference, Innsbruck, September 2014

Title: Evaluation of a programme for menstrual pain management in women with Intellectual Disabilities

Author's Details (Names & Affiliations):

Susan Kennedy, Psychology Department, City University London, UK; Brothers of Charity Services Galway, Ireland

Brian McGuire, School of Psychology, National University of Ireland, Galway, Ireland; Centre for Pain Research, Galway, Ireland

Introduction

Menstrual pain, a type of intermittent chronic pain, is believed to be experienced at a higher rate amongst women with Down syndrome and those with Autistic Spectrum Disorder (ASD), than in the general population (Kyrkou, 2005).

Given the significant personal, social and economic impact of chronic pain, much research attention has been directed towards pain management options. Pain management programmes are not routinely offered to people with an intellectual disability however, and analysis of what elements "work" with this population is an innovative approach which can yield valuable information.

Aim of Investigation

The aims of the study are to develop and evaluate a theory-based cognitive behaviour therapy (CBT) programme for menstrual pain management in young women with intellectual disabilities. Process evaluation will also be conducted to examine which elements of the programme are most successful in promoting change.

Methods

The programme is being delivered as a matched controlled trial to young women aged 12 – 30 years who have a Mild - Moderate Intellectual Disability. It is a group based twelve week programme. The total number of participants will be 36, split between two conditions. The treatment condition receive the intervention and the matched condition receive treatment as usual. Information is gathered throughout the process on a number of key pain variables including impact, knowledge, self-efficacy and coping.

Results

Results to date suggest that participation in the menstrual pain management group has a positive impact in terms of increasing pain knowledge over time, and increasing the use of wellness-focused coping strategies to manage pain in everyday situations.

Conclusions

Preliminary results suggest that a cognitive-behavioural therapy programme can be effectively used to support menstrual pain management amongst young women with intellectual disabilities. Results have implications for personal development training with this population, their parents and support staff.

Acknowledgements

€ 100 euro support from the Centre for Pain Research

Appendix 21: Fidelity Checklist

Group 1

	1	2	3	4	5	6	7	8	9	10	11	12
Attendance	5/5	5/5	5/5	5/5	5/5	5/5	5/5	4/5	4/5	4/5	5/5	5/5
Group Rules Reviewed	√	√	√	√	√	√	√	√	√	√	√	√
Group 2	√	√	√	√	√	√	√	√	√	√	√	√
Session Topic Completed	√	√	√	√	√	√	√	√	√	√	√	√
Session completed as per outline	√	√	√	√	√	√	√	√	√	√	√	√
Modifications /changes required	X	X	X	X	X	X	X	√	X	√	X	X
Details of changes								Extra examples required		Extra examples required		
Group cohesiveness supported with social activity	√	√	√	√	√	√	√	√	√	√	√	√

Group 2

	1	2	3	4	5	6	7	8	9	10	11	12
Attendance	7/7	7/7	7/7	7/7	7/7	6/7	7/7	6/7	6/7	7/7	7/7	7/7
Group Rules Reviewed	√	√	√	√	√	√	√	√	√	√	√	√
Previous session plan and homework reviewed	√	√	√	√	√	√	√	√	√	√	√	√
Session Topic Completed	√	√	√	√	√	√	√	√	√	√	√	√
Session completed as per outline	√	√	√	√	√	√	√	√	√	√	√	√
Modifications /changes required	X	X	X	X	X	X	X	√	X	√	X	X
Details of changes								Extra examples required		Extra examples required		
Group cohesiveness supported with social activity	√	√	√	√	√	√	√	√	√	√	√	√

Group 3

	1	2	3	4	5	6	7	8	9	10	11	12
Attendance	6/6	6/6	6/6	6/6	6/6	5/6	6/6	6/6	5/6	6/6	6/6	6/6
Group Rules Reviewed	√	√	√	√	√	√	√	√	√	√	√	√
Previous session plan and homework reviewed	√	√	√	√	√	√	√	√	√	√	√	√
Session Topic Completed	√	√	√	√	√	√	√	√	√	√	√	√
Session completed as per outline	√	√	√	√	√	√	√	√	√	√	√	√
Modifications /changes required	X	X	X	X	X	X	X	√	X	√	X	X
Details of changes								Extra examples required		Extra examples required		
Group cohesiveness supported with social activity	√	√	√	√	√	√	√	√	√	√	√	√

Section C: PROFESSIONAL PRACTICE

Menstrual pain and quality of life outcomes: Reflections on a behavioural approach to formulation and treatment

The Professional Practice Component of this thesis has been removed for confidentiality purposes.

It can be consulted by Psychology researchers on application at the Library of City, University of London.

Section D: SYSTEMATIC REVIEW OF LITERATURE

How effective are relationships and sexuality education programmes at addressing training needs, as identified by those with intellectual disabilities?

Abstract

Background: Relationships and sexuality education is of critical importance to individuals with intellectual disabilities. The purpose of the current study was to review the effectiveness of relationships and sexuality education programmes in addressing the training needs, as identified by those with intellectual disabilities.

Method: A systematic review was conducted to search for studies which reported on the relationships and sexuality training needs as identified by those with intellectual disabilities and, the effectiveness of training programmes in meeting these needs. Searches were conducted electronically and relevant research studies evaluated using Critical Appraisal Skills Programme (CASP) checklists.

Results: Five journal articles were included in the review. Few studies have specifically sought to determine sexual education training needs directly from individuals with intellectual disabilities. Of those that have, a number of key themes have been consistently identified including knowledge of how the human body works, safe sex and social and emotional aspects of relationships and sexuality. Despite this, sexual education training programmes do not always include these core concepts.

Conclusion: Few studies seek to determine the relationships and sexuality training needs of those with intellectual disabilities and those that have done so have not used this information to develop training programmes specifically targeted to these identified needs. There is limited evidence available to support the efficacy of existing sex education programmes in meeting the training needs as identified by individuals with intellectual disabilities. Those studies that have addressed identified needs have reported some improvements in participants' sexual education knowledge, attitudes

and skills, although the conditions under which these programmes work are unclear. Limitations of the current review include the somewhat narrow search parameters. Recommendations relate to enhancing the quality of future research in this area.

Title

How effective are relationships and sexuality education programmes at addressing training needs, as identified by those with intellectual disabilities?

Background

Relationships and Sexuality Education for Individuals with intellectual disabilities

The field of intellectual disability research has seen significant changes and advances in thinking and practice over the last 20 years, with evidence of this particularly apparent with regard to the issue of relationships and sexuality for individuals with intellectual disabilities. Today, those with intellectual disabilities are living longer, healthier lives, attending mainstream schools and colleges, working, living independently and participating in and fulfilling social roles in society. Much of this is achieved in the same way as their non-disabled peers. With this cultural shift has come increasing awareness of and emphasis on the similarities, rather than the differences, between those with and without disabilities. No-where has this been more evident than in the increasing recognition and acknowledgement that those with intellectual disabilities have the same desires and need for intimacy, connection and sexual expression as their non-disabled peers. A growing consciousness of this issue amongst family members, service providers, care staff and professionals, has placed this topic 'centre stage' in the field of disability research.

Individuals with intellectual disabilities are known to have limited sexual knowledge compared with that of their non-disabled peers (Galea, Butler, Iacono and Leighton,

2004; Murphy and O'Callaghan, 2004). This has been recognised as both a barrier to appropriate sexual expression and a risk factor for exploitation and abuse (Swango-Wilson, 2009). The last twenty years has seen a shift in policy within disability organisations towards providing relationships and sexuality training to individuals with intellectual disabilities. This has been driven in equal measure by internal factors, such as the advocacy and self-advocacy movements, as well as external factors such as shifting societal norms. Psychologists are often involved in both the consultative process surrounding the development of organisational policies regarding relationships and sexuality issues for individuals with intellectual disabilities, and in the subsequent 'roll-out' and implementation of policies into practice. In accordance with the scientist-practitioner model, Psychologists should seek to implement intervention strategies which have proven effectiveness for the population with whom they work.

The current review

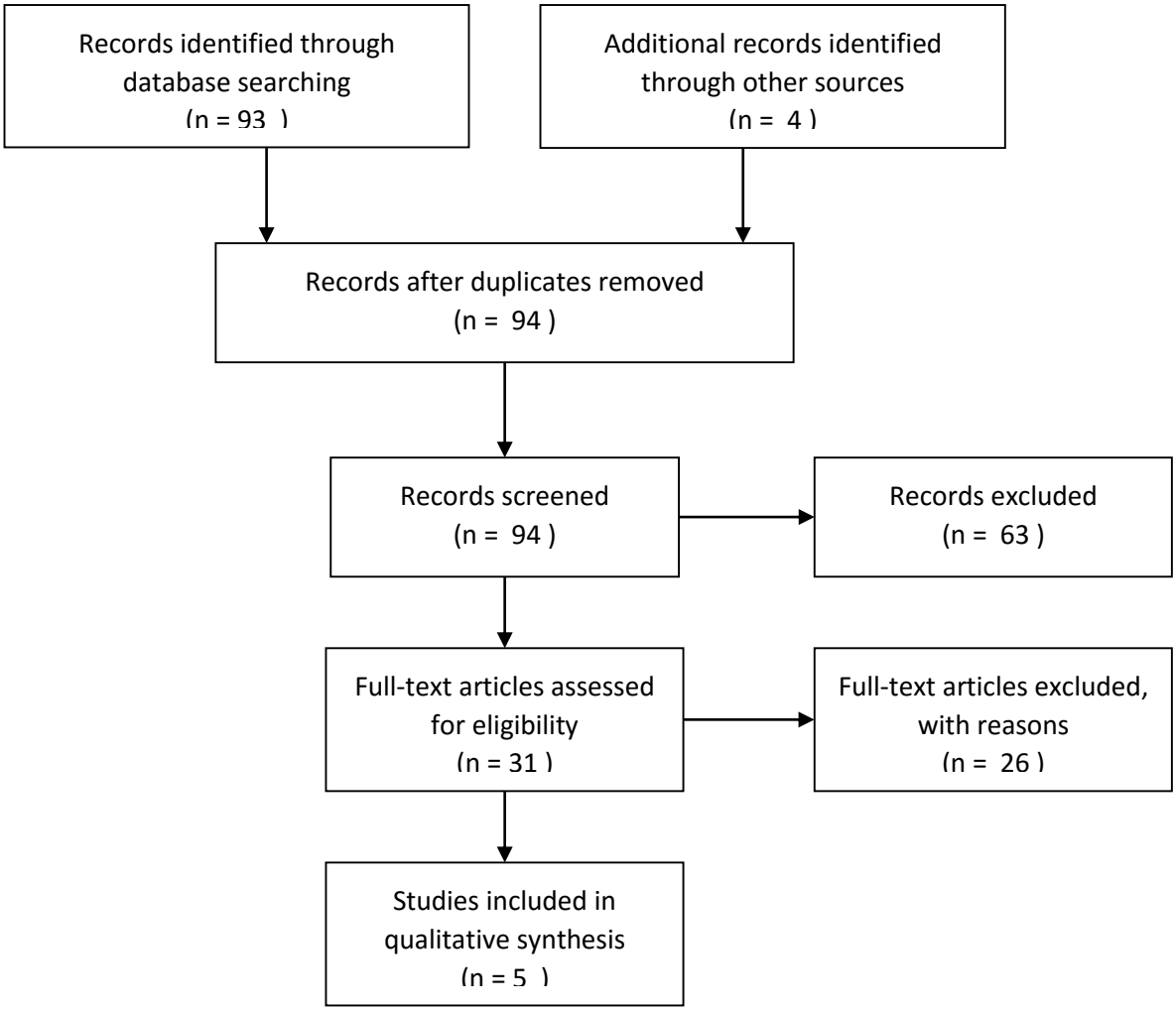
This systematic review aims to examine the efficacy of relationships and sexuality education and training programmes in addressing training needs, as identified by those with intellectual disabilities. The objective of this review is to critically evaluate the literature on this topic both in terms of the subject matter and the methodologies used in relevant research studies.

Literature Review Methodology

Literature search strategy and study selection

A systematic review was conducted to identify articles published in the past 20 years, which investigated relationships and sexuality education programmes for individuals with intellectual disabilities. This review adhered to the Preferred Reporting Items for Systematic Reviews (PRISMA) checklist. An overview of the search strategy is presented in Figure 1.

Figure 1: Flowchart showing overview of systematic review search strategy.



Pertinent research studies for inclusion in this systematic review were identified using the 'PsychInfo' database. This database was searched as it contains records of international studies from the fields of Psychology, Psychiatry and associated disciplines and is widely used as a reference source within the field of Psychology. The search terms used included the following concepts and related terms: "intellectual disability", "developmental disability", "relationships and sexuality", "sex education", "training", "intervention", "sexual knowledge", "efficacy", "effectiveness" and "results". Ancestral searches were also conducted through the reference lists of articles included in the final review. Review papers were considered as an initial starting point for this literature search to ensure that all relevant research was captured and because such studies provide an excellent synopsis of an area, particularly for those who are unfamiliar with the subject matter. In order to provide as broad an overview of the published research as possible, both qualitative and quantitative studies were considered for inclusion in this review. Studies looking at both adolescent and adult populations of individuals with intellectual disabilities were considered and no geographical constraints were imposed in relation to the inclusion of studies. Only programmes delivered to individuals with mild and moderate intellectual disabilities were considered however, as the sexual education and training needs of those with more severe/profound disabilities were deemed to be significantly different, thereby warranting a different type of training programme with different goals. Only journal articles written in English were included in the review.

The search was run in August 2016 and resulted in a list of 97 articles. In the first phase, the titles and abstracts of articles were screened and excluded based on the following criteria:

- article was not written in English
- article relates to individuals with a severe degree of intellectual disability
- article relates to sex education training needs identified by carers, professionals or others
- article relates to specific sex education training needs such as challenging behaviour, protection from abuse, HIV prevention etc.

This resulted in a list of 31 articles. The complete content of these articles was checked. It was important that the article reported on relationships and sexual education training needs as identified by those with intellectual disabilities and/or, sexual education materials or a sexual education programme. Studies that did not directly address these issues were excluded. This reduced the list to 5 articles.

Assessment and reporting of the research articles

In reading the articles, special attention was paid to the specification of the studies goals, the description of the methods used to achieve these goals, the materials used, the study design, the measurements used, the outcomes and evaluation process. Study appraisal and evaluation of quality was guided by checklists from the Critical Appraisal Skills Programme (CASP; Critical Appraisal Skills Programme Checklists, 2017). A descriptive account of extracted data was generated.

Results

This review considered the efficacy of intervention programmes in meeting the relationships and sexuality education training needs of those with intellectual disabilities, as identified by these individuals themselves. The training needs of this population as identified by parents, carers and professionals, have been considered elsewhere e.g. Swango-Wilson (2009) and are beyond the scope of this review.

Looking firstly at the relationships and sexuality training needs identified by individuals with intellectual disabilities, the following key papers will be explored: Löfgren-Mårtenson (2012), Swango-Wilson (2011) and Swango-Wilson (2009). Older influential studies referenced in these papers will also be referred to, for background information. Relationships and sexuality training programmes referenced in review papers by McDaniels and Flemings (2016) and Schaafsma, Kok and Stoffelen (2015) will then be considered in terms of their strengths and limitations. Conclusions will be proposed regarding the efficacy of these programmes in addressing the sexual education training needs identified by individuals who have a diagnosed intellectual disability.

Relationships and Sexuality training needs, as identified by individuals with intellectual disabilities

Background

Research has shown that it is relatively uncommon for young people with intellectual disabilities to learn about sexuality from each other when natural learning

opportunities occur outside of the classroom (Gougeon, 2009). For this reason, sex education training is especially important for this population. Such training needs to address the particular needs of this population otherwise it is a redundant exercise. Whilst much of the research on the sexual education and training requirements of individuals with intellectual disabilities has focused on the needs identified by parents, staff and trained professionals, service users themselves are an under-utilized resource.

As far back as 1993, McCabe observed that individuals with disabilities were not routinely asked for their opinion on their sex education needs and, training programmes for this population were not evaluated for reliability, validity or effectiveness. This was one of the earliest studies to identify the need to include the individual with an intellectual disability in the initial planning phase of a relationships and sexuality training programme in order to address their specific training needs. McCabe (1993) commented on the prevailing practice at the time, which was to consult with family members and carers regarding the content of training programmes, rather than the individuals with intellectual disabilities for whom the training was being provided. If sexual education training is to be both meaningful and effective, it is essential to firstly find out about the lives of those with intellectual disabilities and what they want information on. It is only through these methods of enquiry that their quality of life can be enhanced. Szollos and McCabe (1995) demonstrated this clearly in their study of the sexuality and relationships knowledge needs of those with a mild intellectual disability. The findings of this study suggested that the needs of participants were different from those of the general population. Additionally, differences were also noted between the needs of male and female participants. Whitehouse and McCabe (1997) called on educators to "develop a sense of what the

actual sexual needs and experiences of people with intellectual disabilities are, and then tailor programs to address these needs, rather than imposing the values of the non-disabled culture on people with disabilities". (p. 230).

The current review

The most recent study to consider the specific sexual education training needs of the intellectually disabled population was conducted by Löfgren-Mårtenson, in 2012. This was a qualitative study conducted with adolescents and young adults with intellectual disabilities to determine the key topics these individuals identify for inclusion in sex education programmes. The study had a broader remit and also examined the messages inherent in sex education training for those with intellectual disability, however, this issue is outside the remit of this review. Sixteen young people aged between 16 and 21 years responded to an introductory letter sent to all students with intellectual disabilities attending special education high schools in Malmo, Sweden. These individuals were interviewed and thematic analysis used to analyse the interview data. The following issues were identified as critical for inclusion in sex education training programmes for this population:

- knowledge of how the human body works
- safe sex and the use of contraception, especially condoms
- friendship, relationships and love
- loneliness, alienation and bullying
- how to flirt and start a relationship
- the risks associated with internet use and dating

- when to become sexually active

Participants also offered suggestions on how training could be supported:

- use of a range of instructional formats such as reading books, watching films, role playing and discussion
- discussing critical topics in small groups
- separating groups by gender for certain sensitive or potentially embarrassing topics
- use of same sex instructors for sex education with young women
- use of humour to lighten the mood during instruction
- a staged approach to education and information sharing with repetition of key concepts

Research quality – strengths and limitations

A key strength of this study was the fact that it was qualitative in design thereby giving a voice to an often "voiceless" population. Qualitative approaches to research typically yield much rich information about the lived experiences of participants and can serve as a means to direct further research on a given topic, as in this study. Löfgren-Mårtenson suggested that "future studies should therefore to a greater extent include youth with ID (intellectual disability) as both participants and collaborators in research" (p. 223). A number of limitations were noted in the research design of this study, however, which raise some questions about the findings. Firstly, no information was provided on the admissions criteria for special education high schools in Sweden and no details were provided on the level of cognitive functioning or adaptive behaviour skill level of participants. The absence of this information raises questions about the generalizability of these findings across the intellectually disabled

population, how representative these findings are of the training needs of this population and the feasibility of replicating this study, in the future, in other geographical regions. Furthermore, there were only sixteen (16) participants in this study however we do not know the degree of response rate this represents as we were not told how many letters of invitation were initially sent to potential participants. Again, this raises questions about how representative the findings of this study are for this population. Failure to provide sufficient detail on certain aspects of the study raises similar questions. For example, detailed information is not provided on how facial expressions and body language used by participants during the interviews, were analysed. In addition, there is no rationale provided for the inclusion of particular questions as prompts in the interview guide included in the appendix of the Löfgren-Mårtenson paper. It is unknown whether or not these questions were selected based on theory. This raises some questions as to whether the inclusion of these topics, and the absence of others, might have favoured or biased participants to respond in particular ways. It seems reasonable to query whether the same information and responses might have been obtained if a purely open style of questioning had been used by the researchers, instead.

Other Studies

In spite of the methodological shortcomings outlined above, the results of this study were consistent with two previous studies in this area: Swango-Wilson (2011) and Swango-Wilson (2009). This can be viewed as a significant strength of the research study which lends considerable weight to the findings. Swango-Wilson (2011) used a qualitative inquiry approach to investigate what individuals with intellectual

disabilities require from a sex education programme. The principal aim of the study was to use the results obtained to develop an outline for a sexual education training programme for individuals with intellectual disabilities. Three people were interviewed, each of whom met the criteria for intellectual/developmental disability, as defined by the American Association of Mental Retardation (AAMR). These participants were recruited from a self-advocacy group in Anchorage, Alaska. All participants used speech to communicate and were able to respond verbally to the questions posed by the researcher. A notable strength of the study was the use of an interview guide to ensure all participants were asked the same questions in the same order, using the same terminology and phrasing. In addition, an open-ended style of questioning was used along with audio-recording of interviews, to ensure the richness of participants' responses was fully captured. The use of an open-ended questioning style helped to minimise socially-desirable responding and acquiescence, which can be an issue with this population (Stancliff and Parmenter, 1999). Interviews took place in two half hour sessions to aid participants' concentration and to obtain as rich a response as possible from participants.

The study used a descriptive inquiry approach to data collection and analysis. The rationale for this approach was to "allow for the discovery of multiple realities that occur among groups and between investigator and individual groups (Lincoln and Sage, 1985)" (p. 115). Participants identified three major themes for inclusion in sexual education training programmes and proposed a number of instructional methods to support learning. The themes related to:

- the development of friendships
- the development of lasting relationships and marriage
- safe intimacy

The use of video examples during training, mixed gender classes, classes that focus on practical ways to develop relationships and, homework assignments were suggested as methods to support learning. Participants also mentioned an ongoing need for information on safe sex practice and information on how to safely report abuse by carers.

The themes identified are consistent with previous research conducted Heshusius, as far back as 1982, which lends weight to the credibility of the results. Some methodological weaknesses were noted in the study namely, the absence of information on participants' age and background as well as the specific questions asked of participants. The small sample size used and the geographical region in which the study was conducted, raise questions about how representative the findings are and whether they can be generalised to the wider population of individuals with intellectual disabilities as well as those from other cultures and ethnic backgrounds. As with the Löfgren-Mårtenson (2012) study, the omission of some key and relevant information raises some questions and somewhat dilutes the integrity of the research findings.

Swango-Wilson also examined this same issue in an earlier study conducted in 2009 as "…few if any of these views include opinions from the DD/CD (developmental

disability/cognitive disability) population" (p. 225). The rationale for this approach was to "… increase the visibility of the individual with DD/CD and to promote decision making skills" amongst this population (p.225). At the time of the study, the author identified no sex education training programmes that had been planned in consultation with individuals with intellectual disabilities and the training needs which they themselves had identified.

Swango-Wilson's (2009) study was a small scale project which involved individuals with intellectual disabilities, parents, care staff and health care staff working with these individuals. Only the views of those with intellectual disabilities were relevant to this review. The research design involved a non-probability, purposive, convenience sample. Individuals were identified using the snowballing technique. The sample of individuals with intellectual disabilities was extremely small with just two males and one female aged from 23 – 43 years. Participants all lived in a supported living environment. One participant was married, one individual had been in a long term relationship and the final participant was exploring sexual relationships, at the time the study was completed. The method of data analysis used in this study was not expressly stated in the paper. The themes identified by participants were:

- relationship knowledge
- the development of skills for responsible sexual activity

Again, these topics were similar to the findings of Heshusius (1982). The need to include caregivers in the development of the sex education programme was identified by all groups, including the individuals with disabilities. Interestingly, the need to

include those with intellectual disabilities in programme development was not voiced by their carers. Kelly, Crowley and Hamilton (2009) noted that in the considerable discourse on the rights of people with intellectual disabilities to a sexual life, their own voices remain largely silent. This conclusion remains true today.

Looking at the research design and methodology of Swango-Wilson's (2009) study, some weaknesses were apparent and warrant comment. Consent to participate in the study was obtained from both potential participants, and their guardians. During this process, however, some guardians shared sensitive personal information about the participants' experience of sexual abuse. Swango-Wilson acknowledged that this information influenced the interview process as follow-up questions to some information revealed by participants was avoided, in light of known sensitivities disclosed by guardians. It is unknown if the avoidance of certain questions with some participants, may have influenced the findings of the study. Additional limitations noted in Swango-Wilson's paper included the absence of detailed information on the study findings, the use of a small convenience sample and the possibility of socially desirable responding in response to clarification of questions by the interviewer.

Summary of findings

A review of the literature on sexual education training for individuals with intellectual disabilities suggests that in the first instance, little research has been conducted to identify what it is that these individuals want support to learn. For the most part, the research which has been conducted is small scale and qualitative in nature. These studies represent a starting point in the exploration of this issue. More research is

needed with larger sample sizes, using both qualitative and quantitative research designs as well as more rigorous research methodologies. The training needs identified by those with intellectual disabilities have, however, been consistent across those studies conducted to date. These relate to:

- knowledge of how the human body works
- safe sex and when to become sexually active
- the social and emotional aspects of friendships, relationships and sexuality
- loneliness, alienation and bullying
- the risks associated with internet use and dating

The second part of this systematic review will examine the effectiveness of relationships and sexuality education training programmes in meeting these identified training needs.

Relationships and sexuality training programmes for individuals with intellectual disabilities

Overview

Two recent comprehensive reviews of sex education curricula for individuals with intellectual disabilities were conducted by McDaniels and Fleming (2016) and, Schaafsma et al. (2015). Looking firstly at the McDaniels and Fleming paper, this sought to determine the appropriateness, need, availability and effectiveness of sex education for adolescents with intellectual disabilities. Although this paper constitutes

a wide-ranging appraisal of the literature on this issue, only those studies which examined sexuality education training programmes delivered to individuals with intellectual disabilities were considered, for the purposes of this systematic review.

The current review

Schaafsma, Stoffelen, Kok and Curfs (2013) explored the development and effectiveness of five sexuality education curricula used with individuals with intellectual disabilities in the Netherlands. Interviews were conducted with training programme creators using an intervention mapping framework (Bartholomew, Parcel, Kok, Gottlieb and Fernández, 2011). This approach was used as a guide to assist in describing the process of developing programmes and identifying areas for improvement. This methodology comprises six elements: (1) needs assessment (2) detailing programme outcomes (3) selecting theory and evidence-based intervention methods and practical applications (4) designing and organizing the programme (5) stating implementation plans and (6) producing an evaluation plan. Of the five programmes examined in this study, individuals with intellectual disabilities were only involved in the development of two of these programmes. In both cases, involvement related to testing of the materials developed. The training needs of this population were not directly ascertained by the programme developers of any of the five programmes evaluated, before they created their programmes. Schaafsma et al.'s (2013) study did not provide the names of the programmes evaluated or explicitly detailed information on the content of these curricula. For this reason, it was not possible to determine the effectiveness of any of these programmes in meeting the relationships and sexuality training needs identified by individuals with intellectual

disabilities, as outlined earlier in this review. Schaafsma et al. (2013) concluded that in order to acquire effective sexual education programmes for those with intellectual disabilities, formal needs assessment must be conducted to determine the impact of training programmes on this population.

Dukes and McGuire (2011) conducted a multiple baseline design study using an intervention programme adapted from the "Living Your Life" sexuality education curriculum (Bustard, 2003). The aim of this study was to assess the effectiveness of the intervention in improving capacity to make sexuality-related decisions. This was measured via increased scores on the Sexual Consent and Education Assessment (SCEA) scale (Kennedy, 1993). The study involved four individuals with a moderate intellectual disability, all of whom showed increased knowledge and decision-making capacity in four targeted areas, after participation in the intervention programme. The intervention focused on gaps in knowledge identified from the initial assessments conducted with participants. Knowledge of sexual safety practices and knowledge of the human body, have been identified by individuals with intellectual disabilities as topics which they would like additional information and training on. The study was effective in addressing these specific training needs as the use of a multiple baseline methodology clearly demonstrated a relationship between the intervention and the increase in participants' knowledge.

Schaafsma et al. (2015) conducted an excellent and extremely comprehensive review of the effectiveness of available sexual education training programmes for individuals with intellectual disabilities. Consistent with the search parameters used in this review,

the terms “intellectual disability”, “sexuality” and “education” were used as an initial starting point. A literature search was conducted across several relevant databases and following a lengthy and detailed review process, a final list of 20 relevant articles were identified, in January 2013. The paper proceeded to review and evaluate these articles under five key themes – programme materials used, programme goals and the methods used to achieve these goals, the quality of the research design, the measurement tools used and the results of the studies. The descriptive terminology defined in the intervention mapping protocol (Bartholomew et al., 2011) was again used for this purpose.

Schaafsma et al.’s (2015) study included detailed and informative appendices which provide information on various features of the research papers they reviewed. This additional information was examined to identify those studies which specifically targeted the sexuality education training needs and goals identified by individuals with intellectual disabilities, as outlined above. Only ten of the studies reviewed by Schaafsma et al. (2015) met the criteria for this review i.e. sex education programmes which address training needs, identified by individuals with intellectual disabilities. These studies spanned a 30 year period, from 1981 – 2011 and were considered in terms of their strengths, weaknesses and effectiveness.

Summary of sex education training programmes reviewed

The earliest of these studies was conducted by Zylla & Demetral (1981) who examined the effectiveness of a sex education programme on three participants’ sexual behaviour and knowledge. The programme included the topics of sexual intercourse,

pregnancy, contraception and venereal disease; all of which have been identified as training needs by those with intellectual disabilities. Knowledge was assessed via an interview and increases in participant knowledge were recorded.

Robinson (1984) investigated a ten week sex education programme which examined topics including sexual development and anatomy, conception, gestation and birth, contraception and venereal disease, interpersonal relationships and sexual values and decision making. The study had a large sample size, split between an experimental and control group. Those who received the intervention were found to have significantly more knowledge of sexual matters than those in the control group. Some evidence was also reported for positive changes in participants' attitudes following participation in the sexual education training programme.

Lindsay, Bellshaw, Culross, Staines and Michie (1992) evaluated the acquisition of sexual knowledge after completing a sex education programme which involved body parts, puberty, social interaction, sexuality and childbirth, birth control, venereal disease, parenting and marriage. The experimental and control subjects sexual knowledge was assessed via a questionnaire. There were no significant differences between the groups at baseline but the experimental group had significantly higher levels of sexual knowledge than the control group, following participation in the intervention programme. This study is one of the few studies to have provided adequate pre- and post-test measures, used a control group and provided follow-up data to evaluate whether the information learned by the participants was retained. Some limitations were noted in that the study did not examine whether the knowledge

obtained by the participants was transferred into their daily lives and interactions and whether the participants had more positive feelings towards their sexuality as a result of the programme. These issues were subsequently considered by Lindsay, Michie, Staines and Bellshaw (1994). They measured changes in the attitudes of clients toward sexual behaviour, after participation in a sex education programme, and found that participants' attitudes became more liberal.

Valenti-Hein, Yarnold and Mueser (1994) examined social skills and social sexual knowledge following a dating skills programme. Although participants demonstrated an increase in their social skills following participation in the training programme, their level of anxiety in social situations remained. The researchers concluded that people with an intellectual disability may not be able to generalise the social skills they have been taught to enable themselves to manage their emotions in other situations. McDermott, Martin, Weinrich and Kelly (1999) examined the impact of training on knowledge related to sexuality, hygiene and social skills. Increases in knowledge and hygiene were reported for those who participated in the greatest amount of training sessions.

Garwood and McCabe (2000) examined sexual knowledge, experience and feelings of participants attending two different sex education programmes: the Co-Care and Family Planning Victoria programmes. Both of these programmes were based on practical experience and included topics such as feelings, sexual relationships and sexual protection. Minimal increases in participants' knowledge levels were reported for participants in both programmes. Caspar and Glidden's (2001) sex education

programme sought to increase levels of positive sexual expression and experience by focusing on topics including birth control, sexually transmitted infections and the circle concept for relationships. Participants displayed increased sexual knowledge and slightly less conservative attitudes, following the intervention. Hayashi, Arakida and Ohashi (2011) investigated if there was an improvement in social skills following instruction on topics including first impression and thinking towards your partner, communication training, self-assertiveness training and male-female relationships. Participants described the training programme as beneficial and scores on communication, management and problem-solving skills increased, post-intervention. Dukes and McGuire's (2011) also met the criteria for inclusion in this review and has already been outlined.

Strengths of the studies reviewed

Looking firstly at the strengths of these studies, knowledge of how the human body works, safe sex, when to become sexually active and the social and emotional aspects of friendships, relationships and sexuality, were addressed to varying degrees, by all of the sex education programmes outlined above. These topics were all identified as sexual education training needs by participants in Löfgren-Mårtenson's (2012) study. None of these studies addressed the issues of loneliness, alienation and bullying or the risks associated with internet use and dating. These issues were also identified as training needs by this population. It should be noted however, that the studies outlined above were all completed prior to Löfgren-Mårtenson's (2012) study, which identified these additional trainings needs. A further strength of the studies summarized above is that in each case, the intervention programme resulted in an increase in participants'

sexual knowledge. For those studies which also examined sexual attitudes, positive results were also reported in the form of a shift towards more liberal/less conservative attitudes towards issues related to sexuality and sexual expression.

Limitations

With regard to limitations of these studies, none of them provided details on the justification for the programme content or topics included in their training programme. No evidence was provided in any of the papers to show that the sex education programmes had been developed from a sound theoretical and evidence-based framework. Instead, a number of programmes adopted an 'a la carte' approach whereby training facilitators chose which topics to address based on criteria which were not always clearly and objectively defined. At the very least this is a glaring omission and, a serious methodological flaw, if such factors were not considered by researchers during the process of programme development. The descriptions of the methods of programme delivery used in these studies were generally vague and again, none of the studies provided details on the rationale for the choice of techniques used. Once more, this is a significant oversight as theoretically based intervention methods are known to only work under certain conditions (Bartholomew et al., 2011). Abraham and Michie (2008) argued that if other researchers are to effectively replicate intervention programmes which claim to be successful in achieving their aims, such programmes must provide details of the programme delivery approaches they have used.

Study design, materials and methods

Examination of the aims and objectives of the training programmes and the materials used to deliver the interventions identified the omission of this relevant information in all of the studies reviewed except for Lindsey et al. (1994) and Hayashi et al. (2011). This raises serious questions about claims by the researchers regarding the efficacy of their programmes. The effectiveness of a sexual education training programme for those with intellectual disabilities can only be truly measured by whether clear and precise goals, formulated at the outset of the intervention, have been achieved.

An examination of the research designs used in the studies under consideration in this review identified considerable variation in methodology and experimental rigour. The studies by McDermott et al. (1999), Garwood and McCabe (2000) and, Caspar and Glidden (2001), all used a pre-test and post-test design. This methodology lends support to the generalizability of findings, when a control group is included. Unfortunately, these studies did not include a control group. The inclusion of a control group enables a researcher to attribute changes between baseline and post-testing, to the intervention. This type of study design usually requires a relatively large sample size which is not always feasible due to numerous factors including availability of participants, as well as financial and time constraints. In such circumstances, a multiple baseline design is an acceptable alternative as it enables the measurement of the effect of an intervention using a small sample of participants. Zylla and Demetral (1981) had a small sample size and used a multiple baseline research design. This was a notable strength in their research design. Garwood and McCabe (2000), Caspar and Glidden (2001) and Hayashi et al. (2011) also had small numbers of participants (N =

6, 12 and, 17 experimental 17 control, respectively) but did not use this methodology. The challenge in using small sample sizes is that findings can often only be considered exploratory in nature as it can be difficult to generalize from such results.

Reported findings regarding efficacy and measurements

Examination of claims regarding the effectiveness of sex education programs for individuals with intellectual disabilities, by the programme developers, have a number of methodological flaws. Perhaps the most obvious of these is the lack of quantitative data supporting researchers' claims regarding the efficacy of their programmes. Some researchers claimed to have evaluated their programme but did not include the relevant information in their paper whilst others stated that their programmes were effective but did not include any evaluation measures. Efficacy was primarily evaluated via changes in sexual knowledge and attitudes and, skill acquisition. These changes were measured via questionnaires, interviews and naturalistic observation/assessment. Measuring skills via a verbal report, whilst feasible, is open to the possibility of socially desirable responding. Verbal report can be inaccurate when used for behaviours that do not occur frequently and also, amongst those with intellectual disabilities, where recall and acquiescence can be an issue. Practising and testing skills in-situ is the best approach to measurement as knowledge about correct behaviour does not necessarily lead to a change in behaviour and demonstration of behaviour during role-play does not automatically lead to the implementation of the appropriate behaviour in real-life situations (Dukes and McGuire, 2009). Valenti-Hein et al. (1994) were the only researchers to use in-situ skills testing, in the studies reviewed here.

Other limitations associated with researchers efficacy claims include the fact that the efficacy of educational interventions was primarily measured against treatment as usual (i.e. no training) rather than in comparison with alternative approaches and methods for providing relationships and sexuality training e.g. group versus individual training or a comparison of the efficacy of a training programme provided by different trainers e.g. staff, parent, professional or peer training. Garwood and McCabe (2000) were the only researchers to compare two different sexual education training programmes. It was also noted that studies on the effectiveness of interventions with individuals with intellectual disabilities often did not include follow-up measures. As many individuals with intellectual disabilities have difficulties with long term memory for information, this raises the question as to whether an increase in sex education knowledge is the most appropriate measure of the effectiveness of an intervention if it is unknown whether, and for how long, such an increase in knowledge is maintained for.

Participants and contexts

Further limitations of these studies included the fact that adolescents were not represented in the profile of study participants. For this reason, any conclusions drawn by the researchers about the effectiveness of their sex education programmes can only be applied to an adult population of individuals with intellectual disabilities. For the most part, study participants lived in supported residential settings, rather than in community based independent living situations. The effectiveness of these training programmes, as claimed by their developers, may therefore be influenced by opportunities to implement skills and knowledge obtained. Individuals living in

community settings may have different opportunities for sexual expression and the development of relationships than those who live in residential or supported living situations.

Conclusion:

Servais (2006) concluded that there is very little research describing sex education amongst those with intellectual disabilities. Ten years on, this assessment continues to be true and is particularly pertinent with regard to the efficacy of sex education programmes for this population. To answer the original question posed by this review paper, there is limited evidence available to support the efficacy of sex education programmes in meeting the training needs of individuals with intellectual disabilities, identified by these individuals themselves.

To summarize, very few studies seek to determine the relationships and sexuality training needs of those with intellectual disabilities and those researchers that have done so have not used this information to develop sexual education training programmes specifically targeted to these identified needs. For the most part, programme developers and researchers have not drawn on the available, albeit limited, research identifying the training needs of this population before developing or delivering sex education programmes for individuals with intellectual disabilities. Those studies that have addressed the identified training needs of this population have reported improvements in participants' sexual education knowledge, and attitudes, where these have also been assessed. Much can be learned from this review in terms

of directions for future research and clinical practice with regard to this emotive and topical issue.

Strengths and limitations

PRISMA guidelines and CASP checklists were used in conducting this systematic review and evaluating the quality of the studies included in it. This is a strength worth noting. In addition, the subject matter of the study is a strength in and of itself as this is an area rarely considered despite the growing awareness of the sexual education training needs of those with intellectual disabilities. Despite these strong points, the findings of this study should be considered within the context of the limitations imposed by the search criteria employed. The articles considered for this review were journal articles available online via PsychINFO. Publications from other databases and fields of research may have also contained relevant information. The same may be true of books or other literature sources which were also omitted, from this review.

Recommendations

This review clearly emphasises the need for sex education programme developers and trainers to directly ascertain the training needs of those with intellectual disabilities before developing or delivering training programmes to these individuals. It also identifies the need for greater experimental rigour in studies evaluating the effectiveness of such training programmes. Specifically, greater focus is required by researchers in setting out clear aims and objectives against which, efficacy claims can be evaluated.

References

Abrahm, C. & Michie, S. (2008). A taxonomy of behaviour change techniques used in interventions. *Health Psychology*, 27, p. 379-387.

Bartholomew, L.K., Parcel, G.S., Kok, G., Gottlieb, N.H. & Fernández, M.E. (2011). Planning health promotion programs: An intervention mapping approach (3rd ed.). San Francisco, CA: Jossey-Bass.

Bustard, S. (2003). *Living Your Life: The Sex Education and Personal Development Resource for Special Needs Education* (revised edition). The Ann Craft Trust U.K. Brook Publication, London.

CASP Checklists [http://www.casp-uk.net/casp-tools-checklists]. Accessed 19 July 2017.

Caspar, L.A. & Glidden, L.M. (2001). Sexuality education for adults with developmental disabilities. *Education and Training in Mental Retardation and Developmental Disabilities*, 36, p. 172-177.

Dukes, E. & McGuire, B.E. (2009). Enhancing capacity to make sexuality-related decision in people with an intellectual disability. *Journal of Intellectual Disability Research*, 53, p.727-734.

Galea, J., Butler, J., Iacono, T. & Leighton, D. (2004). The assessment of sexual knowledge in people with an intellectual disability. *Journal of Intellectual and Developmental Disability*, 29(4), Dec, p. 350-365.

Garwood, M. & McCabe, M.P. (2000). Impact of sex education programs on sexual knowledge and feelings of men with a mild intellectual disability. *Education and Training in Mental Retardation and Developmental Disabilities,* 35, p. 269-283.

Gougeon, N.A. (2009). Sexuality education for students with intellectual disabilities, a critical pedagogical approach: outing the ignored curriculum. *Sex Education,* Vol. 9, No. 3, p. 277-291.

Hayashi, M., Arakida, M. & Ohashi, K. (2011). The effectiveness of a sex education program facilitating social skills for people with intellectual disability in Japan. *Journal of Intellectual and Developmental Disability,* 36, p. 11-19.

Heshusius, L. (1982). Sexuality, intimacy and persons we label mentally retarded: What they think - what we think. *Mental Retardation,* 20, p. 164–168.

Kelly, G., Crowley, H. & Hamilton, C. (2009). Rights, sexuality and relationships in Ireland: "It'd be nice to be kind of trusted". *British Journal of Learning Disabilities,* 37, p. 308–315.

Kennedy, C.H. (1993). *Sexual Consent and Education Assessment.* Drexel University: Philadelphia.

Lincoln, Y. & Guba, E. (1985). Naturalistic Inquiry. Beverly Hills: Sage.

Lindsay, W.R., Bellshaw, E., Culross, G., Staines, C. & Michie, A. (1992). Increases in knowledge following a course of sex education for people with intellectual disabilities. *Journal of Intellectual Disability Research,* 36, p. 531-539.

Lindsay, W.R., Michie, A.M., Staines, C. & Bellshaw, E. (1994). Client attitudes towards relationships: Changes following a sex education programme. *British Journal of Learning Disabilities,* 22, p. 70-73.

Löfgren-Mårtenson, L. (2012). "I Want to Do it Right!" A Pilot Study of Swedish Sex Education and Young People with Intellectual Disabilities. *Sex and Disability,* 30, p. 209-225.

McCabe, M.P. (1993). Sex education programs for people with mental retardation. *American Association on Mental Retardation,* 31(6), p. 377-387.

McDaniels, B. & Fleming, A. (2016). Sexuality education and intellectual disability: Time to address the challenge. *Sexuality and Disability,* 34(2), p. 215–225.

McDermott, S., Martin, M., Weinrich, M. & Kelly, M. (1999). Program evaluation of a sex education curriculum for women with mental retardation. *Research in Developmental Disabilities,* 20, p. 93–106.

Moher, D., Liberti, A., Tetzlaff, J., Altman, D.G. (2009). Preferred Reporting Items for Systemic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. Doi:10.1371/jpurnal.pmed1000097

Murphy, G.H. & O'Callaghan, A. (2004). Capacity of adults with intellectual disabilities to consent to sexual relationships. *Psychological Medicine,* 34, p. 1347-1357.

Robinson, S. (1984). Effects of a sex education program on intellectually handicapped adults. *Australia and New Zealand Journal of Developmental Disabilities,* 10, p. 21-26.

Schaafsma, D., Stoffelen, J.M.T., Kok, G. & Curfs, L.M.G. (2013). Exploring the development of existing sex education programs for people with intellectual disabilities: An intervention mapping approach. *Journal of Applied Research in Intellectual Disabilities,* 26, p. 157-166.

Schaafsma, D., Kok, G., Stoffelen, J.M.T. & Curfs, L.M.G. (2015). Identifying effective methods for teaching sex education to individuals with intellectual disabilities: A systematic review. *Journal of Sex Research*, 52(4), p. 412-432.

Servais, L. (2006). Sexual Health Care in Persons with Intellectual Disabilities. *Mental Retardation and Developmental Disabilities Research Reviews,* 12(1), p. 48-56.

Stancliff. R. & Parmenter, T. (1999). The choice questionnaire: A scale to assess choices exercised by adults with intellectual disability. *Journal of Intellectual and Developmental Disabilities,* 24(2), p. 107-132.

Swango-Wilson, A. (2009). Perception of Sex Education for Individuals with Developmental and Cognitive Disability: A Four Cohort Study. *Sexuality and Disability,* 27, p. 223-228.

Swango-Wilson, A. (2011). Meaningful sex education programs for individuals with intellectual/developmental disabilities. *Sexuality and Disability,* 29, p. 113-118.

Szollos, A. & McCabe, M.P. (1995). The sexuality of people with mild intellectual disability: Perceptions of clients and caregivers. *Australia and New Zealand Journal of Developmental Disabilities,* 20, p. 205-222.

Valenti-Hein, D.C., Yarnold, P.R. & Mueser, K.T. (1994). Evaluation of the Dating Skills Program for improving heterosocial interactions in people with mental retardation. *Behaviour Modification,* 18, p. 32-46.

Whitehouse, M.A. & McCabe, M.P. (1997). Sex education programs for people with intellectual disability: How effective are they? *Education and Training in Mental Retardation and Developmental Disabilities,* 32, p. 229-240.

Zylla, T.M. & Demetral, G.D. (1981). A behavioural approach to sex education. *Sexuality and Disability*, 4, p. 40-48.