

**BRIDGING THE GAP BETWEEN CLINICIANS' DELIVERY  
AND PATIENTS' EXPERIENCE OF EATING DISORDER  
DIAGNOSES**

BY

NIMISHA JOSHI

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the award of Doctorate in Counselling Psychology

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Psychology Department

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**pp 261-286:**      **Part C. Publishable Piece:** Patient experience of receiving a diagnosis of an  
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## TABLE OF CONTENTS

ACKNOWLEDGEMENTS	9
DECLARATION	10
TABLE OF ABBREVIATIONS	11
PREFACE	12-18
<b>PART A: THESIS</b>	<b>19</b>
ABSTRACT	19
<b>CHAPTER 1: LITERATURE REVIEW</b>	<b>20</b>
1. THE DSM	20
1.1. Classification Systems	20-21
1.2. DSM- current edition	22
1.3. DSM-5 Controversies	22-29
1.4. DSM-5 changes to eating disorders	29-30
1.5. Advantages of diagnosis	30-31
1.6. Disadvantages of diagnosis	31-34
2. EATING DISORDERS AND QUALITATIVE RESEARCH	35
2.1. Psychological therapies for eating disorders	35-39
2.2. Patients' perceptions on their disorders and on treatment	39-43
3. RATIONALE FOR THE PRESENT RESEARCH	43-44
4. RESEARCH AIM	44

<b>CHAPTER 2: METHODOLOGY</b>	45
1. Introduction to the methodology	45
2. A qualitative research paradigm	45-46
3. Phenomenology	47
3.1. Husserl's (descriptive) versus Heidegger's (interpretative) phenomenology	47-48
4. Epistemological position	48-49
5. Personal reflexivity	49-51
6. Methodological reflexivity	52-54
7. Research design	54
8. Methodological considerations	54-57
9. Ethical considerations	57
9.1. Consent	58
9.2. Confidentiality	58
9.3. Safe-keeping of records	58-59
9.4. Managing distress and de-briefing	59
10. Participant characteristics	60
11. Inclusion and exclusion criteria	60
12. Recruitment	61-62
13. Procedure for data collection	62
14. Semi-structured interviews	62
14.1. Constructing the interview schedule	62-64
15. Conducting the interviews	64-65
16. Transcription	65
17. Introduction to analytic approach	66
18. Procedure for data analysis	66

18.1.	Step 1: Reading and re-reading	66-67
18.2.	Step 2: Initial noting	67
18.3.	Step 3: Developing emergent themes	67-68
18.4.	Step 4: Searching for connections across emergent themes	68-69
18.5.	Step 5: Moving to the next case	69
18.6.	Step 6: Looking for patterns across cases	69
19.	Validity and quality	69-70
20.	Summary	71
<b>CHAPTER 3: ANALYSIS</b>		72
1.	Introduction to the analysis	72
2.	List of the four master themes and their sub-ordinate themes	73
3.	<b>MASTER THEME 1: LIVING WITH AN UNLABELLED CONDITION</b>	74
3.1.	The warning signs	74-78
3.2.	Living without a diagnosis	78-83
3.3.	<b>MASTER THEME 2: PERCEPTION OF THE PATIENT-THERAPIST RELATIONSHIP AND INTERPERSONAL QUALITIES</b>	84-85
3.3.1.	The uncertainty and doubts when receiving a diagnosis	85-90
3.3.2.	Perception of care when receiving a diagnosis	90-94
3.3.3.	Emotional responses to receiving a diagnosis	95-98
3.3.4.	<b>MASTER THEME 3: LIVING WITH THE DIAGNOSTIC LABEL</b>	98
3.3.5.	Living up to the label	98-106
3.3.6.	Perception of others	107-113

3.4.	MASTER THEME 4: A PATHWAY TO RECOVERY	113
3.4.1.	Making it real	113-116
3.4.2.	Leading to a stronger self	116-118
3.4.3.	The start of a new beginning	118-121
4.	Summary	121
<b>CHAPTER 4: DISCUSSION</b>		<b>122</b>
1.	Overview of themes	122-124
2.	The warning signs	124-125
3.	Living without a diagnosis	125-126
4.	The uncertainty and doubts when receiving a diagnosis	126-132
5.	Living up to the label	132-135
6.	Perception of care when receiving a diagnosis	135-138
7.	Implications for clinical practice	138-142
8.	Evaluation and critique of the research study	142-143
9.	Relevance of study to counselling psychology	143-145
10.	Conclusion	146
<b>REFERENCES</b>		<b>147-170</b>
<b>APPENDICES</b>		<b>171</b>
Appendix A	City University London ethics form	171-178
Appendix B	NHS Research Ethical Approval	179
Appendix C	Participant consent form	180
Appendix D	Participant de-brief	181-182
Appendix E	Research proposal	183-219

Appendix F	Participant invitation and information sheet	220-225
Appendix G	Initial noting	226
Appendix H	Developing emergent themes	227
Appendix I	Searching for connections across emergent themes	228
Appendix J	Table of themes for the group	229-232
<b>PART B: CASE STUDY</b>		<b>233</b>
1.	Abstract	233
2.	Summary of Theoretical Basis for Treatment	234-236
3.	Case Introduction	237
4.	Presenting complaints	237-239
5.	History	240-242
6.	Reasons for approaching therapy now	242-243
7.	The development of the therapy	244
7.1.	Treatment and progress	245
7.2.	Creating a personalised formulation	245-246
7.3.	Pros and cons of change	247-248
7.4.	Real-time self-monitoring	248
7.5.	In session-weighing	248-249
7.6.	Events and Moods	249-252
7.7.	Ending well	252-253
8.	Complicating factors	253-254
9.	Reflections and evaluation of interventions, process and learning	254-256
10.	References	257-258

<b>PART C: PUBLISHABLE PIECE</b>	259
1. Abstract	260
2. Introduction	261-262
3. Methodology	263
3.1. Procedure	263
3.2. Participants	263
3.3. Semi-structured interviews	263-264
4. Qualitative analysis	264
5. Results	264
5.1. Theme 1: Living with an unlabelled condition	265
5.1.2. Subordinate theme 1.1: The warning signs	265
5.1.3. Subordinate theme 2.1: Living without a diagnosis	265-266
5.2. Theme 2: Perception of the patient-therapist relationship and interpersonal qualities	266
5.2.1. Subordinate theme 2.1: The uncertainty and doubts when receiving a diagnosis	266-267
5.2.2. Subordinate theme 2.2: Perception of care when receiving a diagnosis	267-268
5.2.3. Subordinate theme 2.3: Emotional responses to receiving a diagnosis	268
5.3. Theme 3: Living with the diagnostic label	269
5.3.1. Subordinate theme 3.1: Living up to the label	269

5.3.2.	Subordinate theme 3.2: Perception of others	269-270
5.4.	Theme 4: A pathway to recovery	270
5.4.1.	Subordinate theme 4.1: Making it real	270-271
5.4.2.	Subordinate theme 4.2: Leading to a stronger self	271
5.4.3.	Subordinate theme 4.3: The start of a new beginning	271-272
<b>6.</b>	<b>DISCUSSION</b>	<b>273-276</b>
6.1.	Implications for clinical practice	276-279
<b>8.</b>	<b>CONCLUSION</b>	<b>280</b>
<b>9.</b>	<b>ACKNOWLEDGEMENTS</b>	<b>281</b>
<b>10.</b>	<b>REFERENCES</b>	<b>282-286</b>
<b>11.</b>	<b>APPENDICES</b>	<b>287</b>
	Appendix A Author guidelines	287-292

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**DECLARATION**

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## TABLE OF ABBREVIATIONS

<b>Abbreviation</b>	<b>Meaning</b>
AN	Anorexia Nervosa
AN-BSD	Anorexia Nervosa and Behaviourally Similar Disorders
APA	American Psychiatric Association
BED	Binge Eating Disorder
BED-BSD	Binge Eating Disorder and Behaviourally Similar Disorders
BCD-ED	Broad Categories for the Diagnosis of Eating Disorders
BN	Bulimia Nervosa
BN-BSD	Bulimia Nervosa and Behaviourally Similar Disorders
BPS	British Psychological Society
CBT	Cognitive Behavioural Therapy
CBT-BN	Cognitive Behavioural Therapy for Bulimia Nervosa
CBT-E	Cognitive behavioural therapy enhanced
CFT	Compassion Focused Therapy
DSM	Diagnostic and Statistical Manual of Mental Disorders
ENDOS	Eating Disorder Not Otherwise Specified
FBT	Family-Based Treatment
FECNEC	Feeding and Eating Conditions Not Elsewhere Classified
GP	General Practitioner
ICD	International Classification of Diseases and Related Health Problems
IPA	Interpretative Phenomenological Analysis
IPT	Interpersonal Psychotherapy
NEDA	National Eating Disorders Association
NICE	National Institute of Clinical Excellence
NOS	Not Otherwise Specified

## **PREFACE**

### *Introduction to the preface*

This preface will introduce the three distinct pieces of work that I have completed as part of my Professional Doctorate in Counselling Psychology portfolio. The pieces included are a research project, a case study and a publishable paper, all of which have equipped me with practical skills and theoretical principles in developing as a counselling psychologist. I will begin with an outline of the portfolio and I will discuss each piece of work which will include a rationale for why I have chosen to include this work in particular and the themes that I have identified. Finally, I provide an overview of how I work in therapy, highlighting what I believe to be unique and important within counselling psychology.

### *Outline of portfolio*

The first piece of work in the portfolio (Part A) is a qualitative piece of research which explored patients' experiences of receiving a diagnosis of an eating disorder. Within the literature, little is known about how patients themselves experience the diagnosis process, which this research aimed to explore. The research project includes several sections: first, I provide a literature review which demonstrates my theoretical knowledge and understanding of the literature relevant to eating disorders. I begin with an introduction to the classification systems of diagnosis including the *Diagnostic and Statistical Manual of Mental Disorders (DSM)* (5th ed., *DSM-5*; American Psychiatric Association, 2013) and *International Classification of Diseases and Related Health Problems (ICD)* (World Health Organization [WHO], 2015). I move on to discuss the current edition and the controversies surrounding DSM-5 together with the changes to eating disorders and highlight the advantages and disadvantages of receiving a diagnosis. Next, I discuss eating disorders and qualitative research with a particular focus on the psychological therapies for eating disorders and patients' perceptions on their disorders and on treatment.

The second section of the research project includes the methodology. Here, I discuss my chosen paradigm and introduce some of the main philosophical underpinnings of interpretative phenomenological analysis drawing on the work of Husserl and Heidegger. I state my epistemological position, research design, chosen method, and personal and methodological reflexivity. This section also includes the ethical considerations, the participants' characteristics, the inclusion and exclusion criteria, recruitment and the procedure for data collection and analysis.

In the third section, I introduce the four overarching themes that emerged from the data which were: (1) living with an unlabelled condition, (2) perception of the patient-therapist relationship and interpersonal qualities, (3) living with the diagnostic label, (4) a pathway to recovery. Living with an eating disorder is an important theme throughout the entire portfolio. Within the research project, there is a sense of progression through the themes that emerged, from disbelief or rejection of a diagnosis, to ideas about recovery and acceptance. The findings provide a rich description on how participants experienced diagnosis. Receiving and living with a diagnosis of an eating disorder was shown to have a significant impact on patients which I argue should be considered throughout their assessment and treatment process. It is argued that increased awareness of patient experience will help clinicians to develop stronger therapeutic alliances and develop new clinical interventions.

The final part of the research project includes a discussion of the theoretical insights and integration of relevant literature, implications for clinical practice, an evaluation of the research, the relevance to counselling psychology, and conclusions from the research overall.

### *Case Study*

The second part of the portfolio (Part B) includes a case study which is a written summary of the key aspects of a counselling session between myself and a patient who was suffering with anorexia nervosa (AN). The patient was treated with enhanced-cognitive

behavioural therapy (CBT-E) which is the latest treatment shown to be effective with eating disorders. Much of our therapeutic work focused on events and moods as this was what was contributing to the maintenance of the eating disorder. I demonstrate my ability to select and apply a specific theoretical model, illustrating several core theoretical principles. I discuss a CBT-E model as a transdiagnostic perspective, thus embracing a broader range of maintaining processes (Fairburn, Cooper & Shafran, 2003). Accordingly, the transdiagnostic cognitive formulation proposes a guide to clinicians in terms of which processes to address and focus on during treatment (Murphy, Straebler & Fairburn, 2010).

Next, I give a clear and coherent account of my clinical skills and reflect upon personal and professional self-awareness. I provide an introduction to the case, together with the presenting complaints, history and the patient's reasons for approaching therapy. I provide a detailed account of the development of the therapy and also consider some of the difficulties that arose and how these were managed. The use of appropriate supervision is discussed together with what I have learnt overall. I chose this client study to form part of the portfolio because it gives a real sense of some of the difficulties within eating disorders and the patient's experience of diagnosis which is the overarching theme within the portfolio.

The impact of living with an eating disorder evolved as a central theme within the case study. The patient began to recognise the warning signs and symptoms of her eating disorder and upon reflection, was able to see her behaviour as unhelpful during treatment. I was able to gain a detailed understanding of the patients' experience, self-awareness and learning. Moving forward the patient here was able to identify her reasons for change and although she still experienced difficulties, she had accepted her diagnosis, in a similar way that participants identified the positive impact of receiving a diagnosis. Their positive regard for diagnosis was not immediate, however this was after further treatment.

*Publishable Paper*

The third piece of work (Part C) will be a publishable research article which reports the findings from my research project. Part C was written for the European Eating Disorders Review in preparing my work for publication. My particular focus were findings I identified as both useful and interesting, and those which I believe will contribute to the eating disorders field. My motivation to publish the research article is also a result of presenting my research at both London and Boston International Eating Disorder Conferences earlier this year. Both conferences were relevant to my research and focused on themes surrounding diagnosis, classification, stigma, shame and disgust, making diagnosis more clinically relevant, evidence based practice, research, and clinical and patient perspectives. I had the opportunity to talk to colleagues in the eating disorders field and attend plenary, paper and poster sessions that were held by some of the leading figures in the field. In addition, the conferences provided me with the opportunity to exchange ideas with other professionals which I found inspiring for my research

#### *My evolving identity as a Counselling Psychologist*

My initial interest in eating disorders stemmed from an earlier experience with a friend who was suffering with AN, together with my clinical experience and training. Prior to this, I had limited knowledge about eating disorders. Having been exposed to various disturbances in eating behaviours, I became extremely curious, trying to understand it, thinking about the relationships we develop with food, different mind-sets and the possible causes of why some people develop problems with food while others do not. I understand this is only the beginning and that eating disorders are far more complex.

Throughout my training, I have had the opportunity to gain experience in the treatment of adults within a variety of mental health settings including the NHS, Mental Health and Substance Misuse voluntary sectors. I have offered psychological therapy to individuals who have experienced a wide range of difficulties including anxiety and panic,

depression, addictions, eating disorders, obsessions, stress and relationship problems. I continue to enjoy working with a wide range of difficulties and I find this is when I am most fulfilled in my role.

The variety has encouraged me to work integratively in therapy. For me, the beauty of my work is that I have the opportunity to work with people from all different walks of life; it is important for me to be innovative, think creatively, be flexible and adapt to the different individuals I meet. The key principles that I adhere to are focused on safe and ethical practice, managing the therapeutic frame and boundaries and connecting with my patient. Being part of a multi-disciplinary team has been important to me as I have learnt a great deal from working collaboratively with professionals from other disciplines.

I am drawn to implementing a cognitive behavioural approach and have the capacity to formulate and apply this to the individual patient. However, I appreciate that this way of working is not for everyone so being able to draw on other modalities from my training is important. I am particularly interested in the experiential exploration within a more relational context, helping patients to make sense of experiences that are perhaps confusing or distressing and helping them to reflect on and develop emotional meanings within this. As a counselling psychologist, maintaining a person-centred stance is important in order for me to work within the immediate therapeutic relationship. For me, good communication is the foundation of any successful relationship; I recognise that it's the non-verbal communication like our facial expressions, gestures, posture, tones of voice that speak the loudest and are a powerful tool that connects us with others. I am also particularly interested in the more analytic nature within psychodynamic therapy and the specific techniques such as being able to work in the transference and counter-transference, and recognise and work with people's defences. I believe what is most important is having the capacity to use clinical judgement when implementing modalities and treatment models within that modality.

Counselling psychology is a discipline that encompasses many different therapeutic approaches which are located within the traditions of humanistic, cognitive-behavioural, psychodynamic and existential therapy (Gillon, 2007). I agree with Milton (2012), who stated, '[w]hen working with clients we are continually navigating between grand narratives about psychological health and pathology on the one hand, and the attempt to find personalised accounts that are meaningful and helpful to individual clients' (p. xiii). As a counselling psychologist, I believe that one of the most important attributes is my focus on the individuals' subjective experience, and this includes their feelings and meanings they attribute to particular experiences (Strawbridge & Woolfe, 2003). I believe that what makes counselling psychology unique from other disciplines is the integration of psychological theory and research with therapeutic practice. The three pieces of work included in this portfolio illustrate both of these components and are consistent with the philosophy of counselling psychology in that they attempt to understand the notion of diagnosis and they are also consistent with the humanistic values and its focus on subjective experience (Milton, 2012).

I hope that the three pieces of work within this portfolio provide an-depth understanding of what it is like to live with an eating disorder and the experience of receiving the diagnosis. I hope that it encourages clinicians to focus more on diagnosis being delivered in a manner that is individually catered in compassion and communication for the patient.

## References

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: American Psychiatric Association.
- Fairburn, C. G., Cooper, Z., & Shafran, R. (2003). Cognitive Behaviour therapy for eating disorders: a “transdiagnostic” theory and treatment. *Behaviour Research and Therapy*, 41, 509-528.
- Gillon, E. (2007). *Person-centred counselling psychology: an introduction*. London: Sage.
- Milton, M. (2012). *Diagnosis and beyond: Counselling psychology contributions to understanding human distress*. Ross-on-Wye: PCCS Books.
- Murphy, R., Straebler, S., Cooper, Z., & Fairburn, C. G. (2010). Cognitive Behavioural Therapy for Eating Disorders. *Psychiatric Clinics of North America*, 33, 3, 611-627.
- World Health Organization. (2015). *Classifications: International classification of diseases (ICD)*. Retrieved from: <http://www.who.int/classifications/icd/ed/>

## **PART A: THESIS**

### **ABSTRACT**

The notion of diagnosis has been shown to have a profound influence within mental health practice with much attention focusing on the controversies and challenges surrounding the diagnostic classification of eating disorders. However, research focusing on how patients experience their eating disorder diagnosis is scarce. The purpose of this research, therefore, was to address this gap in the literature by exploring patients' experiences of receiving a diagnosis of an eating disorder. Ten female patients were recruited from an adult community eating disorders service in the UK. All patients had received an eating disorder diagnosis and were interviewed using a semi-structured interview schedule. Transcribed interviews were qualitatively analysed using the principles of Interpretative Phenomenological Analysis (IPA). Four master themes emerged from the data: (1) Living with an unlabelled condition, (2) Perception of the patient-therapist relationship and interpersonal qualities, (3) Living with the diagnostic label, (4) A pathway to recovery. The findings provide a rich description on how participants experienced diagnosis. Patients' experiences were both negative and positive whereby their experiences progressed from disbelief and rejection of the diagnosis to ideas of acceptance and recovery. Receiving and living with a diagnosis of an eating disorder has a significant impact on patients which should be considered throughout their assessment and treatment process. The need for compassionate care from professionals was an important component that was highlighted and recommendations were made in this regard. It is argued that increased awareness of patient experience will help clinicians to develop stronger therapeutic alliances and develop new clinical interventions.

Key words: DSM; diagnosis; eating disorders; diagnostic label; recovery.

## CHAPTER 1: LITERATURE REVIEW

“Diagnosis. We have probably all wanted it. We all resist it. All the time we feel, clear and rationale we hate the idea of being ‘labelled’. When suffering and uncertain we want to ‘know’. ‘Why am I like this? What is happening to me? Diagnose me Doc! Then cure me, make me feel better. When you have done that I can go back to my normal life, (my fantasy life?), where all is as I wish it could be.”(Milton, 2012, p. xi).

### 1. THE DSM

#### 1.1. Classification Systems

Biomedical models and psychiatric diagnosis are central to mental health practice and have a dominant role in terms of conceptualising distress and unfamiliar experience (Coles, 2010). Diagnosis has shown to be a common routine during referral and assessment pathway, and it often predicts the possible treatments patients will receive (Coles, 2010; Wykes & Callard, 2010). Furthermore, it has formed the basis for research such as the National Institute of Clinical Excellence (NICE) and designing appropriate services for diagnoses. It has also been embedded within major public services including the criminal justice system and social services whereby people are often treated differently and as a result, fall into the ‘mentally unstable’, ‘mentally ill’ categories (Coles, 2010).

Diagnostic systems such as the *Diagnostic and Statistical Manual of Mental Disorders (DSM)* (5th ed., *DSM–5*; American Psychiatric Association, 2013) and *International Classification of Diseases and Related Health Problems (ICD)* (World Health Organization [WHO], 2015), have become prevalent tools for diagnosing and monitoring psychopathology (Eriksen & Kress, 2006). The DSM and ICD are often considered to be two complementary systems (APA, 2013). The DSM is a handbook that is used by a wide range of healthcare professionals as a guide for diagnosing mental disorders. Such professionals include

psychiatrists, psychologists, counsellors, nurses, social workers and physicians. The DSM is therefore used within a wide range of contexts and by professionals in different orientations such as cognitive, behavioural, psychodynamic and family systems (APA, 2013). The main components within the DSM consist of a set of descriptions, symptoms and other criteria that can be used for diagnosing mental disorders (APA, 2013). The DSM provides professionals with a common language when communicating about their patients as well as establishing consistent diagnoses that can be used in the research of mental disorders (APA, 2013). It also provides researchers with a common language when studying the criteria for potential future revisions and to help in terms of the development of interventions such as the use of medication (APA, 2013).

Similarly, the ICD is also used by a range of professionals including researchers, nurses, physicians, health information managers and coders, and policy makers. The ICD enables professionals to classify diseases and other health problems, and it facilitates the storage and retrieval of diagnostic information for clinical, epidemiological and quality purposes (WHO, 2015). In addition, the ICD provides a basis for monitoring the national mortality and morbidity statistics and it is also used for insurance reimbursement (WHO, 2015). The ICD is important as it provides a common language for reporting and monitoring diseases, allowing professionals across the globe to maintain consistency when sharing and comparing data (WHO, 2015). ICD-10 is currently being revised in order to portray a better reflection of the progress within medical practice and health sciences (WHO, 2015). While the DSM and ICD are considered complementary, having two diagnostic systems however can create confusion. The latest version of DSM-5 in particular received a number of controversial suggestions which ICD-11 could learn from instead of these being repeated (Frances & Nardo, 2013).

### 1.2. *DSM-5 – The Current Edition*

Since 1952, the DSM has continued to undergo revisions because new information about mental disorders has been recorded continually (APA, 2013). The DSM-IV was completed almost two decades ago; the new edition is the DSM-5. The DSM-5 Task Force were in charge of the revision process (Welch, Klassen, Borisova & Clothier, 2013) and the goal was to develop an evidence-based manual to better assist clinicians in making an accurate diagnosis (APA, 2013). It was therefore important to carefully consider the advances in research related to each disorder, together with the combined clinical knowledge of experts in that particular field to better distinguish symptoms and behaviours (APA, 2013). It is hoped that by more accurately defining disorders, diagnosis and clinical care will be improved (APA, 2013).

### 1.3. *DSM-5 Controversies*

A number of controversies emerged regarding the development of DSM-5. Robert Spitzer, Chair of the Task Force of the DSM-III, stated his concerns regarding the openness and transparency of the process (Spitzer, 2008). He reported that Daniel Reiger, Vice Chair of the DSM-5 Task Force, would not provide him with a copy of the minutes relating to the meetings, and argued that the revised DSM was being carried out in secrecy (Spitzer, 2008). He further argued that it would be extremely difficult for Task Force members to refrain from having any discussions with their colleagues and that the exchange of information had been encouraged with previous editions including DSM-III, DSM-III-R, and DSM-IV (Spitzer, 2008). Allen Frances, Chair of the DSM-IV Task Force also stated that the revisions of the DSM-IV were transparent and they felt that it was particularly important to get as many comments as possible, seeking opinions from over 1,000 advisors related to the changes being considered (Frances, 2009). In response, Schatzburg, Scully, Kupfer and Regier (2009) argued that the process of DSM-5 has been open and inclusive. In defending the confidentiality agreements, they argued that they

had participated in open discussions with the DSM-5 Task Force and Work Group and such agreements were developed in order to protect the interest of these volunteers (Schatzburg et al., 2009). They described the process of DSM-5 as 'scientific', and one which implemented the same elements found in the process of DSM-IV. In comparing the two versions, Schatzburg et al., (2009) highlighted that the main difference focused on adjusting what was not working in the DSM-IV for example, exploring better ways of addressing the frequent use of Not Otherwise Specified (NOS) disorders (Schatzburg et al., 2009).

Conflict of interest was a significant issue that arose. Concerns were raised regarding the influence of the pharmaceutical industry in the evolution of the DSMs (Pilecki, Clegg & McKay, 2011). The DSM has become particularly important to drug makers because it is more likely that the medication to treat a disorder will be approved if the disorder is listed in the DSM (Batstra & Frances, 2012). Drug promotion was significant at the time of the revision of DSM-IV, whereby pharmaceutical companies were spending much more money on promoting drugs than they were on research and development (Bastra & Frances, 2012). In addition, concerns were raised regarding relationships between DSM-IV members and pharmaceutical industries (Cosgrove, Krinsky, Vijayaraghavan & Schneider, 2006) which led to the APA implementing a policy regarding disclosure of interests and affiliations to determine possible conflicts of interests.

In considering new clinical practice guidelines, Dr Kupfer reported that the APA planned to tighten these policies even further (Brauser, 2013). Some of these included establishing transparency, managing conflicts of interests and updating guidelines. However, the APA have been criticised for their relationship with pharmaceutical companies, resulting in undue industry influence (Moran, 2008). Further to the APA reporting that 69% of DSM-5 Task Force members had industry relationships, Cosgrove and Krinsky (2012) argued that disclosure policies were not enough and that added specific safeguards were required. Kupfer and Regier (2009) confirmed that the pharmaceutical industry did not contribute funds for the

development of DSM-5, arguing that a majority of the APA revenue received from the industry was used for advertising in journals or newsletters.

For many years, there has been an ongoing debate regarding the validity of a categorical versus a dimensional system of classification of psychopathology (Kraemer, 2007). A number of researchers have reviewed the advantages and disadvantages surrounding both dimensional and categorical approaches (First 2010b; Jones, 2012b; Trull & Durrett 2005; Widiger & Samuel, 2005). The DSM has always offered a categorical approach to diagnosis. That is, the patient can definitely be placed in a 'yes' or 'no' category regarding a specific diagnosis. This can be the preferred approach because it is thought to be the easier one of the two since one diagnostic label can provide clinicians with a significant amount of information, making communication much easier (Frances, First & Pincus, 1995; Trull & Durrett, 2005; Widiger & Samuel, 2005). A categorical approach can determine the presence or absence of a disorder and it assumes that individuals of a diagnostic group are more or less similar and that they display a specific set of symptoms which reflect a particular diagnosis (Jones, 2012b). This framework allows clinicians to assess individuals using a checklist approach which involves meeting a minimum number of symptoms in order to be eligible for a diagnosis (Jones, 2012b). It therefore aides the decisions-making process about whether or not to provide treatment, simplifying the choice of clinical focus and assessing the most appropriate treatment (Trull & Durrett, 2005).

The DSM-IV provided a set of diagnostic criteria with the aim of helping clinicians to make the correct diagnosis and also to differentiate one disorder from others which perhaps have similar characteristics (APA, 2000). However, it became apparent that the DSM-IV did not guide clinicians to making a definitive diagnosis (Widiger & Samuel, 2005). Clinicians therefore expressed concerns regarding the inaccurate and misleading descriptions (Kass, Skodol, Charles, Spitzer & Williams, 1985; Maser, Kaelber & Weise, 1991). In addition, categorical classification has resulted in excessive use of the diagnosis, 'not otherwise specified' (NOS)

which is one of the most common diagnosis made in clinical settings (Jones, 2012b; Widiger & Samuel 2005). This is used when a clinician has determined the presence of a disorder, however the individual does not meet the criteria for a specific disorder (APA, 2000). This raised concerns with regards to diagnostic categories lacking clinical utility (Clark, Watson, & Reynolds, 1995; Jones 2012). This was a major criticism with the DSM-IV classification of eating disorders in that 'Eating Disorder Not Otherwise Specified' (EDNOS) encompassed too many cases and was the most common eating disorder diagnosis given (Fairburn et al., 2007). For example, in a study exploring the severity and status of EDNOS, 4.7% met the criteria for anorexia nervosa (AN), 35.3% for bulimia nervosa (BN), and 60% for EDNOS (Fairburn, et al., 2007). Fairburn and Cooper (2011) argue that patients with a diagnosis of either AN, BN and EDNOS share the same clinical features, with many displaying the over-evaluation of shape and weight characteristics together with similar attitudes and behaviours. There are slight differences between the diagnoses in terms of restriction and bingeing episodes, for example a patients weight might be just above the threshold for them to receive a diagnosis of AN or their binge eating frequency might be too low for them to receive a diagnosis of BN (Fairburn, 2008).

In addressing the high prevalence of EDNOS cases, a number of solutions were proposed for DSM-5 (Fairburn & Bohn, 2004; Walsh & Sysko, 2009). The diagnostic criteria for both AN and BN were considered too strict. It was suggested that the amenorrhea criterion for AN should be removed since most men, post-menopausal women or women using hormone treatments, failed to meet this criterion, which meant that they were then diagnosed with EDNOS (Attia, 2009). In another critique, it was found that some individuals experienced all symptoms except menstrual inactivity. A further suggestion for AN was related to the weight threshold being increased (Watson & Anderson, 2003). For BN, it was suggested that the frequency of binge eating and purging episodes were lowered (Wilson & Sysko, 2009); the

most significant change perhaps proposed was for BED to be recognized as its own eating disorder (Fairburn & Cooper, 2011).

In addition, the broad categories for the diagnosis of eating disorders (BCD-ED) was one of the most radical changes considered as an alternative system for classification and involves grouping patients into 1 of 3 broad categories, and if preferred, into a sub-category (Walsh & Sysko, 2009). This includes, Anorexia Nervosa and Behaviourally Similar Disorders (AN-BSD), Bulimia Nervosa and Behaviourally Similar Disorders (BN-BSD), Binge Eating Disorder and Behaviourally Similar Disorders (BED-BSD); and Eating Disorder Not Otherwise Specified (EDNOS). Within this approach, each category includes a “classic” case together with information about additional presenting symptoms that can also be grouped in that particular category (Walsh & Sysko, 2009). There are a number of advantages with this scheme, most importantly, reducing the number of patients receiving an EDNOS diagnosis which is important in terms of support services and offering patients more specific treatment (Walsh & Sysko, 2009). A further advantage relates to diagnosing people outside of specialist settings where a comprehensive psychiatric assessment may not always be possible (Walsh & Sysko, 2009). Patients can therefore be grouped into a broad category using a limited amount of information, for instance, based on body mass index and general physical conditions. Since the BCD-ED scheme includes sub-groups within the broad categories, it offers more specific diagnostic information (Walsh & Sysko, 2009).

However, there are disadvantages with adopting this scheme including the concern that validity relies on assessment of distress/impairment along with concerns related to possible over diagnosis whereby individuals might receive a diagnosis that is not needed (Sysko & Walsh, 2011). While this scheme works, Fairburn and Cooper (2011) argue that the definitions would become unrecognisable if they are to be expanded too far. Further propositions made included grouping disorders under a more general category, for example “Feeding and Eating Disorders” instead of “Disorders Usually First Diagnosed in Infancy,

Childhood, or Adolescence” and included renaming EDNOS to “Feeding and Eating Conditions Not Elsewhere Classified (FECNEC).

While the new diagnostic categories in DSM-5 can be helpful in reducing clinicians’ reliance on using the NOS diagnosis, it can also result in creating boundary disputes, a further issue with categorical approaches (Widiger & Samuel, 2005). Dissatisfaction and frustration with regards to DSM-IV’s categorical approach led to a call for a paradigm shift in psychiatric diagnosis (Kendler & First, 2010). One of the most innovative proposals for revising the classification for DSM-5 was to supplement or replace diagnostic categories with a dimensional component (First, 2010a; Kendler & First, 2010). A dimensional approach measures more than the presence or absence of a disorder: they can provide clinicians with a greater amount of clinical information (Jones, 2012b). It therefore has the potential to convey a more individualised description of psychopathology which can yield specific treatments plans (Widiger & Samuel, 2005). Dimensional approaches can however be more complex than diagnostic categories because it can be easier to inform clinicians that an individual has a personality disorder for instance as opposed to having to describe him or her in terms of various facets along a continuum (Widiger & Samuel, 2005).

First (2010a) highlighted issues regarding the clinical utility in the revision of the DSM. He noted that previous editions of the DSM which implemented severity dimensions had not been promising. For example, severity dimensions were included in DSM-III-R which consisted of generic ‘mild’, ‘moderate’, ‘severe’, ‘impartial remission’, and ‘full remission’ which were intended for every diagnostic category (First, 2010a). The dimensions were provided for eight categories which included deficit/hyperactivity disorder, conduct disorder, oppositional-defiant disorder, dementia, substance dependence, manic episode, major depressive episode, panic disorder with agoraphobia, and paraphilia. However, because this was not well used by clinicians, the dimensions were eliminated in DSM-IV with the exception of major depressive episode and manic episode (First, 2010a).

Frances (2010d) argued that the DSM-5 Task Force did not have the psychometric expertise for making or testing scales and argued this would waste more time and resources. Other clinicians have argued that implementing a dimensional approach for DSM-5 would result in clinicians taking more time and effort to perform dimensional assessments as a result of clinicians not being familiar with it and thus likely to use it incorrectly or ignore it altogether (First, 2010a; Jones, 2012b; Phillips, 2010b).

The issue of diagnostic inflation was a further issue surrounding the development of DSM-5. Frances and Widiger (2012) argued that the Task Force were instructed to think creatively, and thus came up with a number of suggestions for new diagnoses including hypersexual disorder, binge eating, paraphilic coercive, skin picking, and internet sex addiction. However, the authors argued the issue with such diagnostic expansion would involve redefining a significant amount of people already diagnosed. Furthermore, many of the new diagnoses such as mixed anxiety depression, binge eating, and minor neurocognitive would go from mental disorders that are not currently recognised, to becoming the most common disorders and may result in a false increase of people being diagnosed (Frances & Widiger, 2012).

The issue of diagnostic inflation led to controversies regarding the medicalisation of normality. The British Psychological Society (BPS) highlighted several concerns. In their general comments and with regards to feeding and eating disorders, the Society raised concerns that individuals, including the general public are negatively affected by the medicalisation of responses to people's experiences (BPS, 2011). Importantly, they highlight that such responses are normal and natural and will without a doubt have distressing consequences. Furthermore, by classifying people's responses to problems as 'illnesses' we are missing the relational perspective of their problems, and the social causation (BPS, 2011). As the Society put it, "For psychologists, our well-being and mental health stem from our frameworks of understanding

of the world, frameworks which are themselves the product of the experiences and learning through our lives”(p. 19).

#### 1.4. *DSM-5 changes to eating disorders*

Several revisions were made to the chapter on Feeding and Eating Disorders in order to better characterise the symptoms and behaviours of individuals experiencing these conditions (APA, 2013). The most significant changes were the inclusion of BED as a recognised disorder, revisions to the AN and BN diagnostic criteria and the inclusion of Pica and Rumination disorders.

BED is marked by distress and occurs at least once a week over a period of three months, on average. Typical feelings people will experience include guilt, embarrassment and disgust (APA, 2013). One of the main reasons to include BED as a recognised eating disorder was to increase awareness of the important differences between binge eating and overeating (APA, 2013).

There were also some important changes to the criteria for AN. In criterion A, the word ‘refusal’ has now been deleted with regards to patients maintaining their weight. It was thought that this implied that patients were intentionally trying to maintain low weight (APA, 2013). BN is categorized by regular episodes of binge eating together with purging behaviours such as self-induced vomiting or excessive exercising (APA, 2013). In DSM-5, the criteria has reduced the frequency of these behaviours occurring twice weekly to once a week.

Previous research (Birgegard, Norring & Clinton, 2012; Flament et al., 2015; Nakai, Fukushima, Taniguchi, Nin & Teramukai, 2013; Keel, Brown, Holm-Denoma & Bodell, 2011; Sysko & Walsh, 2011) suggests that DSM-5 does appear to reduce residual eating disorder diagnoses; however, it does not eliminate them. Propositions for ICD-11 suggest that the structure will be similar to DSM-5 but with notable differences, such as including subjective binge eating episodes in BN and BED (WHO, 2015).

Despite improvements, further research for feeding and eating disorders is still required. In considering the current status and future direction of eating disorders, Dr Sysko, argued at the London Eating Disorders Conference that it is still not clear whether the current diagnostic systems are the most clinically useful. She further argued the importance of continuing to evaluate clinicians' practice and to continue to collect data.

#### 1.5. *Advantages of diagnosis*

Since diagnosis has shown to have a significant dominant role within mental health practice, it is particularly important for clinicians to acknowledge the different reactions patients' experience when they receive a diagnosis (Rose & Thornicroft, 2010). However, there is limited literature which explores diagnoses from the patients' perspective (Hayne, 2003; Horn, Johnstone & Brooke, 2007; Pitt, Kilbridge, Welford, Northard, & Morrison, 2009; Rose & Thornicroft, 2010). These studies have identified a number of positive consequences that follow a mental health diagnosis.

Horn et al., (2007) explored patients' experiences of receiving a diagnosis of borderline personality disorder (BPD) and found that several patients experienced relief because the diagnosis gave them an explanation to their behaviour following a long period of not knowing what was wrong with them. Other positive experiences were those which enabled patients to access services. Similar findings were identified in a study which examined the impact of diagnosis among individuals who experienced psychosis (Pitt et al., 2009). The participants recruited were individuals who had received a range of diagnoses including bipolar disorder, schizoaffective disorder, schizophrenia, and personality disorder with some also receiving multiple diagnoses. The findings identified the advantages of diagnosis including naming the problem and having access to services. Similarly, Coles (2010) argued that a diagnosis offers patients an explanation to their symptoms or distress, which can reassure people and put them at ease. In addition, diagnosis can enable communication across mental

health services and outside agencies (Coles, 2010) together with legitimizing distress and discouraging feelings of blame for the patients, friends and family members (Coles, 2010; Eriksen & Kress, 2006). A diagnosis can allow people to access information about their condition, for example, their symptoms and treatment options, and it can also allow people to gain access to services such as self-help groups where people can share experiences with others who have the same condition (Rose & Thornicroft, 2010).

For clinicians, the use of a diagnostic system can be extremely reassuring in terms of knowing that there is a support system in place which guides them, particularly when they are faced with patients who are in significant distress or pose a risk to themselves or others (Fletcher, 2012). Furthermore, the diagnostic system can operate at a more societal level in that it provides patients, clinicians and society with a sense of hope, reassurance and support when they experience distressing issues (Fletcher, 2012).

#### 1.6. *Disadvantages of diagnosis*

While there are advantages to receiving a diagnosis, there are also a number of disadvantages which have been identified. Studies have shown that patients receive limited information during the diagnostic process which Rose and Thornicroft (2010) suggest is perhaps because clinicians expect patients to know about their own condition and about how their clinician conceptualises the condition.

Studies investigating information giving found a considerable number of patients who were not well informed about their diagnosis (Magliano et al., 2008; Read, Haslam, Sayce & Davies, 2006). These studies raise an important question of how clinicians should be communicating a diagnosis to patients. In addition, Rose and Thornicroft (2010) raise an important question of whether patients consider the diagnostic process to be one of simple allocation of a label or whether the process is seen as one of negotiation.

A further disadvantage of diagnosis is that it appears to distort research where there is less focus on psychological research and instead, more focus on biological factors and pathologising individuals (Coles, 2010; Boyle, 2002a). The classification system therefore attempts to understand unusual experiences and distress in terms of bodily dysfunction, thus emphasising a medical diagnosis (Coles, 2010). This may inhibit staff who are working with patients in terms of not looking at their difficult environments or the cause of their experiences (Boyle, 2002a). Also, by categorising people via a classification system, it appears to construct an identity that is driven by individual deficits (Coles, 2010).

Borg, Karlsson and Kim (2009) argue that diagnosis can exclude patients' perspectives. While professionals are trying to embrace the interest and awareness of the patients' problems, a number of challenges remain with regards to practice implications (Borg et al., 2009). The two main issues are in relation to framing the problem and its importance, and labelling which often involves stigmatization (Borg et al., 2009). Previous studies (Horn et al., 2007; Pitt et al., 2009) found that the negative impact of diagnosis was related to patients struggling to make sense of the diagnostic label. Rose and Thornicroft (2010) argue that patients may feel confused when they receive multiple diagnoses or when they experience a change from one diagnosis to another. Horn et al., (2007) found negative experiences of diagnosis were related to patients internalising the stigmatizing and rejecting aspects of the diagnosis, which resulted in patients having a negative view of themselves (Horn et al., 2007).

Borg et al., (2009) argue that when a patient initially presents at a mental health service, his or her problems are formulated between the professional and the patient. The problem however is that the professional's voice does not reflect the personal experience and meaning from the patients' perspective (Borg et al., (2009). While there have been a number of criticisms regarding diagnoses and giving people medical labels, the most fundamental criticism appears to focus on the lack of consideration for people's life circumstances and individual problems and symptoms (Read, 2004). This is in contrast to Larsen's (2004)

argument for the importance of valuing and appreciating the individual when attempting to understand and make sense of their experiences. Resolving the differences between the perspectives of the professionals' and the patients' therefore appears to be the primary challenge in terms of aligning the true problems (Borg et al., 2009).

Previous research has demonstrated that mental health disorders overall are stigmatized, with a number of papers specifically looking at depression, schizophrenia and bipolar disorder (Crisp, Gelder, Rix, Meltzer & Rowlands, 2000; Penn et al., 1994). The stigmatizing opinions about individuals with eating disorders has received increased attention

There is a growing body of research that demonstrates that stigmatising opinions about individuals with eating disorders are also widely held (Crisp, 2005; Crisp et al., 2000; Holliday, Wall, Treasure & Weinman, 2005; Stewart, Keel & Schiavo, 2006). Stigma has been defined by Stewart, Schiavo, Herzog and Franko (2008) as the negative response of the general population towards people grouped by common characteristics. Previous studies (Crisp et al., 2000; Roehrig & McLean, 2010) have explored how beliefs and attitudes about eating disorders compare with other mental health disorders. Crisp et al., (2000) examined the perceptions of a British adult population regarding individuals with various mental illness including eating disorders, severe depression, panic attacks, schizophrenia, dementia, and drug and alcohol addiction. Participants were asked to rate their agreement to eight stigmatizing perceptions of the types of mental disorders, including, 'danger to others', 'unpredictable', 'selves to blame'. The findings indicated that eating disorders were considered less stigmatizing when participants rated opinions such as 'danger to others', 'unpredictable' or 'not improved if treated'. Conversely, eating disorders were more stigmatized with opinions about 'selves to blame' and 'pull self together' when compared with severe depression, panic attacks, schizophrenia and dementia.

A similar study by Stewart et al., (2006) explored the stigmatization of AN by examining participants perceptions about an individual with AN compared with a healthy

person, a person with schizophrenia and a person with asthma. The results from this study found that the evaluations of the personal characteristics for AN were mostly negative, with participants rating opinions such as people with AN 'could pull themselves together if they wanted to' or 'they are to blame for their condition' and 'are acting this way for attention'. In addition, participants believed that factors that contributed to individuals' eating disorder included a lack of social support, parenting, self-discipline, biological factors and poor living habits.

Other studies have focused on beliefs and attitudes among different samples, including general population and undergraduate samples (Crisp, 2005; Wingfield, Kelly, Serdar, Shiviy & Mazzeo, 2010) with other studies using a variety of methods to assess participants beliefs and attitudes including vignettes, questionnaires and surveys (Crisp 2005; Crisp et al., 2000; Mond, Hay, Rogers, Owen & Beumont, 2004; Mond, Robertson-Smith & Vetere, 2006). Other related work has explored the experience of parents'/carers' experience of having a child with an eating disorder (Cotte-Lane, Pistrang & Bryant-Waugh, 2004; Svensson & Nilsson, 2013) however there has been relatively little work that has explicitly examined the experience and consequences of stigma in family members. The different aspects of stigma related to eating disorders identified in studies so far suggest that people hold more negative opinions about eating disorders relative to other mental health disorders and non-mental disorders. Furthermore, that an eating disorder is a self-inflicted problem and under the individual's control, suggesting that the condition is voluntary and people can 'pull themselves together' if they wanted to.

## **2. EATING DISORDERS AND QUALITATIVE RESEARCH**

### *2.1. Psychological therapies for eating disorders*

Eating disorders are a challenge for many clinicians as these patients often require both physical management and effective psychological therapy (Waller, 2009). There has been a considerable amount of progress over the years with regards to the development and evaluation of psychological treatments for eating disorders (Wilson, Grilo & Vitousek, 2007). Cognitive Behavioural Therapy (CBT) has been purposefully refined and adapted to best address eating disorders in therapy, with specifications for BN (CBT-BN), AN (CBT-AN) and (CBT-BED) (NICE, 2004). When clinicians are presented with ENDOS, it is recommended that they follow the treatment that best reflects the individual's eating disorder (NICE, 2004).

The theory of CBT-BN proposes that the patient's over evaluation of shape and weight is central to the maintenance of their disorder, that is, the "core psychopathology" (Cooper & Fairburn, 2011). Many of the other features including dietary restraint and restriction, weight-control behaviour, body checking, avoidance and the preoccupation with thoughts about shape, weight and eating emerge directly from this psychopathology (Fairburn, Cooper & Shafran, 2003). Binge eating is the only feature of BN that is not a direct manifestation of the core psychopathology and, as the theory suggests, binge eating is instead considered to be a form of dietary restraint (Cooper & Fairburn, 2011).

Patients with BN are characterised by their highly demanding and specific dietary rules. Patients will often binge eat when they experience an adverse event or mood related changes because the binging temporarily improves their negative states, therefore acting as a distraction from other difficulties (Fairburn et al., 2003). The distraction compromises dietary rules, and are viewed as evidence of a lack of self-control (Cooper & Fairburn, 2011). Patients subsequently respond in over-compensatory ways to purge their consumption (Wilson, Fairburn, Agras, Walsh & Kraemer, 2002). The cycle of binge eating and over-compensation

maintains the core psychopathology as it increases patients' concerns about their ability to control their eating, shape and weight (Cooper & Fairburn, 2011). The treatment involves a range of different cognitive behavioural procedures which consist of a specific set of tasks and experiments. The treatment is outpatient-based and involves 15-20 sessions over a period of five months.

However, despite CBT-BN being the recommended evidence-based treatment Fairburn, Cooper and Shafran (2003) examined several explanations for why patients' conditions did not improve and concluded that the existing theory needed to be extended to address further maintaining mechanisms of the eating disorder within specific sub-groups of patients. These processes include clinical perfectionism, mood intolerance, core low self-esteem and interpersonal difficulties. Both theory and treatment have therefore developed since so that it can be used for all other eating disorder diagnoses, therefore making it transdiagnostic in its scope (Cooper & Fairburn, 2011).

The latest treatment is referred to as Enhanced Cognitive Behavioural Treatment (CBT-E) which addresses the processes that interact with and maintain the eating disorder psychopathology (Fairburn et al., 2008). CBT-E treatment involves 20 sessions of individual therapy and consists of several stages which each have a different aim related to engaging the patient in treatment and change, the transitional stage, addressing the maintaining mechanisms and monitoring progress in treatment and minimising the risk of relapse (for the detailed practice of CBT-E see Fairburn, 2008).

A further leading evidence-based treatment most commonly used with eating disorders is Interpersonal Psychotherapy (IPT) (NICE, 2004). IPT for BN (IPT-BN) was derived from IPT for depression (Klerman, Weissman, Rounsaville, & Chevron, 1984) and was later revised to reflect IPT for all other eating disorders (IPT-ED). Many eating disorder patients experience interpersonal difficulties and this is often a core component of therapy because they can often lead to the development and maintenance of the eating disorder (Hartmann,

Zeeck & Barrett, 2010). In addition, interpersonal difficulties may even develop as a result of the eating disorder itself (Hartmann et al., 2010; Murphy, Straebler, Basden, Cooper & Fairburn, 2012). Murphy et al., (2012) suggest that patients have a limited experience developing and maintaining intimate relationships which is often a result of social withdrawal and low self-esteem. The primary emphasis within IPT is to help patients identify and modify their interpersonal difficulties that appear to be maintaining their eating disorder (Wilson et al., 2007). IPT involves 16-20 sessions over a period of four to five months.

The treatment has three phases which encompasses five main problem areas. Agras et al., (2000) outlined each of the three phases within IPT treatment summarised as follows. The first phase involves a detailed exploration of the patients' interpersonal difficulties in which the eating disorder developed and has subsequently been maintained. This leads to the development of a formulation in phase two which focuses on the presenting problem areas, whereby the therapist encourages the patient to make changes to the identified areas. The final stage is focused on the progress the patient has made throughout the therapy and preparing the patient for potential future interpersonal difficulties and exploring ways of managing these. The five main problem areas include lack of intimacy and interpersonal deficits, interpersonal role disputes, role transitions, grief and life goals which each include a set of aims, strategies and procedures (Murphy et al., 2012).

Focal psychodynamic therapy is the recommended treatment for individuals with AN (NICE, 2004) with some evidence demonstrating its effectiveness in outpatient settings (Dare, Eisler, Russell, Treasure & Dodge, 2001; Zipfel et al., 2014). This treatment is a form of time-limited psychoanalytic therapy in which the therapist adopts a non-direct stance and does not give the patient advice in relation to their eating difficulties or managing their symptoms in three phases (Dare et al., 2001). First, the conscious and unconscious meanings of the patients' symptoms are explored in relation to the patients' history and in particular their family history, exploring whether there were any unresolved conflicts that had arisen in

childhood (Dare et al., 2001). Second, the therapist explores the impact that the patients' symptoms have on their current relationships. Third, the therapist will explore how these influences are then manifested in the patient-therapist relationship, thereby focusing on the transference and countertransference.

Family-based treatment (FBT) is the most widely form of treatment, showing promising outcomes for adolescents with AN (Eisler et al., 2000; Loeb et al., 2007; Murray & Le Grange, 2014; Paulson-Karlsson, Engstrom & Nevenon, 2009). The most well-known family therapy is the Maudsley Model, also referred to as Family-Based Treatment for Anorexia Nervosa (Dare & Eisler, 1997; Lock & Le Grange, 2005). The treatment was first developed at the Maudsley Hospital and encompasses elements of early family therapy techniques, specifically aimed at adolescents with AN (Lock & Le Grange, 2005). This is a highly practical and intensive outpatient approach which utilises the family to help improve eating and re-nourish the adolescent (Couturie, Isserlin & Lock, 2010). The therapist seeks to understand the way the family functions as a whole, thereby having the opportunity to intervene and modify difficulties within the family that appear to be making refeeding more difficult (Le Grange, Eisler, Dare & Russell, 1992; Lock & Le Grange, 2005).

There are three phases within FBT and the family will attend between 15-20 sessions over a 12 month period. Phase one focuses on weight restoration whereby the therapist addresses the negative consequences of starvation (Lock & Le Grange, 2005). This phase includes a family meal where the family and therapist can identify problem areas together, for example anger, blame or avoidance during mealtimes (Lock & Le Grange, 2005). This can therefore be useful in helping the family to think about the impact of the eating disorder, encouraging them to understand each other's experiences. Phase two of treatment focuses on returning the control over food and eating to the adolescent. Both therapist and parent pay close attention to the choices of the adolescent, encouraging personal autonomy (Murray, Wallis & Rhodes, 2012). Phase three involves establishing a healthy adolescent

identity and this phase will only begin once self-starvation has stopped and the adolescent is able to maintain a healthy weight on his or her own (Lock & Le Grange, 2005). In this phase, the treatment begins to shift from the impact of AN to establishing a healthy identity.

## 2.2. *Patients' perceptions on their disorders and on treatment*

Several qualitative studies have examined patients' experiences of living with an eating disorder (Broussard, 2005; Button & Warren, 2001; Fox, Lark, & Leung, 2010; Nordbo, Espeset, Gulliksen, Skarderud, & Holte, 2006; Reid, Burr, Williams, & Hammersley, 2008) which involved positive and negative experiences. Fox et al., (2010) found that patients described their eating disorder as a distraction which helped them to cope when they experienced other difficulties and as a result, the eating disorder provided them with a feeling of comfort. Loss of control has been identified as a negative commonality patients experience in relation to their self-image and difficulties in relationships; thus, focusing on weight provides patients with the feeling of being in control (Button & Warren, 2001). In addition to being in control, the eating disorder has found to provide patients with a sense of stability, security, self-confidence and the experience of positive feelings in relation to a new identity (Nordbo et al., 2006).

However, this can lead to patients developing a fear of living without the eating disorder (Broussard, 2005; Fox et al., 2010) and patients can experience ambivalence about whether the eating disorder is a way of exerting control or whether it is a disorder that controls them (Reid et al., 2008). Furthermore, Broussard (2005) explored patients' experiences of bulimia and found negative meanings in relation to patients' fear of being negatively judged by others because they interpreted binge eating and self-induced vomiting as abnormal. Similarly, in a study exploring compulsive overeaters, Lyons (1998) found that common negative emotional consequences of overeating included shame, guilt, denial and blame. The findings also identified patients' perceived loss of control with their eating with

some patients eating significant amounts of food without even realising, and others reported a need to eat everything (Lyons, 1998).

Given that patients use eating disorders to regain their sense of control, stability and security, the care and treatment of patients with eating disorders can be complex, and can also involve a number of different professionals and treatment experiences (Newton, 2001). Patients' views on the interventions and services they receive are therefore likely to have an influence on key aspects including the patient-clinician relationship, treatment satisfaction and overall outcomes (Swain-Cambell, Surgenor, & Snell, 2001). Previous studies exploring patients' views on eating disorder services have found that interventions that focus solely on weight gain and other medical interventions are often viewed negatively by patients (Bell, 2003; De La Rie, Noordenbos, Donker, & Van Furth, 2006, Newton, Robinson, & Hartley 1993).

Instead, findings suggest that a holistic approach, addressing related issues increase patients' treatment satisfaction and improve recovery (De La Rie, et al., 2006; Pettersen & Rosenvinge, 2002). Pettersen and Rosenvinge (2002) aimed to understand improvement and recovery from the patients' perspective. Forty eight women were recruited from patient organisations and a university eating disorder unit. Participants included those who were a minimum age of 18 years, had their eating disorder for three years and had received treatment for their eating disorder. All patients were invited to take part in completing a standard questionnaire and a qualitative open interview which was audio recorded and transcribed. Pettersen and Rosenvinge (2002) found that factors which patients considered important included a desire to change, receiving professional treatment, nonprofessional care and having important people in their lives. Patients further stressed the importance of acceptance of oneself, interpersonal relationships, problem solving and body satisfaction.

Other beneficial components of treatment refer to patients receiving support from professionals who have expert eating disorder knowledge, together with developing a positive

therapeutic relationship (Bell, 2003; Clinton, Bjorck, Sohlberg & Norring, 2004; De La Rie, et al., 2006; Pettersen & Rosenvinge, 2002; Rosenvinge & Klusmeier, 2000; Timulak et al., 2013). De La Rie, et al., (2006) investigated how patients evaluate their eating disorder treatment. Participants included 44 AN, 43 BN, 69 EDNOS and 148 former ED patients who were recruited from a large community in the Netherlands. Two questionnaires were administered to participants including the Eating Disorder Examination Questionnaire (EDQ) and a further questionnaire focusing on treatment history and the evaluation of treatment from the patients' perspective. The results showed that patients found treatment in specialised ED centres, self-help groups and treatment with a partner most helpful. Other beneficial components involved the communication skills from the professional, the therapist-patient relationship, contact with peers and the importance of treatment focusing on underlying issues in addition to ED symptoms.

In addition, support from friends, relatives and co-patients is another helpful aspect patients identified in their treatment (Bell, 2003; De La Rie, et al., 2006; Pettersen & Rosenvinge, 2002; Timulak et al., 2013).

Existing literature highlights the importance of patients being able to actively participate in their own treatment which may increase both patient satisfaction and therapeutic success (Bell, 2003; Clinton et al., 2010; Offord, Turner & Cooper, 2006; Timulak et al., 2013). Offord, Turner and Cooper (2006) conducted a qualitative study to explore patients' views of treatment and discharge. Seven young adults who had received treatment for AN in general adolescent psychiatric units agreed to participate in the study. All participants were interviewed using a semi-structured interview schedule. Transcribed interviews were qualitatively analysed using the principles of Interpretative Phenomenological Analysis. For several participants, successful in-patient treatment was a result of collaboration in their own care such as deciding on their own goals, making decisions and feeling listened to. Participants also described a strong sense of empowerment when they were involved in their own

treatment. For example, those who had received psychological therapy identified client-led approaches as extremely helpful (Offord et al., (2006).

Helpful therapeutic approaches and interventions identified in previous studies include individual psychotherapy and group therapy; patients tend to find family therapy less helpful (Bell, 2003; Escobar-Koch et al., 2010; Rosenvinge & Klusmeier, 2000). Some studies have identified self-help groups as being helpful to patients (Bell, 2003; De La Rie et al., 2006; Rosenvinge & Klusmeier, 2000). In contrast, Escobar-Koch et al., (2010) explored patients' views of eating disorder services and compared patients' perspectives from the United States and the United Kingdom. One hundred and forty four US patients and one hundred and fifty UK patients took part in the study and they were required to complete a questionnaire and the data was later analysed using a content analysis. Escobar-Koch et al., (2010) found that self-help groups were not valued highly with 2.2% of US responses and 2.8% of UK responses, and suggest that such discrepancies may be a result of the difference in samples. For example, only 2% of US and 15.3% of UK patients reported being members of the National Eating Disorders Association (EDA), whereas Newton et al., (1993) found that those who rated self-help groups as being helpful, were all members of the EDA.

Other studies have found that patients' negative experiences were largely associated with a lack of care, feeling neglected and being treated as the disorder rather than an individual (Button & Warren, 2001; Colton & Pistrang, 2004; Offord, Turner & Cooper, 2006). Colton and Pistrang (2004) explored adolescents' experiences of inpatient treatment of AN. Nineteen participants were recruited from two inpatient units and semi-structured interviews were conducted and analysed using interpretative phenomenological analysis. The results indicated that participants' negative views were associated with being treated as 'just another anorexic' rather than an individual which they experienced as unhelpful. In addition, participants described being 'treated' and felt that they did not have a choice in their treatment (Colton & Pistrang, 2004).

While there has been a strong interest in the satisfaction and dissatisfaction of treatment, there remains a lack of research which solely investigates the characteristics of the therapists. In considering this, Gulliksen et al., (2012) conducted an in-depth systemic study which explored AN patients perspectives' in relation to which therapist characteristics they preferred. Thirty eight women, aged 18-51 were recruited from five clinical institutions in Norway. All participants were interviewed using a phenomenological design and interviews were tape recorded and transcribed. Patients identified four factors they associated with therapist satisfaction including acceptance, vitality, challenge and expertise. Gulliksen et al., (2012) highlighted the importance of clinicians therefore being able to work with complex behaviours throughout treatment. The findings from this study are consistent with previous research (Offord, Turner & Cooper, 2006).

### **3. RATIONALE FOR THE PRESENT RESEARCH**

The DSM continues to be the main classification system of mental disorders that is used, with its intention of being applicable to a range of services and professionals. The launch of DSM-5 however, resulted in much debate and criticism among existing mental health professionals, even before it was published. The most significant criticism to these changes has been focused around the understanding of mental disorders, the clinical reality and how such disorders are thought about. In response to the launch of the new DSM-5, the BPS expressed concerns around the risk of the DSM-5 leading to pathologizing individuals and obscuring social and relationship factors (BPS, 2012). A significant concern raised has specifically been with regards to lowering the diagnostic thresholds across all disorders as there were concerns around this resulting in medical explanations as opposed to individual experiences (BPS, 2012).

The classification of eating disorders in particular and recent changes have too been largely criticised for its emphasis on the two main eating disorders, AN and BN despite the most common diagnosis being EDNOS. Similarly, Fairburn (2011) proposed for the

diagnostic criteria to be relaxed. With the criteria for AN and BN being so strict, people receive the EDNOS diagnosis as they do not quite meet the criteria. Given this context and controversy regarding diagnosis and debate around rejecting medical diagnoses, it is worthwhile to hear what patients think and their experience of being diagnosed. This qualitative study will give patients the opportunity to talk in depth about their experiences of receiving a diagnosis. For clinicians working in the field, the research will increase both understanding and knowledge in this area in order for them to work more effectively with eating disorder patients. This is fundamental throughout the assessment and treatment process as it will give further insight into what people experience first-hand as opposed to solely relying on diagnostic criteria, which as the literature suggests, does not always reflect the clinical reality. As a result, further implications for clinical practice and areas for further research can be identified.

#### **4. RESEARCH AIM**

The aim of the current research is to explore patients' experiences of receiving a diagnosis of an eating disorder.

## **CHAPTER 2: METHODOLOGY**

### **1. INTRODUCTION TO THE METHODOLOGY**

This chapter outlines the methodology which is structured as follows: in the first section, I will provide a brief overview of a qualitative research paradigm, paying close attention to some of the important characteristics. In the second section, I will discuss my epistemological position that supports the approach that I have chosen. Here, I introduce the importance of reflexivity in qualitative research. In the third section, I provide a rationale for my choice of method and in the last section, I outline my sample, ethical considerations and the procedures for data collection and analysis.

### **2. A QUALITATIVE RESEARCH PARADIGM**

Qualitative research has become particularly influential to the field of social sciences in recent years (Mcleod, 2001). The primary aim within qualitative research is to understand and interpret people's experiences as they encounter them (Elliot, Fischer & Rennie, 1999). For researchers, the aim is to understand what their participants' experiences are like first-hand; researchers are interested in how participants make sense of their experiences, what this means, what this feels like, the language they might use, together with the implication and consequences of their experiences for themselves and others (Willig, 2012). Qualitative researchers attempt to gather rich data including in-depth interviews and focus groups (Howitt, 2010) and explore small, yet in-depth amounts of data, for example eight to ten semi-structured interviews or individual cases (Landridge, 2007). There are several approaches to qualitative research including, phenomenology, narrative analysis, discourse analysis, grounded theory, ethnography, conversation analysis and social action research. While all of these approaches have established their own traditions of rigour and communication, they share the same purpose which is to contribute to a process of

developing understanding rather than to draw conclusions (Elliot et al., 1999). There are several common features of qualitative research which are important to highlight.

Willig (2012) argues that if possible, qualitative researchers should try to collect their data where the experience actually took place as they are concerned with the real-life context; however, this is not always possible for ethical and practical reasons, resulting in much qualitative data taking the form of transcripts of interviews after the event.

Qualitative research views meaning in context thus the researcher is interested in the individual participants' experience within a particular context (Willig, 2012).

Reflexivity has become a primary focus within the qualitative tradition and is considered an integral aspect, especially to researchers (Finlay & Gough, 2003). There are two types of reflexivity. First, personal reflexivity which encompasses the researchers' subjective thoughts and feelings experienced during the research together with positioning the researcher and their knowledge-making practices within relevant contexts (Finlay & Gough, 2003). Second, methodological reflexivity, which involves reflecting on the research question, the design of the study, the method of analysis, the data and findings. For example, how the research question has defined and limited the findings or how the research question could be explored differently reflect methodological reflexivity. Such questions encourage the researcher to reflect on the assumptions they have made throughout the research process, as well as encourages them to consider the implications for their findings (Willig, 2013).

In practise, the researcher should try to 'bracket' their own assumptions throughout the research process in an attempt to achieve phenomenological reduction (Mcleod, 2001). The challenge for qualitative researchers is to allow the things they experience into their consciousness as if this were the first time they were experiencing it (Landridge, 2007).

### **3. PHENOMENOLOGY**

#### *3.1. Husserl's (descriptive) versus Heidegger's (interpretative) phenomenology*

Phenomenology is located within the traditions of two of the most influential philosophers, Edmond Husserl (descriptive) and Martin Heidegger (interpretative). While the work of these major philosophers is far too extensive for the purpose of this thesis, I would like to describe some of their key ideas and developments in phenomenology.

Husserl (1927) was the founder of phenomenology and was interested in the description of peoples' experience as a way of accessing the content of their consciousness. Husserl used the term 'intentionality', a philosophical concept to describe the process of being conscious of something, such as our thoughts, perceptions, decisions or recollections. For example, when we think, we think about something. As Smith et al., (2012) state, "that something – the object of which we are conscious – may have been stimulated by a perception of a 'real' object in the world, or through the act of memory or imagination" (p. 13).

Husserl used the term 'natural attitude' to describe the assumptions we use to understand our everyday experience (Mcleod, 2001). For Husserl, phenomenology strives to go further than a 'natural attitude' by accepting a 'transcendental attitude'. For example, the phenomenologist shifts their focus from the object, towards their perception of that object, thus adopting a much more reflexive stance (Smith et al., 2012). Consequently, Husserl developed a 'phenomenological method' and his main concept was 'bracketing', also referred to as 'epoche', which in essence, means to suspend our knowledge about the phenomenon under investigation (Giorgi, 1992). Husserl was interested in finding the essence of the individuals' subjective experience and in order to achieve this, he proposed a series of 'reductions' which he termed 'edietic reduction' and 'transcendental reduction'. The 'edietic reduction' involves a technique which Husserl termed 'free imaginative variation' where one carefully examines the essential features of the experience (Smith et al., 2009). The aim of the

'transcendental reduction' is to establish the content of the individuals' conscious experience which is achieved by focusing on and describing the experience and its specific features (Smith et al., 2009).

Heidegger was another key figure in philosophy and well-known for his work, *Being and Time* in which his main interest was ontology, the science of being (Heidegger, 1962). Heidegger was a student of Husserl's and his main philosophy centred on phenomenology and hermeneutics, the theory of interpretation, two concepts which he suggested should be considered integral to our way of knowing about existence (Mcleod, 2001). For Heidegger, the person is always a worldly 'person in context'. Heidegger used the term 'intersubjectivity' to describe a phenomenological concept which refers to the shared and relational nature of our being-in-the-world which attempts to describe the relatedness and explain how we communicate and make sense of one another other (Smith et al., 2012). For Heidegger, hermeneutics goes beyond description of the individuals' experience and attempts to seek meaning and interpret their experience that may not be immediately obvious to the person (Willig, 2012). The researcher makes an interpretation of what the participant's experience is like for them, how they make sense of something, making use of their clinical interpretative skills and giving deeper meaning to the narratives.

#### **4. EPISTEMOLOGICAL POSITION**

Epistemological positions are characterized by a set of assumptions about knowledge and knowing that provide answers to the question "What and how can we know?" (Willig, 2012, p.9-10). There are three broad approaches which include realist knowledge, phenomenological knowledge, and constructionist knowledge. For this research, the type of knowledge I have aimed to produce is interpretative phenomenological whereby my aim is to capture my participants' thoughts, feelings and perceptions, that is, their subjective experiences. I am therefore not making any claims with regards to the accuracy of their

accounts. In this research, I am interested in what it is like to receive a diagnosis of an eating disorder; it is the knowledge of the quality and texture of my participants' experiences that I am interested in which make it phenomenological knowledge (Willig, 2012).

As previously discussed, while phenomenological knowledge aims to increase the researchers understanding of an individual's experience, there are two varieties including descriptive phenomenology and interpretative phenomenology. The position adopted for this research is the latter as I aspire to attribute meaning to my participants' experiences. In addition, I am interested in stepping outside their accounts, and reflecting and interpreting the wider meanings (Larkin, Watts, & Clifton, 2006). Furthermore, the assumptions I am making about the social and psychological world(s) that I am studying are experientially diverse.

On a methodological level, the initial process will be very similar to that of a descriptive phenomenologist. Like a descriptive phenomenologist, I will conduct semi-structured interviews and produce descriptions of the participant's experience with the aim of understanding what that experience was like for them. A number of papers have outlined the analytic steps within the IPA process (e.g. Osborn & Smith, 1998; Smith et al., 2007). The interpretative phenomenologist however aspires to give meaning to the account and go deeper (Smith, Flowers & Larkin, 2007). Through the hermeneutic circle of giving meaning, the researcher is closely involved in making sense of one's story (Willig, 2012).

## **5. PERSONAL REFLEXIVITY**

In acknowledging that reflexivity is an important part of qualitative research, Landridge (2007) highlighted a series of questions to encourage a reflexive approach to the research. In considering these questions, this section will focus on personal reflexivity. I will discuss epistemological reflexivity towards the end of the chapter. At the initial stage of the research, it was important for me to understand why I was carrying out the research and what I hoped to achieve from it. As part of my doctorate in Counselling Psychology, I was required

to undertake a novel empirical piece of research which forms part of a portfolio. Since the research project is a fundamental part to the doctorate, it was important for me to think carefully about what I wanted to explore. As previously stated, I have always had an interest in eating disorders and as a counselling psychologist working in different settings, I often encountered different diagnoses, particularly within the NHS. This encouraged me to think more about my own position and relationship with diagnosis and importantly how patients themselves experience diagnosis. Throughout the initial stages of my training for instance, I experienced conflict in terms of whether I align myself within a more relational or medical position which I think can be influenced within particular settings. For example within a more clinical setting, there is a specific type of language that it used including words such as 'symptoms', 'diagnosis' or 'treatment'. I therefore agree with Larsson et al., (2012) who state that 'the way we speak of things not only reveals, but also influences, the underlying assumptions on which the profession rests' (p.63). As a Counselling Psychologist I feel that is important to work from the assumption whereby I am not pathologising which one might question as we do work within a medical framework. However, I continue to work from this assumption and for me, it is important that I work with the individual person and what they choose to bring to therapy instead of focusing on the diagnosis, categorising or labelling the person. Furthermore, it is important and positive that I consider myself as a science-practitioner which combines humanistic qualities and evidence-based scientific practice.

Landridge (2007) argued that reflexivity becomes more important when the researcher is interested in studying vulnerable populations and when they have not experienced the phenomenon under investigation themselves. He further argued that this may lead to misinterpreting and instead constructing a topic that reflects the researchers own position as an outsider. In acknowledging my relationship to the topic being investigated, I was therefore mindful of my friend who had suffered with AN and what this experience was like together with my theoretical knowledge and clinical experience of eating disorders which has

contributed to my interest in the research. It was important for me to 'bracket' my own beliefs and assumptions and try to adopt a more phenomenological way of thinking. I considered how participants might potentially view me as an insider and outsider. On the one hand, I am interested in eating disorders and I want to hear about their experiences and I am taking the time to do this, thus I may be viewed as an insider. On the other hand, I would be able to empathise with my participants but only to a certain degree as I have not received a diagnosis of an eating disorder myself.

It was also important for me to think about who I am and how I might influence the research I am conducting. I considered my age of 29 and that participants might see me as being less experienced or may not feel comfortable talking with a younger person. In contrast, younger participants or those of a similar age might feel more comfortable with me; however this might pose the issue of the interview being viewed as a therapeutic session. While this is an unavoidable issue, I ensured that I remained professional throughout the research process and ensured that I informed participants of the form the interview would take. I considered my sex and that participants may have experienced issues with either sex and therefore feel less comfortable with me interviewing them which may result in not obtaining enough data.

In considering the personal and cultural contexts in which I am embedded and the impact this may have on my role as the researcher, I feel it is necessary to mention culture. I have knowledge and understanding of the socio-political influences such as immigration, minority status and class which led me to thinking about potentially interviewing Asian participants. Due to my mixed English and Indian background, I have considered both the advantages and the disadvantages related to interviewing Asian participants. I am able to relate to and communicate with those who are from the same ethnic background, which participants might feel more comfortable with. However, I was also aware of how this might hinder the interviews as it is common in some ethnic groups to feel ashamed or embarrassed about disclosing personal issues/experiences to someone from the same ethnic group.

## **6. METHODOLOGICAL REFLEXIVITY**

As indicated earlier, the notion of reflexivity is important in qualitative research as it encourages the researcher to think carefully about how they may shape and impact the data. In addition, it is equally important for the researcher to consider themselves as a theorist/thinker, and to consider the epistemological reflexivity (Willig, 2013). In this section, I will discuss my relationship with the data.

My initial research proposal aimed to better understand participants' experiences of the maintenance factors in eating disorders. However, I recognised that my scope was too broad. Since then, my ideas have evolved and I have narrowed my scope to focus my research on how a diagnosis impacts people with eating disorders. Prior to the recruitment process, I felt that the word 'impact' immediately made the assumption that there was an impact which would potentially bias participants towards fulfilling that expectation. Furthermore, I felt this would have limited my findings and I therefore changed this to 'Patients' experience of receiving a diagnosis of an eating disorder' This was appropriate for what I was hoping to achieve which was to gain further insight and a better understanding of my participants' experiences.

I took time to prepare questions when constructing a schedule for the semi-structured interview. I intentionally chose open rather than closed questions when phrasing my questions which were descriptive, narrative, structural, evaluative and circular. I made use of prompts and probes where necessary. I discussed the list of questions with my research supervisor which was useful for putting the questions in the most suitable sequence and choosing those which would ultimately answer my research question.

I began collecting data in November 2013 which took approximately 5 months. During the data collection process, I kept a reflexive diary where I made notes about my own thoughts and feelings, my experience of the interviews and my relationship with the participants as well as the data. Although I was able to remember each individual interview, I

found keeping the diary useful as it encouraged me to think about my own experience and response to my participants' experiences.

I was able to establish a good rapport with all of my participants which was particularly important at the beginning of the interviews (Smith et al., 2009). I did this by taking time to explain the process of the interview and ensuring they felt comfortable before I started recording. I noticed that it was also important for me to feel comfortable before conducting the interview.

During the interview, I noticed that I tended to intervene far too quickly, leaving me feeling somewhat anxious. Once I had conducted the first two interviews, I met with my research supervisor and reflected on my difficulty with the dual role of being a trainee counselling psychologist and a researcher. Particularly from the first interview, I was very aware of my struggle when probing the participant to go deeper with their response. There were potential moments where I found myself stepping into the therapist role. This also encouraged me to think about my responses to the participants' experiences and the importance of maintaining a neutral stance which was challenging as there were moments where I felt moved by what my participants were saying, and I may have shown an emotional reaction. It was therefore important to remind myself that the interviews were not taking the form of a therapeutic session. There appeared to be a fine line between making use of my clinical skills and maintaining my position as the researcher. It was helpful for me to reflect on this and have this discussion with my supervisor at the earliest stage. It was important for me to find a comfortable 'research persona' for myself whereby I put aside certain habits such as sharing experience and knowledge, exercising my clinical skills or guiding participants towards specific aspects of their experience which may then influence my data and subsequently my analysis (Smith et al., 2009).

I was also aware that I was conducting the interviews at NHS sites where all participants had received their diagnoses. In addition, I had established a professional

relationship with some of the clinicians in the team who may have delivered the diagnoses. In this respect, I might have been viewed as an outsider.

When re-reading the transcripts, I experienced a range of emotions in response to my participants' experiences including, shock, disappointment, empathy. Overall, the interviews allowed me to enter the world of my participants and provided me with a detailed understanding of their experiences. Importantly the participants themselves expressed feeling comfortable with the schedule of the interview and the questions they were asked.

## **7. RESEARCH DESIGN**

A qualitative design, using the principles of IPA, was adopted. This approach was chosen as it explores how people make sense of real-life experiences, an integral aspect of IPA. Semi-structured interviews were employed with all ten participants, which were audio recorded and transcribed verbatim. The data were analysed using IPA analysis in order to produce a rich and detailed account of the participants' experiences.

## **8. METHODOLOGICAL CONSIDERATIONS**

In acknowledging that there are no 'right' or 'wrong' methods, I chose to employ a qualitative design as it is more appropriate to my research question than a quantitative design (Willig, 2013). Once I had formulated my research question, it was important for me to think carefully about the data collection technique and method of data analysis as all three are dependent on one another (Willig, 2013). To achieve the aim of my research, the use of audio recordings of semi-structured interviews was the preferred method of data collection. This provided me with information about what the experience of receiving a diagnosis is for participants; the semi-structured interviews produced data that I could then analyse using an interpretative phenomenological analysis (IPA).

IPA is an increasingly developing approach to qualitative inquiry and it precedes through a series of stages which will be outlined in detail at the end of the chapter. IPA involves an in-depth and detailed examination of a persons' subjective experience in a way which enables one to get as close as possible to that experience and this is what makes it phenomenological and relates to Husserl and Heidegger's main ideas that were introduced earlier (Smith et al., 2009). In particular, IPA has been influenced by Heidegger's (1927) concept of the hermeneutic circle which describes the relationship between the part and the whole. For example, Smith et al., (2009) argue that "the meaning of a word only becomes clear when seen in the context of the whole sentence" (p.28). The IPA process itself involves moving back and forth through the data, thus the hermeneutic circle is useful in terms of the researcher thinking about the meaning of the text and relationship with the data (Smith et al., (2009).

I was aware that qualitative research could be analysed by several different methodologies which were considered in addition to IPA. Grounded Theory is also compatible with a semi-structured interview technique. It is a methodology that originated in sociology and was developed by Glaser and Strauss (1967). Its aim is to develop a theory from the data and this theory is 'grounded' from the data of participants who have experienced the phenomenon under investigation (Petty, Thompson & Stew, 2012). Similar to other qualitative methodologies, the data from a grounded theory approach can emerge from different sources including interviews, observations and video tapes. Corbin and Strauss (1990) suggested that grounded theory involves several stages. The primary step in grounded theory is coding and there are three types of coding, open coding, axial coding and selective coding. During open coding, the researcher will start to break the data down analytically, helping to gain new insights into the data. Axial coding involves the process of relating categories to one another and selective coding is where all of the categories are combined around a central category. This process is facilitated by a method known as constant comparison which involves

comparing the similarities and differences that emerge within the data (Petty et al., 2012). Although grounded theory has become a popular methodology within qualitative research, the primary limitation would undermine the data. Grounded theory's concern with identifying social pressures appears to limit its appropriateness to phenomenological research questions (Willig, 2013). While grounded theory has been adopted as a qualitative research method in more recent years, Willig (2013) suggests that when it is applied to questions which focus on participants' experiences rather than uncovering social pressures, it results in a technique for systemic categorisation. In other words, once the researcher has transcribed the interviews and coded the transcripts using the principles of grounded theory, this results in a map of categories that are used by the participants. While the researcher may be able to gain a better understanding of participants' experiences from this, it functions at a descriptive level rather than explanatory. In considering the suitability for psychological research, Willig (2013) argues that research questions that are concerned with nature of experience are more appropriately addressed using a phenomenological method.

Thematic analysis was another methodology considered, a process whereby the researcher identifies and analyses themes that emerge from the data (Braun & Clarke, 2006). While this methodology has been widely used in qualitative research, there is no consensus in relation to how the method should be carried out with a number of papers offering different examples of a thematic analysis (e.g. Attride-Stirling, 2001; Braun & Clarke, 2006; Howitt, 2010; Joffe, 2012). Braun and Clarke, for example, suggest six phases to a thematic analysis which involve familiarising oneself with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report itself. The variety of choices for conducting a thematic analysis does not provide the researcher with a clear theoretical basis for their research which means that they have to do a lot of work before they can even start the actual research (Willig, 2013). Furthermore, Braun and Clarke (2006) state that "it is relatively easy to conduct a good thematic analysis on qualitative data, even

when you are still learning qualitative techniques” (p 94). This may result in the researcher conducting the analysis without locating it theoretically and epistemologically (Willig, 2013). In comparison to other qualitative methods such as grounded theory and narrative analysis, thematic analysis has been considered a poor method because it has not previously been acknowledged as a ‘named’ analysis (Braun & Clarke, 2006) and has only recently been identified as a recognised method (Joff, 2012).

Finally, narrative analysis was a further methodology considered for the present research. Narrative psychologists argue that people can create and re-create themselves through the stories they tell (Crossley, 2000). Similar to other methodologies, a variety of sources can be used to collect data, including interviews, observations, photographs, diaries and letters, all of which are considered to provide the researcher with an in-depth conceptualisation of the participants’ narrative (Petty et al., 2012). The purpose of narrative analysis is to identify central themes or categories within the participants’ narrative rather than exploring their stories as a whole (Smith & Sparkes, 2005). McAdams (1993) developed an interview protocol that researchers can use for exploring their participants’ narrative and this includes several questions related to life chapters, key events, significant people, future scripts, stresses and problems, personal ideologies and life themes. While narrative analysis offers a unique and in-depth approach to analysing data, a main concern was related to the narratives getting fragmented and the absence of meaning.

## **9. ETHICAL CONSIDERATIONS**

Ethical approval was granted from City University London ethics committee (see Appendix A) and by Harrow NHS Research Ethics Committee (see Appendix B). The ethical principles outlined by the British Psychology Society (2014) were also followed.

### 9.1. *Consent*

Informed written consent to participate in the study was required from all participants (see Appendix C). Participants were required to confirm that they had read and understood the participant information sheet and that their participation was voluntary where they could withdraw at any time. Participants were also asked to confirm they understood that relevant sections of their data collected may be used by the NHS Trust for research purposes. Participants were asked to confirm they understood that their GP would be informed about their participation in the study. Participants' written consent was stored in a separate file in a locked cabinet.

### 9.2. *Confidentiality*

Participants were fully informed about confidentiality. I explained that all information would remain confidential and for the purpose of the research only. Participants were informed that the interviews would be transcribed verbatim and that their names would be replaced with a pseudonym to preserve confidentiality. They were further informed that additional identifiable information would be removed from the research. Participants were told that supervisors of the research would look at the anonymised transcriptions. I informed participants about the limits of confidentiality and the statutory obligation to break this if I felt the participant posed a risk either to themselves or others.

### 9.3. *Safe-keeping of records*

Participants were made aware that the interviews would be recorded and that this material would be stored in a secure place. Confidential data such as participants' demographics, diagnoses and transcriptions were stored in a locked cabinet at all times. The digital dictaphone was also stored in a locked cabinet which was backed up on my computer.

The security measures outlined below were implemented:

- Personal data was not stored on portable devices such as memory sticks/cards.
- Firewall and virus-checking were installed on my computer.
- The latest security was updated and an anti-spyware tool was installed to help protect and monitor my computer from any threats.
- Only I had access to the information on the computer, and passwords were not shared at any time.
- Any personal information that was stored electronically was encrypted.
- I took regular back-ups of the information stored on my computer which was stored in a separate place. In case of loss of the computer, the information would not be lost.
- Participants' data will be retained for five years, which is in line with NHS guidelines. Following this period, all information including audio data will be destroyed.

#### 9.4. *Managing distress and de-briefing*

Participants were provided with a full explanation of the study (see Appendix D). This gave the participants the opportunity to reflect on the topic of interest, the interview questions and the opportunity to inform the researcher about what they found helpful or unhelpful about the research. Prior to conducting the interviews, I considered the potential impact of my interview schedule in that the questions might have triggered a range of emotions (BPS, 2014). Precautions were therefore taken to manage distress experienced during the interview which involved providing participants with the appropriate support and informing their clinician. The support available to participants was also included on the de-briefing form which was offered to participants.

## **10. PARTICIPANT CHARACTERISTICS**

Following ethical approval, a purposive sample of ten female participants were recruited from an adult community eating disorders service. All participants had received a diagnosis of an eating disorder which included anorexia nervosa, bulimia nervosa and atypical eating disorders including binge eating disorder. All participants were British and their ages ranged from 18-50 years.

## **11. INCLUSION AND EXCLUSION CRITERIA**

Participants had to have received an eating disorder diagnosis, including anorexia nervosa, bulimia nervosa, EDNOS or binge eating disorder. This was identified by the clinicians at the eating disorders service. The main focus was on the participants' experience of receiving the diagnosis. While the primary interest lies with those who have an eating disorder, I anticipated that participants may have comorbidities. However, since the interview schedule was focused towards eating disorders, there appeared to be no reason to exclude people because of other diagnoses they may have.

This study welcomed males and females to participate. Although using one sex may be a more homogeneous sample, I was aware that men have received little attention in the eating disorders field. I therefore thought this would be an interesting aspect of the research. Participants had to be a minimum age of 18 as the research interests were amongst adults. There was no cut off point with regards to participants' age. Instead, I proposed that as long as individuals felt they were able to articulate their thoughts and feelings and have capacity to consent in taking part, they were welcome to take part. There were no criteria for exclusion in this research as I did not feel there were good enough reasons to exclude anyone from taking part.

## **12. RECRUITMENT**

Participants were recruited from a community eating disorders service. This is a county-wide service which forms part of a University NHS Foundation Trust. The service consists of a multi-disciplinary team, comprising of psychiatrists, psychologists (clinical and counselling), psychotherapists, nurse specialists, a dietician, a support worker and administrative staff. The service offers support to adults who have moderate to severe eating disorders, including anorexia nervosa, bulimia nervosa and atypical eating disorders including binge eating disorder. I submitted a research proposal (see Appendix E) which included the aim of the study, a literature review, method, methodology and analytic procedures. Thereafter, I received notification that the service was happy to support my research project and that I was welcome to recruit all participants from the service.

A field supervisor, Chartered Clinical Psychologist & Family & Systemic Psychotherapist was assigned to support me throughout the recruitment process. Following ethical approval, the recruitment procedure commenced. The field supervisor informed all clinicians at the service about my research project. I later attended a team meeting to present my research and provided the team with participant invitation and information sheets (see Appendix F).

In line with the inclusion/exclusion criteria, clinicians identified suitable participants for the study, and gave the potential participants an overview of what the research involved. Clinicians provided prospective participants with the invitation and information sheet. Clinicians used their clinical judgement to determine whether or not individuals were appropriate to participate. Clinicians informed me of potential participants by email. In following ethical procedures, I did not make initial contact with any of the participants. Instead, if potential participants were interested, they had the option to contact me by telephone, text message or email which were included on the information sheet. The recruitment process took five months approximately. Ten participants made initial contact

mostly by telephone and email expressing their interest in the research project. The multi-disciplinary team were informed as soon as the required number of participants had been recruited for the research.

### **13. PROCEDURE FOR DATA COLLECTION**

Following initial contact, I arranged to meet with individual participants at one of four NHS sites. Room booking was organised by the field supervisor and administrative staff at each site. There, the study was outlined to participants. Participants were required to sign a consent form confirming that they understood the study and agreed to participate. Following consent, participants were required to undergo a semi-structured interview which was audio recorded. The interview schedule consisted of ten questions which related to their experience of receiving a diagnosis of an eating disorder. Interviews lasted 40 to 60 minutes. After the interview, participants were debriefed which involved a full explanation of the study. This gave participants the opportunity to let me know what they found helpful or unhelpful which can often be valuable information. A reflexive diary which comprised my own thoughts and feelings was kept. The field supervisor and the relevant clinicians were informed of each participant's attendance.

### **14. SEMI-STRUCTURED INTERVIEWS**

#### *14.1. Constructing the interview schedule*

Semi-structured interviews were the chosen method to collect data. A considerable amount of time was devoted to developing a schedule for the interview since the aim was to obtain a detailed account of the participants' experiences. The interview questions included narrative, descriptive and analytic or evaluative questions. The topics were put in the most appropriate order and the phrasing of the questions was carefully considered to ensure that the questions were clear and participants would understand them. Participants were asked a

total of ten questions, along with prompts. The list of questions was discussed with the research and field supervisors and re-drafted as appropriate.

1. I am interested in exploring with you your experience of receiving a diagnosis of an eating disorder. To start with, can you please recall when you first suspected that you had an eating disorder?

*Possible prompts: how long ago? Who made the informal diagnosis? Themselves? Family members? Friends?*

2. Who were the first people to use terms such as eating disorder?

*Possible prompts: Themselves? Family members? Friends? Professionals?*

3. How long was it until you received a formal diagnosis?

*Possible prompts: What was the diagnosis? Who from? How? Where? What happened? How did you feel?*

4. How did you feel afterwards?

*Possible prompts: how did you feel about yourself?*

5. What else was the experience like of receiving a formal diagnosis?

6. What was the experience like of receiving a formal diagnosis versus living with informal knowledge that this was possibly an eating disorder?

7. How well did the formal diagnosis encapsulate the experience of living with an eating disorder?

8. What has been positive about receiving a diagnosis?

*Possible prompts: How do you feel about these changes? Can you tell me a bit more about that? What else?*

9. What has been negative about receiving a diagnosis?

*Possible prompts: How do you feel about these changes? Can you tell me a bit more about that? What else?*

10. What do you think others think about your diagnosis?

*Possible prompts: friends, family, partner, professionals, and work colleagues?*

11. Is there anything else you would like to add to help me understand what the experience was like for you of receiving a formal diagnosis of an eating disorder'?

**15.** *Conducting the interviews*

The interviews were arranged by telephone and email and they all took place at an NHS site to which all of the participants agreed. I ensured that I learnt the interview schedule as best I could before conducting the interview which allowed for a more interactive interview style where participants felt comfortable to go deeper with their experiences. As suggested by Smith et al., (2012), at the beginning of the interview, I informed all participants that I was interested in exploring their experience of receiving a diagnosis of an eating disorder. I also explained that throughout the interview I would say very little because I was interested in

making sense of their experience. It was at this stage of the research process that I was entering the hermeneutic circle of the participants' world (Smith et al., 2012).

## **16. TRANSCRIPTION**

Participants were required to give consent for the interviews to be audio recorded and transcribed verbatim. As stated earlier, participants' data were stored in a locked cabinet in my office to which only I had access. While there are various guidelines for transcription, I chose to follow those set out by Smith et al., (2012). The transcripts showed all the words spoken by the participant and the researcher. Line numbers were used in order to specify the sequence of the conversation and were useful during data analysis when I was required to extract quotes from the entire transcript. A space was left between each turn in the conversation and 'I' represented comments from the interviewer and 'R' represented comments from the respondent. In the transcripts, ellipsis '...' represent a significant pause; square brackets, '[ ]', represent omitted material and italic text in brackets, '*[name of place]*', indicates explanatory material added by the researcher. Extremely detailed transcriptions such as a precise record of all non-verbal utterances and the length of pauses were not made, as the main aim within IPA is to interpret the meanings of the participants accounts (Smith et al., 2012). Wide margins were made in order to allow me to write comments during the initial coding process.

## **17. INTRODUCTION TO ANALYTIC APPROACH**

As discussed earlier on this chapter, within qualitative research, interpretation plays a central role as it allows us to understand our data (Willig, 2012). For this study, IPA was employed to analyse the data as this approach allowed for a detailed analytic focus on the participants' experiences (Smith et al., 2012). Making sense of an individual's personal and social world is central to the aims of IPA (Smith & Osborn, 2008). This type of research is therefore helpful for reflecting and exploring meaning-making. In order to obtain meaning and significance of individual experiences, thoughts and feelings, it is important for questions to be directed towards these areas in order to start making connections within the data (Willig, 2012). Within phenomenological research, the focus is very much on the participants own description of an account, thus the process of analysis is fundamental to ensure these descriptions are produced as accurately as possible (Willig, 2012)

## **18. PROCEDURE FOR DATA ANALYSIS**

This qualitative research took the form of verbal transcripts of an interview which was audio recorded in order to capture everything that was being said. This also meant that I was able to focus completely on the session, building a rapport without disruption (Smith & Osborn, 2008). Following this, there were several important steps that I followed when carrying out the IPA analysis which are outlined below.

### *18.1. Step 1: Reading and reading*

Reading and re-reading the transcript gave me the opportunity to familiarise myself with the text. For a more complete analysis, Smith et al., (2012) suggest that it is helpful to listen to the audio recording to assist with this which is something I did and I found this helped me to familiarise myself much more with data. The primary reason for Step 1 is to encourage

the researcher to focus on the participant only and to begin to enter their world (Smith et al., 2012).

### *18.2. Step 2: Initial noting*

The initial noting was the most time-consuming part of the analysis as it involved closely examining the language and content (Smith et al., 2012). This involved making notes of any interesting comments that arose from the transcript. The first level of annotation involved descriptive comments such as key words, phrases, emotional responses or sounds bites. Second, linguistic comments which focused on the participants' use of language including pauses, laughter, metaphor or repetition were annotated (Smith et al., 2012). Third, conceptual comments which involved becoming more interpretative and conceptual with the transcript (Smith et al., 2012). This process was therefore much more a descriptive stage as the aim was to capture the meaning within the text (Willig, 2012). Here, I tried to suspend any judgments and instead focus on what was being said in the transcript. As mentioned earlier, this is often referred to as 'bracketing' one's own assumption about the phenomenon (Willig, 2012). Closely examining the text, gives further insight into how the participant understands a particular issue. As suspected, Steps 1 and 2 merged during the initial stages of the analysis as I had already made notes when first reading the transcript (Smith et al., 2012) (see Appendix G). In order to help distinguish between the levels of annotation, I used a red pen for the descriptive comments, a blue pen for the linguistic comments and a black pen for the conceptual comments.

### *18.3. Step 3: Developing emergent themes*

By Step 3, I was very familiar with each transcript and the emergent themes were then identified through the comprehensive exploratory commenting that has been outlined (Smith et al., 2012). The aim of Step 3 was to reduce the transcript and initial notes into

emergent themes, thus I worked from the initial notes as opposed to the entire transcript. In order to establish the themes, the narrative was broken up so I was focusing on big parts of the transcript. This part of the analysis therefore focused on a set of parts, thus turning the notes into themes was the main aim (see Appendix H).

#### *18.4. Step 4: Searching for connections across emergent themes*

From creating the set of themes, the task in Step 4 was to search for connections across the emergent themes, which in essence, involved thinking about how they fit together (Smith et al., 2012). I made use of the specific ways of searching for connections within the emergent themes and identifying patterns; these are summarised below:

**Abstraction:** this involves placing like with like and identifying a new name for a cluster (Smith et al., 2012). There may, for example, be a number of similar emergent themes which can then be put under one title, referred to as a super-ordinate theme (Smith et al., 2012).

**Subsumption:** this is where the superordinate theme brings out other related themes.

**Polarization:** this involves focusing on the opposite relationships within the emergent themes, for example, focusing on the differences as opposed to the similarities.

**Contextualization:** this involves focusing on the contextual elements with specific reference to narrative, cultural and temporal themes.

**Numeration:** this includes the frequency of the emergent theme appearing within the text.

**Function:** the researcher might focus on the function of the emergent theme which involves interpreting further than what the participant describes in the interview (Smith et al., 2009).

In searching for connections within the emergent themes and identifying patterns, Smith et al., (2012) suggest that organising themes in more than one way can be creative and push the analysis to a higher level (Smith et al., 2012) (see Appendix I).

*18.5. Step 5: Moving to the next case*

This step involved moving onto the next participant and beginning the same process again.

*18.6. Step 6: Looking for patterns across cases*

This step involved identifying patterns across all participants with a focus being on the connection across them, identifying the most powerful themes. This involved laying each table out on a large surface and looking across them. The final results were presented in a master table of themes for the group (see Appendix J).

**19. VALIDITY AND QUALITY**

Yardley (2000) suggested that there are a number of characteristics that are essential for conducting a good piece of qualitative research. This criteria includes sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance. This criteria has been followed to ensure the validity and quality of the present research. I shall discuss the form that each of these can take here, and towards the end of the thesis, I shall return to this discussion, demonstrating how my research has met this criteria.

Sensitivity to context comprises of many different elements, all of which are considered important (Yardley, 2000). This can be demonstrated through the context of theory and understanding previous researchers who have conducted similar methods. In addition, sensitivity to context is also demonstrated through the researchers' awareness of the previous literature that is relevant to their topic of interest. It is also demonstrated during the data

collection and analysis stage, for example, during the interview process and the researchers attempt to put the participants at ease or showing empathy (Smith et al., 2012). Similarly, during the analysis stage the researcher becomes immersed in the data, attempting to make sense of their participants' experience.

Commitment and rigour can also be demonstrated in several different ways. Yardley (2000) suggested that commitment involves the researchers continued engagement with the topic in the capacity of the researcher and patient. In addition, commitment can take the form of the researchers' skill and methodological competence. Rigour refers to the thoroughness of the research in relation to the suitability of the research question, the sample, the interview and the analysis.

Transparency and coherence refers to the clarity of the stages in the research process. For example, during the write up, the researcher can demonstrate this by carefully describing how their participants were recruited, how the interview schedule was constructed and by describing the stages in the analysis process (Smith et al., 2012). In addition, transparency and coherence can be demonstrated through the clarity and power of the argument and the fit between the theory and method (Yardley, 2000).

Impact and importance is the final criteria and refers to the impact and utility of the research itself. Yardley (2000) argues that, "It is not sufficient to develop a sensitive, thorough and plausible analysis, if the ideas propounded by the researcher have no influence on the beliefs or actions of anyone else" (p. 223). It is therefore important for the research to assess the value of their research in terms of its theoretical understandings and its practical value for who the research is intended (Yardley, 2000).

## **20. SUMMARY**

The aim of this chapter was to outline the methodology for the present research. In doing so, I have introduced my chosen paradigm and epistemological position. I have introduced a qualitative research paradigm and in considering my epistemological position, I have acknowledged that there are three broad types of knowledge including realist, phenomenological and constructionist and that my research has aimed to produce interpretative phenomenological knowledge. I have considered the importance of reflexivity within qualitative research, evaluated both my relationship to the topic being investigated and my relationship with the data. In terms of the method, I have outlined the sample and recruitment, ethical considerations and the procedures for data collection and analysis. Now I will report the findings that emerged from the data and I will provide an IPA analysis of the findings.

## CHAPTER 3: ANALYSIS

### 1. *Introduction to the analysis*

This chapter explores the narratives of patients' experiences of receiving a diagnosis of an eating disorder. It outlines the four master themes and the sub-ordinate themes that emerged from the data. Each theme is described and illustrated with participants' quotations which captured their experience of receiving a diagnosis of an eating disorder. The master themes were identified as, 'living with an unlabelled condition', 'perception of the patient-therapist relationship and interpersonal qualities', 'living with the diagnostic label' and 'a pathway to recovery'. In the quoted extracts, ellipsis '...' represent a significant pause; square brackets '[' ]' represent omitted material and italic text in brackets [name of place] indicates explanatory material added by the researcher. Participants' quotations are labelled with a pseudonym to protect confidentiality, followed by the page and line number of which the quotation has appeared in the original transcription within parenthesis, such as, '(Alex, 1-2.13-14)'. The four themes and their sub-ordinate themes are listed in the table on the following page. An introduction to each master theme is then provided, followed by the sub-ordinate themes.

2. *List of the four master themes and their sub-ordinate themes*

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**Table 1**  
Superordinate themes and subordinate themes

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<b>SUPERORDINATE THEMES</b>	<b>SUBORDINATE THEMES</b>
Living with an Unlabelled condition	<ul style="list-style-type: none"><li>▪ The warning signs</li><li>▪ Living without a diagnosis</li></ul>
Perception of the patient-therapist relationship and interpersonal qualities	<ul style="list-style-type: none"><li>▪ The uncertainty and doubts when receiving a diagnosis</li><li>▪ Perception of care when receiving a diagnosis</li><li>▪ Emotional responses to receiving a diagnosis</li></ul>
Living with the diagnostic label	<ul style="list-style-type: none"><li>▪ Living up to the label</li><li>▪ Perceptions of others</li></ul>
A pathway to recovery	<ul style="list-style-type: none"><li>▪ Making it real</li><li>▪ Leading to stronger self</li><li>▪ The start of a new beginning</li></ul>

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### 3. MASTER THEME ONE: LIVING WITH AN UNLABELLED CONDITION

Participants' experiences of living with an unlabelled condition are conceptualised in terms of two sub-themes: the warning signs and living without the diagnosis. *The warning signs*: participants described various physical, psychological and behavioural symptoms which lead them to suspect something is wrong. Some women experienced difficulties from an early age, while others described living in denial prior to a diagnosis. *Living without a diagnosis*: participants reflect on what it is like to live with such symptoms yet remain without a diagnosis. For some, this was negative because they had little or no explanation and they were unable to make sense of their difficulties. For others, living without a diagnosis provoked a deep fear of the unknown, and thought of their pre-diagnosed condition as lonely, not realising that others had been through a similar experience.

#### 3.1. The Warning Signs

The majority of participants experienced symptoms including purging, dieting, excessive weight loss, binge eating and being in denial. Alex for example, described herself as someone who was 'weird' with food and it was not until she started purging, that she considered this behaviour to be a problem:

*Um well I actually told my mum because like I said I've always been a bit weird about food but then, earlier this year I started purging. And that was a really obvious thing to me that like wasn't normal. And I had this one day where I purged like seven times and I was really stressed and I told my mum and she [pause] yeah she said that's, that's obviously a problem and she booked a GP appointment for me. (Alex, 1-2.13-17)*

Her use of the words, 'weird', 'wasn't normal' and 'obviously a problem', articulates her belief that she perhaps sees herself as being different to others. It was as though she learnt to accept herself as being 'weird about food', however at the same time, she felt concerned that she had started purging. She gave a sense that her behaviour had become an obsession when she stated 'and I had this one day where I purged like seven times'. It seemed that she felt the obsession had gone further than what she was comfortable and accepting.

Similarly, Imogen's account of her experience of the warning signs emphasised that her reactions to food were not 'normal'. She described her experience of this during dinner:

*I remember someone putting roast potatoes on my plate and I actually got like quite upset cos I found I couldn't eat them and I think that's when I realised like that's not a normal reaction to having a potato on your plate. So kind of there might be something wrong here. (Imogen, 1.10-13)*

It seemed that there was sadness and the experience of shock for Imogen as she expressed feeling upset and her realisation that something was 'wrong'. It was as though her issues with food had been looming and perhaps she had not been in a situation where she had to confront the difficulty before. The experience of feeling exposed in front of others increased her distress and perhaps this was why her reactions to food became worse.

Hana was shocked by her appearance and described herself as 'scarily thin':

*I just looked scarily thin and not really healthy and we went to the hospital and they said that I would need to be hospitalised and that was really really scary for me because I'd never been in a hospital. (Hana, 2. 22-24).*

This quotation suggests that Hana was extremely concerned for herself and had been living in fear. The thought of being hospitalised increased her distress and anxiety because it reinforced her belief that she was 'scarily thin' and confirmed that she was underweight.

The warning signs for Carrie were related to the cyclical nature of her on-off dieting and her difficulty to gain control over food. She explained:

*So basically what had happened is my whole life I guess really I've been on and off diets and constantly in that cycle of being really black and white. So I'm either dieting or I'm not dieting and I'm not really controlling what I eat or just everything basically was being eaten. (Carrie, 1.12-15)*

Carrie experienced a lifetime of dieting. She seemed to experience a lack of boundaries/restriction and knowing the appropriate portions and foods. It was as though there was an internal battle and the experience of feeling out of control which then perpetuated the cyclical relationship with her food.

Dani described her experience of being both underweight and overweight. At first, she did not consider her weight as problematic even though she engaged in behaviours such as 'being sick' and 'taking laxatives'. She talked about those behaviours being 'stopped' which suggested that the opportunities to engage in those behaviours were taken away from her and perhaps realised her dependency on purging behaviours. Regardless of how the behaviours were 'stopped', it seemed it was helpful as it allowed Dani to recognise that her weight was out of control and resulted in her seeking help:

*Underweight. It wasn't a problem at all. And I contained how I put on weight before because I used to be sick and take laxatives and everything and then [pause] that got stopped and the weight gained and that's why I came (to the eating disorder clinic) again this time because I've just got to stop it. (Dani, 5.63-66)*

Dani's account indicated that her difficulties with food existed for a long period. Up until then, Dani conveyed a sense of trying to conceal her behaviour; however, there was a shift in thinking as she seemed to understand the dysfunction of her food-related practices. Georgina, on the other hand, spoke about her experience of rejecting the possibility that she might have a problem.

*I was still completely in denial like there's nothing wrong with me, yeah I'm a bit skinny but they were really really worried about me and I was trying to think back, I was trying to think back this morning about what weight I was and I remember my lowest weight was about five and a half stone and at that time I must have been about [pause] I was probably slightly more than that, probably about maybe six stone, just over six stone but I completely didn't think there was anything wrong, you know I just couldn't see it at all. (Georgina, 2.22-29)*

Georgina struggled to identify anything beyond her body being 'a bit skinny'. Her denial of excessive weight loss and being 6.5 stone appeared to reflect a distorted self-image. Her use of language emphasises how concerned other people were which implied the seriousness of her distortions. Georgina appeared to have an inaccurate perception of her body and how she looked compared to those around her as she stated, 'I didn't think there was anything wrong, I just couldn't see it all'. Perhaps 'seeing it' required action and change

which she was fearful of. At that moment, she saw herself as being in control; if she gave in to the realisation that her behaviour was not normal, she would no longer be in control.

### **3.2. Living without a diagnosis**

Further to participants' identifying various warning signs, some found themselves then living without a diagnosis and experiencing a significant amount of frustration, hopelessness and uncertainty. They talked about '*going off on tangents*', '*not knowing*', '*feeling sick and numb*'. Michelle, for example, felt stuck because she continued to move from one problem to another:

*So my GP, we started off with irritable bowel and then we moved to something else so we'd gone off on lots of other tangents and different avenues and then I went to my GP [pause] and said do you think? [laughs]. (Michelle, 1.11-13)*

Michelle knew that she had an eating disorder and her frustration was apparent as she stated '*we'd gone off on lots of other tangents*'. The experience of trying to seek an explanation meant that she failed to make sense of her symptoms. She laughed as she said '*I went to my GP and said do you think*' which suggested that she felt embarrassed to say that she might be right and that she did have an eating disorder. In a similar way, Jo tried to make sense of why she binge ate and explained:

*Yeah so er my ex-husband left me in um [sigh] 2010. Yeah 2010 um and it was just, I'd just started er to binge eat um on different occasions um I can't remember, I think I can remember the first (time) I did that um but wasn't quite sure why um I can't purely put it down to the divorce um however I'd never really, I'd never done that before so um I'd been doing that on and off for four years. (Jo, 2.19-22)*

In this extract, there is evidence of Jo's confusion. Reflecting back, she acknowledged that her binge eating behaviour was not solely a result of the divorce which suggested that she could have been experiencing other issues simultaneously. For Jo, perhaps binge eating allowed her to access comfort and manage her emotions which may have contributed to convincing herself that she did not have an eating disorder.

Michelle reflected on her experience of living without a diagnosis. Michelle's words came across as though she was concerned for her body; Michelle emphasised that there may have been something 'physically wrong':

*Because over the years I kept thinking maybe there is something actually physically wrong with my digestive system and it's never been looked at properly and I could die, I could die because I'm not eating properly, I don't look after myself properly and maybe my GP has not sent me for the right tests, not sent me to see the right person. (Michelle, 26.373-376)*

This extract captures Michelle's overwhelming emotions as she said, 'I could die, I could die because I'm not eating properly'. If she was not 'looking after [herself] properly', it may have been due to feeling unable to cope and fearing the worst. It was as though a diagnosis would allow her to feel safe because what was 'physically wrong' could have been acknowledged. In the second part of her extract, Michelle shifted blame from herself to the GP. She felt like she was not addressing the problem if she was not seen by the 'right' person.

*Because that really made me realise, hang on a minute. But this is over a period of years because you know like I had my gallbladder removed in two thousand and [pause] five [pause] yeah two thousand and five and it wasn't really until five years later so that's five years of big problems. (Michelle, 8. 11-13)*

Michelle's account captured the critical sense of time frame as she stated 'that's five years of big problems'. It was as though her symptoms were a threat to her as she acknowledged being in a constant cycle of complication. Her experience of having to wait perhaps increased a sense of powerlessness as she realised how long her problems had been going on for.

Bryony described feeling 'silly' and 'causing problems'. It seemed that she had parts of an eating disorder but a professional did not give her the recognition of having it:

*Um I felt a bit silly I think. I felt a bit silly, I felt like I was just causing problems which is what I felt like anyway being you know a bit of a, a wreck anyway um [pause] yeah and I didn't, it made me not understand even, even more what I was doing because on the one hand I had all these emotions and feelings and things that I was doing, but I'd been told by a professional that I didn't have a problem in that respect um so yeah it was confusing I think. (Bryony, 9.155-159)*

Bryony felt shame and belittled in this extract as she described feeling 'silly' and like 'a wreck' which suggested that she experienced her symptoms as emotionally draining. Perhaps without a diagnosis, Bryony would continue to blame herself which reinforced how she defined herself. There was a sense of feeling rejected as she was told that she '[did not] have a problem' which left her feeling confused. Without an explanation, Bryony was unable to make sense and validate her experience.

For Georgina, the experience of living without a diagnosis meant that she was vulnerable and isolated from support as she described feeling 'threatened', 'sick', 'numb' and 'crying through fear' about being admitted to hospital:

*When they started threatening me with hospital I just felt, sick and numb and just completely felt alone even though my parents were really supportive, just so alone cos I thought if they put me in hospital it's me whose gonna have to deal with it um and I just remember crying through fear literally and I still am I mean I went to see [name of therapist] yesterday and I'm still worried that you know they're gonna stop me doing things because at the very beginning people stopped me doing stuff.*  
(Georgina, 7-8.114-120)

Georgina's account captured her perception of feeling threatened with the concept of hospitalisation. She appeared conflicted with feeling alone at the thought of hospitalisation yet having supportive parents and she expressed being fearful of having to 'deal with it' herself. The word 'hospital' evoked unpleasant thoughts and feelings related to people stopping her from doing 'stuff'. Similarly, Imogen expressed feeling 'petrified of being hospitalised' and explains:

*Um, I think it's quite scary because you think, I was petrified of being hospitalised not because of my health because at that time I really didn't care what happened to me, I was thinking, I mean I didn't have the energy to actually think rationally at that point, but I was just terrified that someone was just gonna put me in a hospital and literally feed me up and then send me out again and that I would be made to eat all these things before I was ready and I guess, and also the thing that scared me was the fear of the unknown.* (Imogen, 14.219-225)

Imogen explained that she did not have 'the energy to actually think rationally' and expressed a lack of care as she explained, 'I really didn't care what happened to me'. Her perception of hospital involved others trying to 'feed her up' and make her eat which she

feared. From this, she gave a sense that she was frightened of losing control over her food and leaving her vulnerable. A deeper fear she expressed is related to the unknown as she explained, 'the thing that scared me was the fear of the unknown'. Perhaps for Imogen, not knowing meant that she would lose control altogether.

For Faye, there was an understanding of the significance of the terms used by health professionals. This meant she was not willing to accept that she would have to be admitted to hospital because her perception of reality and the diagnosis seemed incongruent. It was as though 'hospital' was used by clinicians as a threat and Faye seemed to experience the use of hospital as coercive.

*Well when my GP and my, the child and adolescence mental health team did realise how bad things were and it was openly used as a term that I'd then end up in hospital but [pause] I think at the time I wasn't willing to accept that it was because of behaviour and my physical health it felt like it was a lot more to do with the formal process of, it was like if they diagnose it, it means they realise what it is and they're fully aware of and gonna act on it. Whereas the longer I can put it off and be left alone, sort of the longer it would carry on but then [pause] on reflection [pause] that was sort of my interpretation about it at the time. (Faye, 10.165-172)*

Faye interpreted a formal diagnosis as taking action and explained that she was not 'willing to accept' this. She emphasised the 'formal process' of the diagnosis which indicated that it was official and she was not prepared for the negatively-perceived consequences. There was a sense of loss of choice or control when she stated they 'realise[d] how bad things were'. Perhaps for Faye, if she kept her behaviour hidden, she could continue to feel safe and protected, away from hospital.

For Georgina, there is a clear sense of worry as she describes feeling 'sick' in response to others talking about hospital:

*I felt, I felt sick because I was so worried 'cause people had started talking about hospitals and that was the worst thing for me to go into hospital 'cause I was like I don't want to be surrounded by anorexic people, people who can't eat anything cos I was still eating. (Georgina, 7.101-104)*

This quotation suggested that Georgina perceived the hospital as a threat which she described as being the 'worst thing'. She expressed her fear of being surrounded by 'anorexic people' which suggested that she did not identify or categorize herself as being 'anorexic'. She appeared to have created an image of what an 'anorexic' was and described this as 'people who can't eat anything' from whom she differed.

By contrast, Bryony described her experience of being hospitalised following an overdose:

*I took an overdose and ended up in hospital and, and I sort of shocked myself really that, that had happened and I think I had to, so I tried desperately from then to eat and to pull myself together. (Bryony, 11-12.200-202)*

In this quotation Bryony felt shocked following her overdose and she used this experience to help her eat which keeps her away from hospital.

### **3.3. MASTER THEME TWO: PERCEPTION OF THE PATIENT-THERAPIST RELATIONSHIP AND INTERPERSONAL QUALITIES**

The patient-therapist relationship and interpersonal qualities has been shown to be an important element of participants' experiences when receiving a diagnosis in this study and is the second master theme identified in the analysis. The master theme consists of three sub-themes. In the first sub-theme, 'the uncertainty and doubts when receiving a diagnosis', participants described their dissatisfaction with the communication surrounding their diagnosis. Some participants felt they had not received enough information including how they were assessed, what classified them as having a diagnosis and the severity of their diagnosis. Some participants felt there had been insufficient discussion: they were not asked how they felt about the diagnosis and their questions had not been answered satisfactorily which left them feeling confused. Some described being referred to several services and emphasised the time taken to be diagnosed. Other participants talked about the assessment process, and the relevance of the questions to eating disorders. In contrast, some participants highlighted the impact of therapists answering an insufficient number of questions, and expressed fear of not meeting the criteria and having less of chance of being diagnosed. As a result of this, participants felt pressure to meet the criteria.

In the second sub-theme, 'perception of care when receiving diagnosis', participants described a lack of care from the professionals delivering the diagnosis. Participants described their experience as 'shocking' where they were made to feel like 'a random patient' and 'part of a queue'; participants also described feeling like 'a robot' and being treated in inhumane ways. Practices associated with this experience included being given poor introductions, not asking participants how they felt about their diagnosis, cold responses to emotion shown and only having a 'clinician-patient' dialogue. Others felt they were treated as if they were 'a nuisance', 'silly' and 'causing problems'. Participants also

highlighted the importance of the care they received after the diagnosis and the significance of their relationship with the professional.

In the third sub-theme, 'emotional responses to receiving a diagnosis', participants describe a range of challenging emotions they experienced in response to being diagnosed. For some, this involved shame, guilt and embarrassment. Others expressed negative feelings associated with being part of an 'eating disorder category' and described feeling like 'a bit of a statistic'.

### **3.3.1. The uncertainty and doubts when receiving a diagnosis**

Communicating the diagnosis of an eating disorder with care was identified as being of utmost importance to several participants. Faye, for example, described her experience of receiving a diagnosis, emphasising the communication practices:

*I know a lot of people in mental health services, both eating disorders and general mental health have had like a sit down meeting where someone has presented and said with a GP or with a Psychiatrist and gone this is your diagnosis or even determined or however the conversation happens but [pause] this is your diagnosis and this is like a treatment plan or whatever, I've never had a formal meeting where someone said this is what your diagnosis is. It's [pause] so I kind of was very quickly admitted to an in-patient eating disorders unit which [pause] is kind of a formal diagnosis. (Faye, 4-5.69-76)*

In this account, Faye described other people's experiences, emphasising the importance of the professionals who determine the diagnosis and the contrast to her own experience. There is a sense that she has missed out and was treated differently. She experienced the process of diagnosis as 'quickly' which suggests that she did not have time to

ask questions and emotionally and cognitively process any diagnosis. There was a sense that she was not acknowledged and involved in the process which meant that she would not have known what to expect, which may have increased her anxiety.

Participants' narratives tended to focus on the classification of their eating disorder where they questioned how one determines the diagnosis. Faye continued to explain:

*No one ever asked me about how those boxes were decided on like how a diagnosis judges severity of eating disorders, isn't necessarily how it works in my life and there is the difference between behaviour and the psychology of it like so it's like I wasn't consulted with the criteria of how you're gonna mark me on having an eating disorder or [laughs] whether you're gonna decide I do or don't but it's just been handed down or given to me um so I don't know. (Faye, 26-27.459-464)*

In this extract, Faye appeared to experience confusion as she questioned the 'boxes' that determined her eating disorder diagnosis. It seems that her lived experience presented quite differently from the 'boxes' she associated with the disorder. The diagnosis left her feeling as though it was imposed on her without her involvement as she said, 'I wasn't consulted' and 'it's just been handed down or given to me'. Because she experienced being uninvolved in the process of the diagnosis, it appeared she felt disconnected to the diagnosis, and the disorder itself. The impact of the disconnection between self and diagnosis may have been negatively delayed or affected treatment and recovery.

Similarly, Imogen was left with questions after she received her diagnosis, emphasising her confusion with 'the classifications':

*I then felt really confused cos I thought hold on what are you, cos then I guess no one had actually said to me this is what the classifications for it are or this is how we're assessing you um, so I thought at that time, I thought hold on a second*

*maybe I'm a bit underweight but I don't have all these other things that are embedded in this eating disorder. And I guess for me, it made me think, they've got it wrong here, not they've got it wrong but as in okay maybe I've been classified in terms of my weight but I then felt like everyone's making a big hoo ha about something when actually I'm not exercising manically, I'm not this that and the other. (Imogen, 26-27.432-439)*

In this extract there is a sense of Imogen's disbelief and uncertainty in terms of what classified her as having an eating disorder. She seemed to experience distress and anger because she felt that her lived experience of her symptoms was not being considered. This meant that she could not identify with the diagnosis as she understood it. Perhaps for Imogen, this meant that she did not see herself as having 'a real' eating disorder. She continued to describe her experience, questioning how her diagnosis was actually classified:

*So if someone actually said to me this is what we'd classify an eating disorder cos even now I don't really know, I know that it was my weight profoundly that actually diagnosed me but I don't actually know what she was looking for when she was trying to classify it. (Imogen, 27.439-442)*

In this account, it seems that the lack of information that accompanies the diagnosis appears to contribute significantly to Imogen's dissatisfaction. The experience of feeling confused and wanting more information meant that she was unable to fully make sense of her diagnosis.

In contrast, Jo talked about her fear of being told 'no' and not meeting the criteria for a diagnosis and described her assessment experience:

*Biggest fear going into the assessment was that [therapist's name] and it was [other therapist's name] at the time were going to just say sorry but you don't fit our criteria, you don't have an eating disorder and for me to then have to continue on my own trying to work this out. (Jo, 6.95-98)*

The consequential problem Jo was identifying was being left alone and without support. It seemed that she actively wanted a diagnosis and felt herself at risk if she did not receive a diagnosis which may have increased her anxiety. Her account reflects a sense of helplessness and the daunting prospect of perhaps continuing on her own. She continued to describe the impact of her answering 'no' to diagnostic questions in the extract below:

*Every time I answered no it just I felt it knocked me down the scale of having a possible eating disorder um so I actually genuinely thought that when I came to the end of the session I was gonna be told I wasn't, I didn't have an eating disorder. (Jo, 13.206-209)*

Jo's description of the assessment period suggests that she feared her responses would leave her without an eating disorder diagnosis, expressing signs of being let down and fear. It seemed that she lost hope because she thought that she would be rejected which perhaps meant she would continue to exist in a constant state of unknown. Perhaps this also meant she would be left worrying, unsettled and essentially without access to support.

Dani also talked about her experience of the assessment in which she struggled to see the relevance of the tools used and explained:

*The questionnaire, the booklet they gave me, do I hear voices in the head and it was things like this and I felt [pause] this isn't, this isn't for me cos a lot of it I was just thinking no and then the bits that were for me I was thinking well that's got nothing*

*to do with an eating disorder. So for me I couldn't see [pause] the questions they were asking, what that had to do with an eating disorder, I just thought there's gotta be something wrong with me, not my mind, not that I was causing it. So it was like this has got to be wrong, there's got to be something medically wrong with me, not mentally wrong with me. (Dani, 18.256-263)*

Dani's account reflects a sense of confusion with the questions she was asked; she appeared conflicted with how she understood the eating disorder. Dani stated that the tools of assessment made her consider that there was something 'medically wrong' with her, not 'mentally'. She continued to explain that talking with friends helped her to understand her diagnosis better:

*When I was diagnosed they didn't really explain much to me at the time so it wasn't until I went away and talked with friends that [pause] I couldn't see a lot of it in me, sounds awful doesn't it, because at the time I didn't want to see. (Dani, 18.256-263)*

Dani perceived a lack of explanation from the professional delivering her diagnosis. There is a sense of her wanting to develop her understanding of the diagnosis as she confides in friends, something which is important in helping her to 'see [the diagnosis]' even though she did not want to.

When talking about the assessment period with Michelle, highlighted her understanding of the recovery process:

*And it wasn't just gonna be oh here we are here's some tablets, these are gonna make you better. It's gonna be a long drawn out process which would involve [pause] you know not just the physical side of not eating but the emotional, the*

*anxiety, all those, negatives that are attached to eating disorders would be um become [sighs] even, cos you can, I think it's very easy to sort of dismiss things and just think oh well. (Michelle, 20.289-293)*

Michelle acknowledged that the diagnosis would not yield be 'a quick fix' solution. There is a sense of being fearful of what the consequence of a diagnosis would stir up for her when she said, 'not just the physical side of not eating, but the emotional, the anxiety, all those, negatives...'. Michelle seems to refer the 'long drawn out process' as dealing with the psychological effects of the eating disorder. As Michelle continued, she let out a sigh of despair:

*Cos you've got different issues at different stages in your life so [pause] and because it's gone on for so long. So somebody being treated for or being diagnosed with an eating disorder as a teenager will have a completely different [pause] I think, its gonna come from a different place to being an older person getting a diagnosis um [pause]. I think I did feel um I felt quite sad that it had taken such a long time that we hadn't realised and by we I mean myself and my GP. That we hadn't sort of thought actually could this. But I do appreciate how difficult it would be for a GP, with someone presenting with all different sorts of problems that she took, she took very seriously and referred me to all sorts of different people. (Michelle, 34.489-498)*

This quotation implied that the root of the problem would be different in teenage and adult years. Michelle experienced disappointment and self-blame as she stated she felt 'quite sad that it had taken such a long time' which suggests that she wanted to get better. There is also a sense of relief as she reflects on her difficulties.

### 3.3.2. Perception of care when receiving diagnosis

Five out of ten participants experienced a lack of care by professionals when they received their diagnosis, leaving them feeling frustrated and upset; some reported feeling like a nuisance and others reported feeling non-human. Participants also experienced a lack of support after receiving their diagnosis and emphasised the importance of the care once the diagnosis was made. Imogen described her experience of this below:

*I found it quite, not just frustrating but quite upsetting actually going through all of that and I very much felt at the very beginning that I was like [pause] just a random patient as in, there could have been a whole queue of people outside waiting to be assessed and it was just very much I'm gonna ask you these questions, I'm gonna weigh you' I'm gonna assess you and then you're gonna go away you you'll be referred. I didn't actually feel like I was being treated like an individual um, and that was hard as well. (Imogen, 10.153-158)*

Imogen described not being acknowledged by the clinician and described feeling like a 'random patient' highlighting the impersonal delivery of a personal condition. It seemed that she experienced the process as being very formal, like a tick box exercise against which she appeared to struggle. Imogen experienced the clinician as impersonal which contributed to her not feeling like she was treated 'like an individual'. Imogen went on to describe a robotic experience:

*Um, I was made to feel like, for starters I don't even think she knew my name. I think my name was on the document, but she never once actually said to me hello what's your name or my name is, it was like, I felt almost like I could have been a robot like coming into a room um, she had a set of questions she had to ask me and*

*she didn't let, she didn't let me talk, she kind of, she didn't cut me off as, per say but she didn't probe me in areas where I felt like she should've um, to make me understand what was underneath the surface. (Imogen, 525-531)*

Imogen expressed her frustration with the interaction between herself and the clinician. For Imogen, the clinician failed to address her as a person and the description suggests that she was confined to answering a set of questions, allowing very little room for discussion. It appears that Imogen was seeking for a more interactive process with compassionate actions however these needs were not met. Imogen further reflected that she felt the clinician lacked a basic level of care:

*I didn't feel like she was treating me like a human being, I didn't feel like how, I was never asked how do you feel about that or are you alright with that or do you need and I remember crying actually when I was diagnosed and she just kind of offered me a tissue, it wasn't like a, and I very much felt like I was just a random, I could have been anyone and I mean obviously I don't expect them to get to know my life story or anything but I felt like she had a very cold reaction towards me and it was like oh I see this every day or you're not the worst, you know kind of brushing it off, you're not the worst I have seen or anything or it's fine um. (Imogen, 16-17.264-271)*

Imogen's reflection highlights the clinician's failure to meet her needs as she stated 'I was never asked how do you feel about that or are you alright with that or do you need'. This indicates a cold clinician-patient dialogue with a lack of recognition of humanity and individuality from the clinician which Imogen struggled with. She explained, 'I remember crying actually when I was diagnosed'. She further described the process of her diagnosis:

*Um, it wasn't very nice, not that it's ever gonna be a pleasant experience but it was shocking and it was also shocking to me how cold um, and inhumane I felt because of the way the diagnosis was given um, it was within about a forty minute period and it was just me in a room literally being weighed um, and questioned, blood pressure taken um, height taken to work out my BMI and then at the end well I can, it was literally very much a case, I can diagnose you've got anorexia and I think she signed a form um, and dated it to say that I actually had it but then [laughs a little] it wasn't like [pause] it was kind of like oh we can help you, I'll refer you to this and CBT um, but I didn't feel like she was treating me like a human being. (Imogen, 16. 256-264)*

Imogen's account of her experience seems to be one in which the clinician deliberately did not recognise, Imogen's humanity; the clinician comes across as heartless and cold. It is as though having her weight, blood pressure and height taken symbolizes her being part of a system. Imogen experienced the communication as poor, the clinician as dismissive and felt excluded from being involved in the decisions about her care. There is a real sense of disbelief in her account which affected her ability to process what was going on.

In contrast, Michelle described her experience while in search of a diagnosis where she was made to feel like a nuisance. She explained:

*He made me feel like I was a flipping nuisance because he sort of, his, the insinuation was if we send you to this place and they don't know what to do with you then you're just gonna have to come back to us and we really don't know what to do with you. I could sort of feel frustration because well what do we do with this person. (Michelle, 38-39.559-562)*

In this account it seemed that there was the experience of prolonged frustration and feelings of guilt as Michelle described feeling like a 'flipping nuisance'. It seemed that she felt lost and that she did not belong anywhere. There is a real sense of disappointment as Michelle summarises of her clinician's opinion of her, 'well what do we do with this person'.

Participants' narratives also emphasised the importance of the care and support they received after a diagnosis was given, often because of the absence of care in their case. Imogen, for example, described being 'diagnosed and left':

*So I was diagnosed and then left in my opinion. Um, and I wasn't actually told how I can help myself with dealing with that so I was diagnosed and then it wasn't and how do you feel about that and what can we do for you or do you like. Even if they had given me the name of a website maybe with other stuff, I don't know but anything that could've helped me or maybe try and read this or something like that. It was just very much a case of you're diagnosed with this, we'll do this, goodbye.*  
(Imogen, 31.512-518)

Imogen's account reflects a sense of abandonment and isolation as she did not feel supported after she received her diagnosis. It seems that she required further help and support, however, she was unable to ask for it, perhaps because she did not experience a supportive environment that fostered such openness. She felt like the clinicians did not really care about what happened to her after the diagnosis and that she almost had to help herself.

### 3.3.3. Emotional responses to receiving a diagnosis

Participants experienced a range of emotions when they received their diagnosis which is what the third sub-theme captures. Some of the emotions include shock, embarrassment, guilt and shame as described by feeling like a fraud. Feeling 'too big' or seeing 'fat everywhere' on her body is something that Alex experienced which meant it became a real struggle for her to identify with and accept a diagnosis of anorexia. She explained:

*I mean that's what I felt since I got the diagnosis and I thought when I went to my GP I thought that there's no way that I would ever get diagnosed with anorexia because I was too big. And it wasn't even that I weighed a lot, it's just like I could see that I had all this like fat everywhere. (Alex, 46.646-649)*

Confusion and disbelief are reflected in Alex's account and it is as though she did not deserve a diagnosis for an eating disorder because she considered herself 'too big'. She felt that she could not conform to her diagnosis because she was not 'really skinny'.

*I felt embarrassed [pause] yeah and guilty and I felt like I didn't deserve the diagnosis (Alex, 45.633-634).*

Perhaps Alex did not consider herself as a 'good enough' anorexic. If she considered herself engaging in activities that are not considered 'anorexic', she experienced feelings of guilt by being labeled by the term. Perhaps she experienced feeling misunderstood because of the disconnect between her perception of her body and the diagnosis which would potentially disrupt treatment.

Bryony explained that she felt ashamed to fit the category of someone who had an eating disorder and explained:

*I would say for me the only thing that's negative, apart from the fact that you've got it is um [pause] sometimes if I'm watching things on tele or, or you know you read articles or anything to do with eating disorders, you can feel a bit ashamed to fit into that category, you know a bit of a statistic. (Bryony, 18.315-318)*

Bryony appeared to have a negative perception of someone who fell under the category of an eating disorder and she interpreted herself as being 'a statistic'. This suggests that she saw herself as being another number instead of a person with valid experiences. Bryony appeared to feel ashamed because she experienced the diagnosis as something that was not normal and was perhaps concerned about how others would perceive her.

Imogen's extract illustrates the intensity of her emotions when she first received her diagnosis:

*Um, so being actually formally diagnosed [pause] was just a huge shock and it sent me into turmoil because I didn't quite know what it was and I didn't know what it meant and I was then doing my own research about it and finding things out. (Imogen, 23.376-379)*

It is clear from Imogen's response that she felt extremely anxious and was concerned for herself because she did not know what the diagnosis meant. Imogen wanted further support and it seemed that she wanted to know more about the diagnosis as a way of helping her to make sense of it. It seemed that Imogen felt alone and abandoned by the clinician when she said 'I was then doing my own research about it' which increased her fear surrounding the diagnosis and perhaps made it more difficult for her to accept it.

Alex described feeling like 'a fake' and appeared to question whether other people have similar feelings as she stated:

*[pause] I don't know I think, I don't know if it's just me or lots of people with eating disorders, but if you [pause] this is what I mean by feeling like a fake because I'm doing all these things and I'm not like trying to get attention, I don't want everyone to. I don't want to think I'm attention seeking but [pause] I almost like want people to notice there's something wrong. Because [pause] yeah I, so the fact that I have this diagnosis of anorexia people take me more, I can't it's so difficult to explain but [pause]. Sorry since having this diagnosis I've just [pause] I don't feel like I have anything to prove anymore. (Alex, 29-30.410-417)*

In this account Alex reflected a sense of ambivalence of being pulled between wanting people to know her distress, but not wanting to feel that she is seeking undeserved attention. Perhaps for Alex, having the diagnosis meant that others would take her more seriously and notice her. If she was 'attention seeking', her relationships may have been impacted because she had a specific goal from her interactions which was attention to her distress; perhaps she was fearful of being rejected.

*Um [pause] I felt like a bit of a fraud. I felt like a fake like, I don't know (Alex, 27.386).*

Alex's experience of feeling misunderstood seems to reinforce feeling like 'fraud' and a 'fake'. She did not think she had a 'real' eating disorder whereas everyone else thinks she did which made her feel guilty.

Dani highlighted the emotional impact and drew particular attention to the timing of the diagnosis. She explained:

*I think [pause] if you haven't got certain things sorted out [pause] you cannot, it doesn't matter what you're diagnosed with, you can't deal with it [pause] and I feel if you get told too soon it's another burden, it's something else to carry, something else to feel guilty about and all you're doing is setting (off) so many triggers inside.*

(Dani, 30.436-440)

Dani's excerpt suggests that she perceives a diagnosis as meaningless if she has not addressed other issues. This suggests that she was perhaps not ready for a diagnosis and was fearful about the emotional consequences. Perhaps she was already experiencing some of these difficult feelings and she was afraid that the diagnosis would reinforce these.

### **3.4. MASTER THEME THREE: LIVING WITH THE DIAGNOSTIC LABEL**

For most participants, the label of the eating disorder was an integral part of the experience of receiving the diagnosis. In the first sub-theme 'living up to the label', participants described the diagnosis as a negative and embarrassing label that could not be erased. It was described as a 'life sentence' and something which remained a legacy. In the second sub-theme two 'perceptions of others' were perceptions concerned with participants' experiences of negative reactions from, and the perception of others' understanding of an eating disorder, the associated stigma and their fear of judgment.

#### **3.4.1. Living up to the label**

Several participants spoke about the battle of living with the label of an eating disorder. Alex explained how she experienced her diagnosis as 'abnormal':

*I, it's er kind of embarrassing label to have because it's [pause] abnormal or weird, I mean [pause] I think binge purge anorexia is a really kind of difficult label. Yeah I*

*think it's not a thing that lots of people are familiar with. Because lots of people kind of have this idea that anorexics you know never eat. [pause] and so because I do eat [pause] yeah it's difficult. And that's cos, do you know what I mean like that's the stereotype of what is anorexic and what is bulimic and I'm not kind of exactly either one. (Alex, 34-34. 471-481)*

This quotation reinforces the negative association that Alex has with the label because it was considered to be lesser known, and perhaps, perceived by others as less valid than a 'normal' eating disorder. She defined it as 'embarrassing', 'abnormal' and 'weird' which suggests that it is unwanted and outside of what is accepted by society. Her experience of the disconnection between diagnosis and not identifying with it may give her a sense of not belonging. Alex drew attention to the use of language and explained that others were not familiar with the term 'binge-purge anorexia' which suggests that there were concerns related to disclosure and a fear of being 'different'. The stereotype attached to the diagnosis of anorexia is rigid and strongly associated with people who do not eat which Alex struggled with. The diagnosis did not make her feel 'normal' or adequately explain her behaviour which may have given her a sense of belonging in the 'anorexia' community.

Similarly, Bryony described being part of a 'bad' and 'dysfunctional' group of people and she felt that others also viewed her in this way:

*Um well people like to generalise don't they and you know it could be [pause] I don't know it's like you're part of a bad group you know it's like a dysfunctional group of people and you're actually part of that and that's a really awful thing to say but that's how you feel that from other people that its viewed. (Bryony, 19.333-336)*

Bryony's use of the words 'bad' and 'dysfunctional' suggests that she associated the label with someone who is unable to function normally. She seemed to be critical of the perceived group of people with eating disorders and perhaps she felt that it was okay for others to have problems but did not want to be viewed as one of those people. It was as though she wanted to be treated on an individual basis, rather than treated as the prototype of the 'group'.

Georgina expressed her concern with regards to the powerful impact of the label 'anorexic' and explained:

*And I think cos I spent so long in denial [pause] I suppose it was again it just comes back to you label yourself something and then maybe you start to think if someone's telling you you're anorexic all the time then you're gonna start believing it and so you're gonna start, like I said you know you're gonna start taking on the traits of what an anorexic does and so you're gonna stop yourself eating or you know you're gonna feel a fraud if you eat something. (Georgina, 22.356-361)*

Georgina was aware that she had been in denial for a long period, however also recognised that the more she was told that she was 'anorexic', the more she started to believe it. Accepting the diagnosis increased the likelihood of her taking on the behaviour of that label. She illustrated how powerful the impact of the label can be as she stated 'you're gonna feel like a fraud if you eat something'. It is as though she had to live up to her diagnosis and it became something that shaped, her experience with food. This demonstrates the complexity associated with diagnostic labels and can result in conflicting feelings associated with a person's usual behaviour. Alex gives an example of this in the following quotation:

*Like every time I [pause] eat. Like with my birthday recently, if I'd said to my friends that I had anorexia and then I ate cake they'd be like what is she doing, she's clearly pretending to have anorexia. So I feel like you know, I feel like I have to kind of like play up to the stereotype. And that's why I haven't told anyone because [pause] yeah just I don't know if that makes sense, probably not. (Alex, 35.488-492)*

This account reflects a sense of confusion and bewilderment of being trapped between different thoughts related to food. Alex recognised that her friends understanding of the eating disorder could make her behave in ways other than her usual behaviours to prove the disorder to her friends.

In contrast, Faye focused on the positive labels that a person misses out on when they are unwell:

*When you've been unwell and you've missed out on all of that, or you've missed out on all of these other positive labels or successful labels that other people create for themselves, that's all you've got like. So then when you remove that, it's like what do I replace that with. (Faye, 16.282-285)*

It seems that without the eating disorder label, Faye did not have a way to think about herself because the positive labels that other people have were not considered to be available to her. The essence of this is captured as she says, 'you've missed out on all of that'. Perhaps in some way, she experienced loss for herself because the positive labels had been taken away from her, leaving her feeling as though she had failed. Her experience appears to have exaggerated her identity as only being concerned with one label; even though it was considered a less 'positive' or 'successful' label, Faye appears to have considered it better to have a label rather than have no label.

Hana talked about not wanting to live with her label and acknowledged the profound impact of her experience of the diagnosis. Hana explained:

*Um well I, guess I accepted it but I didn't want to live with it. I didn't want to live with a diagnosis cos er it was kind of like labelled to be mentally ill and that was quite scary and especially coming from [name of place] where, where if you were disabled or mentally unstable, you were like hidden away, it wasn't really talked about. It was something like a taboo sort of thing. (Hana, 6.81-83)*

Rejection of the label is reflected in Hana's account as she recognised that her diagnosis means that she will not be accepted by society. Her realisation of this is captured as she described others with labels being 'hidden away' and mental instability as 'taboo'. The label reinforced the earlier idea that Hana was different to others which was associated with rejection. While Hana stated 'I accepted it', she did not want to live with it as it meant she would then be labelled 'mentally ill' or 'mentally unstable'. It is more of society's rejection of people with labels than her own perception.

For Faye, the disadvantage of having a label of an eating disorder meant that it left a 'legacy' which appears to emphasise its impact within society:

*Um [pause] just thinking about the negatives, I suppose then it does leave a legacy like if in like five-ten years time or whatever, there will always be that point of looking back and it will always remain in a legacy of being an eating disorder, it will never I can't sort of [pause] change my perception of that you know like if something else happened that was difficult or bad you can [pause] reflect on it positively or you can try and think about it differently or you can just kind of skim over it in your memory, but that will never happen. There will never be a point of it*

*not having been a diagnosis. I mean people cannot have that diagnosis anymore and they could've been recovered or their life could have changed but there was always that time period where um you were unwell like and like I'd have to acknowledge that in my relationships in the future, probably um [pause] so it feels a bit like once it's there it's hard to move past like. (Faye, 27.472-482)*

In this quotation Faye described the negative impact of receiving a diagnosis as she looks towards the future. It seems that there is sadness and the experience of loss, perhaps for herself and that she would never be able to think of herself as un-diagnosed. She went on to talk about how the diagnosis did not always encapsulate her experience of living with an eating disorder:

*I don't know how well it matches my sort of lived experience or informally my experience of having an eating disorder. I feel like sometimes it does but sometimes it really doesn't. And there have been [pause] a lot of time where you slip out of meeting the specific criteria for having that diagnosis and what then? Like when I went into hospital and it was almost forced that I had to change my behaviour and I had to change my weight and I had to change all these different things so I didn't meet the criteria anymore if you wanna take it strictly on a clinical level. What does that mean then because nothing about my thinking has changed. As soon as I'm not under this set of very specific conditions everything's gonna be exactly the same as it is so, so I don't know. (Faye, 12-13.205-214)*

It seems that Faye's experience was only partly being represented or described by the characteristics of the diagnosis' however for her, the reality was more complex than weight. It seems that Faye experienced the diagnosis as being a simplistic reflection of her

lived experience and the diagnostic symptoms failed to condense something that is so complex into a few words. It seems the diagnosis only helped Faye when she was underweight; when Faye put weight on and maintained her other behaviours and cognitions, she was unsupported. If she 'slips out' of meeting the criteria for her diagnosis, she felt this impacted her behaviour which increased her confusion.

Imogen described how, for her, the formal diagnosis did not capture her lived experience very well:

*It was very much I'm terrified I'm eating a bit more because I'm scared my weight's gonna go up and then being formally diagnosed, she really made it sound like I was trying to make my weight go down um, and she said you're obviously feared about weight gain but I don't think anyone quite realised that I wasn't trying to get my weight down and I realised it wasn't good it was going down, it was just I was terrified I was putting weight on. (Imogen, 24.401-413)*

The diagnostic criteria of anorexia was used by others to describe Imogen's experience which did not effectively describe her actual experience. Imogen did not want to be thinner, she did not want to put on weight. This seems to be an important distinction for Imogen, but not one that she experienced as being recognised by others.

In a similar way, Alex reflected on feeling misunderstood and explained:

*Um [pause] I think it made my behaviour around food worse um [pause] and I felt a bit kind of misunderstood that everyone thought I had this bulimia I never, I don't think I've ever had that. So yeah, I think just felt misunderstood [laughs]. (Alex, 27.382-384)*

Alex's emphasis on feeling 'misunderstood' indicates that the diagnosis did not encapsulate her lived experience. This further suggests that she was not being listened to as 'everyone' thought she had bulimia. The experience of feeling misunderstood increased her distress and perhaps this is why her behaviour around food became worse.

Some participants, including Georgina and Bryony who both received a diagnosis of anorexia, have the same perception that someone who has anorexia refuses to eat, which was not how either of them are living. Georgina acknowledged that she did not feel like she had an eating disorder altogether. She described how she struggled to identify herself as 'anorexic' as she was not engaging with particular behaviours associated with anorexia. She explained:

*I couldn't identify myself as anorexic because I was like well I don't starve myself, I don't [pause] I didn't, from what I knew about anorexia, from what you see on the TV and stuff like that, I wasn't [pause] wasn't starving myself, I wasn't compulsively going to the gym, I wasn't doing anything like that, I wasn't being sick, I wasn't you know I didn't have any, to me I didn't have any of the traits or the symptoms other than being skinny of someone who is anorexic. You know it was just me watching what I was eating [pause] so [pause] again I couldn't relate it to me that the formal diagnosis, living with the eating disorder cos in a way I didn't think that I had been living with an eating disorder. I just thought I'd been living (Georgina, 13.207-216).*

Georgina focused on the physical characteristics as she described her perception of an 'anorexic'. She experienced disbelief, rejection and felt misunderstood. Georgina's interpretation of anorexia was influenced by representations in the media, which appeared to support her belief that she was not 'an anorexic'. Perhaps if she accepted and defined herself as an 'anorexic', her lived experience would be compromised, together with the

representation of the self. She appears unable to relate to the diagnosis, which meant she dissociated herself and was resistant to it.

Faye repeatedly drew attention to the diagnosis being a 'very simplified version' of her life, indicating that her lived experience was far more complex. She concluded:

*I think if you look at it very clinically [pause] for the most part it matches [pause] a very simplified version of my life so [pause] but it feels [pause] it feels like that formal diagnosis [pause] kind of takes something that is really complicated and really difficult and not black and white whatsoever. It's, for me in my experience it's a very grey area of and in the same way that your day yesterday wasn't the same as today and tomorrows gonna be different like. Or mood like you can't condense something so complex into a few words so I personally find that difficult like I feel like it, it stereotypes me and I don't necessarily every single day of my life meet the criteria of that diagnosis. (Faye, 12.196-204)*

For Faye, receiving a diagnosis did not emphasise the variance in experiences of her experience of living with an eating disorder which she perhaps wanted. The diagnosis appeared to over-simplify the complexity of her experience. She came across as though she was resistant to being stereotyped and felt that the diagnosis was not a true representation of her subjective experience. It seems Faye felt that she was not being heard and that her experience was being described for her of which she struggled to make sense.

### 3.4.2. Perception of others

Participants were aware that having a diagnosis influenced how they are then perceived by others. Several participants described concerned reactions from other people as well as being fearful of being rejected by society, experiencing stigma, fear of judgment and discrimination. Hana explained that her mum was ‘terrified’ because she was unfamiliar with the disorder:

*Um well my mum obviously she was terrified because she hasn't heard about the illness um but in a way she was obviously glad that I was receiving help because um I could have died my weight was so low. Um my friends didn't really, well I suppose at school yeah they realised that I lost weight but then it wasn't really talked about kind of thing and I didn't have lots of friends back then cos I just came over to a new country and um just kind of started learning the language and so on but um I suppose when I came back to school they were supportive and you know and they kind of welcomed me back and so on um [pause] yeah. (Hana, 12.176-183)*

There is a sense of relief for Hana's mother in knowing that Hana was being supported with her eating disorder. It was easier for Hana to not talk about her eating disorder with others because she seemed to have already been feeling isolated, having few friends, arriving in a new country and not being able to speak the language.

For Jo, the diagnosis confirmed what her friends and family already suspected. In talking about the different perceptions, she appeared to distinguish between those who are close to her and those who did not know her so well, explaining that:

*I think close friends and family probably knew about it and alluded to it beforehand so I think for them it's just [pause] we knew it already. For work colleagues and people that don't know me as well have actually admitted watching me eat over my*

*lunch break and can't see a problem, what's happened so how can I have an eating disorder and so [pause] for them it's difficult, especially to people that look at me and say you exercise regularly, you look healthy, you're not over or underweight, how can you have an eating disorder? Um but to be honest with you, I think it's got to the point where I don't really care and I'm such a people pleaser and normally [pause] like to [pause] I suppose value highly what other people think of me more so than I should but when it comes down to this now cos I've got a diagnosis I don't really care so much what people think about me. I've been diagnosed clinically with an eating disorder. (Jo, 16-17.258-269)*

Jo's account illustrates the various responses from her friends, family and work colleagues. Her experience at work seems to be one that was invasive where others had been watching her. However for Jo, the diagnosis meant that other people's views and opinions were less important now that she has been formally diagnosed. With a diagnosis, Jo does not have to explain or prove herself to others; there is a sense of empowerment for Jo. The diagnosis seemed to have given her a way of resisting, or perhaps responding to other peoples' assessment of her when before her concerns were more with pleasing them.

Dani described how others were 'disgusted' with her behaviour with food and that they struggled to make sense of her diagnosis. She explained:

*Some are quite disgusted. I've that, lost lots of friends because of it erm they can't get their head round it [pause] erm and they feel because I've got over a lot of things [pause] why hasn't that, why hasn't my size come down as I've got over things. I don't know, I can't tell you. It's in my head but I can't tell you. If I could I wouldn't be like this it's not through choice [pause] and that's the point, the*

*contradiction of it, it is through choice but it isn't and that's the hard part and getting the two to marry up. (Dani, 27.384-389)*

Dani acknowledged that friends were frustrated that she managed to overcome issues in the past but she had not managed to overcome her eating disorder. This added to her own frustration that she was unable to express why she still engaged in the behaviours, 'I don't know, I can't tell you.' Although Dani perceived her behaviour as contradictory, it appeared important for her that others were aware that her 'size come down' was not through choice which she felt frustrated and confused with herself.

Alex talked about her experience at work with colleagues which she found 'weird' and described some of the comments she received:

*Actually I think being at work is weird, my colleagues all think I'm really skinny which I've never kind of got from anyone else. They're always commenting on how skinny I am and [pause] that makes me feel really awkward. (Alex, 38.533-535)*

Working was 'awkward' for Alex because she felt vulnerable and exposed by the comments about her weight. The quotation suggests that Alex interpreted the term 'really skinny' negatively or undeserved and was resistance to accepting this image of herself.

Georgina highlighted the stigma surrounding mental health when talking about how her dad responded to her diagnosis:

*Um well my dad doesn't really understand it, he's still very ignorant about mental illness um and [pause] you know he will say, not meaning to but he'll just say just eat it, you just need to eat more you just need to um yeah you're too thin you just need to eat more which you know isn't very helpful and stuff like that and I think, I*

*think I don't know whether he does but I think sometimes he thinks that it's something that I can help you know that I'm putting it on to get attention or whatever. Um [pause] so my dad's very ignorant about it. (Georgina, 26.422-428)*

Georgina described what it was like to live with stigma and acknowledged that her dad's attitude to her diagnosis was not helpful and something she found difficult. We get a sense that she felt misunderstood as her dad often stated 'you're too thin', 'you just need to eat more' as if the condition had a simple solution. This suggests he had a lack of knowledge about eating disorders as he believed it was something which can be helped or something that Georgina was 'putting on' to 'get attention'. This was a similar experience to Dani's experience about being perceived as having control when she experienced having none.

*Cos I'm sure people you know look at me and bet when I was skinner than I am now, people always used to turn round and look at me when I was walking down the street and stuff like that and you know, you can tell that [pause] they're judging you and they're thinking ah poor girl, anorexic oh [pause] but it's so much more than just not eating and wanting to be thin. (Georgina, 20.33-337)*

Georgina was self-conscious of how her appearance was viewed by others. She asserted her assumption that other people judged and felt sorry for her. As Georgina put it, 'they're thinking ah poor girl'. She described how, for her, the experience of having anorexia goes beyond 'not eating' and 'wanting to be thin'. Georgina spoke about the stigma whereby others did not understand what it meant to be 'anorexic' and that others were focused on weight, but for Georgina, the experience of living with an eating disorder seemed to involve psychological issues too:

*I think there's still a stigma attached to it, I still don't think people understand what it, what it actually is um and people need to be more informed about it and I think they they, I think as soon as you say anorexic people still do think oh well it's just know you stop yourself eating, you wanna, you wanna be skinny relate it to the fact that there's something actually mentally wrong with you. (Georgina, 25.408 413)*

Other people's perceptions were important and added further depth to Georgina's experience of receiving a diagnosis of an eating disorder:

*It's made me want to um t-to talk about it um and to stop it being such a taboo issue and for people to stop thinking that it's just people, it's just naïve teenagers who want to look like skinny models or the people that they see on [pause] on the tv. That it's not that, it's actually a mental illness that you can't control um and it's [pause] you know if only people knew what's going on your head all the time they wouldn't be so judgmental. (Georgina, 20.328-333)*

While such perceptions are not positive, this allowed Georgina to recognise the presence of eating disorders as being 'such a taboo issue' and develop a voice in wanting to change such perceptions which do not always reflect the true reality of what it means to live with an eating disorder. When Faye talked about others' perceptions of anorexia, she said:

*There is a very entrenched stereotypical idea of what that means um people sometimes can't comprehend that you might not fit that exact stereotype of media images or whatever that they have in their mind um [pause] so I don't know but for the most part it's not something that I talk to other people about or that I [pause] I tell as few people as possible um [pause] that I have an eating disorder or that I've been diagnosed with anything um so I haven't had a huge amount of experience*

*with other people's reactions er so for example compared to someone who's quite open about it um [pause] so yeah. (Faye, 20.346-351)*

Faye appeared to protect herself from others' reactions by not telling them of her diagnosis; this meant that she was not being compared or stereotyped which she appeared to be resistant to. In contrast, Imogen differentiated between those who have experienced others with an eating disorder:

*I've realised that people who have experienced other people having an eating disorder have got a lot more understanding and a lot more [pause] they haven't made it such a big deal, I would say. (Imogen, 33-549-552)*

For Imogen, to be more understanding means that others did not make 'a big deal' which perhaps minimises the seriousness of the diagnosis or did not treat her differently. In comparison, she goes on to describe the responses of those who were not appropriately aware of eating disorders:

*Whereas the people that [pause] haven't been aware of an eating disorder, have been more dramatic about it um, maybe even to the point where I've had loads of people, they just kind of [pause] and I can see why they're doing it, they're trying to ignore the fact that I have one and they're just doing that because they know I'm quite a private person and if I wanna talk about it I'll talk about it, but if not why bring it up kind of thing. So I guess people's reactions have been [pause] in that way quite understanding because everyone I've come across have just wanted to do the right thing. (Imogen, 33-34.552-558)*

Imogens' experience of other people's responses vary, although she recognised that those who were less familiar with eating disorders appeared more 'dramatic'. This extract suggested that she reached a stage of acceptance in terms of how other people respond to her diagnosis.

### **3.5. MASTER THEME FOUR: A PATHWAY TO RECOVERY**

Several participants described how the diagnosis facilitated their recovery; this is the fourth and final master theme. In sub-theme one, 'making it real', some participants explained that the diagnosis offered them an explanation, making their diagnosis more tangible. Others described the diagnosis as a formal recognition and something valuable because it was clinically recognised by professionals. In sub-theme two, 'leading to a stronger self', participants described how the diagnosis enabled them to regain control over their eating disorder and become physically and psychologically stronger. Sub-theme three, 'the start of a new beginning', demonstrated how the diagnosis allowed them to move forward and consider the future. For some, the diagnosis enabled access to support services and some even described it as a life changing experience.

#### **Making it real**

Several participants described their diagnosis as validation that their experience was 'real' and perceived it as a 'formal recognition' of their behaviour. Bryony talked about receiving a diagnosis that she agreed with and understood which made the process easier for her:

*That having been given a diagnosis that I agree with and understand um it's just made it easier to deal with it because it's made it real. It's something that um yeah it's like going to get antibiotics or something, it's, it's real. It almost makes it tangible. (Bryony, 17.292-294).*

In this quotation, Bryony described the diagnosis as something that was 'real' and 'tangible' which suggests that she perceived it as being concrete and noticeable. She compared the diagnosis to flu which suggests that it is medically proven and she interpreted the diagnosis as a means of access to treatment. Having a diagnosis meant that Bryony would receive more care and support because it was a 'real' and a recognised diagnosis.

Similarly, Faye realised that the diagnosis qualified her for treatment and she appeared to make sense of why her mum has been 'pushing so hard' for a diagnosis:

*On reflection I've realised why my mum pushed so hard because if you don't have any diagnosis, no one will do anything. So at the time I was very unwell and I really needed help of some sort and wasn't willing to seek it out on my own or to access it and the only way that anything would happen was if there was that formal recognition by relevant professionals okay there really is something wrong this, this meets the criteria of being an eating disorder. Because nobody did anything and nobody gave me any help at the time or my mum any help apart from A&E which is not a viable treatment route. (Faye, 10-11.172-179)*

Faye too, emphasises the formal recognition and in this quotation, there appears to be a realization of how 'unwell' she was. She appeared conflicted because she realized how unwell she was yet was unable to seek help until there is some form of recognition by a professional. Perhaps without the diagnosis, she could not fully accept that there was 'something wrong' as she needed to hear 'okay there really is something wrong' and 'this meets the criteria of being an eating disorder'. Similarly, Jo also described her 'eating problem' as being 'clinically recognized':

*I suppose to find out that I actually did have a, an eating problem that was clinically recognised just took a massive weight off my shoulders cos at long last I didn't blame myself. (Jo, 4.60-62)*

In this quotation, Jo described her experience of receiving a diagnosis as taking a 'massive weight' off her shoulders. Having a formal diagnosis meant that she could understand herself better and not feel responsible for her eating disorder. Jo felt relieved with her diagnosis and instead of blaming herself, the diagnosis allowed her to access positive feelings whereby she felt understood and was no longer facing the eating disorder alone.

For Michelle, receiving a diagnosis meant that it narrowed her options down where she could then identify and focus on a specific phenomenon:

*Um [pause] so now to be able to focus on specifically what the problem is and address the, the issues and do something [pause] is and be proactive that that's the most important thing for me, that's made a huge difference. (Michelle, 35.506-508)*

This quotation suggests that Michelle feels relieved with having a diagnosis as it allows her to focus and address her difficulties.

Jo described her own behaviour as 'disgusting'; it was not something she was proud of which suggests there is a strong disapproval and potentially, self-loathing. Since receiving her diagnosis, she acknowledged that she was not so concerned with what others thought as the diagnosis offered an explanation to her behaviour:

*It's just disgusting like um I'm not proud of that at all so, but now I've got an eating disorder, one I don't really care, a diagnosis, one I don't very much care about having to explain myself to other people but two because I know there's other*

*people out there with it, I feel more able to say to people this is what I do behind closed doors, this is why I do it. If I felt that I needed to, I've almost got the um credibility now I feel um because it's a recognised disorder. (Jo, 18.285-290)*

Jo appears to be comforted in knowing that other people suffer from the same difficulties as her. She appears to be less apologetic for her behaviours because it was a 'recognised disorder' and shared a sense of relief that she was not the only one.

### **3.5.1. Leading to a stronger self**

Some participants felt that the diagnosis enabled a 'stronger self' which they attributed different meanings to, for example, becoming physically and psychologically stronger, regaining control and accepting the diagnosis. Imogen found that the diagnosis enabled her to 'kick back at the eating disorder':

*It feels really good cos it feels like [pause] I feel stronger now and I feel like I'm kicking back at the eating disorder and that helps me in my recovery, it helps me to challenge it. (Imogen, 37.627-629)*

This quotation suggests that Imogen personified the diagnosis and perceived it as being helpful in her own recovery. Feeling stronger meant that she could challenge the eating disorder and help others, which contributed to feeling positive and facilitated openness with others:

*So I think the pride of being able to help other people and to think I'm in charge of getting myself better and I'm taking control of it that way, in terms of I'm trying to*

*get healthier, actually is helping replace the euphoria of what was losing weight. So that, it makes me feel quite proud actually. (Imogen, 38-39.639-642)*

Imogen emphasised how proud she felt by helping others as this meant she was taking charge and control which represented a healthier self. Interestingly, Imogen described this as 'replacing the euphoria of what was losing weight' which suggested that she could access this feeling in another healthier way.

Some participants such as Georgina and Jo talked about the importance of acceptance in developing a strong sense of self:

*I was actually able to accept that there was something wrong with me and that I was anorexic and that it was nothing to be ashamed of um and um [pause] and from there it's kind of, it's been really, it has been really hard and I haven't gained as much weight as I should have you know I've kind of become complacent but um just having [pause] having an acceptance of it now I think is just a lot better and, and I'm able to talk to people about it you know and things like that and open up about it rather than kind of saying ah there's nothing wrong you know. (Georgina, 3.44-51)*

For Georgina, acceptance meant that she was no longer ashamed about being diagnosed with anorexia. The repetition of 'it's been really' emphasised how difficult it was for her to reach this level of acceptance. She described becoming 'complacent' as a result of not gaining as much weight which suggested that she perhaps no longer worries about this. The main emphasis appears to focus on accepting the diagnosis as this allowed her to be honest and open instead of resistant.

Similarly, Jo talked about accepting herself and gaining the acceptance of others which she described as being ‘a massive thing’ for her:

*Now I can say this is my treatment, this is what I need to do um because I’ve now been diagnosed um so I suppose just accepting myself and for other people to accept me with that, I think that’s been a massive thing. (Jo, 15.240-243)*

### **3.5.2. The start of a new beginning**

The third and final sub-theme ‘the start of a new beginning’, demonstrates how participants perceived the diagnosis as something that allowed them to consider a future. Carrie reflected on her experience of group sessions which were emotional for her:

*And then in the last one um [pause] I cried again but for a totally different reason that I was so proud of what I had achieved in the past like January to June um and how much my life had changed and become more of the old person that I was again. So having the diagnosis I guess made a real difference because if I hadn’t have had it you know if they turned around and said um you don’t match with what we’re looking for then potentially I’d still be in that cycle of not knowing how to help myself and things would be a lot different I guess then they are now. (Carrie, 13.192-198)*

Towards the end of the sessions, Carrie recognised that she was crying because she appeared to feel liberated from the eating disorder, and liberated towards being ‘the old person [she] was’. She expressed what the value of having a diagnosis, describing this as making ‘a real difference’ as it brought her out of that ‘cycle of not knowing how to help’.

Part of 'the start of a new beginning' involves patience, preparing to change and believing in oneself. Dani described her experience as 'very, very positive':

*Yeah very, very positive [pause] it's like where before I'd do everything and I have to do it before a certain day because I always have to know where I'm going. It's like this time, I know it going to take time, it's a complete change of lifestyle. That's the thing you've got to be prepared to change and believe in. When you have an eating disorder [pause] you can't half-heartedly do it, you've got to [pause] change everything because otherwise you're still in it. Not that, I know when you have an eating disorder, but you're in control of it rather than it being in control of you. (Dani, 16-17.233-240)*

In this quotation, Dani emphasised the importance of being prepared to change everything to be 'in control' of the eating disorder. She seemed to take an active approach in her recovery as she talked about being 'prepared to change everything' and stated the impossibility of doing it 'half-heartedly'.

Considering the future was particularly important to Alex. She talked about receiving a diagnosis as an opportunity to 'do things' and move forward:

*Um well [pause] since I've had this diagnosis it made me realise I want to be able to do things. Like next year, cos I'm obviously not doing anything this year really, I'm on a gap year but I want to be able to go to uni and I wanna be able to eat normally and I think it would be nice to be able to like eat out at restaurants and stuff like that. (Alex, 48-.683-686)*

This quotation illustrates Alex's empowerment as she identified her needs and aspirations for the future. Her reference to the current year as 'a gap year' suggested a sense

of freedom; although having the diagnosis was a positive term used as she felt that she had the opportunity to do the things she wanted to.

For Bryony, the diagnosis allowed her to understand her eating disorder and become more open with others:

*It's enabled me to process it better in my own head and also like to speak to other people and speak to my friends and stuff and um and that's been really good cos before it was all just secretive and then it just compounds the issue because you feel guilty and um you know it makes you worse, which makes you worse again.*

(Bryony, 17.298-302)

Talking with others instead of being secretive about her eating disorder allowed Bryony to access positive feelings. She felt comforted and knowing that others have accepted her diagnosis allowed her to also accept it and feel good about herself.

In a similar way, it seemed that Dani regained perspective as she discussed acceptance as an important component of recovery:

*For me this is the last massive hurdle, everything else is just [pause] life and you're going to have to accept certain things and this is how you're going to react and be able to deal with it and I think this, I think with [pause] food, because we need it to survive [pause] it is very difficult to ensure that you only [pause] you eat to live rather to live to eat. (Dani, 34.495-499)*

Dani appeared to convey a sense of rebuilding control within herself as she highlighted the eating disorder as being the 'last massive hurdle' and perceived everything else as 'just life'. The hurdle metaphor suggested that she acknowledged that recovery is a

gradual process. While Dani reflected on the importance of eating, the challenge involved putting it into practice and, as she stated, 'it is very difficult to ensure that you only, you eat to live rather to live to eat'.

#### **4. Summary**

The findings from this study suggested that patients' experiences were both positive and negative in regards to receiving a diagnosis, whereby their experiences progressed from disbelief and rejection of the diagnosis to ideas of acceptance and recovery. Living with unexplained symptoms was a common issue encountered by participants before receiving the diagnosis. Several participants described various physical, psychological and behavioural symptoms which led them to suspect something was wrong. The majority struggled to make sense of their difficulties both with and without the diagnosis. Ways in which the diagnosis was delivered were identified as being of utmost importance with several participants perceiving a lack of care from professionals when receiving their diagnosis. Participants struggled with living up to the label of an eating disorder and the diagnosis was often considered to be a simplified version of their experience and did not capture the complexity of living with the mental health problem. Finally, participants recognised that receiving a diagnosis facilitated change and recovery and enabled them to access mental health services.

## CHAPTER 4: DISCUSSION

### 1. Overview of themes

Participants' experiences remind us of the complexity of receiving a diagnosis of an eating disorder. Giving a patient a diagnosis is considered to be an important first step for the clinician in helping the patient to make sense of their presenting difficulties and to determine the appropriate treatment (Bentall, 2009). However, for the patient, receiving the diagnosis will often evoke a negative emotional response, and more so if that diagnosis carries stigma (Bentall, 2009). Although there appear to be several database listings for the term 'diagnosis', there does not appear to be a specific clinical focus on the lived experience of being diagnosed as an important aspect of a person's mental health experience (Hayne, 2003).

The aim of this study was to therefore gain an in-depth understanding of patients' experiences of receiving a diagnosis of an eating disorder. Participants were interviewed using a semi-structured schedule which produced a rich description of what participants experienced. Transcribed interviews were qualitatively analysed using the principles of IPA from which four overarching themes emerged: 'living with an unlabelled condition'; 'perception of the patient-therapist relationship and interpersonal qualities'; 'living with the diagnostic label'; and 'a pathway to recovery'. In these themes, there is a sense of progression which appear to fit into a longitudinal pattern, demonstrating a sense of development from when participants first suspected the eating disorder to recovery. Given that previous empirical research has not yet fully explored patients' views on diagnoses, the aim of this study was to address this gap in the literature. It was hoped that the use of qualitative methods would raise awareness of the patients' perspective and increase our understanding and knowledge in the eating disorders field. This chapter will summarise the key findings from the study and discuss the theoretical insights, integrating the relevant literature. The implications for clinical practice will be discussed, together with an evaluation of the study and

its relevance to the discipline of counselling psychology. Finally, the chapter will conclude with a summary of the study. Before we continue, let us remind ourselves of the four superordinate themes that emerged from the analysis.

For all participants, there appeared to be a theme of living with an unlabelled condition. In particular, they recognised a number of warning signs which led them to suspect something was wrong. These symptoms varied across all of the participants and included bingeing, purging, restricting and resisting or rejecting symptoms. In addition, this theme captured participants' experience of living with the disorder but without a formal diagnosis. Several participants described how they felt frustrated, hopeless and uncertain without a diagnosis. Some also emphasised the fear they experienced at the prospect of being admitted to hospital.

Several participants experienced uncertainty and doubts in relation to the delivery of their diagnosis and the lack of communication that accompanied the diagnosis. Participants explained that they felt their individual experience was not being recognised together with their humanity. Some participants expressed their fear of being rejected and saw themselves at risk without a diagnosis. The emotional responses to receiving a diagnosis were closely linked to this theme which varied across all of the participants and included shock, disbelief, fear, shame, anger and relief.

Following on from participants' experiences of receiving their diagnosis, participants recognised the impact of then having to live with a diagnostic label which they experienced as negative. Several participants made reference to 'living up to their label' and in some cases this meant that their thoughts and behaviours around food became worse. In addition, participants explained how they felt that their lived experience was only partly being represented and described by the diagnosis. For the majority, their experience of living with an eating disorder was far more complex than what the diagnostic criteria suggested and it did not fully encapsulate their lived experience.

A number of participants experienced the diagnosis positively in relation to naming the problem and making sense of what was 'wrong' with them. Several participants explained that the diagnosis served as a formal recognition and something that was clinically recognised by professionals. Related to this theme was participants' ability to regain control over their eating disorder which enabled them to become both physically and psychologically stronger. The diagnosis provided participants with a sense of relief where they were able to move forward and access support from services.

## 2. *The warning signs*

Eating disorders can involve a number of physical, psychological, behavioural and social consequences; everyone with an eating disorder will experience different symptoms which may change over time and some may experience more than one type of eating disorder (BEAT, 2015). In this study, participants' narratives about their early experiences with food and first suspecting that they had an eating disorder varied. The majority of participants had first suspected something was wrong, but did not necessarily think that they had an eating disorder. However, several stated they knew their behaviour was not normal and described a range of symptoms. For example, Alex described being 'weird' with food and realised there was a problem when she started purging multiple times a day. Imogen realised something was wrong from her adverse reactions to certain foods and found herself rather emotional when she struggled to eat them. Hana on the other hand, described herself as 'scarily thin' and was extremely fearful of being admitted to hospital as result of being underweight.

Carrie had always suspected an eating disorder however explained that 'when you're going through it, you don't really stop and think that you have one'. Being on and off diets and having a lack of control over food were typical behaviours for Carrie which, at the time, she believed were normal.

Interestingly, when Dani lost weight, she did not suspect this was an eating disorder, however she considered an eating disorder when she started to gain weight.

Georgina rejected the term eating disorder and did not perceive herself as being 'really skinny' like others did. Georgina's weight continued to reduce, without knowing she had lost control.

All of the participants spoke about the concern expressed by family members which appeared to be the main reason for participants seeking initial help from their GP. However, talking about the eating disorder and seeking help was a concern for many participants. Some found it exceptionally difficult to tell others about their behaviour because they felt too ashamed. Despite being close to friends and family, some participants explained that it was still very difficult to disclose to others that they were engaging with behaviours such as self-induced vomiting, misusing laxatives or restricting food.

### 3. *Living without a diagnosis*

Participants' experience of trying to gain a diagnosis was not always easy and often left participants feeling hopeless and uncertain with regards to being able to move forward. Some described how they were often going to and from services without a diagnosis for some time. Previous research (De La Rie, Noordenbos, Donker, & Van Furth, 2006; Rosenvinge & Klusmeier, 2000) found that participants expressed dissatisfaction and concern with regards to GP's lack of knowledge of eating disorders and their failure to impart timely diagnoses. In this study, GP's were usually the starting point of the diagnostic process and often determined which services participants were referred to. This highlights the importance of providing GPs with appropriate eating disorder training as this may increase early diagnosis and access to services. Consistent with previous findings, the negative feelings regarding participants' care and treatment was a result of them being passed between different services (Fox & Diab, 2015). In addition, and in accordance with this study, being passed between services then

appeared to reinforce participants' feelings of not fitting anywhere (Fox & Diab, 2015). This evoked feelings of hopelessness, uncertainty about treatment and a sense of being abandoned by clinicians (Fox & Diab, 2015). This may be an important reason for why some participants experienced feelings of isolation during these initial stages.

Others expressed a fear of being admitted to hospital and it seemed that they experienced the threat of hospital as coercive which significantly contributed to participants' reasons for not wanting to seek help. The anticipated consequence of undergoing therapy is a possible barrier to seeking help and patients tend to avoid situations in which they anticipate risks, which researchers have referred to as the individuals' perception of the possible threats associated with self-disclosure (Vogel & Wester, 2003). It has been suggested that people who have issues with food or weight fear of treatment may be associated with their fear of being forced to gain weight or their fear of losing control of their eating disorder altogether (Pike & Striegel-Moore, 1997; Reid, Burr, Williams & Hammersley, 2008).

#### 4. *The uncertainty and doubts when receiving a diagnosis*

Participants received their diagnosis from different professionals, including GPs and Psychologists. Some participants were not always sure what diagnosis they had been given, often being left to make their own assumptions. For example, Faye spoke about being admitted to a community mental health team and assumed that this meant she had been given a diagnosis. Similarly, others spoke about not always being told what the diagnosis was, but had seen a diagnosis written down or found in letters they had received. This finding highlights the importance of explicit communication between the patient and clinician. For the patient, not knowing exactly what diagnosis they have been given could potentially have important implications for seeking help, engaging in treatment and ultimately, recovering from the eating disorder.

Participants experienced a range of emotional responses to receiving their diagnosis. Shock was a common response that was shared and this was often a result of not agreeing with the diagnosis. Alex, for example was diagnosed with AN and spoke about her disbelief which was associated with all the fat that she could see on her body. The concept of shame was also common among participants with the majority expressing their fear of being labelled with an eating disorder. Several participants referred to their eating disorder as something that was 'weird', 'abnormal', 'dysfunctional' and some interpreted it as being part of a 'bad group' of people. Participants often described negative perceptions of others with regards to their eating disorder. A number of participants were often concerned with how their friends, family and colleagues would respond to their being diagnosed and were worried about being judged and discriminated against. Participants reflected on what they thought others thought about their diagnosis which seemed to vary. Some family members for instance, were terrified because they had not heard of the term 'eating disorder' or did not know that much about the particular disorder; other participants experienced disgust and ignorance from some family members, which left them feeling as though they were unable to talk openly about their eating disorder.

Participants also spoke about others having a stereotypical idea of what it means to have an eating disorder which again, made participants less inclined to want to talk about their experiences. Rich (2006) also found that women's narratives emphasised that their eating disorder was often misunderstood by their friends, families, peers and in some cases, their therapists too. Rich (2006) argued that as clinicians, we must therefore continue to develop our understanding of the complexity of the patient we are to fully understand the relationship that people have with their eating disorders.

Consistent with previous research, labelling the person then subjected them to stigmatization from friends, families and colleagues (Borg, Karlsson & Kim, 2009; Pitt, Kilbride, Welford, Northard, & Morrison, 2009). Similarly, participants mentioned concerns regarding

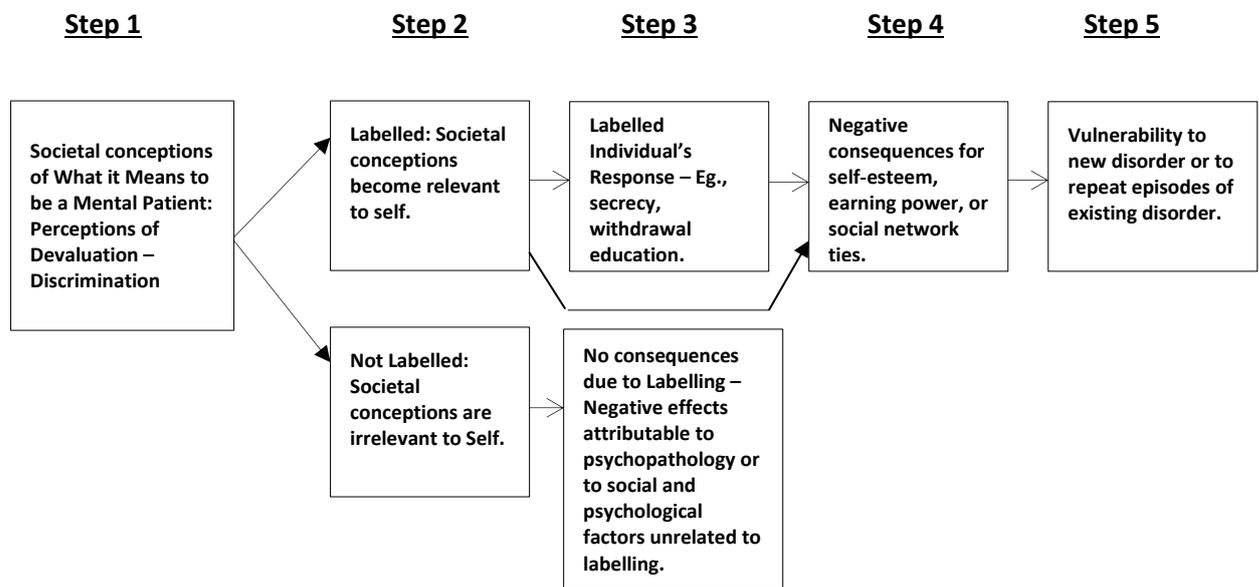
public awareness, stigma and discrimination. De La Rie et al., (2006) argued that concerns with stigma and discrimination lead to a delay in seeking treatment. Other research has found that stigmatization can often result in negative responses from others and lead to self-stigmatization where patients with a mental health diagnosis may start to internalise negative responses leading to negative perceptions of themselves and ultimately leading to low self-esteem (Corrigan, 2004; Link, Struening, Neese-Todd, Asmussen, & Phelan, 2001).

Cachelin and Striegel-Moore (2006) explored help seeking and barriers to treatment and found that people experiencing eating disorder symptoms might have negative attitudes about seeking help because they are fearful of being labelled Corrigan (2004). For some participants in this study, the label was perceived as stopping them from doing things, such as enrolling on to courses or impacting employment. In addition, the label was perceived as something that would never disappear or be forgotten and some would never be able to think of themselves as untarnished. In this study, it seemed that participants' feelings were related to a sense of grief and missing out on other positive labels. This is consistent with previous findings whereby people have the desire for recovery and consider positive experiences such as going to work or developing interests, however because they have had their eating disorder for a long time, they do not express this to be a possible reality (Fox & Diab, 2015). People are often faced with the difficulty of not knowing how to 'get rid' of something that has been part of them for so long, which leaves them feeling upset and confused with how to manage their eating disorder and still be able to live their lives (Fox & Diab, 2015).

Link, Cullen, Struening, Strout and Dohrenwend's (1989) modified labelling theory may increase understanding of the experience of being labelled with an eating disorder. They propose that patients internalise societal beliefs in terms of what it means to be labelled with a mental health diagnosis and this also includes the extent to which patients believe that society will devalue and discriminate against mental illness (Link et al., 1989). This may explain

why participants in this study described the term 'eating disorder' negatively and feared that others would discriminate against them. It is possible that participants have internalised the societal beliefs that an eating disorder means that people are 'weird', 'dysfunctional', or that they now belong to a 'bad group'. Link et al., (1989) stated that patients receive their 'official' label via treatment contact which is important in terms of the patient's perspectives about the beliefs of the community towards individuals with mental health. Link et al., (1989) suggested three potential responses to the stigmatizing status of the patients label: secrecy, withdrawal/limiting social interaction, and educating others about their label in an attempt to reduce negative views and attitudes. Similar to the results in Link et al.'s study, participants in this study responded to others' ignorance about mental illness or others negative perceptions by withdrawing or reducing social interaction. Link et al., (1989) argued that the negative consequences associated with secrecy, withdrawal and education may protect patients from labelling, but can also limit the number of opportunities taken. As a consequence of being labelled and the reactions of others, Link et al., (1989) suggested that a number of patients will lack growth such as self-esteem, social networking and employment which are considered risk factors for the development of future disorders. A diagrammatic representation of Link et al.'s (1989) modified labelling approach is shown in figure 1.

Figure. 1. Diagrammatic Representation of the Modified Labelling Approach (Link et al., 1989)



Interestingly, participants' experiences seemed to follow a pattern of disbelief to acceptance of the diagnosis. Those diagnosed with AN tended to struggle with this diagnosis as they believed that they were not 'thin enough' and could not identify themselves with the diagnosis. For example, participants' perceptions of someone with AN typically involved someone who was severely underweight and someone who did not eat. The diagnosis left some participants feeling like a 'fraud' or a 'fake' and they believed that their problems were not as serious as other peoples' problems. Participants often compared themselves with others who they perceived as having more serious eating disorders and as a result, felt that they were not 'that ill'. Participants considered other people to be worse off than participants' perception of their own difficulties.

Imogen believed that there had always been a stigma around what an eating disorder was and she strongly believed that she would never suffer from AN. In her mind, anorexia belonged to someone who did not eat at all or someone who was so extremely thin that they're in hospital. Imogen explained that she did not realise there was such a thing as a

'functioning anorexic' and so it never occurred to her that she could have an eating disorder. For Imogen, other things were more likely to happen such as cancer. Everyone around her had suspected an eating disorder which made her feel quite angry and confused. Findings from previous research suggest that people tend to use statements such as 'real bulimics' when comparing themselves with others as this often minimizes the severity of their own behaviour (Broussard, 2005).

Making sense of the diagnosis was something that participants tended to struggle with. They often felt that they did not conform to their diagnosis. While some participants knew things were not right, they were resistant to accepting a diagnosis for a long time. Faye for example, explained that she was resistant to the terms 'anorexia' and 'bulimia' when they were used to describe her or her behaviour at first. Over time she was more willing to accept that the professionals were perhaps right and accept her diagnosis.

Kubler-Ross' (1969) theory of grief can bring further theoretical insight to the findings here. The theory proposes five stages of grief which may increase the understanding of participants' disbelief of their eating disorder. These five stages include denial and isolation, anger, bargaining, depression and acceptance. It is important to highlight that patients do not always go through all five stages nor do they go through the stages in the order that is proposed (Kubler-Ross & Kessler, 2005). In her book, 'On Death and Dying', Kubler-Ross (1969) suggested that denial refers to the patients disbelief of their diagnosis and as she discussed with the patients that she interviewed, most of the responses included "No, not me, it cannot be true." (p. 31). For some of the participants in this study, their denial seemed to be supported by making comparisons with others with eating disorder who they considered 'worse off' which helped to maintain this stage. Kubler-Ross (1969) argued that "denial functions as a buffer after unexpected shocking news, allows the patient to collect himself and with time, mobilize other, less radical defences" (p.32). In addition, she argued that the patient's defence mechanisms are dependent on how the patient is told about their diagnosis,

the amount of time they have to acknowledge it and whether or not they have been prepared to cope with it (Kubler-Ross, 1969).

Patients experience anger when they can no longer maintain their denial which can be difficult, not only for the patient, but also for those around them (Kubler-Ross, 1969). It seemed this is what Imogen was experiencing as she felt angry at everyone around her who believed that she had an eating disorder, causing confusion for her. According to Kugler-Ross (1969), the patients' anger will be directed at many different people, for different reasons and may be expressed sporadically. Kubler-Ross (1969) stated that the problem is the disconnection of the diagnosis from the patient's perspective nor the attempt to make sense of patient's anger.

#### 5. *Living up to the label*

Living up to the label of the eating disorder was identified in participants' responses. Participants discussed the impact of repeatedly being labelled with an eating disorder which they felt was also a result of them taking on the traits of their diagnosis. Feelings of guilt seemed to be a main cause of why people blamed or punished themselves for eating. This resulted in participants becoming extremely anxious around food and what appeared to make it difficult for the participants to function normally, particularly in social environments. For example, Alex experienced an enormous amount of guilt after she ate some birthday cake because her perception was that someone with anorexia would not consider eating birthday cake. This increased her feeling that she was not 'a good enough anorexic'. This also increased the anxiety and preoccupation about what other people thought. These findings are important when considering the barrier of language between the clinician and patient and is supported by Coles' (2010) claim that individuals can feel inferior in terms of their understanding of their own experiences. Participants described their receiving of a sub-type diagnosis such as AN and BN as confusing and they often questioned what happened to

their existing diagnosis. Some participants experienced more than one type of eating disorder which also confused them. The current findings support Bentall (2009) who argued that people become confused when they receive multiple diagnoses; likewise, patients also become confused when their experiences are being explained under a single label. Understanding the prevalence of confusion when diagnoses are given, these findings suggest that it is important for clinicians to ensure that the patient understands the diagnosis, particularly when a sub-type diagnosis is given. Furthermore, it is important that the clinician attempts to understand the patients' understanding of the diagnosis

Dual diagnoses were also common among participants which also resulted in much confusion. Being previously diagnosed or suffering with other mental health conditions, such as obsessive compulsive disorder, depression and self-harm, meant that participants made links to other behaviours and diagnoses and in some cases, this seemed to help participants to reject their eating disorder diagnosis.

Others spoke about how eating disorders were not really spoken about which meant that they felt they had to keep their eating disorder a secret. More specifically, Hana spoke about her experience of being diagnosed outside of a western society where mental health conditions were often considered taboo. Alarcon (2009) and Alarcon, Westermeyer, Foulks and Ruiz (1999) argued that culture plays an important role in the process of diagnosis and it is therefore important that the clinician thoroughly understands the patient's cultural background and identity during treatment. Consistent with Alarcon's (2009) argument, it seems that the cultural factors for Hana had a powerful impact on keeping her eating disorder hidden and subsequently delaying her seeking help. Alarcon argued that culture has been used very poorly in diagnostic practice and that there are limitations with regards to cultural formulation, culture in clinical assessments, and training programmes. Previous studies have found that shame and self-loathing are barriers to seeking (Cachelin & Striegel-Moore, 2006; Meyer, 2001; Pike & Striegel-Moore, 1997).help and it has been suggested that people with

eating disturbances may be in therapy for prolonged periods before they feel they can disclose issues related to their eating. Further, Wanlass, Moreno and Thompson (2005) found that ten participants reported specific concerns regarding therapy including difficulty trusting and not feeling safe in a group. Identifying and understanding the reasons why individuals who experience eating difficulties avoid seeking help could lead to more effective interventions that are specifically aimed at increasing the likelihood of seeking help for an eating disorder (Hackler, Vogel & Wade, 2010).

Social identity theory seems pertinent to the discussion here. Social identity theory was first developed by Tajfel (1978, 1979) and proposed that individuals have a need to achieve and maintain a positive identity within society to maintain self-esteem (Ison & Kent, 2010). However, some groups, such as those who have been labelled with a mental health diagnosis, can be perceived negatively by the rest of society, which can make it difficult for people to obtain a positive identity because they can be considered to belong to a group that is of a low status (Hall & Cheston, 2002).

Tajfel (1979) proposed three main processes that underpin social identity theory including social categorization, social comparison and social identity. Social categorizations 'create and define the individual's place in society' (Tajfel, 1979, p. 40). Trepte (2006) argued that we categorize ourselves into various groups such as social class, gender, sports and so on, although not all of these groups share the same significance. In addition, we evaluate and compare ourselves with others against within the group we belong to which is referred to as social comparison (Trepte, 2006). Social identity is a process beyond social categorization which Tajfel (1982) defined as 'part of the individual's self-concept which derives from their knowledge of the membership of a social group (or groups) together with the value and emotional significance attached to that membership' (p. 63). The theory proposes that the individuals' main aim is to achieve a positive social identity.

The participants in this study recognized a shift in their social identity after diagnosis and described their perception of the out group, that is, people without an eating disorder. For example, Hana explained that her eating disorder was viewed as taboo and as result, anticipated rejection which influenced her decision to conceal her eating disorder. When she could conceal it no more, her eating disorder did not allow her to achieve and maintain a positive identity and instead she was viewed as belonging to a stigmatizing group which is not considered the norm within society (Hall & Cheston, 2002).

6. *Perception of care when receiving a diagnosis*

Participants' perception of the patient-therapist relationship and interpersonal qualities is an important finding from this study. Participants often expressed uncertainty and dissatisfaction in regards to the communication between the clinician and themselves. Participants often felt that they had not received sufficient information in regards to what classified them as having an eating disorder. There were concerns related to the lack of discussion with questions not being answered satisfactorily, often leaving participants feeling confused. Consistent with previous research examining the patients' perspectives on therapist characteristics, the theme of passivity is evident whereby participants experienced the therapist as being inactive and unengaged resulting in feelings of loneliness (Gulliksen et al., 2012). Participants' perception of the patient-therapist relationship and interpersonal qualities seemed to be related to poor introductions, not allowing participants to talk, not asking participants how they felt about their diagnosis, cold responses to emotion shown and limiting conversation to a 'clinician-patient' dialogue. Echoing a previous study (Escobar-Koch et al., 2010), one of the main barriers for patients' involvement in their care referred to the lack of individualised care they received. This included not being able to voice their own opinions and ask questions; there also appeared to be a strong desire to be involved in their own treatment by being able to make active decisions. These findings also support previous

literature that explored the experience of disregard whereby the therapist fails to pay attention to the patients' feelings and opinions, displaying a lack of care and compassion for the patient (Gulliksen et al., 2012). Similarly, previous research examined the experience and meaning of compassion found that participants largely associated this with kindness towards people and that compassion requires action, which involves practical and emotional support (Pauley & McPherson, 2010). In line with previous findings (Escobar-Koch et al., 2010), participants identified client-centred care as an essential aspect of eating disorder services. Similarly, Bell's (2003) review of qualitative literature and consumer related studies found that participants' responses highlighted the importance of support, understanding and empathic relationships. Pitt et al., (2009) found that the lack of information provided to participants was one of the main causes of disempowerment. Similar to Rogers (1957), a humanistic psychologist and founder of person-centred therapy, who theorised that several conditions were essential for facilitating the patient's distress and for allowing change to occur. This included a relationship, the state of the client, the therapist's genuineness in the relationship, unconditional positive regard, empathy and the clients' perception of the therapist. It is possible that the lack of these therapeutic conditions meant that participants in this study felt they were unable to explore and make sense of their diagnosis.

Participants also stressed the importance of receiving adequate care after they received their diagnosis. Previous findings (Clinton, 2001; Clinton, Bjorck, Sohlberg & Norring, 2004) found that feeling supported by clinicians throughout the recovery process is an important predictor for patients' satisfaction. Furthermore, receiving continuous support from services during all stages of patients' treatment has shown to be important to patients. Escobar-Koch et al., (2010) have also shown that participants experienced a lack of long-term care provided by eating disorder services. For instance, patients were often discharged once they had reached their target weight, even though they still required further psychological treatment, without which their risk of relapse increased.

All participants spoke about the positive impact of receiving a diagnosis with recovery being an important aspect. Kubler-Ross (1969) found that patients reach a stage of acceptance if they have had enough time and support to work through the other stages of grief. Importantly, she highlights that acceptance should not be confused with happiness and as she states in her discussion of *On Grief and Grieving*, “we will never like this reality or make it okay, but eventually we accept it. We learn to live with it. It is the new norm with which we must learn to live. This is where our final healing and adjustment can take a firm hold, despite the fact that healing often looks and feels like an unattainable state” (Kubler-Ross & Kessler 2005, p.25).

A number of participants spoke about feeling fed up with living with their eating disorder and the significant effect that it had on themselves and on those around them. This fits with existing literature as Rorty et al., (1993) found that the majority of participants were motivated to recover because they realised how much their eating disorder dominated their lives, acknowledging that it was a problem for them. In accordance with previous findings, some participants experienced the diagnosis positively as they felt that naming the problem gave them a sense of relief because it gave them an explanation to their behaviour (Pitt et al., 2009). The diagnosis allowed participants to make sense of their symptoms which supports Karp’s (1992) claim that receiving a diagnosis could mean the process of interpreting meaning to the illness despite the feelings experienced by the label. The diagnosis was often interpreted as something that was clinically recognised which diminished feelings of blame and that participants were making things up. The diagnosis made life easier and helped participants to better understand and make sense of what they were experiencing and allowed them to access treatment. Participants also felt that the diagnosis allowed them to develop a stronger self to which they attributed different meanings. This included accepting the diagnosis, becoming physically and psychologically stronger and regaining control over themselves and their eating disorder. The diagnosis was seen as the start of a new beginning

which became more of reality to a number of participants. With a diagnosis, participants felt that they no longer had to explain themselves to others. Knowing that other people suffered from eating disorders was a positive experience as well as being able to help other people who were also suffering. These findings support Coles (2010) in that receiving a diagnosis appeared to legitimise much distress for participants.

## **7. Implications for clinical practice**

This study provides further insight into the phenomenon of receiving a diagnosis of an eating disorder and has important implications for clinicians in their role in imparting diagnoses. Furthermore, the findings from this research suggest that there is a need to investigate how the initial contact with the clinician can be strengthened and how this may influence a patient's response to a diagnosis, treatment and their recovery. In particular, there is a need for compassionate care among individuals suffering with eating disorders. Several participants in this study felt that the clinician lacked basic components of care including not treating patients like human beings, not being empathetic, seemingly withholding sufficient information about the diagnosis and a lacking in emotional support. For many participants, the lack in care determined whether or not they felt comfortable to open up to the clinician and also appeared to impact how patients responded to their diagnosis.

If we are to think of ways of moving forward, we need to focus our attention on how clinicians work in everyday, real-life settings and promote their development by helping clinicians learn new ways of focusing on their strengths and improving their weaknesses (Clinton, 2010). In considering this, it is useful to focus on the notion of compassion. Cole-King and Gilbert (2011) highlight key attributes which appear useful in terms of understanding how clinicians develop their compassion which will be explored next.

It is important that clinicians are motivated to be caring, supportive and helpful to their patients. Cole-King and Gilbert (2011) argue that motivation is a fundamental component

that shapes the other attributes such as sensitivity, sympathy, empathy and being non-judgemental. Sensitivity requires the clinician to pay attention to when the patient needs help (Cole-King & Gilbert, 2011). The clinician can therefore not be in a rush, too busy or pre-occupied with other tasks, which several participants in this study experienced. Sympathy involves the clinicians' emotional response to the patients suffering or distress. In the present study, the participants often experienced a great deal of anxiety; for the clinician who wants to develop or extend compassion, they must be moved by their patient's suffering or distress and want to do something to help relieve the patient (Cole-King & Gilbert, 2011). Distress tolerance requires the clinician's ability to cope with difficult emotions within themselves and for their patients which some clinician's might find difficult and this is perhaps why they turn away from their patient (Cole-King & Gilbert, 2011).

Empathy has shown to be an important attribute missing in clinicians' practice according to participants in this study. Empathy has both emotional and cognitive elements: it requires the ability to recognise another human being's feelings, motivation and intentions and to be able to make sense of their feelings as well and to be able to make sense of our own emotional responses (Cole-King & Gilbert, 2011). Finally, being non-judgemental, refers to not placing a negative value on a person's pain or distress and accepting and validating their experience. Similarly, Rorty, Yager and Rossotto (1993) argued the importance of being empathetic, understanding and respecting the patient as a whole person and not as a collection of symptoms. The findings from this study suggest that as clinicians, it is important to spend time with patients explaining the diagnosis, what it means and exploring the positive and negative impact of the diagnosis. Clinicians should also be encouraged to promote patient participation as this may benefit patients' satisfaction and enhance therapeutic success (Rorty et al., (2011).

Considering the impact of culture during the diagnosis and treatment process is important for culturally diverse patients. As found in this study, receiving a diagnosis can add

further complexities when the patient has a different cultural background to the clinicians. It is therefore important for clinicians to have some knowledge about, and be sensitive to, their patients' cultural background. It seems particularly important to also focus on how the patient personally defines their diagnosis and expresses their symptoms. The term, 'eating disorder', has shown to be powerful for many participants with several misconceptions being associated with it which contributed to people's disbelief and rejection of their diagnosis. Educating everyone about eating disorders and providing accurate information about the various eating disorder diagnoses is therefore crucial, together with identifying self-help and support networks.

There is a need to address the stigma associated with eating disorders. A majority of the participants spoke about the negative perception of their eating disorder which induced their fear of stigmatization. Participants often described feelings of shame and blame, and feared that others perceived them negatively. The stigma surrounding eating disorders was highlighted and was a particular focus at the 12<sup>th</sup> International Eating Disorders Conference in early 2015. Dr Bryant-Waugh and colleagues discussed the findings from their recent study which investigated the experiences of stigma in three different groups: individuals with an eating disorder, parents, and siblings of individuals with an eating disorder. Dr Bryant-Waugh explained that the results showed that a high number of participants in all three groups rated their peers and friends highest with regards to holding stigmatizing attitudes. From this, we can see that individuals who have an eating disorder or know someone with an eating disorder perceive others as having negative views about eating disorders which may or may not accurately reflect actual perceptions.

In thinking about suggestions and strategies for reducing stigma, Evans-Lacko, Brohan, Mojtabai and Thornicroft (2012) recommended a combined approach targeted at the public which targets knowledge, attitudes and behaviours in society regarding mental ill-health. More specifically, attention should be directed at promoting the understanding of

eating disorders by targeting the general public through anti-stigma interventions. It is hoped that this may lead to a more positive cycle by reducing the negative feedback caused by public stigma, which can then reduce self-stigma among individuals with mental health issues (Evans-Lacko et al., 2012). Similarly, Corrigan and Watson (2002) focused their proposal on education, contact and protest in their strategy for tackling the stigmatization of people suffering with mental illness. The first element is education which involves improving knowledge, increasing awareness and understanding in the general public. The second is contact which involves providing support and the third is protest and involves taking action with the situation (Evans-Lacko et al., 2012). Finally, we must not forget the role of families and carers since a number of participants in this study explained that the initial concern often came from a family member.

This study found patients experienced the delivery of their diagnosis negatively. Knowing this, it is important that the clinician expresses a sense of hope and recovery when giving a diagnosis to prevent patients understanding their diagnosis in terminal ways. The positive impact surrounding the diagnosis of an eating disorder should be a particular focus, which was identified by our study in which all participants spoke about the importance of recovery and moving forward being emphasised during diagnosis. In order to encompass a richer array of relevant resources, clinicians therefore need to spend time exploring patients' definitions of recovery (Clinton, 2010).

A greater understanding between clinicians and researchers is required in order to achieve a more clinically relevant and holistic picture (Clinton, 2010). Attention should be directed towards producing more qualitative research in order get a better understanding of patients' experiences in clinical settings for treatment to be more effective. For example, involving patients more in research and gaining their perspectives on what constitutes success in the diagnosis, assessment and treatment of eating disorders could be recommended for future studies.

Based on this study's findings, there is a need for further training for professionals working in the eating disorders field in order to gain a better understanding of the positive and negative impact of diagnosis. Increasing the awareness of the experiences of patients, parents, carers and siblings is therefore essential. Further work exploring the experience and consequence of stigma in family members and the attitudes of professionals towards people with eating disorders may be worthwhile.

#### **8. Evaluation and critique of the research study**

This study was evaluated using Yardley's (2000) four criteria to evaluate the quality of research. The first criterion involves sensitivity to context. I have shown sensitivity to the theory by providing the reader with a review of the relevant literature to the phenomenon under investigation. I have attempted to show sensitivity to the participants by asking them to talk about their experiences which they felt were important and let them know they could leave the research at any time. I have shown sensitivity to ethical issues and protecting the interests of the participants by undergoing NHS ethical approval in addition to the universities ethical procedure. I have shown sensitivity to the data by carefully transcribing and analysing the interviews myself which allowed me to thoroughly engage with the data. Several months were devoted to thinking carefully about the interpretations of the data and engaging with IPA.

The second criterion involves commitment and rigour. I have ensured that I have continued to keep up-to-date in the eating disorders field by reading the relevant literature and I have attended international eating disorders conferences. I have developed and maintained a strong professional relationship with the eating disorders service where the participants were recruited from and I have presented my findings for an article as part of the eating disorders awareness week.

The third criterion involves transparency and openness. Throughout the research process, I have been transparent and open about all aspects of the research including the literature review, methodology, methods, data collection and analysis. I have engaged with regular supervision and I have kept a research diary. I have presented clear and concise findings to other researchers and clinicians who have knowledge about diagnosis and eating disorders and have encouraged feedback and critique throughout the process. A limitation of this study involves the small sample size and that all of the participants were recruited from one NHS eating disorders service. It would most certainly be worthwhile to explore patients' experiences using a larger sample size. While this study did not exclude anyone, all of the participants that were recruited were female and therefore did not capture male's experiences which would be valuable for considering for future research.

The fourth criterion involves impact and importance. This study has explored the notion of diagnosis, a topic that is fundamental to the practice of mental health and which continues to undergo much debate across a number of different disciplines including psychiatry, clinical psychology and counselling psychology. This study has narrowed its scope to focus specifically on patients' experiences of receiving a diagnosis of an eating disorder. To the researcher's knowledge, this is a novel piece of research which adds further insight into the phenomenon of eating disorders. The women that participated in this study had all received a different eating disorder diagnosis including anorexia nervosa, bulimia nervosa, EDNOS and binge-eating disorder. To date, anorexia nervosa has received more attention in the literature compared with the other eating disorder diagnoses. The findings from this study may therefore provide a valuable contribution to extend our knowledge across eating disorder diagnoses and the impact that diagnosis can have on individuals who experience eating disorders.

## **9. Relevance of study to counselling psychology**

Counselling psychology was officially recognised in 1994 by the British Psychological Society as a distinct and unique profession (Corrie & Callahan, 2000). Counselling psychologists work within a wide range of settings including the NHS, inpatient and outpatient mental health settings, forensic settings, private practice, academic and research settings. The NHS in particular has become an increasingly common setting for counselling psychologists where the diagnostic classification is a dominant language for understanding an individual's difficulties (Golsworthy, 2004). This may result in counselling psychologists finding themselves in a difficult position whereby they feel they have to adopt a medical discourse instead of a humanistic approach (Larsson, Brooks & Loewenthal, 2012).

As counselling psychologists, we argue that we do not work from the assumption of pathology and yet, we conceptualise psychological processes using modalities that are 'disorder' specific. Within the literature, Douglas (2010) questioned how counselling psychologists can "retain a humanistic value base within a framework dominated by a medical model of distress in which treatment guidelines focus on disorder" (p. 24). Similarly, Sequeira and Van Scoyoc (2002) raised issues relating to the maintenance of a professional identity that is grounded in humanism and at the same time using a system where psychiatric discourse is dominant. As a result, it is not surprising that counselling psychologists might experience ambivalence in terms of whether they choose to align themselves on a more clinical model or a more relational one (Golsworthy, 2004; Larsson et al., 2012). Within counselling psychology literature, there appear to be two conflicting epistemological positions (Williams & Irving, 1996). The first is that counselling psychology should value a phenomenological experience of the individual without assumption and without the use of labels as found in diagnostic categories (Larsson et al., 2012). The second assumes a more empiricist view, whereby counselling psychology should be more willing to engage with and support the use of diagnostic categories (Larsson et al., 2012).

While diagnoses can be helpful, it can also add another dimension to an individual's difficulties as found in the present study. Given the controversy surrounding diagnostic systems such as the DSM (Welch, Klassen, Borisova, & Clothier, 2013), it seems that counselling psychologists are in a position to make valuable contributions with regards to gaining a better understanding of the potential positive and negative aspects of diagnosis and how this interacts with our work. An increased awareness of the patients' experience may therefore help in developing stronger therapeutic alliances and develop new interventions.

This research is particularly relevant to counselling psychology as it is a qualitative piece of research that has explored patients' experiences of receiving a diagnosis of an eating disorder. In this study, although the majority of participants were resistant to the use of diagnostic categories which was mainly based on concerns related to labelling and stigma, participants also described positive experiences of diagnosis. Similarly, counselling psychologists appear conflicted as on the one hand, there is a need to engage with diagnostic classification, and on the other hand, there is also a resistance based on concerns related to losing their identity as counselling psychologists (Larsson et al., 2012).

To this end, the debate will remain as to whether counselling psychologists, who move closer towards to the NHS, will be able to maintain their value of non-pathologizing within an environment that appears to be dominated by a medical model (Larsson et al., 2012). More attention should therefore be focused on counselling psychologists' experiences of working within this framework.

## **10. Conclusion**

This research has endeavoured to contribute to the existing research within the field of eating disorders by exploring patients' experiences of receiving a diagnosis of an eating disorder. The interviews allowed an in-depth exploration of participants' experiences which revealed four overarching themes: living with an unlabelled condition, perception of the patient-therapist relationship and interpersonal qualities, living with the diagnostic label and a pathway to recovery. These themes have shown to be fundamental in terms of raising awareness of the patients' perspective and gaining a better understanding of the positive and negative impact that a diagnosis can have on people with an eating disorder. The research has demonstrated that the impact of receiving and living with a diagnosis of an eating disorder should be considered throughout a patient's assessment and treatment process.

As we have seen, much attention has focused on the controversies and challenges surrounding the diagnostic classification of eating disorders. It seems that we need to be working together, bringing researchers and clinicians closer together if we are to address these challenges and make diagnosis more clinically relevant (Clinton, 2012). Most importantly, we need to focus on involving our patients more in the work that we do. According to this study's findings, understanding the person with an eating disorder in their entirety and placing value on their input could lead to better perceived therapeutic practice and more holistic recoveries for patients.

## REFERENCES

- Agras, W. S., Walsh, B. T., Fairburn, C. G., Wilson, G.T., & Kraemer, H.C. (2000). A multicentre comparison of cognitive-behavioural therapy and interpersonal psychotherapy for bulimia nervosa. *Archives of General Psychiatry*, *57*, 459–466.
- Alarcon, R. D. (2009). Culture, cultural factors and psychiatric diagnosis: review and projections. *World Psychiatry*, *8*, 131-139.
- Alarcon, R., Westermeyer, J., Foulks, E., & Ruiz, P. (1999). Clinical relevance of contemporary cultural psychiatry. *The Journal of Nervous & Mental Disease*, *187*, 465-471.
- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders*. Washington, DC: American Psychiatric Association.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders*. Washington, DC: American Psychiatric Association.
- Attia, E., & Roberto, C. (2009). Should amenorrhea be a diagnostic criterion for anorexia nervosa? *International Journal of Eating Disorders*, *42*, 581-589.
- Attride-Stirling, J. (2001). Thematic networks: an analytic tool for qualitative research. *Qualitative Research*, *1*, 385-405.

- Batstra, L., & Frances, A. (2012). Diagnostic inflation: Causes and a suggested cure. *The Journal of Nervous and Mental Disease*, 200, 474–479.
- Beating Eating Disorders. (2015). *Types of eating disorder*. Retrieved from <http://www.beat.co.uk/about-eating-disorders/types-of-eating-disorder>
- Bell, L. (2003). What can we learn from consumer studies and qualitative research in the treatment of eating disorders? *Eating and weight disorders - Studies on anorexia, bulimia and obesity*, 8, 181-187.
- Bentall, R. (2009). *Doctoring the mind: Why psychiatric treatments fail?* London, England: Allen Lane.
- Birgegard, A., Norring, C., & Clinton, D. (2012). DSM-IV versus DSM-5: Implementation of proposed DSM-5 criteria in a large naturalistic database. *International Journal of Eating Disorders*, 45, 353-361.
- Borg, M., Karlsson, B., & Kim, H. S. (2009). User involvement in community mental health services: Principles and practices. *Journal of Psychiatric and Mental Health Nursing*, 16, 285-292.
- Boyle, M. (2007). The problem with diagnosis. *The Psychologist*, 20, 290 - 292.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77-101.

- Brauser, D. (2013). *APA Answers Criticism of Pharma-Influenced Bias in DSM-5*. Retrieved from <http://www.medscape.com/viewarticle/777132>
- Broussard, B. (2005). Women's experiences of bulimia nervosa. *Journal of Advanced Nursing*, *49*, 43-50.
- Button, E. J., & Warren, R. L. (2001). Living with anorexia nervosa: the experience of a cohort of sufferers from anorexia nervosa 7.5 years after initial presentation to a specialized eating disorders service. *European Eating Disorders Review*, *9*, 74-96. doi: 10.1002/erv.400
- Cachelin, F. M., & Striegel-Moore, R. H. (2006). Help seeking and barriers to treatment in a community sample of Mexican American and European American women with eating disorders. *International Journal of Eating Disorders*, *39*, 154-161.
- Clark, L. A., Watson, D., & Reynolds, S. (1995). Diagnosis and classification of psychopathology: Challenges to the current system and future directions. *Annual Review of Psychology*, *46*, 121–153.
- Clinton D. (2001). Expectations and experiences of treatment in eating disorders. *The Journal of Treatment & Prevention*, *9*, 361–371.
- Clinton, D. (2010). Towards an ecology of eating disorders: Creating sustainability through the integration of scientific research and clinical practice. *European Eating Disorders Review*, *18*, 1-9.

- Clinton, D., Bjorck, C., Sohlberg, S., & Norring, C. (2004). Patient satisfaction with treatment in eating disorders: Cause for complacency or concern? *European Eating Disorders Review, 12*, 240–246. doi: 10.1002/Erv.582
- Cole-king, A., & Gilbert, P. (2011). Compassionate care: The theory and the reality. *Journal of Holistic Healthcare, 8*, 29-37.
- Coles, S. (2010). *Position on psychiatric diagnosis: East midlands psychosis and complex mental health special interest group*. Retrieved from [http://www.bcu.ac.uk/cmsproxyimage?path=/media/docs/ccmh\\_emids\\_sig.pdf](http://www.bcu.ac.uk/cmsproxyimage?path=/media/docs/ccmh_emids_sig.pdf)
- Colton, A., & Pistrang, N. (2004). Adolescents' experiences of inpatient treatment for anorexia nervosa. *European Eating Disorders Review, 12*, 307-316. doi: 10.1002/erv.587
- Cooper, Z., & Fairburn, C. G. (2011). The evolution of “enhanced” cognitive behaviour therapy for eating disorders: Learning from treatment nonresponse. *Cognitive and Behavioural Practice, 18*, 394-402.
- Corbin, J., & Strauss, A. (1990). Grounded theory research: Procedures, canons and evaluative criteria, *Qualitative Sociology, 13*, 3–21.
- Corrie, S., & Callahan, M. (2000). Counselling Psychology: A review of the scientist-practitioner model: Reflections on its potential contribution to counselling psychology within the context of current health care trends. *British Journal of Medical Psychology, 73*, 413-427.

- Corrigan, P. W. (2004). Target-specific stigma change: A strategy for impacting mental illness stigma. *Psychiatric Rehabilitation Journal, 28*, 113–121.
- Corrigan, P. W., & Watson, A. C. (2002). Understanding the impact of stigma on people with mental illnesses. *Journal of World Psychiatry, 1*, 6–19.
- Corrigan, P. W., & Watson, A. C. (2002). Understanding the impact of stigma on people with mental illnesses. *Journal of World Psychiatry, 1*, 6–19.
- Cosgrove, L., & Krinsky, S. (2012). A comparison of *DSM-IV* and *DSM-5* panel members' financial associations with industry: A pernicious problem persists. *PLoS Medicine, 9*, doi:10.1371/journal.pmed.1001190
- Cottee-Lane, D., Pistrang, N., & Bryant-Waugh, R. (2004). Childhood onset anorexia nervosa: The experience of parents. *European Eating Disorders Review, 12*, 169-177.
- Couturier, J., Isserlin, L., & Lock, J. (2010). Family-based treatment for adolescents with anorexia nervosa: A dissemination study. *The Journal of Treatment and Prevention, 18*, 199-209.
- Crisp, A. (2005). Stigmatization of and discrimination against people with eating disorders including a report of two nationwide surveys. *European Eating Disorders Review, 13*, 147-152.
- Crisp, A. H., Gelder, M. G., Rix, S., Meltzer, H. I., & Rowlands, O. J. (2000). Stigmatization of people with mental illnesses. *The British Journal of Psychiatry, 177*, 4-7.

- Crossley, M. (2000). *Introducing narrative psychology: Self, trauma, and the construction of meaning*. Buckingham, England: Open University Press.
- Dare, C., & Eisler, I. (1997). Family therapy for anorexia nervosa. In D. M. Garner & P. E. Garnek (Eds.), *Handbook of treatment for anorexia nervosa and bulimia nervosa* (pp. 307-326). New York: Guilford Press.
- Dare, C., Eisler, I., Russell, G., Treasure, J., & Dodge, L. (2001). Psychological therapies for adults with anorexia nervosa: Randomised controlled trial of out-patient treatments. *The British Journal of Psychiatry*, 178, 216-221.
- De La Rie, S., Noordenbos, G., Donker, M., & Van Furth, E. (2006). Evaluating the treatment of eating disorders from the patient's perspective. *International Journal of Eating Disorders*, 39, 667-676.
- Douglas, B. (2010). Disorder and its discontents. In R. Woolfe, S. Strawbridge, B. Douglas & W. Dryden (Eds.), *Handbook of counselling psychology* (pp. 23-43). London: Sage.
- Eisler, I., Dare, C., Hodes, M., Russell, G., Dodge, E., & Grange, D. (2000). Family therapy for adolescent anorexia nervosa: The results of a controlled comparison of two family interventions. *Journal of Child Psychology and Psychiatry*, 41, 727-736.
- Elliott, R., Fischer, C., & Rennie, D. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, 38, 215-229.

- Eriksen, K., & Kress, V. E. The DSM and the professional counselling identity: Bridging the gap. *Journal of Mental Health Counseling, 28*, 202-217.
- Escobar-Koch, T., Banker, J., Crow, S., Cullis, J., Ringwood, S., Smith, G., ... Schmidt, U. (2010). Service users' views of eating disorder services: An international comparison. *International Journal of Eating Disorders, 43*, 549-559.
- Evans-Lacko, S., Brohan, E., Mojtabai, R., & Thornicroft, G. (2012). Association between public views of mental illness and self-stigma among individuals with mental illness in 14 European countries. *Psychological Medicine, 42*, 1741-1752.
- Fairburn, C. G. (2008). *Cognitive behaviour therapy and eating disorders*. New York: Guilford Press.
- Fairburn, C. G., & Bohn, K. (2005). Eating disorder NOS (EDNOS): An example of the troublesome "not otherwise specified" (NOS) category in DSM-IV. *Behaviour Research and Therapy, 43*, 691-701.
- Fairburn, C. G., & Cooper, Z. (2011). Eating disorders, DSM-5 and clinical reality. *The British Journal of Psychiatry, 198*, 8-10. doi: 10.1192/bjp.bp.110.083881
- Fairburn, C. G., Cooper, Z., & Shafran, R. (2003). Cognitive behaviour therapy for eating disorders: A "transdiagnostic" theory and treatment. *Behaviour Research and Therapy, 41*, 509-528.

- Fairburn, C. G., Cooper, Z., Bohn, K., O'Connor, M., Doll, H., & Palmer, R. (2007). The severity and status of eating disorder NOS: Implications for DSM-V. *Behaviour Research and Therapy*, 1705-1715.
- Fairburn, C. G., Cooper, Z., Shafran, R., Bohn, K., Hawker, D., Murphy, R., & Straebl, S. (2008). Enhanced cognitive behaviour therapy for eating disorders: The core protocol. In C. G. Fairburn (Eds.), *Cognitive behaviour therapy and eating disorders* (pp. 45-72). New York: Guilford Press.
- Finlay, L. (2003). *Reflexivity: A practical guide for researchers in health and social sciences*. Malden: Blackwell Science.
- First, M. B. (2010a). Clinical utility in the revision of the diagnostic and statistical manual of mental disorders (DSM). *Professional Psychology: Research and Practice*, 41, 465-473.
- First, M. B. (2010b). Paradigm shifts and the development of the diagnostic and statistical manual of mental disorders: Past experiences and future aspirations. *The Canadian Journal of Psychiatry* 55, 692–700.
- Flament, M., Buchholz, A., Henderson, K., Obeid, N., Maras, D., Schubert, N., ... Goldfield, G. (2015). Comparative distribution and validity of DSM-IV and DSM-5 diagnoses of eating disorders in adolescents from the Community. *European Eating Disorders Review*, 23, 100-110.

- Fletcher, R. (2012). Introduction: Dealing with diagnoses. In M, Milton (Eds.), *Diagnosis and beyond: Counselling contributions to understanding human distress* (pp. 1-6). Ross-on-Wye: PCCS Books.
- Fox, A., Larkin, M., & Leung, N. (2010). The personal meaning of eating disorder symptoms: An interpretative phenomenological analysis. *Journal of Health Psychology, 16*, 116-125. doi: 10.1177/1359105310368449
- Fox, J., & Diab, P. (2013). An exploration of the perceptions and experiences of living with chronic anorexia nervosa while an inpatient on an eating disorders unit: An interpretative phenomenological analysis (IPA) study. *Journal of Health Psychology, 20*, 27-36.
- Frances, A. (2009). *A warning sign on the road to DSM-V: Beware of its unintended consequences*. Retrieved From <http://www.psychiatrictimes.com/articles/warning-sign-road-dsm-v-beware-its-unintended-consequences>
- Frances, A. (2010). *Rating scales: DSM5 bites off far more than it can chew*. Retrieved from <http://www.psychiatrictimes.com/articles/rating-scales-dsm5-bites-far-more-it-can-chew>
- Frances, A. J., First, M. B., & Pincus, H. A. (1995). *DSM-IV guidebook*. Washington, DC: American Psychiatric Press.

- Frances, A. L., & Widiger, T. A. (2012). Psychiatric diagnosis: Lessons from the DSM-IV past and cautions for the DSM-5 future. *The Annual Review of Clinical Psychology, 8*, 109-130. doi: 10.1146/annurev-clinpsy-032511-143102
- Frances, A., & Nardo, J. (2013). ICD-11 should not repeat the mistakes made by DSM-5. *The British Journal of Psychiatry, 203*, 1-2. doi: 10.1192/bjp.bp.113.127647
- Giorgi, A. (1992). Description versus interpretation: Competing alternative strategies for qualitative research. *Journal of Phenomenological Psychology, 23*, 119-229.
- Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory, strategies for qualitative research*. New York: Aldine.
- Golsworthy, R. (2004). Counselling psychology and psychiatric classification: Clash or co-existence? *Counselling Psychology Review, 19*, 23–28.
- Gulliksen, K., Espeset, E., Nordbo, R., Skarderud, F., Geller, J., & Holte, A. (2012). Preferred therapist characteristics in treatment of anorexia nervosa: The patient's perspective. *International Journal of Eating Disorders, 45*, 932-941.
- Hackler, A., Vogel, D., & Wade, N. (2010). Attitudes toward seeking professional help for an eating disorder: The role of stigma and anticipated outcomes. *Journal of Counseling & Development, 88*, 424-431.
- Hall, S., & Cheston, R. (2002). Mental health and identity: The evaluation of a drop-in centre. *Journal of Community and Applied Social Psychology, 12*, 30–43.

- Hartmann, A., Zeeck, A., & Barrett, M. (2010). Interpersonal problems in eating disorders. *International Journal of Eating Disorders, 1*, 619-627.
- Hayne, Y. (2003). Experiencing psychiatric diagnosis: Client perspectives on being named mentally ill. *Journal of Psychiatric and Mental Health Nursing, 10*, 722-729.
- Heidegger, M. (1962). *Being and time*. Oxford: Blackwell Publishers.
- Holliday, J., Wall, E., Treasure, J., & Weinman, J. (2005). Perceptions of illness in individuals with anorexia nervosa: A comparison with lay men and women. *International Journal of Eating Disorders, 37*, 50-56.
- Horn, N., Johnstone, L., & Brooke, S. (2007). Some service user perspectives on the diagnosis of personality disorder. *Journal of Mental Health 16*, 255-269.
- Howitt, D. (2010). *Introduction to qualitative methods in psychology*. Harlow: Pearson Education.
- Husserl, E. (1927). *Phenomenology*. Retrieved from <http://www.scribd.com/doc/60798124/60798124/Husserl-Encyclopedia-Britannica-Article#scribd>
- Ison, J., & Kent, S. (2010). Social identity in eating disorders. *European Eating Disorders Review 18*, 475-485. doi: 10.1002/erv.1001

- Joffe, H. (2012). Thematic analysis. In D. Harper & A. R Thompson (Eds.), *Qualitative research methods in mental health and psychotherapy* (pp. 209-223), Chichester: John Wiley.
- Jones, K. D. (2012b). Dimensional and cross-cutting assessment in the DSM-5. *Journal of Counselling & Development, 90*, 481-487.
- Karp, D. A. (1992) Illness ambiguity and the search for meaning. *Journal of Contemporary Ethnography 21*, 139–170.
- Kass, F., Skodol, A., Charles, E., Spitzer, R., & Williams, J. (1985). Scaled ratings of *DSM-III* personality disorders. *American Journal of Psychiatry, 142*, 627–630.
- Keel, P., Brown, T., Holm-Denoma, J., & Bodell, L. (2011). Comparison of DSM-IV versus proposed DSM-5 diagnostic criteria for eating disorders: Reduction of eating disorder not otherwise specified and validity. *International Journal of Eating Disorders, 44*, 553-560.
- Kendler, K. S., & First, M. B. (2010). Alternative futures for the DSM revision process: Iteration v. paradigm shift. *The British Journal of Psychiatry, 197*, 263–265.
- Klerman, G.L., Weissman, M. M., Rounsaville, B. J., & Chevron, E. S. (1984). *Interpersonal psychotherapy of depression*. New York: Basic Books.
- Kraemer, H. C. (2007). DSM categories and dimensions in clinical and research contexts. *International Journal of Methods in Psychiatric Research, 16*, 8-15.

- Kubler-Ross, E. (1969) *On Death and Dying: What the dying have to teach doctors, nurses, clergy and their own families*. London: Routledge.
- Kubler-Ross, E., & Kessler, D. (2005). *On Grief and Grieving: Finding the meaning of grief through the five stages of Loss*. London: Simon & Schuster UK Ltd.
- Kupfer, D. J., & Regier, D. A. (2009). *Toward credible conflict of interest policies in clinical psychiatry [Counterpoint]*. Retrieved from [http://www.psychiatrictimes.com/display/article/10168/1364672?pageNumber\\_2](http://www.psychiatrictimes.com/display/article/10168/1364672?pageNumber_2)
- Langdridge, D. (2007). *Phenomenological psychology: Theory, research and method*. Harlow, England: Pearson Education Limited.
- Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology, 3*, 102-120.
- Larrison, P., Brooks, O., & Loewenthal, D. (2012). Counselling psychology and diagnostic categories: A critical literature review. *Counselling Psychology Review, 27*, 55-67.
- Larsen, J.A. (2004) Finding meaning in first episode psychosis: experience, agency, and the cultural repertoire. *Medical Anthropology Quarterly, 18*, 447-471.
- Le Grange, D., Eisler, I., Dare, C., & Russell, G. (1992). Evaluation of family treatments in adolescent anorexia nervosa: A pilot study. *International Journal of Eating Disorders, 12*, 347-357.

- Link, B. G., Cullen, F. T., Struening, E., Shrout, P. E., & Dohrenwend, B. P. (1989). A modified labelling theory approach to mental disorders: An empirical assessment. *American Sociological Review*, *54*, 400-423.
- Link, B., Struening, E., Neese-Todd, S., Asmussen, S., & Phelan, J. (2001). Stigma as a barrier to recovery: The consequences of stigma for the self-esteem of people with mental illnesses. *Psychiatric Services*, *52*, 1621-1626.
- Lock, J., & Le Grange, D. (2005). Family-based treatment of eating disorders. *International Journal of Eating Disorders*, *37*, 564-567.
- Loeb, K., Walsh, B., Lock, J., Grange, D., Jones, J., Marcus, S., & Dobrow, I. (2007). Open trial of family-based treatment for full and partial anorexia nervosa in adolescence: Evidence of successful dissemination. *Journal of the American Academy of Child & Adolescent Psychiatry*, *46*, 792-800.
- Lyons, M. A. (1998). The phenomenon of compulsive overeating in a selected group of professional women. *Journal of Advanced Nursing* *27*, 1158–1164.
- Magliano, L., Fiorillo, A., Malangone, C., Vecchio, H., & Maj, M. (2008). Views of persons with schizophrenia on their own disorder: An Italian participatory study. *Psychiatric Services*, *59*, 795-799.
- Maser, J. D., Kaelber, C., & Weise, R. F. (1991). International use and attitudes toward *DSM-III* and *DSM-III-R*: Growing consensus in psychiatric classification. *Journal of Abnormal Psychology*, *100*, 271–279.

- McAdams, D. (1993). *The stories we live by: Personal myths and the making of the self*. New York: William Morrow.
- McLeod, J. (2001). *Qualitative research in counselling and psychotherapy*. London: Sage.
- Meyer, D. F. (2001). Help-seeking for eating disorders in female adolescents. *Journal of College Student Psychotherapy, 15*, 23–36.
- Milton, M. (2012). *Diagnosis and beyond: Counselling psychology contributions to understanding human distress*. Ross-on-Wye: PCCS Books.
- Mond, J., Hay, P., Rodgers, B., Owen, C., & Beumont, P. (2004). Beliefs of women concerning the severity and prevalence of bulimia nervosa. *Social Psychiatry and Psychiatric Epidemiology, 39*, 299–304.
- Mond, J., Robertson-Smith, G., & Vetere, A. (2006). Stigma and eating disorders: Is there evidence of negative attitudes towards anorexia nervosa among women in the community? *Journal of Mental Health, 15*, 519-532.
- Moran, M. (2008). Senator wants APA records of drug-industry interactions. *Psychiatric News, 43*, 1-3.
- Murphy, R., Straebl, S., Basden, S., Cooper, Z., & Fairburn, C. G. (2012). Interpersonal psychotherapy for eating disorders. *Clinical Psychology and Psychotherapy, 19*, 150-158.

- Murray, S. B., & Le Grange, D. (2014). Family therapy for adolescent eating disorders: An update. *Current Psychiatry Report, 16*, 447. doi: 10.1007/s11920-014-0447-y
- Murray, Wallis., & Rhodes (2012) The questioning process in maudslay family-based treatment: Part 1. Deviation Amplification. *Contemporary Family Therapy, 34*, 582-592.
- Nakai, Y., Fukushima, M., Taniguchi, A., Nin, K., & Teramukai, S. (2013). Comparison of DSM-IV versus proposed DSM-5 diagnostic criteria for eating disorders in a Japanese sample. *European Eating Disorders Review, 21*, 8-14.
- National Institute for Health and Clinical Excellence. (2004). *Core interventions in the treatment and management of anorexia nervosa, bulimia nervosa and related disorders*. Retrieved from <http://www.nice.org.uk/CG009>
- Newton, J. T., Robinson, P. H., & Hartley, P. (1993). Treatment for eating disorders in the United Kingdom. Part II. Experiences of treatment: A survey of members of the eating disorders association. *European Eating Disorders Review, 1*, 1, 10-21.
- Newton, T. (2001). Consumer involvement in the appraisal of treatments for people with eating disorders: A neglected area of research? *European Eating Disorders, 9*, 301-308. doi: 10.1002/erv.435
- Nordbo, R., Espeset, E., Gulliksen, K., Skarderud, F., & Holte, A. (2006). The meaning of self-starvation: Qualitative study of patients' perception of anorexia nervosa. *International Journal of Eating Disorders, 39*, 556-564.

- Offord, A., Turner, H., & Cooper, M. (2006). Adolescent inpatient treatment for anorexia nervosa: A qualitative study exploring young adults' retrospective views of treatment and discharge. *European Eating Disorders Review, 14*, 377-387.
- Osborn, M., & Smith, J. A. 1998: The personal experience of benign lower back pain: an interpretative phenomenological analysis. *British Journal of Health Psychology 3*, 65-83.
- Pauley, G., & McPherson, S. (2010). The experience and meaning of compassion and self-compassion for individuals with depression or anxiety. *Psychology and Psychotherapy: Theory, Research and Practice, 83*, 129–143.
- Paulson-Karlsson, G., Engstrom, I., & Nevonen, L. (2008). A pilot study of a family-based treatment for adolescent anorexia nervosa: 18- and 36-month follow-ups. *Eating Disorders: The Journal of Treatment and Prevention, 17*, 72-88.
- Penn, D., Guynan, K., Daily, T., Spaulding, W., Garbin, C., & Sullivan, M. (1994). Dispelling the stigma of schizophrenia: What Sort of Information Is Best? *Schizophrenia Bulletin, 20*, 567-578.
- Pettersen, G., & Rosenvinge, J. (2002). Improvement and Recovery from Eating Disorders: A patient perspective. *Eating Disorders, 10*, 61-71.
- Petty, N., Thomson, O., & Stew, G. (2012). Ready for a paradigm shift? Part 2: Introducing qualitative research methodologies and methods. *Manual Therapy, 17*, 378-384.

- Phillips, J. (2010). The muddle that is DSM-V. *Association for the Advancement of Philosophy and Psychiatry Bulletin*, 17, 10-12.
- Pike, K. M., & Striegel-Moore, R. H. (1997). Disordered eating and eating disorders. In S. J. Gallant, G. P. Keita, & R. Royak-Shaler (Eds.), *Health care for women: Psychological, social, and behavioural influences* (pp. 97-114). Washington, DC: American Psychological Association.
- Pilecki, B. C., Clegg, J. W., & McKay, D. (2011). The influence of corporate and political interests on models of illness in the evolution of the DSM. *The Journal of the European Psychiatric Association*, 26, 194–200. doi:10.1016/j.eurpsy.2011.01.005
- Pitt, L., Kilbride, M., Welford, M., Nothard, S., & Morrison, A. (2009). Impact of a diagnosis of psychosis: User-led qualitative study. *Psychiatric Bulletin*, 33, 419-423.
- Read J. (2004) Does 'schizophrenia' exist? Reliability and validity. In J. Read, R. Bentall & L. Mosher. (Eds.), *Models of Madness: Psychological, Social and Biological Approaches to Schizophrenia* (pp. 43-57). Brunner-Routledge: New York.
- Read, J., Haslam, N., Sayce, L., & Davies, E. (2006). Prejudice And Schizophrenia: A Review of the mental illness is an illness like any other' Approach. *Acta Psychiatrica Scandinavica*, 114, 303-318. doi: 10.1111/j.1600-0447.2006.00824.x
- Reid, M., Burr, J., Williams, S., & Hammersley, R. (2008). Eating disorders patients' views on their disorders and on an outpatient service: A qualitative study. *Journal of Health Psychology*, 13, 956-960. doi: 10.1177/1359105308095070

- Rich, E. (2006). Anorexic dis(connection): managing anorexia as an illness and an identity. *Sociology of Health and Illness*, 28, 284–305.
- Roehrig, J., & Mclean, C. (2009). A comparison of stigma toward eating disorders versus depression. *International Journal of Eating Disorders*, 43, 671-674.
- Rogers, C. (1957). "The necessary and sufficient conditions of therapeutic personality change". *Journal of consulting psychology*, 21, 95-103.
- Rorty, M., Yager, J., & Rossotto, E. (1993). Why and how do women recover from bulimia nervosa? The subjective appraisals of forty recovered for a year or more. *International Journal of Eating Disorders*, 14, 249–260.
- Rose, D., & Thornicroft, G. (2010). Service user perspectives on the impact of a mental illness diagnosis. *Epidemiology and Psychiatric Sciences*, 19, 140-147.
- Rosenvinge, J., & Klusmeier, A. (2000.). Treatment for eating disorders from a patient satisfaction perspective: A Norwegian replication of a British study. *European Eating Disorders Review*, 8, 293-300.
- Schatzberg, A., Scully, J., Kupfer, D., & Regier, D. (2009). *Setting the record straight: A response to Frances commentary on DSM-V*.  
Retrieved from <http://www.psychiatrictimes.com/dsm-5-0/setting-record-straight-response-frances-commentary-dsm-v>

- Sequeira, H., & Van Scoyoc, S. (2002). Division Round Table 2001: Should counselling psychologists oppose the use of DSM-IV and testing? *Counselling Psychology Review, 16*, 44-48.
- Smith, J. A., & Osborn, M. (2008). Interpretative phenomenological analysis. In J. A. Smith (Eds.), *Qualitative psychology: A practical guide to methods* (pp. 53-81). London: Sage.
- Smith, J., & Flowers, P. (2009). *Interpretative phenomenological analysis: Theory, method and research*. Los Angeles: Sage.
- Smith, J. A., & Sparkes, A. C (2005). Men, sport, spinal cord injury and narratives of hope. *Social Science and Medicine, 61*, 1095-105.
- Spitzer, R., L. (2008). DSM-V: Open and transparent? Retrieved from <http://psychiatryonline.org/doi/full/10.1176/pn.43.14.0026#>
- Stewart, M. C., Keel, P. K., & Shiavo, R. S. (2006). Stigmatization of anorexia nervosa. *International Journal of Eating Disorders, 39*, 329-325.
- Stewart, M., Schiavo, R., Herzog, D., & Franko, D. (2008). Stereotypes, prejudice and discrimination of women with anorexia nervosa. *European Eating Disorders Review, 16*, 311-318.

Svensson, E., Nilsson, K., Levi, R., & Suarez, N. (2013). Parents' experiences of having and caring for a child with an eating disorder. *The Journal of Treatment and Prevention, 21*, 395-407.

Swain-Campbell, N., Surgenor, L., & Snell, D. (2001). An analysis of consumer perspectives following contact with an eating-disorders service. *Australian and New Zealand Journal of Psychiatry, 35*, 99-103.

Sysko, R., & Walsh, B. (2011). Does the broad categories for the diagnosis of eating disorders (BCD-ED) scheme reduce the frequency of eating disorder not otherwise specified? *International Journal of Eating Disorders, 44*, 625-329.

Tajfel, H. (1979). Individuals and groups in social psychology. *British Journal of Social and Clinical Psychology, 18*, 183-190.

Tajfel, H. (1982). Social psychology of intergroup relations. *Annual Review of Psychology, 33*, 1-39.

The British Psychological Society (2011). *Response to the American Psychiatric Association: DSM-5 Development*. Retrieved from <http://apps.bps.org.uk/publication/consultation-responses/DSM-5%202011%20-%20bps%20response.pdf>

The British Psychological Society (2012). *DSM-5: The future of psychiatric diagnosis*. Retrieved from

<http://apps.bps.org.uk/publicationfiles/consultation-responses/DSM-5%202012%20-%20BPS%20response.pdf>

The British Psychological Society (2014). *Code of human research ethics*. Retrieved from [http://www.bps.org.uk/system/files/Public%20files/code\\_of\\_human\\_research\\_ethics\\_dec\\_2014\\_inf180\\_web.pdf](http://www.bps.org.uk/system/files/Public%20files/code_of_human_research_ethics_dec_2014_inf180_web.pdf)

Timulak, L., Buckroyd, J., Klimas, J., Creaner, M. Wellsted., Bunn, F., ... Green, G. (2013). *Helpful and unhelpful aspects of eating disorders treatment involving psychological therapy: a meta-synthesis of qualitative research studies*. Lutterworth: British Association for Counselling and Psychotherapy.

Trepte, S. (2006). Social identity theory. In J. Bryant, & P. Vorderer (Eds.), *Psychology of Entertainment* (pp. 255-272). NY: Lawrence Erlbaum Associates.

Trull, T. J., & Durrett, C. A. (2005). Categorical and dimensional models of personality disorder. *Annual review of clinical psychology, 1*, 355–80.

Vogel, D. L., & Wester, S. R. (2003). To seek help or not to seek help: The risks of self-disclosure. *Journal of Counselling Psychology, 50*, 351-361.

Waller, G. (2009). Recent advances in therapies for the eating disorders. *F1000 Medicine Reports, 1*, 1-4. doi: 10.3410/M1-38

- Walsh, B., & Sysko, R. (2009). Broad Categories For The Diagnosis Of Eating Disorders (BCD-ED): An alternative system for classification. *International Journal of Eating Disorders, 42*, 754-764. doi: 10.1002/eat.20722
- Wanlass, J., Moreno, K. J., & Thomson, H. M. (2005). Group therapy for eating disorders: A retrospective case study. *Journal for Specialists in Group Work, 30*, 47–66.
- Watson, T., & Andersen, A. (2003). A critical examination of the amenorrhea and weight criteria for diagnosing anorexia nervosa. *Acta Psychiatrica Scandinavica, 108*, 175-182.
- Welch, S., Klassen, C., Borisova, O., & Clothier, H. (2013). The DSM-5 controversies: How should psychologists respond? *Canadian Psychology 54*, 166-175.
- Widiger, T., & Samuel, D. (2005). Diagnostic categories or dimensions? A question for the diagnostic and statistical manual of mental disorders fifth edition. *Journal of Abnormal Psychology, 114*, 494-504.
- Willig, C. (2012). Perspectives on the epistemological bases for qualitative research. In H. Cooper, M. P. Camic, D. Long, A.T. Panter, D. Rindskopf & K. J. Sher (Eds.), *APA handbook of research methods in psychology. Volume 1, Foundations, planning, measures, and psychometrics* (pp. 5-21). Washington, DC: American Psychological Association.
- Willig, C. (2013). *Introducing qualitative research in psychology*. New York: Open Press University.

- Wilson, G., Fairburn, C. G., Agras, W., Walsh, B., & Kraemer, H. (2003). Cognitive-behavioural therapy for bulimia nervosa: Time course and mechanisms of change. *Journal of Consulting and Clinical Psychology, 70*, 267-274.
- Wilson, G., Grilo, C., & Vitousek, K. (2007). Psychological treatment of eating disorders. *American Psychologist, 62*, 199-216.
- Wingfield, N., Kelly, N., Serdar, K., Shiv, V., & Mazzeo, S. (2011). College students' perceptions of individuals with anorexia and bulimia nervosa. *International Journal of Eating Disorders, 44*, 369-375.
- World Health Organization. (2015). *Classifications: International classification of diseases (ICD)*. Retrieved from: <http://www.who.int/classifications/icd/ed/>
- Wykes, T., & Callard, F. (2010.). Diagnosis, diagnosis, diagnosis: Towards DSM-5. *Journal of Mental Health, 19*, 301-304.
- Yardley, L. 2000: Dilemmas in qualitative health research. *Psychology and Health 15*, 215-28.
- Zipfel, S., Wild, B., Grob, G., Friederich, H. C., Teufel, M., Schellberg, D., ... Herzog, W. (2013). Focal psychodynamic therapy, cognitive behaviour therapy, and optimised treatment as usual in outpatients with anorexia nervosa (ANTOP study): randomised controlled trial. *The Lancet, 383*, 27–37.

## Ethics Release Form for Student Research Projects

All students planning to undertake any research activity in the School of Arts and Social Sciences are required to complete this Ethics Release Form and to submit it to their Research Supervisor, **together with their research proposal clearly stating aims and methodology**, prior to commencing their research work. If you are proposing multiple studies within your research project, you are required to submit a separate ethical release form for each study.

This form should be completed in the context of the following information:

- An understanding of ethical considerations is central to planning and conducting research.
- Approval to carry out research by the Department or the Schools does not exempt you from Ethics Committee approval from institutions within which you may be planning to conduct the research, e.g.: Hospitals, NHS Trusts, HM Prisons Service, etc.
- The published ethical guidelines of the British Psychological Society (2009) [Guidelines for minimum standards of ethical approval in psychological research](#) (BPS: Leicester) should be referred to when planning your research.
- **Students are not permitted to begin their research work until approval has been received and this form has been signed by Research Supervisor and the Department's Ethics Representative.**

### Section A: To be completed by the student

Please indicate the degree that the proposed research project pertains to:

BSc          M.Phil          M.Sc          **D.Psych**          n/a

Please answer all of the following questions, circling yes or no where appropriate:

1. Title of project

Patient experience of receiving a diagnosis of an eating disorder

2. Name of student researcher (please include contact address and telephone number)

Nimisha Joshi

Mobile: [REDACTED]

3. Name of research supervisor

Dr Julianna Challenor

4. Is a research proposal appended to this ethics release form? Yes **No**

5. Does the research involve the use of human subjects/participants? **Yes** No

If yes,

a. Approximately how many are planned to be involved?

Maximum 10

b. How will you recruit them?

Participants will be recruited via clinicians at Hertfordshire Community Eating Disorders Service. The service offers support to adults who have moderate to severe eating disorders, including anorexia nervosa, bulimia nervosa and atypical eating disorders including binge eating disorder.

The following steps will be taken:

1. Once ethical approval has been granted, clinicians at the service will be informed about the research project.
2. I will attend a team meeting to present my research and provide the team with the participant invitation and information sheets.
3. Clinicians at the service will then identify suitable participants for the study, and they will use their clinical judgement to determine whether or not individuals are appropriate to participate.
4. Clinicians will provide the potential participants with an overview of what the research will involve.
5. Clinicians will provide prospective participants with the invitation and information sheet.
6. Clinicians can inform me of potential participants by email.
7. I will not make initial contact with any of the participants. Instead, if potential participants are interested, they will have the option to contact me by telephone, text message or email which will be included on the information sheet.
8. The team will be informed as soon as the required number of participants have been recruited for the research.

c. What are your recruitment criteria?

*(Please append your recruitment material/advertisement/flyer)*

- Participants aged 18+ will be recruited for this research.
- Participants may include both men and women.
- The research is interested in recruiting those who have a current eating disorder diagnoses (Anorexia Nervosa, Bulimia Nervosa, Eating Disorder Not Otherwise Specified or Binge Eating Disorder). Evidence of this will be documented on their assessment which would have been carried out by their clinician.

d. Will the research involve the participation of minors (under 18 years of age) or vulnerable adults or those unable to give informed consent? Yes **No**

d1. If yes, will signed parental/carer consent be obtained? **N/A**

d2. If yes, has a CRB check been obtained? Yes (not appended) **No**

*(Please append a copy of your CRB check)*

6. What will be required of each subject/participant (e.g. time commitment, task/activity)? *(If psychometric instruments are to be employed, please state who will be supervising their use and their relevant qualification).*

- Time commitment will be required of each participant.
- Participants will be required to answer ten questions related to their experience of receiving a diagnosis of an eating disorder.
- Interviews will last up to 90 minutes (maximum time of interview) and this will be audio recorded.
- Participants will **not** be required to bring any materials for participating in this research.

7. Is there any risk of physical or psychological harm to the subjects/participants? **Yes**  
No

If yes,

a. Please detail the possible harm?

**Psychological harm:**

- If there are more than 10 individuals who show an interest in taking part, those that are not selected may feel rejected.
- There is a possibility that participants might become upset or distressed during the interview from the nature of the questions that will be asked.

**Physical harm:**

- There is no physical harm to the participants.

b. How can this be justified?

**Psychological harm:**

1. To prevent individuals from feeling rejected, I will clearly outline on the participant information sheet that participants will be selected for the study on a 'first come, first served' basis.
2. To prevent or alleviate any distress or upset, I will ensure the following steps have been taken:
  - Prior to the study: the nature of the questions being asked will be carefully considered by the researcher.
  - During the study: participants will be given the option of taking a short break or withdrawing from the study altogether.
  - A full de-briefing will be provided to all participants who have taken part (both those who completed and those who have withdrawn). This will explain the purpose of the study and where participants can ask questions about the research.

c. What precautions are you taking to address the risks posed?

- Participants will be informed that their participation is voluntary and that they are free to withdraw at any time.
- Participants will be fully informed about confidentiality and its limits.
- I will inform participants of my statutory obligation to break confidentiality if I feel the participant poses a risk either to themselves or others. I will ensure that I inform the field supervisor and clinician should this issue arise.
- If a participant becomes upset or distressed, the interview will be stopped and I will use my clinical skills to manage the situation.
- I will ensure that I inform the field supervisor and clinician if a participant becomes upset or distressed at any point.
- A full de-brief will be provided to all participants who have taken part (both those who completed and those who have withdrawn). This will explain the purpose of the study and will give participants the opportunity to ask questions about the research.
- The de-brief sheet will include details of additional support that participants can access.

8. Will all subjects/participants and/or their parents/carers receive an information sheet describing the aims, procedure and possible risks of the research, as well as providing researcher and supervisor contact details?

Yes No

Participants will be given a participation information sheet which will outline the aims, procedure, the possible risks of the research and the contact details for the researcher and supervisor.

*(Please append the information sheet which should be written in terms which are accessible to your subjects/participants and/or their parents/carers).*

9. Will any person's treatment/care be in any way be compromised if they choose not to participate in the research?

Yes No

10. Will all subjects/participants be required to sign a consent form, stating that they fully understand the purpose, procedure and possible risks of the research?

Yes No

If no, please justify

N/A

If yes please append the informed consent form which should be written in terms which are accessible to your subjects/participants and/or their parents/carers)

11. What records will you be keeping of your subjects/participants? (e.g. research notes, computer records, tape/video recordings)?

Consent Form  
Research notes  
Audio recordings  
Transcriptions

12. What provision will there be for the safe-keeping of these records?

**Data Storage:**

All records including audio, will be stored in a locked cabinet.

13. What will happen to the records at the end of the project?

All records will be retained for 5 years, unless stated otherwise by the University.  
Participant's anonymised names and data will be kept separate from each other in a locked cabinet.

14. How will you protect the anonymity of the subjects/participants?

**Data Protection:**

- The research will abide by the Data Protection Act (1998) to ensure personal security of all participants.
- Participants will be informed that the interviews will be transcribed verbatim and that their names will be replaced with a pseudonym to preserve confidentiality.
- Participants will be informed that additional identifiable information will be removed from the research.
- Participants will be informed that supervisors of the research will look at the anonymised transcriptions.
- The only records that the researcher may need to have access to will be the risk assessment, should there be any potential risk/harm to the researcher. This will be addressed at the earliest stage with all parties involved with the research (City University, Supervisor, and Eating Disorders Service).
- Participant's and friends/family names will remain anonymous during every stage of the research.

15. What provision for post research de-brief or psychological support will be available should subjects/participants require?

- A de-brief sheet will be provided, detailing information about the aims and objectives about the research.
- It acknowledges that the research may have caused participants upset or distress and therefore includes a list of services that participants can access for support.

*(Please append any de-brief information sheets or resource lists detailing possible support options)*

If you have circled an item in **underlined bold** print or wish to provide additional details of the research please provide further explanation here:

---

Signature of student researcher – Nimisha Joshi

Date

**CHECKLIST:** the following forms should be appended unless justified otherwise

Research Proposal

Recruitment Material

Information Sheet

Consent Form

De-brief Information

**Section B: Risks to the Researcher**

1. Is there any risk of physical or psychological harm to yourself?    Yes    No

If yes,

a. Please detail possible harm?

There may be a possible risk of physical harm to the research since this is a vulnerable client group. Participants might become distressed from having to talk about their personal experiences, which could result in angry or aggressive behaviour.

Like with many other client groups, it is difficult to anticipate how individuals will respond to particular questions. Furthermore I will not be able to predict whether something else on that particular day has resulted in psychological or physical harm.

c. What precautions are to be taken to address the risks posed?

I aim to avoid this from occurring by the following:

- I will ensure all interviews are conducted in an environment where I can remain safe, i.e. the Eating Disorders Service or City University premises.
- I will inform the field supervisor of my whereabouts including precise times during the interview process.
- I will inform all participants that if they find a question too difficult or do not want to answer they can skip this.
- All participants are welcome to a short break if they need to take time out from the interview.
- I will check during the interview that participants feel okay to continue.
- If for any reason participants remain extremely distressed or become physically aggressive during the interview I will inform a member of the eating disorders service.

**Section C: To be completed by the research supervisor**

*(Please pay particular attention to any suggested research activity involving minors or vulnerable adults. Approval requires a currently valid CRB check to be appended to this form. If in any doubt, please refer to the Research Committee.)*

Please mark the appropriate box below:

Ethical approval granted

Refer to the Department's Research and Ethics Committee

Refer to the School's Research and Ethics Committee

Signature



----- Date



**Section D: To be completed by the 2<sup>nd</sup> Departmental staff member** *(Please read this ethics release form fully and pay particular attention to any answers on the form where underlined bold items have been circled and any relevant appendices.)*

I agree with the decision of the research supervisor as indicated above

Signature



-----

Date



## APPENDIX B: NHS Research Ethical Approval



### Health Research Authority

**NRES Committee London -** [REDACTED]

Bristol Research Ethics Committee Centre  
Level 3, Block B

Whitefriars

Lewins Mead

Bristol

BS1 2NT

Telephone: 0117 342 1384

Facsimile: 0117 342 0445

24 September 2013

Miss Nimisha Joshi  
Doctoral Student  
City University  
Northampton Square  
London  
EC1V 0HB

Dear Miss Joshi

**Study title:** The experience of receiving a diagnosis of an eating disorder: An Interpretative Phenomenological Analysis.  
**REC reference:** 13/LO/1293  
**IRAS project ID:** 130955

Thank you for your letter of 19 September 2013, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Vice-Chair.

#### Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so.

Publication will be no earlier than three months from the date of this favourable opinion letter.

Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager, [REDACTED] at:

#### Ethical review of research sites

##### NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

APPENDIX C: Participant consent form



School of Arts  
and Social Sciences  
CITY UNIVERSITY LONDON

Department of Psychology  
Northampton Square  
London EC1V 0HB

**PARTICIPANT CONSENT FORM**

*Patient Experience of Receiving a diagnosis of an Eating Disorder*

Title of Project: **[THE EXPERIENCE OF RECEIVING A DIAGNOSIS OF AN EATING DISORDER]** Name of Researcher: **[NIMISHA JOSHI]**

Please initial all  
boxes

- 1. I confirm that I have read and understand the information sheet dated **[04/11/13]** (version **[1.1]** for the above study). I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
  
  - 2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
  
  - 3. I understand that my information will be stored in a locked cabinet and that the information I provide will be anonymised.
  
  - 4. I give consent for the interview to be audio recorded, transcribed and for direct quotes to be included in the research report which I understand will be anonymous.
  
  - 5. I understand that relevant sections of my data collected during the study, may be looked at by individuals from **[CITY UNIVERSITY LONDON]**, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to access my records.
  
  - 6. I give permission for my GP to be informed of my participation in this study.
  
  - 7. I agree to take part in the above study.
- |  |  |  |
|--|--|--|
| <hr style="border: none; border-top: 1px solid black;"/> | <hr style="border: none; border-top: 1px solid black;"/> | <hr style="border: none; border-top: 1px solid black;"/> |
| Name of Participant                                      | Date   | Signature  |
| <hr style="border: none; border-top: 1px solid black;"/> | <hr style="border: none; border-top: 1px solid black;"/> | <hr style="border: none; border-top: 1px solid black;"/> |
| Name of Person taking consent.                           | Date   | Signature  |
- 8. I am willing to participate in the second, optional feedback session.



## **PARTICIPANT DE-BRIEF FORM**

### *Patient Experience of Receiving a diagnosis of an Eating Disorder*

Thank you very much for your time and taking part in this research.

This study was interested in exploring people's experiences of receiving a diagnosis of an eating disorder. I was particularly interested in the following areas:

- When you first suspected that you had an eating disorder.
- Your experience of an informal diagnosis.
- Your experience of receiving a formal diagnosis.
- Who the people were that used the term eating disorder.
- How you felt after you were diagnosed.
- Your experience of receiving a formal diagnosis versus living with an eating disorder.
- Positive and negative aspects about receiving a diagnosis.
- What you think others think about your diagnosis.

The existing literature has focused on eating disorders and diagnostic criteria; however there remains little research into people's subjective experiences. There is an ongoing debate regarding diagnostic criteria, whereby a significant proportion of people are not receiving treatment because they do not quite meet the criteria. Diagnosis therefore remains a very important area and given this context, it is extremely useful to hear what service users think and experience first-hand.

### **Sources of support**

Talking about your own personal experiences may have caused some upset, which is very normal and you should find that these feelings ease shortly. If however, you continue to experience upset or any distress, the researcher has provided a list of organisations below that can offer you support:

1. Your care co-ordinator is aware of your participation in this study and you have the option of talking to them if you require any further support.
2. You may feel comfortable to discuss any issues with family members or friends.
3. <http://www.b-eat.co.uk/>

### **Helplines**

For the **Adult Helpline**, please call 0845 634 1414. This helpline is available to anyone over the age of 18 and is open Monday to Friday 10.30am to 8.30pm and Saturdays 1.00pm - 4.30pm. Alternatively, you can email [help@b-eat.co.uk](mailto:help@b-eat.co.uk)

For the **Youthline**, please call 0845 634 7650. The Youthline is available to anyone aged 25 or under, and is open Monday to Friday from 4.30pm to 8.30pm and Saturdays 1.00pm - 4.30pm. You can also text the Youthline on 07786 20 18 20 - send us a message and we will get back to you within 24 hours. There is also a Youth line email service at [fyp@b-eat.co.uk](mailto:fyp@b-eat.co.uk)

### **4. Samaritans**

Available 24 hours a day to provide confidential emotional support  
08457 90 90 90  
<http://www.samaritans.org/>

5. If you would like to discuss any aspect of the study further, you are more than welcome to contact the researcher or the supervisor:

### **Nimisha Joshi**

Trainee Counselling Psychologist

T: [REDACTED]

E: [REDACTED]

### **Dr Julianna Challenor**

Chartered Counselling Psychologist  
Research Supervisor, City University

[REDACTED]

### **Dr David Viljoen**

Chartered Clinical Psychologist & Family and Systemic Psychotherapist  
Field Supervisor, [REDACTED] Eating Disorders Service

E: [REDACTED]

*Thank you again for taking part*

**APPENDIX E: Research proposal**

**THE RESEARCH PROPOSAL**

*Nimisha Joshi*

# Patient experience of receiving a diagnosis of an eating disorder

**Miss Nimisha Joshi**

*Counselling Psychology Trainee  
& Principle Investigator for this research  
City University, London*

T: [REDACTED]

E: [REDACTED]

**Dr David Viljoen**

*Chartered Clinical Psychologist  
& Family and Systemic Psychotherapist*

[REDACTED] *Eating Disorders Service*

T: [REDACTED]

E: [REDACTED]

**Dr Julianna Challenor**

*Chartered Counselling Psychologist  
& Research Supervisor for Doctoral Students  
City University, London*

T: [REDACTED]

E: [REDACTED]

**Dr Jessica Jones Nielsen**

*Deputy Programme Director  
Research Coordinator & Personal Tutor  
City University, London*

T: [REDACTED]

E: [REDACTED]



## **ABSTRACT**

This protocol presents a detailed description upon which the doctoral research will be based. It will combine three parts of information. First a literature review, which seeks to explore the topic of interest and therefore includes a description of the general context of diagnosis and eating disorders. It will also refer to previous work that has been addressed along with the key issues that have not yet been addressed. Finally, it will include a brief argument for why this research is a worthy area of study and whom it will benefit. Second, the methodology of the research is described in detail, which includes the chosen design, sampling, materials, procedure, analysis and data storage and confidentiality. Third, a business plan is considered which includes the potential benefits and outcomes as well as the practicalities such as finance/costs and audit procedures.

**Key words:** Eating disorders, diagnosis, interpretative phenomenological analysis

## **LITERATURE REVIEW**

### *A description of the general context & Previous Work*

Biomedical models and psychiatric diagnosis are central to mental health practice and have a dominant role in terms of conceptualising distress and unfamiliar experience (Coles, 2010). Diagnosis has shown to be a common routine during referral and assessment pathway, and it continues to be the root of explanation for distress to both service users and family members (Coles, 2010). Furthermore, it has formed the basis for research such as the National Institute of Clinical Excellence (NICE) and designing appropriate services for diagnoses. It has also been embedded within major public services including the criminal justice system and social services whereby people are often treated differently and as a result, fall into the “mentally unstable”, “mentally ill” category (Coles, 2010).

Diagnostic systems like the DSM and ICD have become prevalent tools for communication regarding client problems (Eriksen & Kress, 2006). The Diagnostic and Statistical Manual of Mental Disorders (DSM) for instance, is a well-known classification system used within the Mental Health profession (APA, 2000). The manual is deemed important as it contains a list of the diagnostic criteria for all psychiatric disorders in both adults and children (APA, 2000). DSM-IV-TR uses a multiaxial system and includes five dimensions as a way of thoroughly evaluating an individuals’ level of functioning (APA, 2000). The five dimensions consider clinical disorders, personality disorders, acute medical conditions, psychosocial and environmental factors (APA, 2000). The manual may be particularly useful for professionals as it considers how a persons’ mental illness may be impacting other aspects of their life and vice-versa. Furthermore, it can be helpful in trying to understand a person’s illness and ensure the appropriate treatment is offered at the earliest stage. The DSM however, continues to undergo changes with the aim of improving its validity, much of which has stemmed from early research where there was often disagreement amongst professionals around giving someone the correct diagnosis (Coles, 2010).

### *Current functions of Psychiatric Diagnosis*

Several functions of diagnosis have been offered. First, communication: psychiatric diagnosis enables communication across mental health services as well as outside agencies (Coles, 2010). Second, legitimating distress: psychiatric diagnosis can discourage any feelings of blame and instead help people to feel understood. People may therefore find

that having a diagnosis offers an explanation to symptoms or distress, which reduces such feelings and instead reassures and puts people at ease (Coles, 2010). Equally important, when considering friends and family members, a diagnostic label can remove blame or identifying someone as the “enemy” (Eriksen & Kress, 2006). Third, treatment is an important component when exploring diagnosis. It has been argued that diagnosis may be particularly important in terms of medication and outcome prediction (Coles, 2010). Additionally, Pitt, Kilbride, Welford, Nothard and Morrison (2009) highlight the importance of treatment in terms of empowering people to feel knowledgeable. Eriksen and Kress (2006) argue that protocols like the DSM can provide clients with a concrete and direct explanation regarding their behaviour.

### *Negative Impact of Psychiatric Diagnosis*

From the profound magnitude of the presence of diagnosis, a number of negative effects have been highlighted. First, privileging Biology, pathologising individuals and obscuring context (Coles, 2010). For example, the classification system appears to understand unusual experiences and distress in terms of bodily dysfunction, which appears to emphasise a medical diagnosis (Coles, 2010). It has been argued (Boyle, 2002a) that this can inhibit staff who are working with these individuals in terms of not looking at their difficult environments or the cause of their experiences. Interestingly, Boyle (2002a) argues that diagnosis distorts research as there appears to be less focus on the psychological research and instead more focus on the biological factors. Also, by categorising people via a classification system, it appears to construct an identity that is driven by individual deficits (Coles, 2010).

Second, diagnosis appears to impose a western culture worldview whereby it appears to be a homogeneous way of classifying illness and abnormality; however such experiences are viewed very differently across cultures (Coles, 2010). For example, within mental health practice, hearing voices is regarded as an illness, however in other communities this is seen as a spiritual gift. Even though some diagnostic classifications are not valid in other cultures, this lack of recognition suggests that the practice of diagnosis is being applied universally (Coles, 2010). This leaves people who diverge from a western background feeling pathologised and misunderstood.

Third, diagnosis acts as a barrier to communication, whereby the specialist language used by professionals can make individuals feel inferior with regards to the

explanation and understanding of their own experiences (Coles, 2010). In essence, the lack of a shared language results in a breakdown of communication in which the diagnosis holds little explanatory value for the individual (Coles, 2010).

Fourth, diagnosis can exclude service user perspectives and hinder shared explanations (Borg, Karlsson & Kim, 2009). While professionals are trying to embrace the interest and awareness of the service users' problems, a number of challenges remain with regards to practice implications (Borg et al., 2009). *Challenge 1:* Assumptions about the nature of the problems. The two main issues are in relation to framing the view of the problem and its importance, and the attribution of labels (Borg et al., 2009). When a service user initially presents at a mental health service, his or her problems are formulated between the professional and the service user. The problem however is that the professional's voice does not reflect the personal experience and meaning from the service users' perspective. While there have been a number of criticisms regarding diagnoses and giving people medical labels, the most fundamental appears to focus on the lack of consideration for people's life circumstances and individual problems and symptoms (Reed, 2004). Similarly, Larson (2004) argues the importance of valuing and appreciating the individual for attempting to understand and make sense of their experiences. Resolving the differences between the perspectives of the professionals' and the service users' therefore appears to be the primary challenge in terms of aligning the true problems (Borg et al., 2009).

#### *A description of the particular problem & Key Issues*

Eating disorders are classified using the DSM which focuses on Anorexia Nervosa (AN) and Bulimia Nervosa (BN) along with a remaining diagnostic category referred to as Eating Disorder Not Otherwise Specified, EDNOS (Fairburn, 2008). It has been argued (Fairburn & Cooper, 2007) that there are fundamental flaws with the DSM classification system with regards to eating disorders, with specific reference to this remaining category. EDNOS has shown to be the most common diagnosis made within clinical practice in comparison to anorexia nervosa and bulimia nervosa, however surprisingly there are no criteria for this category (Fairburn & Cooper, 2007). Another issue that has been highlighted focuses on the DSM's usefulness and its diagnostic distinctions (Fairburn, 2007). For example, it becomes apparent that a proportionate amount of cases of anorexia nervosa often develop into bulimia nervosa or EDNOS and cases of bulimia nervosa develop

into EDNOS. In thinking about such distinctions, Fairburn and Cooper (2007) propose that such clinical changes do not give a true reflection of recovery in terms of the development of one psychiatric diagnosis to another.

Eating disorders are divided into three main diagnostic categories within the DSM-IV-TR (APA, 2000). The criteria for anorexia nervosa includes: a refusal to maintain body weight at or above a minimally normal weight for age and height; intense fear of fatness or gaining weight, disturbed shape and evaluation of weight and amenorrhea, where at least 3 sequential menstrual cycles are absent (APA, 2000). There are two sub-types within the anorexia nervosa category, the restricting type which includes people who do not binge-eat or engage with purging behaviour such as vomiting. The second type is referred to as the binge eating/purging type which includes people who binge or purge on a regular basis (APA, 2000).

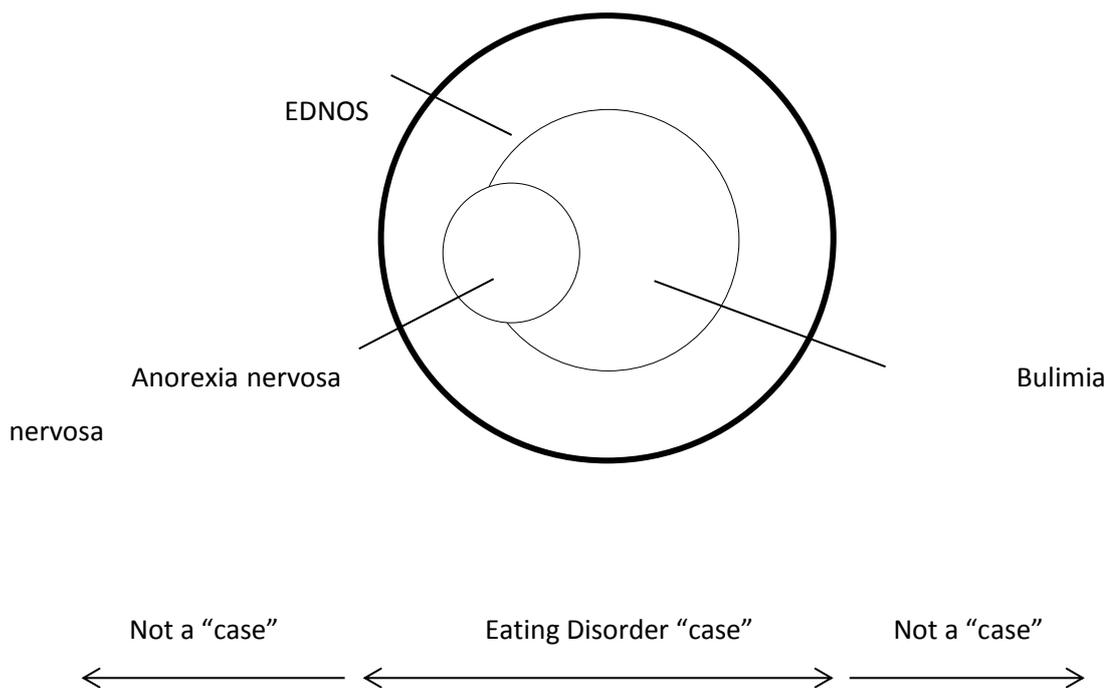
The criteria for bulimia nervosa are: repeated episodes of binge eating behaviour whereby the person usually consumes the food within a distinct time period. The food he or she consumes will usually be much more than a person can eat within that period of time. During this period, people will often feel little or no control over what they're eating or how much they're eating and as a result may engage with compensatory behaviour such as misusing laxatives and excessive exercise. Within the bulimia nervosa criteria, there are also two sub-types, these include purging type where people regularly engage with the compensatory behaviours mentioned, however the focus being on the self-induced vomiting, misuse of laxatives or diuretics. The other sub-type is the non-purging type where the individual has engaged with compensatory behaviours, but does not engage with self-induced vomiting, misuse laxatives or diuretics (APA, 2000).

The remaining EDNOS category that was introduced previously does not have a diagnostic criteria according to the DSM IV-TR and instead is often referred to within the literature as a "residual" category, in essence, it is a category for those who do not meet the criteria for anorexia nervosa or bulimia nervosa (Fairburn, 2008). Similarly, the somewhat new binge eating disorder is viewed as a form of EDNOS at present, although this may change in later revisions of the DSM (Fairburn, 2008).

A high proportion (70%) of people fall under the EDNOS category, which means a large number of people experience disturbed eating behaviours (Tasca, Maxwell, Bone, Trinneer, Balfour & Bissade, 2012). A number of options have therefore been proposed for the diagnostic criteria for the DSM-5, with the aim of reducing these figures (Sysko & Walsh, 2011). First, alterations with the wording in the current diagnostic criteria; second

changes to the anorexia nervosa criterion and deleting the amenorrhea which appears to be somewhat ambiguous and is not relevant for men with eating disorders (Keel, Brown, Hol-Denoma & Bodell, 2011). Second, a change to the bulimia nervosa criterion with regards to the frequency of binge eating and its validity (Keel et al., 2011). Third, and the most drastic change to binge eating disorder has been proposed in terms of including it in the DSM , thus making it a formal diagnosis (Keel et al., 2011).

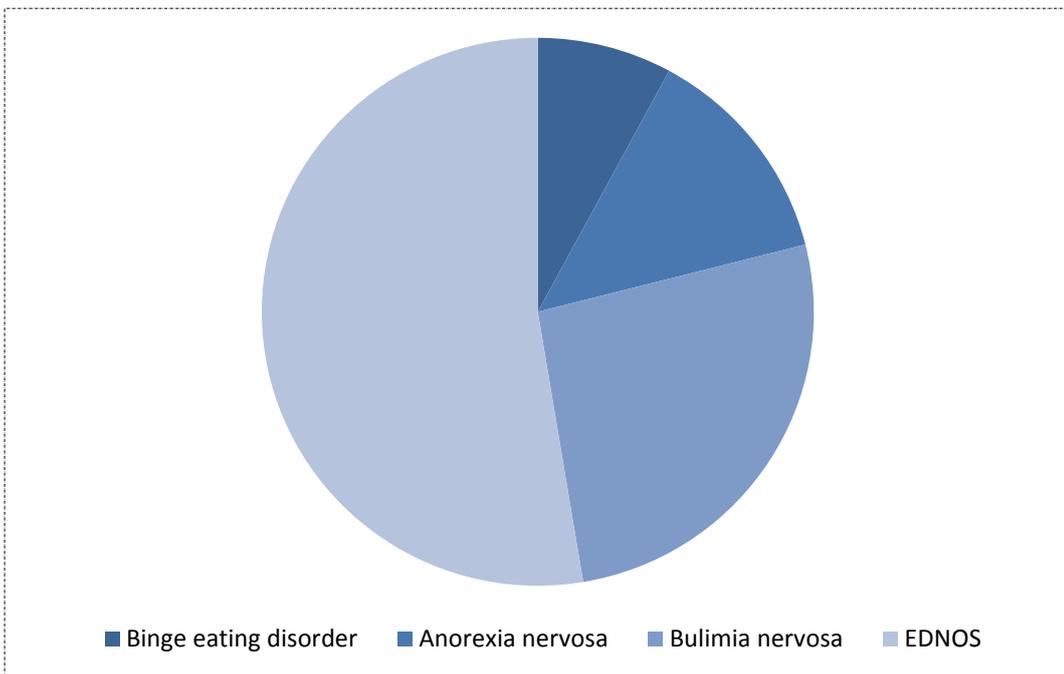
Figure 1 illustrates the relationship between all 3 diagnoses with anorexia nervosa and bulimia nervosa being represented in the two smaller circles which intersect. According to Fairburn (2008), the overlap is representing the people who would meet the diagnostic criteria for both; however the anorexia nervosa takes priority over bulimia nervosa. The larger defined outer circle represents the boundary that determines what is and is not an eating disorder (Fairburn, 2008).



**FIGURE 1:** A schematic representation of the relationship between anorexia nervosa, bulimia nervosa and EDNOS (Adapted from Cognitive Behavior Therapy and Eating Disorders, New York, Fairburn, 2008)

Figure 2 illustrates the prevalence of the three main eating disorder diagnoses in adults which includes binge eating disorder, a provisional category within the DSM IV-TR (Fairburn, 2008). There are two main sub-groups within EDNOS which are useful to

distinguish, especially since it has shown to be a particularly common eating disorder. The first sub-group includes people who present with similar clinical features of anorexia nervosa or bulimia nervosa; however they marginally do not meet the diagnostic criteria (Fairburn, 2008). For example, in the criteria for anorexia nervosa, an individual might just be above the minimal weight and therefore fail to meet the criteria, thus not an eating disorder case. Although it appears unlikely that the DSM V will stretch the boundaries for such cases, Fairburn (2008) suggests a possible need for this to be included in anorexia nervosa and bulimia nervosa diagnoses.



**FIGURE 2:** A representation of the prevalence of the three main eating disorder diagnoses (EDNOS (Adapted from Cognitive Behavior Therapy and Eating Disorders, New York, Fairburn, 2008)

### *The Psychopathology of Eating Disorders*

While this chapter has so far focused on the classificatory scheme, an emphasis being on the DSM, it is fundamental to highlight the similarities within these eating disorders. In considering the classification of eating disorders, Fairburn and Cooper (2007) mention that it is equally important for research to focus on the question “What is an Eating Disorder”? Unfortunately this is scarce within the literature and surprising, given the importance it may have for deciding whether an individual’s; problem with eating is severe

enough to be an “eating disorder case” (Fairburn & Cooper, 2007). The psychopathology across the specified eating disorders and indeed, the severity amongst the eating disorders is much the same (Fairburn, 2008). The core psychopathology is with regards to the components of over-evaluation and control, with a focus on ones’ shape and weight. Whereas those without an eating disorder are likely to judge themselves in terms of other domains such as relationships and work (Fairburn, 2008). This is consistent with both men and women. People with eating disorders may express this core psychopathology in different ways; for instance, those severely concerned about their weight might constantly weigh themselves, which leads to becoming preoccupied with weight and having little or no interest in other areas of their life. In contrast, others may want to completely avoid knowing what their weight is, however it still remains problematic as they are still very concerned about it (Fairburn, 2008). Similarly, some individuals are highly concerned with their shape which results in constant checking and scanning the body, whereas others will avoid such behaviour and it is these two key types of behaviour which appear to maintain concerns regarding shape and weight (Fairburn, 2008).

#### *The importance of this research and its benefits*

The DSM continues to be the main classification system of mental disorders that is used, with its intention of being applicable to a range of services and professionals. The recent launch of the fifth edition of the DSM however, resulted in much debate and criticism amongst existing mental health professionals, even before it was published. The most significant criticism to these changes has been focused around the understanding of mental disorders, the clinical reality and how such disorders are thought about. In response to the recent launch of the new DSM-V, the British Psychological Society expressed concerns around the risk of the DSM-V leading to pathologizing individuals and obscuring social and relationship factors (BPS, 2012). A significant concern raised has specifically been with regards to lowering the diagnostic thresholds across all disorders as there were concerns around this resulting in medical explanations as opposed to individual experiences (BPS, 2012). The classification of eating disorders in particular and recent changes have too been largely criticised for its emphasis on the two main eating disorders only; anorexia nervosa and bulimia nervosa. However, and as Fairburn (2011) highlights, a proportionate amount of people fall under the residual diagnosis “Eating Disorder Not Otherwise Specified”. That said, it does not appear to reflect the clinical reality and account for the most common diagnosis that is made. Similarly, Fairburn (2011) proposes for the

diagnostic criteria to be relaxed. With the criteria for anorexia nervosa and bulimia nervosa being so strict, this essentially results in people receiving the “Not Otherwise Specified” diagnosis as they don’t quite meet the criteria. Given this context and controversy regarding diagnosis and debate around rejecting medical diagnoses, it will be worthwhile to hear what service users think and their experience of being diagnosed. This research will give service users the opportunity to talk about what they actually experience and rather than focusing on strict diagnostic criteria it places importance and meaning on the individual. For NHS staff, the research will increase both understanding and knowledge in this area in order for them to work more effectively with people. This is fundamental, and will give further insight into what people experience first-hand as opposed to solely relying on diagnostic criteria, which as the literature suggests, does not always reflect the clinical reality.

## **METHODOLOGY**

### *Design*

This study will use a qualitative research design which is the appropriate methodology description for this research since the focus is on individuals’ personal meaning and experience, which are key features of this particular approach. Semi-structured interviews will be employed with a maximum of 10 participants, which will be audio recorded and transcribed verbatim. An interpretative phenomenological approach will be used to analyse the data in order to obtain a rich and detailed account of individual experiences. The objective of this research is to qualitatively explore people's experience of receiving a diagnosis of an eating disorder which will be answered by the following interview schedule:

1. I am interesting in exploring with you your experience of receiving a diagnosis of an eating disorder. To start with, can you please recall when you first suspected that you had an eating disorder?

*Possible prompts: how long ago? Who made the informal diagnosis? Themselves? Family members? Friends?*

2. Who were the first people to use terms such as eating disorder?

*Possible prompts: Themselves? Family members? Friends? Professionals? How did this feel?*

3. How long was it until you received a formal diagnosis?  
*Possible prompts: who from? How? Where? What happened? How did you feel?*
4. How did you feel afterwards?  
*Possible prompts: how did you feel about yourself?*
5. What was the experience like of receiving a formal diagnosis versus living with informal knowledge that this was possibly an eating disorder?
6. How well did the formal diagnosis encapsulate the experience of living with an eating disorder?
7. What has been positive about receiving a diagnosis?  
*Possible prompts: How do you feel about these changes? Can you tell me a bit more about that? What else?*
8. What has been negative about receiving a diagnosis?  
*Possible prompts: How do you feel about these changes? Can you tell me a bit more about that? What else?*
9. What do you think others think about your diagnosis?  
*Possible prompts: friends, family, partner, professionals, and work colleagues?*
10. Is there anything else you would like to add?

From the above interview schedule I hope to achieve a detailed account of people's experience of receiving a diagnosis. The interview therefore includes a range of descriptive, narrative, structural and contrast questions in order to encourage participants to talk comfortably and provide a detailed account.

### *Participants*

A maximum of 10 participants, males and females aged 18 and above will be recruited from [REDACTED] Eating Disorders Service. All participants will have received an eating disorder diagnosis. Those who suffer with a comorbid disorder will be allowed to take part, as long as their eating disorder is the primary problem, which will be identified via their care coordinator.

Since this research will involve qualitative methods only, the participants will not be determined using a statistical power calculation. The total UK sample size chosen for this research is 10. The targeted participants will be those who have been diagnosed with an eating disorder. This sample group in particular is being targeted as it is relevant to the aims of the research question. According to Interpretative Phenomenological Analysis (IPA), there is not a correct sample size to use. However some important factors to consider include the constraints the researcher is working under, the degree of commitment of each participant and the richness of the participants' interview. Taking this all into consideration, I have opted for a sample size of 10. This number of participants will allow for an adequate amount of time and commitment with each participant during data analysis, thus resulting in a more concentrated focus with each one.

### *Inclusion and exclusion criteria*

The inclusion criteria for this study are:

1. Participants will have to have received an eating disorder diagnosis, which can include: Anorexia Nervosa, Bulimia Nervosa, EDNOS or Binge Eating Disorder. The sampling has not been narrowed down to focus on specific types of eating disorders, but is instead interested in eating disorders overall. The main focus is on the participants' experience of receiving the diagnosis. While the primary interest lies with those who have an eating disorder, I anticipate that participants may have comorbidities. However, since the interview schedule is focused towards eating disorders, there appears to be no reason to exclude people because of other diagnoses they may have. Furthermore, recruitment material will state this information clearly.
2. Participants will include both males and females. Although using just one may include a more homogeneous sample, there is little attention on men with eating

disorders. This will therefore be a further interesting aspect of the research should men decide to participate.

3. Participants must be a minimum age of 18 as the research interests are amongst adults. There is no cut off point with regards to participants' age. Instead, I propose that as long as individuals feel they are able to articulate their thoughts and feelings and have capacity to consent in taking part, they are welcome to take part.

There are no criteria for exclusion in this research as I do not feel there are good enough reasons to exclude anyone from taking part.

The use of translators and interpreters will be provided for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs.

If a participant, who has given informed consent, loses capacity to consent during the study then he/she will be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.

### *Recruitment*

The researcher will visit the team during a team meeting to explain to relevant care co-ordinators what the study entails as well as what is expected of them in terms of recruitment. Eligible participants will be informed about the study during their outpatient appointment by their care co-ordinators. The researcher will provide the care-coordinators with the inclusion criteria (see appendix 2) and a Participant Information Sheet (see appendix 3) so that they are aware of what participation will involve and which patients will be suitable. Potential participants will be informed that a maximum of 10 participants will be required for the study. The care co-ordinators will offer the Participant Information Sheet to those who express an interest which will contain the researchers contact details. The researcher will not at any point contact potential participants. Participants who are interested will be able to contact the researcher directly. Those who make contact with the researcher via telephone/email will be asked if they require any further information about

the study, which will be provided where needed. If they are happy to continue, they will be invited to attend an appointment. During this appointment, the researcher will confirm that the individual still wishes to take part. All participants will then be required to sign a consent (see appendix 4) form prior to the interview which will include permission for the researcher to approach their GP (see appendix 5).The researcher will inform care co-ordinators as soon as the required number of participants has been recruited.

### *Materials*

Materials that will be essential for running the study will include the following:

### *Individual files*

- To keep participants data separate from one another (i.e. consent forms, interview notes, transcriptions).

### *Consent forms*

- To confirm that participants have read and understood the participant information sheet.
- To ensure that participants understand that their participation is voluntary and they are free to withdraw at any time.
- To ensure that participants understand that their information will be stored in a locked cabinet at all times and that this information will remain anonymous.
- To ensure that participants understand that the interview will be audio recorded, transcribed and that direct quotes will be included in the research report which they understand will be anonymous.
- To ensure that participants understand that relevant sections of their data collected during the study, may be looked at by individuals from City University, from regulatory authorities or from the NHS Trust, where it is relevant to them taking part in this research.

### *Participant Information Sheets*

- To provide participants with information about the research, its purpose, what will happen to them if they take part and detailed information about the conduct of the study.

### *De-brief Sheets*

- To de-brief participants about the aims of the research and provide sources of support.

### *Semi-structured interview schedules*

- To guide participants in generating an interaction about the topic of interest.

### *Digital Dictaphone*

- To record the interviews.

### *Procedure*

1. The study will take place at [REDACTED] Eating Disorders Service and will be conducted by a Counselling Psychology doctoral student. This will be under the supervision of Dr Julianna Challenor from City University and Dr David Viljoen from [REDACTED] Eating Disorders Service. Ethical approval must first be granted by NHS Ethics and [REDACTED] Research Ethics Committee in order to conduct the study.

2. Participants will be fully informed about confidentiality. The researcher will explain that all information will remain confidential and for the purpose of the research only. Participants will be made aware that the interviews will be recorded and that this material will be stored in a locked cabinet at all times. They will also be informed that the interviews will be transcribed verbatim and that all identifiable information such as names, addresses will be removed from the research. Participants will be told that supervisors of the research will look at the anonymised transcriptions. The researcher will inform participants about the limits of confidentiality and the statutory obligation to break this should she feel the participant is at risk either to themselves or others.

3. Informed consent to participate in the study will be required from all participants, confirming they have read and understood the Participant Information Sheet and that their participation is voluntary where they can withdraw at any time. Participants will be asked to confirm they understand that relevant sections of their data collected, may be looked at from regulatory authorities or from the NHS Trust for research purposes. Participants will also be asked to confirm that they give permission for their GP to be approached prior to

the study. Participants who do not wish to provide written consent to take part will be excluded from the study. All information will be destroyed.

4. Participants will be required to undergo a semi-structured interview with the researcher only, at [REDACTED] Eating Disorders Service. This will involve the researcher asking 10 questions.

5. Interviews will last a maximum of 90 minutes, which is in line with IPA research which proposes that a schedule with 6-10 questions will usually last between 45- 90 minutes. Since the researcher will use semi-structured interviews, there are fewer time constraints compared with a structured interview. That said, the researcher will need to be able to facilitate and guide the participant which may require the use of minimal probes if participants move away from the topic of interest or spend too much time on one question.

6. Participants data will be captured using a digital Dictaphone. All interviews will be recorded and later transcribed verbatim and the transcript will be analysed according to the procedures of IPA.

7. A full explanation of the study will be provided by the researcher (see appendix 5). This will also give participants the opportunity to let the researcher know what they found helpful or difficult which can often be valuable information. The interviews may illicit a range of emotions which will be taken into consideration. As the researcher, I therefore aim to conduct the interviews in a sensitive way. The debriefing can also provide a safe space to provide additional support and resources, should participants experience any emotional distress from this study.

8. Participants will be seen by the researcher on 3 occasions:

- At the interview stage
- To comment on emergent themes at the analysis stage
- To receive feedback about the results of the research they have contributed to.

### *Analysis*

Within qualitative research, interpretation plays a central role as it allows us to understand our data (Willig, 2012). For this study, an Interpretative Phenomenological Approach (IPA) will be used to analyse the data as this will allow for a detailed analytic

focus on the participants' experiences (Smith, Flowers & Larkin, 2012). Making sense of an individual's personal and social world is central to the aims of IPA (Smith & Osborn, 2008). In other words, the researcher is very much interested in exploring the detailed experiences which come from the heart of the individual. This type of research is therefore helpful for reflection and exploring meaning-making. In order to obtain this meaning and significance of individual experiences, thoughts and feelings, it is important for questions to be directed towards these areas in order to start making connections within the data (Willig, 2012). Within phenomenological research, the focus is very much on the participants' own description of an account, thus the process of analysis is fundamental to ensure these descriptions are produced as accurately as possible (Willig, 2012).

This qualitative research will take the form of verbal transcripts of an interview which will be audio recorded in order to capture everything that is being said. This also means that the researcher can focus completely on the session, building a rapport without any disruption (Smith & Osborn, 2008). Following this, there are several important steps to follow when carrying out IPA analyses which are outlined below.

### **Step 1: Reading and re-reading**

Reading and re-reading the transcript gives the researcher an opportunity to familiarise themselves with the text. For a more complete analysis Smith, Flowers and Larkin (2012) suggest that it is helpful to listen to the audio recording to assist with this. The primary reason for step one is to encourage the researcher to focus on the participant only and to begin to enter their world (Smith et al., 2012).

### **Step 2: Initial noting**

The initial noting is the most time-consuming part of an IPA analysis as it involves the process of closely examining the language and content (Smith et al., 2012). This will therefore involve the researcher making notes of any interesting comments that arise from the transcript. The first level of annotation involves descriptive comments such as key words, phrases, emotional responses or sound bites. Second, linguistic comments which focus on the participants' use of language including pauses, laughter, metaphor or repetition (Smith et al., 2012). Third, conceptual comments which involve the researcher becoming more interpretative and conceptual with the transcript data. More specifically, the focus shifts towards the participants' understanding about the area/issue being discussed. This requires time, focus and reflection (Smith et al., 2012).

This process is therefore much more a descriptive stage as the aim is to capture the meaning within the text (Willig, 2012). Here, the researcher should try to suspend any judgments and instead focus on what is being said in the transcript. This is often referred to as 'bracketing' one's own assumption about the phenomenon (Willig, 2012). From closely examining the text, this gives further insight into how the participant talks about and understands a particular issue. It is likely that steps one and two will therefore merge during the initial stages of the analysis as the researcher is most likely to make notes when first reading the transcript (Smith et al., 2012).

### **Step 3: Developing emergent themes**

By step 3, the researcher will be very familiar with the transcript and the emergent themes will be identified through the comprehensive exploratory commenting that has been outlined (Smith et al., 2012). The aim of step three is to reduce the transcript and initial notes into emergent themes, thus the researcher will work from the initial notes as opposed to the entire transcript. In order to establish the themes, the narrative will need to be broken up, thus the researcher is focusing on big parts of the transcript. This part of the analysis therefore focuses on a set of parts, thus turning the notes into themes is the main aim.

### **Step 4: Searching for connections across emergent themes**

From creating the set of themes, the task in step four is to search for connections across the emergent themes, which in essence, involves thinking about how they fit together (Smith et al, 2012). It is important to note that the researcher may choose to remove some of the emergent themes at this point, which is fine as they do not all have to be included (Smith et al., 2012). Instead the main purpose is to draw on the participants' most interesting parts of their account, thus you are attempting to have some form of structure. There are specific ways of searching for connections within the emergent themes and identifying patterns and these are summarised below:

Abstraction which involves placing like with like and identifying a new name for a cluster (Smith et al., 2012). There may for example, be a number of similar emergent themes which can then be put under one title, referred to as a super-ordinate theme (Smith et al., 2012).

Subsumption - this is where the superordinate theme brings out other related themes.

Polarization - this involves focusing on the opposite relationships within the emergent themes, for example focusing on the differences as opposed to the similarities.

Contextualization - this involves focusing on the contextual elements with specific reference to narrative, cultural and temporal themes.

Numeration – this includes the frequency of the emergent theme appearing within the text.

Function- the researcher might focus on the function of the emergent theme.

#### **Step 5: Moving to the next case**

This step involves moving onto the next participant and beginning the same process again.

#### **Step 6: Looking for patterns across cases**

This step involves identifying patterns across all participants with a focus being on the connection across them, identifying the most powerful themes. The final results can be presented either as a graph or included in a master table of themes for the group (Smith et al., 2012).

The proposed analysis will enable the researcher to answer the research question as it will identify key themes regarding people's experiences about receiving a diagnosis. From this, it will indicate what appears to be most prevalent for people.

#### *Data Storage & Confidentiality*

Participants will be fully informed about confidentiality. The researcher will explain that all information will remain confidential and for the purpose of the research only. Participants will be made aware that the interviews will be recorded and this material will be stored in a secure place. They will also be informed that the interviews will be transcribed verbatim and that all identifiable information such as names will be removed from the research. Participants will be told that supervisors of the research will look at the anonymised transcriptions. The researcher will inform participants about the limits of confidentiality and the statutory obligation to break this should she feel the participant is at risk either to themselves or others.

## SECURITY

1. Confidential data such as participants' demographics, diagnoses and transcriptions will be stored in a locked cabinet at all times.
2. All transcriptions will be stored in a locked cabinet in the researcher's office. Only the researcher will have access to this information.
3. The digital Dictaphone will also be stored in a locked cabinet in the researcher's office. This will be backed up on the researcher's computer. The security measures outlined below will be implemented.
4. Participants' data will be retained for 5 years, which is in line with NHS guidelines. Following this period, all information including audio data, will be destroyed by the researcher.
5. Personal data will not be stored on portable devices such as memory sticks/cards.

## FOR COMPUTER SECURITY

1. Firewall and virus-checking will be installed on the researcher's computer.
  2. The latest security will be updated and an anti-spyware tool will be installed to help protect and monitor the computer from any threats.
  3. Only the researcher will have access to the information on the computer, and passwords will not be shared at any time.
  4. Any personal information that is stored electronically will be encrypted.
- 5) The researcher will take regular back-ups of the information stored on the computer which will be stored in a separate place. In case of loss of the computer, this means the information will not be lost.
- 6) If the researcher decides at any point to dispose of or change computers, all information will be securely removed (i.e. with use of technology or disposing hard disk).
- 7) Email security will be considered. This will include the content of the email and whether this should be encrypted and protected. If so, the researcher will liaise with the IT team for further assistance.

8) The researcher will remain cautious when sending emails. Blind Carbon Copy will be used (bcc) and group emails will be checked thoroughly.

## **PRACTICALITIES OF RESEARCH**

### *Potential Benefits and outcomes*

This research will give people who have received a diagnosis of an eating disorder the opportunity to define and make sense of their own experience. Rather than focusing on strict diagnostic criteria it places importance and meaning on the individual. The outcome of the research will endeavour to provide further understanding within eating disorder diagnoses and the subjective experience rather than seeing this as a mere state of symptoms. As a way forward, this will add to a much more meaningful recovery, providing further knowledge, understanding and effective ways of working with people for the professionals who are involved. This in itself is crucial in order for professionals to be able to work effectively with people and have insight and understanding of what that person actually experiences first-hand. Fundamentally the research moves far beyond pathologizing individuals and instead is far more focused on human experience which is an invaluable component. There remains ongoing debate regarding diagnosis, the DSM and incorporating patient's subjective experience into this framework as an important predictor for treatment outcomes.

### *Finance/costs*

The finance/cost for carrying out this research is outlined below:

<b>CONDUCTING THE RESEARCHER</b>	<b>COSTS</b>	<b>ADDITIONAL INFORMATION</b>
Staff costs directly associated with carrying out the research	£0	None Identified
Supervision	£0	Offered as part of research project
Professional Translation Services	Pending	The researcher will have to pay for a translation service if this is required. Action – To discuss with field supervisor once participants have been identified.
Travel costs	£25.20	Paid by researcher/ Zones 3-5 @ 1 week = £25.20 Covered in researchers' monthly oyster card,

		zones 1-5
Digital Dictaphone Storage – 2 drawer locked filing cabinet (quote from Staples)	£40.00 £60.00	The researcher will pay for all consumables.
Room Charge	£0	There are no room charges at the research site. Researcher to book rooms in advance with field supervisor.

Table 1: Finance/cost for carrying out the research.

### Audit Procedures

#### *Participants*

- The researcher will maintain a separate file for each participant.
- Contact details of participants will be documented in a separate file.
- Informed consent will be thoroughly documented.
- Evidence that the Participant Information Sheet and Consent have been approved will be documented.
- Original copies of Participant Information Sheet and Consent will be stored in the patients file.

#### *Audio Data*

- To demonstrate that the interviews have actually taken place, all interviews will be audio recorded using a digital Dictaphone. All audio data will be transferred onto the researcher's computer where all security measures will adhere to the Data Protection Act (1998).
- To ensure the interviews have been accurately transcribed, the researcher will be responsible for transcribing all of the interviews. The researcher will be familiar with the material and will dedicate several months to the transcription process alone to ensure that accuracy account has been obtained.
- A copy of the research questions will be documented in a file.

#### *Ethical Approval*

- The researcher will retain copies of the following documentation:
- A copy of the Research Protocol

- Evidence of registration of study with the Trust
- A copy of the NHS Ethics application
- A copy of the R&D application
- A copy of the Site-Specific Form
- Letters from R&D Offices (approval/amendments)
- Honorary Contracts

*Indemnity Insurance & Sponsors*

-The researcher will retain copies of the following documentation in a separate file which will be securely stored in the researcher's office:

- Evidence of insurance - Letter
- Evidence of sponsor - Letter
- CV of the researcher
- CV of the research supervisor

**REFERENCES**

American Psychiatric Association (2000). *Diagnostic and statistical manual of mental disorders*. Washington, DC: American Psychiatric Association.

British Psychological Society (2005). *Code of Conduct, ethical principles and guidelines*. Leicester: The British Psychological Society.

Borg, M., Karlsson, B., & Kim, H. S. User involvement in community mental health services: Principles and practices. *Journal of Mental Health Counselling*, 28, 202-217.

Boyle, M. (2002a). *Schizophrenia: A scientific delusion?* London: Routledge.

Coles, S. (2010). Position on psychiatric diagnosis: East midlands psychosis and complex mental health special interest group. 1-17. Retrieved from [http://www.bcu.ac.uk/cmsproxyimage?path=/media/docs/ccmh\\_emids\\_sig.pdf](http://www.bcu.ac.uk/cmsproxyimage?path=/media/docs/ccmh_emids_sig.pdf)

Corrie, S. & Callahan, M.M. (2000). A review of the scientist-practitioner model: Reflections of its potential contribution to counselling psychology within the context of current health care trends. *British Journal of Medical Psychology*, 73, 413-427.

Eriksen, K., & Kress, V. E. The DSM and the professional counselling identity: Bridging the gap. *Journal of Mental Health Counseling* 28, 202-217.

- Fairburn, C. G. (2008) *Cognitive behaviour therapy and eating disorders*. New York: The Guildford Press.
- Fairburn, C. G., & Cooper, Z. (2007). Thinking afresh about the classification of eating disorders. *International Journal of Eating Disorders*, 40, 107-110.
- Golsworthy, R. (2004) Counselling psychology and psychiatric classification: Clash or co-existence? *Counselling Psychology Review*, 19, 23-28.
- Keel, P. K., Brown, T. A., Holm-Denoma, J., & Bodell, L. P. Comparison of DSM-IV versus proposed DSM-5 diagnostic criteria for eating disorders: Reduction of eating disorder not otherwise specified and validity. *International Journal of Eating Disorders*, 44, 553-560.
- Larsson, P., Brooks, O., & Loewenthal, D. (2012) Counselling psychology and diagnostic categories: A critical literature review. *Counselling Psychology Review*, 27, 55-65.
- Pitt, L., Killbride, M., Welford, M., Northard, S., & Morrison, P. (2009). Impact of a diagnosis of psychosis user-led qualitative study. *Psychiatric Bulletin*, 33, 419-423.
- Punch, K. (2006). *Developing effective research proposals*. London: Sage.
- Smith, J. A and Osborn, M (2008). Interpretative phenomenological analysis. In J. A . Smith (Eds.), *Qualitative Psychology: A Practical Guide to Methods*. (pp. 53-81). London: Sage.
- Sysko, R., & Walsh, B. T. Does the broad categories for the diagnosis of eating disorders (BCD-ED) scheme reduce the frequency of eating disorder not otherwise specified? *International Journal of Eating Disorders*, 44, 625-629.
- Tasca, G. A., Maxwell, H., Bone, M., Trinneer, A., Balfour, L., & Bissada, H. (2012). Purging disorder: Psychopathology and treatment outcomes. *International Journal of Eating Disorders*, 45, 36-42.
- William, D.G., & Irving, J.A. (1996). Counselling Psychology: A conflation of paradigms. *Counselling Psychology Review*, 11, 7-18.
- Willig, C. (2012). A Phenomenological Reading. In C. Willig (Eds.), *Qualitative Analysis and Interpretation in Psychology* (pp. 96-111). Maidenhead: Open University Press



## INTERVIEW SCHEDULE

1. I am interesting in exploring with you your experience of receiving a diagnosis of an eating disorder. To start with, can you please recall when you first suspected that you had an eating disorder?

*Possible prompts: how long ago? Who made the informal diagnosis? Themselves? Family members? Friends?*

2. Who were the first people to use terms such as eating disorder?

*Possible prompts: Themselves? Family members? Friends? Professionals?*

3. How long was it until you received a formal diagnosis?

*Possible prompts: who from? How? Where? What happened? How did you feel?*

4. How did you feel afterwards?

*Possible prompts: how did you feel about yourself?*

5. What was the experience like of receiving a formal diagnosis versus living with informal knowledge that this was possibly an eating disorder?

6. How well did the formal diagnosis encapsulate the experience of living with an eating disorder?

7. What has been positive about receiving a diagnosis?

*Possible prompts: How do you feel about these changes? Can you tell me a bit more about that? What else?*

8. What has been negative about receiving a diagnosis?

*Possible prompts: How do you feel about these changes? Can you tell me a bit more about that? What else?*

9. What do you think others think about your diagnosis?

*Possible prompts: friends, family, partner, professionals, and work colleagues?*

10. Is there anything else you would like to add?



## **INCLUSION CRITERIA**

The inclusion criteria for this study are:

1. Participants will have to have received an eating disorder diagnosis, which can include: Anorexia Nervosa, Bulimia Nervosa, EDNOS or Binge Eating Disorder.
2. Participants can include both males and females.
3. Participants must be a minimum age of 18 as the research interests are amongst adults. There is no cut off point with regards to participants' age. Participants must have capacity to give consent to take part.

**Appendix 3**  
Version 1.0 (July 2013)

Date: .....

Dear .....

Re: *Letter of Invitation*

This is a letter of invitation to enquire if you would like to take part in a research project at [REDACTED] Eating Disorders Service.

My name is Nimisha Joshi and I am a Trainee Counselling Psychologist at City University. I am conducting some research as part of my Doctorate in Counselling Psychology. The research is being supervised by Dr Julianna Challenor (Academic research supervisor and Chartered Counselling Psychologist at City University) and Dr David Viljoen (Chartered Clinical Psychologist at [REDACTED] Eating Disorders Service).

The purpose of the research is to explore people's experience of receiving a diagnosis of an eating disorder. Areas of particular interest are around: when people first suspected they had an eating disorder, informal diagnosis versus formal diagnosis, whether or not receiving a formal diagnosis encapsulates that of living with an eating disorder and positive and negative aspects about diagnosis.

Before you decide whether you would like to take part, I would like you to understand why the research is being done and what it would involve for you. I have enclosed a participant information sheet which includes further information regarding the conduct of the study.

Meanwhile, please do not hesitate to contact me if you have any questions.

Best Wishes

**Nimisha Joshi**  
*Trainee Counselling Psychologist*

## **PARTICIPANT INFORMATION SHEET**

### *The Experience of Receiving a diagnosis of an Eating Disorder*

#### **Introduction**

You have been invited to take part in a research study which explores the experience of receiving a diagnosis of an eating disorder. Before you decide I would like you to understand why the research is being done and what it would involve for you. A member of the team will go through the information sheet with you and answer any questions you have. I suggest this should take about 30 minutes. Talk to others about the study if you wish. Part 1 tells you the purpose of this study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study. Please ask if there is anything that is not clear.

#### **Part 1: The Researchers**

My name is Nimisha Joshi and I am a Trainee Counselling Psychologist at City University. I am conducting this research as part of my Doctorate in Counselling Psychology. The research is being supervised by Dr Julianna Challenor (Academic research supervisor and Chartered Counselling Psychologist at City University) and Dr David Viljoen (Chartered Clinical Psychologist at [REDACTED] Eating Disorders Service).

#### **What is the purpose of the research?**

The purpose of the study is to explore people's experience of receiving a diagnosis of an eating disorder. Areas of particular interest are around: when people first suspected they had an eating disorder, informal diagnosis versus formal diagnosis, whether or not receiving a formal diagnosis matches that of living with an eating disorder and positive and negative aspects about diagnosis. The research to-date has largely focused around how eating disorders are classified with an emphasis on diagnostic categories. There remains a gap in the evidence base however which explores the experience of receiving the diagnosis itself.

Once you have decided that you would like to take part; you can contact me using the details provided. This will also give you the opportunity to ask further questions about the research. I will arrange a time to meet with you at [REDACTED] Eating Disorders Service. During the meeting, I will confirm that you still want to take part in the research. If you are happy to continue I will ask you to sign a consent form. Once you have provided written consent, I will start the interview which will last a maximum of 90 minutes and this will be audio recorded.

**Why have I been invited?**

You have been invited to take part as you have experienced receiving a diagnosis of an eating disorder which is the area this study hopes to explore further. A total of 10 people will be recruited for this study and this will be on a 'first come, first served' basis.

**Do I have to take part?**

You are under no obligation to take part in the study; it is completely up to you to decide. We will describe the study and go through this information sheet with you. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive.

**What will happen to me if I take part?**

Nothing will happen directly to you. Instead, you will be asked 10 questions about your experience of receiving a diagnosis of an eating disorder.

**What will I have to do?**

You will be asked to attend an interview with the researcher at [REDACTED] Eating Disorders Service which will last a maximum of 90 minutes. Questions will be focused around the following:

- Your experience of an informal diagnosis.
- Your experience of receiving a formal diagnosis.
- How you felt after you were diagnosed.
- Your experience of receiving a formal diagnosis versus living with an eating disorder.
- Positive and negative aspects about receiving a diagnosis.
- What others think about your diagnosis.

You will not be required to bring anything with you on the day. The interview will be audio recorded by the researcher.

**What are the possible risks or disadvantages of taking part?**

The interview schedule will require you to talk about your personal experiences which may cause some distress. This however, will be managed appropriately and you may pause at any point during the interview or be entitled to a short break should you need this. Additionally, if you do not feel comfortable to answer a particular question you can skip this. A de-brief will be provided at the end of the interview where there will be an opportunity for feedback and support.

**What are the possible benefits of taking part?**

We cannot promise the study will help you but the information we get from this study will help improve the understanding of eating disorders. The research will give you the opportunity to talk openly and honestly about your experiences. I hope that from conducting this research it will improve the understanding of living with an eating

disorder and shift towards focusing on people's experiences rather than solely on diagnostic criteria.

### **What happens when the research study stops and to the results?**

Once the researcher has conducted all of the interviews, the data will be analysed in order to examine your experiences in close detail. This analysis will then form part of the research thesis which will be reviewed by an academic group of people at City University. Your data will be stored in a locked storage facility for one year, which is in line with the university's data storage policy. If the research is publishable, then data will be stored for 5 years, which is in line with the NHS data storage policy. Following the retention period, all of your information will be destroyed by the researcher. With regards to the results, you will have the opportunity to meet with the researcher to receive feedback on the outcome of the research that you have contributed to.

### **What if there is a problem?**

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

### **Will my taking part in the study remain confidential?**

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. These details are included in Part 2.

### **This completes part 1.**

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decisions.

## **PART 2: What will happen if I don't want to carry on with the study?**

If you withdraw from the study we will destroy all identifiable information.

### **What if there is a problem?**

#### **Complaints**

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this via the NHS Complaints Procedure or Private Institutional arrangements. Details can be obtained from the researcher.

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against [City University, NHS Trust] but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you (if appropriate).

### **Will my taking part in the study be kept confidential?**

All information which is collected about you during the course of the research will be kept strictly confidential, and any information about you which leaves the service will have your name and address removed so that you cannot be recognised.

**What will happen to the information I give?**

The researcher will listen to the audio recording and type up the interview. The reason for this is to identify important patterns and themes in order to get an in-depth understanding about your experiences. All information, including the audio recording and transcriptions will remain anonymous and kept in locked cabinet. The research supervisor will look at the anonymous information from the interview. This information will also be looked at by professional and academic committees to examine the quality of the doctoral research. As required by the University, I will write up a report which will include the anonymous transcripts in order to illustrate accurately the patterns and themes.

**Who has reviewed the study?**

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by [REDACTED] Ethics Committee.

**Contact Details**

**Nimisha Joshi**

Trainee Counselling Psychologist

T: [REDACTED]

(Telephone messages can be left through the course administrator Alison Peach)

E: [REDACTED]

**Dr Julianna Challenor**

Chartered Counselling Psychologist

Research Supervisor, City University

[REDACTED]

**Dr David Viljoen**

Chartered Clinical Psychologist & Family and Systemic Psychotherapist

Field Supervisor, [REDACTED] Eating Disorders Service

E: [REDACTED]



Appendix 4  
Version 1.0 (July 2013)

**PARTICIPANT CONSENT FORM**  
*The Experience of Receiving a diagnosis of an Eating Disorder*

Title of Project: **[THE EXPERIENCE OF RECEIVING A DIAGNOSIS OF AN EATING DISORDER]** Name of Researcher: **[NIMISHA JOSHI]**

Please initial all boxes

- 8. I confirm that I have read and understand the information sheet dated **[DATE]** (version **[VERSION NUMBER]** for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
- 9. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
- 10. I understand that my information will be stored in a locked cabinet and that the information I provide will be anonymised.
- 11. I give consent for the interview to be audio recorded, transcribed and for direct quotes to be included in the research report which I understand will be anonymous.
- 12. I understand that relevant sections of my data collected during the study, may be looked at by individuals from **[CITY UNIVERSITY LONDON]**, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research.
- 13. I give permission for my GP to be approached before taking part in the study.
- 14. I agree to take part in the above study.

_____	_____	_____
Name of Participant	Date	Signature

_____	_____	_____
Name of Person taking consent.	Date	Signature

Appendix 5

Version 1.0  
01/07/2013

Dr  
GP Surgery

Nimisha Joshi  
Trainee Counselling Psychologist

T: [REDACTED]

E: [REDACTED]

Date: .....

Dear Dr .....

Re: *Patient name*

Date of birth: *date of birth*

My name is Nimisha Joshi and I am a Trainee Counselling Psychologist at City University. I am conducting some research as part of my Doctorate in Counselling Psychology. The research is being supervised by Dr Julianna Challenor (Academic research supervisor and Chartered Counselling Psychologist at City University) and Dr David Viljoen (Chartered Clinical Psychologist at [REDACTED] Community Eating Disorders Service).

The purpose of the research is to explore people's experience of receiving a diagnosis of an eating disorder. Areas of particular interest are around: when people first suspected they had an eating disorder, informal diagnosis versus formal diagnosis, whether or not receiving a formal diagnosis encapsulates that of living with an eating disorder and positive and negative aspects about diagnosis.

Your patient, (*patient name*), is interested in taking part in the research and has been offered an initial appointment on (*date*) where he/she will be asked to sign a consent form. Following this, (*patient name*) will be invited to attend an interview with myself at [REDACTED] Community Eating Disorders Service which will last a maximum of 90 minutes. (*Patient name*) has been informed that the interview will be audio recorded, which is also clearly stated in the consent form.

I have attached a copy of the participant information sheet which includes further information regarding the conduct of the study. Meanwhile, please do not hesitate to contact me should you require any further information.

Yours Sincerely

Nimisha Joshi  
Trainee Counselling Psychologist

**Appendix 6**  
Version 1.0 (July 2013)

## **PARTICIPANT DE-BRIEF FORM**

### *The Experience of Receiving a diagnosis of an Eating Disorder*

Thank you very much for your time and taking part in this research.

This study was interested in exploring people's experiences of receiving a diagnosis of an eating disorder. I was particularly interested in the following areas:

- When you first suspected that you had an eating disorder.
- Your experience of an informal diagnosis.
- Your experience of receiving a formal diagnosis.
- Who the people were that used the term eating disorder.
- How you felt after you were diagnosed.
- Your experience of receiving a formal diagnosis versus living with an eating disorder.
- Positive and negative aspects about receiving a diagnosis.
- What you think others think about your diagnosis.

The existing literature has focused on eating disorders and diagnostic criteria; however there remains little research into people's subjective experiences. There is an ongoing debate regarding diagnostic criteria, whereby a significant proportion of people are not receiving treatment because they do not quite meet the criteria. Diagnosis therefore remains a really important area and given this context, it is extremely useful to hear what service users think and experience first-hand.

### **Sources of support**

Talking about your own personal experiences may have caused some upset, which is very normal and you should find that these feelings ease shortly. If however, you continue to experience upset or any distress, the researcher has provided a list of organisations below that can offer you support:

6. Your care co-ordinator is aware of your participation in this study and you have the option of talking to them if you require any further support.

7. You may feel comfortable to discuss any issues with family members or friends.
8. <http://www.b-eat.co.uk/>

### **Helplines**

For the **Adult Helpline**, please call 0845 634 1414. This helpline is available to anyone over the age of 18 and is open Monday to Friday 10.30am to 8.30pm and Saturdays 1.00pm - 4.30pm. Alternatively, you can email [help@b-eat.co.uk](mailto:help@b-eat.co.uk)

For the **Youthline**, please call 0845 634 7650. The Youthline is available to anyone aged 25 or under, and is open Monday to Friday from 4.30pm to 8.30pm and Saturdays 1.00pm - 4.30pm. You can also text the Youthline on 07786 20 18 20 - send us a message and we will get back to you within 24 hours. There is also a Youth line email service at [fyp@b-eat.co.uk](mailto:fyp@b-eat.co.uk)

### **9. Samaritans**

Available 24 hours a day to provide confidential emotional support  
08457 90 90 90  
<http://www.samaritans.org/>

10. If you would like to discuss any aspect of the study further, you are more than welcome to contact the researcher or the supervisor:

### **Nimisha Joshi**

Counselling Psychology Doctoral Student

T: [REDACTED]

(Telephone messages can be left through the course administrator Alison Peach)

E: [REDACTED]

### **Dr Julianna Challenor**

Chartered Counselling Psychologist  
Research Supervisor, City University

[REDACTED]

*Thank you again for taking part.*

## APPENDIX F: Participant invitation and information sheet



**School of Arts  
and Social Sciences**  
CITY UNIVERSITY LONDON

**Department of Psychology**  
Northampton Square  
London EC1V 0HB

### *Letter of Invitation*

Dear Participant,

This is a letter of invitation to enquire if you would like to take part in a research project at [REDACTED] Eating Disorders Service.

My name is Nimisha Joshi and I am a Trainee Counselling Psychologist at City University. I am conducting some research as part of my Doctorate in Counselling Psychology. The research is being supervised by Dr Julianna Challenor (Academic research supervisor and Chartered Counselling Psychologist at City University) and Dr David Viljoen (Chartered Clinical Psychologist at [REDACTED] Community Eating Disorders Service).

The purpose of the research is to explore people's experience of receiving a diagnosis of an eating disorder. Areas of particular interest are around: when people first suspected they had an eating disorder, informal diagnosis versus formal diagnosis, whether or not receiving a formal diagnosis encapsulates that of living with an eating disorder and positive and negative aspects about diagnosis.

Before you decide whether you would like to take part, I would like you to understand why the research is being done and what it would involve for you. I have enclosed a participant information sheet which includes further information regarding the conduct of the study.

Meanwhile, please do not hesitate to contact me if you have any questions.

Best Wishes

**Nimisha Joshi**  
*Trainee Counselling Psychologist*



## **PARTICIPANT INFORMATION SHEET**

### *The Experience of Receiving a diagnosis of an Eating Disorder*

#### **Introduction**

You have been invited to take part in a research study which explores the experience of receiving a diagnosis of an eating disorder. Before you decide whether or not you would like to participate I would like you to understand why the research is being done and what it would involve for you. A member of the team will go through the information sheet with you and answer any questions you have. I suggest this should take about 30 minutes. Talk to others about the study if you wish. Part 1 tells you the purpose of this study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study. Please ask if there is anything that is not clear.

#### **Part 1: The Researchers**

My name is Nimisha Joshi and I am a Trainee Counselling Psychologist at City University. I am conducting this research as part of my Doctorate in Counselling Psychology. The research is being supervised by Dr Julianna Challenor (Academic research supervisor and Chartered Counselling Psychologist at City University) and Dr David Viljoen (Chartered Clinical Psychologist at [REDACTED] Community Eating Disorders Service).

#### **What is the purpose of the research?**

The purpose of the study is to explore people's experience of receiving a diagnosis of an eating disorder. Areas of particular interest are around: when people first suspected they had an eating disorder, informal diagnosis versus formal diagnosis, whether or not receiving a formal diagnosis matches that of living with an eating disorder and positive and negative aspects about diagnosis. The research to-date has largely focused around how eating disorders are classified with an emphasis on diagnostic categories. There remains a gap in the evidence base however which explores the experience of receiving the diagnosis itself.

If you decide that you would like to take part; you can contact me using the details provided. This will also give you the opportunity to ask further questions about the research. I will arrange a time to meet with you at [REDACTED] Community Eating Disorders Service. During the meeting, I will confirm whether you still want to take part in the research. If you are happy to continue I will ask you to sign a consent form. Once you have provided written consent, I will start the interview which will last a maximum of 90 minutes and this will be audio recorded.

#### **Why have I been invited?**

You have been invited to take part as you have experienced receiving a diagnosis of an eating disorder which is the area this study hopes to explore further. A total of

10 people will be recruited for this study and this will be on a 'first come, first served' basis.

### **Do I have to take part?**

You are under no obligation to take part in the study; it is completely up to you to decide. We will describe the study and go through this information sheet with you. If you agree to take part, we will then ask you to sign a consent form. Your GP will also be informed about your involvement in the study. If participants refuse permission to inform their GP, they will unfortunately be excluded from the study. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive.

### **What will happen to me if I take part?**

Nothing will happen directly to you. Instead, you will be interviewed about your experience of receiving a diagnosis of an eating disorder.

### **What will I have to do?**

You will be asked to attend an interview with the researcher at [REDACTED] Eating Disorders Service which will last a maximum of 90 minutes. Questions will be focused around the following:

- Your experience of an informal diagnosis.
- Your experience of receiving a formal diagnosis.
- How you felt after you were diagnosed.
- Your experience of receiving a formal diagnosis versus living with an eating disorder.
- Positive and negative aspects about receiving a diagnosis.
- What others think about your diagnosis.

You will not be required to bring anything with you on the day. The interview will be audio recorded by the researcher.

You will have a de-briefing session after the interview which will last 20 minutes. You will also have the option to attend a separate second session to discuss the themes raised in your interview. This session will last 90 minutes.

### **What are the possible risks or disadvantages of taking part?**

The interview schedule will require you to talk about your personal experiences which may cause some distress. This however, will be managed appropriately and you may pause at any time during the interview or take a short break. Additionally, if you do not feel comfortable to answer a particular question you can skip this. A de-brief will be provided at the end of the interview where there will be an opportunity for feedback and support.

**What are the possible benefits of taking part?**

We cannot promise the study will help you but the information we get from this study may help the understanding of eating disorders. The research will give you the opportunity to talk openly and honestly about your experiences. I hope that from conducting this research it will improve the understanding of living with an eating disorder and shift towards focusing on people's experiences rather than solely on diagnostic criteria.

**What happens when the research study stops and to the results?**

Once I have conducted all of the interviews, I will analyse the data in order to examine your experiences in close detail. This analysis will then form part of the research thesis which will be reviewed by an academic group of people at City University. Your data will be stored in a locked cabinet at all times for one year, which is in line with the universities data storage policy. If the research is publishable, then data will be stored for 5 years, which is in line with the NHS data storage policy. Following the retention period, I will ensure that all of your information will be destroyed in a secure environment. With regards to the results, you will have the opportunity to meet with me again to receive feedback on the outcome of the research that you have contributed to.

**What if there is a problem?**

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

**Will my taking part in the study remain confidential?**

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. These details are included in Part 2.

**This completes part 1.**

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decisions.

**PART 2: What will happen if I don't want to carry on with the study?**

Participation is entirely voluntary, and you can decide not to participate, or withdraw at any time, without giving a reason, and without your medical care or legal rights being affected.

If you withdraw from the study I will destroy all identifiable information

**What if there is a problem?****Complaints**

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this via the NHS Complaints Procedure or Private Institutional arrangements. Details can be obtained from the researcher.

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal

action for compensation against [City University, NHS Trust] but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you (if appropriate).

### **Will my taking part in the study be kept confidential?**

All information which is collected about you during the course of the research will be kept strictly confidential, and any information about you which leaves the service will have your name and address removed so that you cannot be recognised. With your consent, I will inform your GP of your involvement with the study. Should you disclose anything that indicates potential harm to either yourself or others, I have a statutory obligation to break confidentiality.

### **What will happen to the information I give?**

I will listen to the audio recording and type up the interview. The reason for this is to identify important patterns and themes in order to get an in-depth understanding about your experiences. All information, including the audio recording and transcriptions will remain anonymous and kept in locked cabinet. My research supervisor will look at the anonymous information from the interview. This information will also be looked at by professional and academic committees to examine the quality of the doctoral research. As required by the University, I will write up a report which will include the anonymous transcripts in order to illustrate accurately the patterns and themes. The study data and audio recordings will be retained for 1 year which is in line with the universities data storage policy. If the research is publishable, then data will be stored for 5 years, which is in line with the NHS data storage policy.

### **Who has reviewed the study?**

The study has been reviewed by London – [REDACTED] Research Ethics Committee.

### **Contact Details**

#### **Nimisha Joshi**

Trainee Counselling Psychologist

T: 07534 22 0563

E: [REDACTED]

#### **Dr Julianna Challenor**

Chartered Counselling Psychologist

Research Supervisor, City University

E: [REDACTED]

#### **Dr David Viljoen**

Chartered Clinical Psychologist & Family and Systemic Psychotherapist

Field Supervisor, [REDACTED] Eating Disorders Service

E: [REDACTED]

### **Sources of support**

A list of organisations has been provided below should you require additional support:

<http://www.b-eat.co.uk/>

### **Helplines**

For the **Adult Helpline**, please call 0845 634 1414. This helpline is available to anyone over the age of 18 and is open Monday to Friday 10.30am to 8.30pm and Saturdays 1.00pm - 4.30pm. Alternatively, you can email [\*\*help@b-eat.co.uk\*\*](mailto:help@b-eat.co.uk)

For the **Youthline**, please call 0845 634 7650. The Youthline is available to anyone aged 25 or under, and is open Monday to Friday from 4.30pm to 8.30pm and Saturdays 1.00pm - 4.30pm. You can also text the Youthline on 07786 20 18 20 - send us a message and we will get back to you within 24 hours. There is also a Youth line email service at [\*\*fyp@b-eat.co.uk\*\*](mailto:fyp@b-eat.co.uk)

### **Samaritans**

Available 24 hours a day to provide confidential emotional support

08457 90 90 90

<http://www.samaritans.org/>

APPENDIX G: Initial Noting

Transcript: Participant 1

- 119 R: Because I think my eating disorder is obviously a control thing. And in April or end of  
 120 March when I was on this holiday, it was coming up to my A levels [pause] so I was  
 121 really stressed about that. And [pause] I think I was [pause] so that was stressful. I was  
 122 with these people who [pause] I, some of them I saw once a year. And I'm quite shy  
 123 and anxious and so just all these really stressful things and the way I would usually  
 124 deal with that is through food and, that was taken away from me [pause] but yeah.
- 125 I: How did you manage that?
- 126 R: Well I think I was very um [pause] stropky [laughs]. And yeah I was just a bit moody.  
 127 I was [pause] depressed and because [pause] yeah because my friend. I always seem quite  
 128 kind of in control. I think that's how people think of me and then on this holiday I wasn't  
 129 and I was really upset and [pause] yeah I don't know [laughs].
- 130 I: Okay. When, when you went to the GP with your mum and you received that formal  
 131 diagnosis,
- 132 R: I don't know if I got a formal diagnosis from my GP.
- 133 I: Okay.

Eating disorder is about control.

shy)

with people she didn't know. shy & nervous. stressed & unable to cope. (her food was taken away from her. (her awareness of being out of control & how food helps her to cope with stress. What happens when food is taken away? Stopping & moody. There's a shift with her laughing to a more serious response. It's a bit of a momentary pause. Over practice he was being in control. Questioning herself. What was it that made her not in control?

Uncertain about formal diagnosis

APPENDIX H: Developing emergent themes

Transcript: Participant 1

Lack of control over self	<p>119 R: Because I think my eating disorder is obviously a control thing. And in April or end of March when I was on this holiday, it was coming up to my A levels [pause] so I was really stressed about that. And [pause] I think I was [pause] so that was stressful. I was with these people who [pause] I, some of them I saw once a year. And I'm quite shy and anxious and so just all these really stressful things and the way I would usually deal with that is through food and, that was taken away from me [pause] but yeah.</p>	<p>Eating disorder is about control. stress.</p>
I:	How did you manage that?	<p>With people she doesn't expect. She's anxious. She's a little bit more. She's food was taken away from her. She's moments of getting out of control is how food helps her to cope with stress. What happens when food is taken away? She's a bit more. There's a shift when she's laughing to a more relaxed response. There's a bit more relaxed moment before.</p>
R:	Well I think I was very um [pause] stropky [laughs]. And yeah I was just a bit moody.	
I was [pause] depressed and because [pause] yeah because my friend. I always seem quite kind of in control. I think that's how people think of me and then on this holiday I wasn't and I was really upset and [pause] yeah I don't know [laughs].		<p>One's perceive her as being in control. Questioning herself. What's in other than if she's not in control?</p>
I:	Okay. When you went to the GP with your mum and you received that formal diagnosis,	
R:	I don't know if I got a formal diagnosis from my GP.	<p>Uncertain about formal diagnosis</p>
I:	Okay.	

## APPENDIX I: Searching for connections across emergent themes

<b>Box 1 Table of major themes and themes from one participant</b>		
<b><i>Challenging Emotions</i></b>	<b>Page/Line</b>	<b>Key words</b>
A recent diagnosis	44.623-626	Difficult
Difficult emotions	45.634	Embarrassed and guilty
Difficult to express feelings	58.834-837	Can't express
Unexpected	46.646-649	No way
Time Frame	2.23-25	Started doing it
Going through phases	17.237-239	Go through times
Phases with food	1.4-7	Gone through phases
Extreme denial	23.321-323	Extreme denial
A fake	29.410-412	Like a fake
Fraud and fake	27.386	A fraud/Like a fake
Waiting time for therapy	20.280-285	Quite a while

**APPENDIX J: Looking for patterns across cases**

Superordinate themes	Sub themes	Quote location
Living with an unlabelled condition	The warning signs	A1-2.13-17 A5.64-67 A8.105-109 A12.166-168 A18.246-248 A21.287-289 A21.296-298 A24.340-342 A25.344-349 A29-30.142-417 A31-32.443-447 A53.753-755 A57.819-824 C1.4-10 C1.12-6 C2.24-27 C2.35-42 C3.42-47 D11-12.155-163 D19-20.274-283 D24-25.352-357 D25.357-359 D25-26.367-370 G2.20-28 G3.36-41 G7.104-109 G10.156-164 G11-12.12-188 G19.313-316 G19.313-316 H1-2.15-18 G19.313-316 H1-2.15-18 H2.22-27 H3537 H37-45 H5.66-71 H7-.95-101 H8-9.107-111 H12.176-178 H13.193-198 H14.201-207
	Living without a diagnosis	A46.653-655 A47.523-524 A43.606 A46.653-2.201-206 B14.238-242 B30.525-527 D20-21.293 22-328 M27.388-395 M32.460-470 M41.595-8282-287 M21.307-310 M26.373-376 M29.424-429-36 G5.78-85 G2-3.29-36 G5.78-85 G7.101-10356-366 I28.458-465 I35.579-588 J1.4-7 J1.7-113-60 J7.105-106 J12.193-196 J17.276-279 J17.274 G7-8.112-120 G15.246-249 G30.498-501 M4.554.759-770 A59.839-841 A59-60.697-701 A53-546 I4-5.60-68 I5.75-79 I6.87-91 I22.351-356 I22.6.216-227 M22.312-313 M22.318-322 M22-23.3655 A47.669-671 A49.694-695 A49.697-701 A5367 A32.453-454 A37.523-524 A43.606 A43.608-6759-770 A59.839-847 A59-60.852-855 B1-8.11 B9 A11.147-148 A15.209-211 A16.223 A19.265-299 D21.299-305 D21-22.307-317 G1.14-17 G2-3. B2.26-30 B3.42-43 B3.32-35 B3.46-49 B4.55-60 B4.63-67 B5.75-81 B6.92-96 B11-12.196-200 B1J2.18-22 J2.14-26 J2.22-24 J.28-30 J3.40-46 J4.5M.111-13 M3.38-40 M6.51-86 M8.109-112 M20M42-607-614 M4-5.57-64 M5-6.70-76 M7.92-95M8.114-115 M9-10.126-136 M13.184-187 M15-D4.51-53 D6.78-85 D12-13.175-178 D14.193-203D15.211-214 D18.256-263 F1.8-11 F4-5.69-76 F6-7.101-110 I11.190-193 F14.219-225 I17.273-278 I17-18.278-284 I25.408-413 I26-27.432-439 I27.439-442 I27.445-447 I31.507-512 J6.95-97 J6-7.98-105 J7.106-112 J112.117 J13.202-203 J13.203-209 J13.209-213 J16.251-255 J21.202-203 J13.203-209 J16.251-255 J21-22.348-356 J22.359-363 J22.363-369 M7.95-100 M17.238-240 M20.289-293 M21.298-305 M34.489-498 M35-36.514-521 M3738.530-574 M38.551-558 M38-39.559-5
Perception of lack of compassion when receiving diagnoses	The uncertainty & doubts when receiving a diagnosis	D4.51-53 D6.78-85 D12-13.175-178 D14.193-203D15.211-214 D18.256-263 F1.8-11 F4-5.69-76 F6-7.101-110 I11.190-193 F14.219-225 I17.273-278 I17-18.278-284 I25.408-413 I26-27.432-439 I27.439-442 I27.445-447 I31.507-512 J6.95-97 J6-7.98-105 J7.106-112 J112.117 J13.202-203 J13.203-209 J13.209-213 J16.251-255 J21.202-203 J13.203-209 J16.251-255 J21-22.348-356 J22.359-363 J22.363-369 M7.95-100 M17.238-240 M20.289-293 M21.298-305 M34.489-498 M35-36.514-521 M3738.530-574 M38.551-558 M38-39.559-5
	Perception of care when receiving a	D19.269-272 D22-23.322-330 D23-24.332-340 D30.436-440 I10.154-159 I14.225-230 I16.256-264I16-17.264-271 I18.284-289 I18.289-296 I19.307

diagnosis	312 I30.492-497 I30-31.501-507 I31.512-518 I31.518-521 I32.525-531 J5.77-81 J16.259-264 J17.273-276 J18-19.301-306 J19.306-315 J19-20.317-324
Emotional responses to receiving a diagnosis	A1.4-7 A2.23-25 A17.237-239 A20.280-285 A23.321-323 A27.386 A29.410-412 A44.623-626 A45.634 A46.646-649 A58.834-837 B8.125-128 B9.14-148 B9.155-160 B10.174-178 B12.1 B14.223-236 B18.315-318 B20.341-245 B20-21.356-359 B21.361-368 B28.490-496 C2.27-34 C5.74-78 C.106-108 C8.122-126 C9.137-145 C11.175-182 C13-14.207-2013 C15-16.245-250 I2.19-23 I3.41-46 I572-75 I7-8.114-118 I15.242-244 I15-16.248 254 I19.305-307 I19.312-315 I20.320-327 I23.376-379 I27.28.44-453 I28.453-458
Living with the diagnostic label	A2.27-29 A7.90-93 A20.275-276 A25.351-352 A33.471 A34.473-475 A34.477-481 A35.488-492 A44.626-628 A62.881-883 B1-2.16-20 B3.49-51 B4-6 B8-9.137-143 B10.171-172 B19.324-326 D4.57-58 D5.68-70 D6.74-76 D8.103-104 D8.103-104 D8.105-107 D9-10.127-133 D12.171-173 D15.206-209 D24.342-350 D30.447-448 F2.22-27 F2.27-34 F8.132-135 F15.261-266 F16.275-279 F16.279-282 F16.282-285 F17.289-294 F19.327-336 F20.342-351 F21-22.367-378 F25-26.442-447 F27.472-782 G8-9.131-138 G9-10.147-155 G10-11.166-173 G12.192-196 G12.199-203 G15.238-246 G21.339-346 G22.356-361 H1.4-8 H1.8-13 H2.29-32 H5.73-77 H10.152-153 H11.168-169 A3.36-39 A3.42-45 A4.47-48 A4.53-57 A5.61 A6.80-82 A15.213-216 A15.203-206 A17.239-241 A18.252-256 A24.331-338 A32.456-458 A33.463-465 A40.563-564 A45.632-633 A45.633-634 A45.639-41 A52.733 A52.739-741 B6.100-104 B7.115-117 B7.117-120 B10.162-164 B11.183-187 B11.191-93 B13.224-225 B15-16.267-272 B16.279-283 B23.394-397 F3.44-51 F3-4.51-56 F7.110-112 F7-8.120-127 F8-9.140-145 F9.145-152 F152-159 F159-172 F11.183-187 F12.196-200 F12.13207-214 F13.219-226 F15-16.266-275 F17.294-301 F18.305-311 F21-22.356-366 F22.378-388 F22-23.390-396 F23.402.408 F25.436-442 F26.454-458F27.446 467 F27.427-467 G4.57-59 GG4-5.67-74 G9.92-95 G8.129-130 G13.207-213 G22.361-369 G23.375-387 GG23-24.387-394 G28.463-468 I1-2.16-18 I3.34-39 I5-6.81 I7.99-107 I8.123-127 I8-9.127-132 I9.132-135 I9.138-142 I13.203-211 I13-14.211 216 I15.232-240 I9.301-305 I23-24.379-388 I24.3
Living up to the label	

	<p>88-391 I24.391-398 I25-26.413-422 I33-34.552-57  7 135.576-579 I35-36.588-594 I36.596-605 I39.645  I39-40.649-658 M52-159 M18-19.266-270 M29.416-418  M39.563-574 M40.575-582 M44-45.645-652  A8.113-114 A8-9.102-105 A9.127-129 A13.177 A27.382-384  A30.419-422 A35.495-496 A35-36.500-503 A37.517-520  A38.533-538 A38.540-543 A39-545-547 A39.552-555  A40.566-568 A40.571-572 A41.574-577 A41.579-580  A42.595-598 A55.805 A55.780-786 A57.809-813 A59.845-848  C5-684 C14-15.223-232 C16-17.257-263 C17.263-268  C17.272-275 C17.275-280 C18-19.292-303 D10.134-138  D26.372-375 D26.377-382 D27.384-389 D28.406-413  G4.61-66 G20.328-333 G20.333-337 G25.408-413  G25.413-419 G26.422-428 G27.441446 H6.81-83  H89-95 H11.155-161 H14.211-214 I20-21.327-335  I21-22.349-351 I33.549-552 I34.557-561 I34.561-565  I34.565-569 I34-35.569-574 I36-37.605-609  I37.609-611</p>
<b>A pathway to recovery</b>	<p>A10.145 A11.150-151 A14.188-192 A22.308-309  27.373-376 A51.722-724 A51.728-731 A58.827-828  A60.860-861 B5.81-83 B11.180-183 B12.210213  B15.254-258 B16.5 B17.289-291 B22.3 B22.6  B24.413-414 B29.512-525 B30.520-523 J2.32-38  J3.38-40 J4.60-62 J6.94-95 J7-8.118-119 J8.128-131  J9.134-141 J10.155-165 J11.175-182 J18.285-290  J20-21.334-338 J21.338-339 M2.21-25 M2.27-29  M10-11.144-150 M12-13.167-182 M23.330-336  M23-24.340-345 M25.362-368 M26-27.378-388  M28.406-410 M30.428-440 M35.506-508 M35.500-504  M36.523-528 M41.591-592</p>
	<p>F10-11.171-179 F14.241-244 F14.244-248 F19.325-327  F19-20.336-343 G3.44-51 G16.253-254 G16-17.263-271  G172 G17-18.285-290 G20.323-327 G21.347-354  G26.428-435 G27.446-450 G31.515-517  I12.180-184 I12.188-192 I12-13.195-203 I21.342-344  I28-29.467-472 I29.427-478 I29.478490 I30.497-499  I37-38.620-625 I37.611-620 I38627-629 I38.633-639  I38-39.639-642 J2.30-32 J45.62-68 J5-6.81-84  J6.84-86 J6.86-89 J6.89-92 J8.119-124 J8.124-126  J11.172-174 J12.184-186 J12.186-193 J14.229-234  J14.225-227 J15.234-237 J15.234-237 J15.240-243  J16-17.264-270 J18.297-300 J20.325-331</p>
	<p>A14.5 A14.197-201 A22.311-312 A25-26.356-360  A28.392-394 A28-29.398-404 A29.407-408 A30.427-430  A43.610-612 A44.617-618 A48.674-677</p>
<b>Perceptions of others</b>	
<b>Making it real</b>	
<b>Leading to a stronger self</b>	
<b>The start of a new beginning</b>	

	8	A48.683-686	A49.688-691	B5.88-91	B13.220-2
	2	B17.298-302	B22.387-390	B23.398-403	B23.40
	5-409	B253.434-441	B26.461-463	B27.479-785	B
	29.6	C4.57-59	C4.59-66	C5.78-82	C7.108-115
		C8	128-130	C8-9.130-133	C9-10.148-158
		C10.11	C1	2-13.186-198	C12.185-186
		C13.203-207	C16.250	253	C19.305
		C19.308-313	C20.315-324	D16.224	
	231	D16-17.223-240	D30-31.440-447	D31.450-45	
	3	D31-32.456-459	D33.478-490	D34.495-497	D3
		4.497-500	H6.85-87	H10.143-150	H11.161-163
		H12.81-183			

**PART C: PUBLISHABLE PIECE**

**Patient experience of receiving a diagnosis of an eating disorder**

Nimisha Joshi<sup>1</sup>, David Viljoen<sup>2</sup>, Julianna Challenor<sup>3</sup>

<sup>1</sup>Department of Psychology, City University, Northampton Square, London, EC1V 0HB, 020

7040 5060

<sup>2</sup>



**\*Correspondence**

Nimisha Joshi

Email: 

## **ABSTRACT**

The notion of diagnosis has been shown to have a profound influence within mental health practice with much attention focusing on the controversies and challenges surrounding the diagnostic classification of eating disorders. However, research focusing on how patients experience their eating disorder diagnosis is scarce. The purpose of this research, therefore, was to address this gap in the literature by exploring patients' experiences of receiving a diagnosis of an eating disorder. Ten female patients were recruited from an adult community eating disorders service in the UK. All patients had received an eating disorder diagnosis and were interviewed using a semi-structured interview schedule. Transcribed interviews were qualitatively analysed using the principles of Interpretative Phenomenological Analysis (IPA). Four master themes emerged from the data: (1) Living with an unlabelled condition, (2) Perception of the patient-therapist relationship and interpersonal qualities, (3) Living with the diagnostic label, (4) A pathway to recovery. The findings provide a rich description on how participants experienced diagnosis. Patients' experiences were both negative and positive whereby their experiences progressed from disbelief and rejection of the diagnosis to ideas of acceptance and recovery. Receiving and living with a diagnosis of an eating disorder has a significant impact on patients which should be considered throughout their assessment and treatment process. The need for compassionate care from professionals was an important component that was highlighted and recommendations were made in this regard. It is argued that increased awareness of patient experience will help clinicians to develop stronger therapeutic alliances and develop new clinical interventions.

Key words: DSM; diagnosis; eating disorders; diagnostic label; recovery