EXPLORING THE LIVED EXPERIENCE OF AN EATING DISORDER: A QUALITATIVE ANALYSIS

by

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Thesis Overview

This thesis compromises two chapters, which were submitted as per the requirements for the degree of Doctor of Clinical Psychology.

Chapter I: Research Chapter

The research component contains a literature review, an empirical paper and a press release. The literature review is a qualitative evidence synthesis exploring male experiences of Eating Disorders. Fourteen papers were synthesised to create four themes. The empirical paper is a qualitative research project exploring young people’s experiences of treatment for Anorexia Nervosa. Five young people were interviewed and their experiences analysed to develop themes that related to either the role of the individual or the role of others. Finally, two press releases provide an accessible overview of the literature review and empirical paper.

Chapter II: Clinical Chapter

The clinical chapter incudes five clinical practice reports. The first presents a case study of a 22-year-old male whose deterioration in mental state was formulated from two perspectives. The second presents a service evaluation of Feedback Received on the Delivery of Psychology Training within Secure Care and Offender Health Services. The third presents a single case experimental design evaluating the effectiveness of Cognitive Behavioural Therapy for Anxiety adapted for an LD population with a 26-year-old male.

The fourth presents a case study of a 76-year-old female receiving Cognitive Behavioural Therapy for Hoarding Disorder. Lastly, the fifth presents a case study of a 12-year-old male receiving Cognitive Behavioural Therapy for Obsessive Compulsive Disorder.

Dedication

To all the people who I have had the fortune to work with over the years,

thank you for trusting in me, challenging me and thus enabling me to develop, but, most importantly, thank you for inspiring me.

Acknowledgements

I would like to take this opportunity to thank all of the participants for taking the time to meet with me and share their experiences. I feel privileged to have listened to your stories. Without you this would not have been possible.

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Contents

Volume I

Chapter 1: Literature Review

Chapter 2: Empirical Paper

Chapter 3: Press Release

Chapter 1: Literature Review Appendicies

Chapter 2: Empirical Paper Appendicies

Volume II

Clinical Practice Report 1

Clinical Practice Report 2

Clinical Practice Report 3

Clinical Practice Report 4

Clinical Practice Report 5

Clinical Practice Report 2 Appendices

List of Illustrations

Volume I

Chapter 1: Literature Review

Volume II

Clinical Practice Report 1

Clinical Practice Report 2

Clinical Practice Report 3

Clinical Practice Report 4

List of Tables

Volume I

Chapter 1: Literature Review

Chapter 2: Empirical Paper

Volume II

Clinical Practice Report 1

Clinical Practice Report 2

Clinical Practice Report 3

Clinical Practice Report 4

Volume I

Chapter 1: Literature Review

“The male elephant in the room”: A Qualitative Evidence Synthesis Exploring Male Experiences of Eating Disorders.

Abstract

Objectives

The qualitative evidence synthesis aimed to explore the qualitative literature relating to male experiences of an Eating Disorder, in order to synthesise the findings and offer a transcendent understanding of the existing literature.

Method

Clearly defined search strategies were applied to multiple databases in order to enable a systematic search of the literature. Strict inclusion and exclusion criteria were applied to the findings resulting in 12 papers deemed suitable for inclusion. A Meta-Ethnographic approach to synthesising the data was undertaken.

Findings

Four themes were identified: *'Societal Construction of the Perfect Male', 'Striving to Maintain a Masculine Identity', 'The Interconnectedness of Control and Self-Worth'* and '*The Hidden Man'*. There appeared to be an underlying concept relating to the conflict of being male, with what is perceived to be a female illness and how this challenged an individual's masculinity, as well as challenging wider societal concepts.

Conclusions

Societal constructions, combined with both internal and external conflict in relation to societal expectations and gender norms intensified the

male experience of an Eating Disorder. The male experience of an Eating Disorder occurred in the context of societal assumptions, which enabled the illness to remain hidden. The notion of a female illness and gendered norms further compounded the experience of males in terms of maintaining masculine norms and fitting societal ideals. To enable a shift in the male experience of an Eating Disorder change needs to be implemented at varying levels.

Introduction

Eating Disorders

Eating Disorders (EDs) are characterised by a psychopathology that incorporates a preoccupation with weight, shape and food (American Psychiatric Association, 2013). Eating Disorder (ED) psychopathology is central to Anorexia Nervosa (AN), Bulimia Nervosa (BN), Binge ED (BED) and Other Special Feeding and ED (OSFED), despite the difference in clinical presentation (see Appendix A). EDs are considered to have a low prevalence rate when compared to other psychiatric presentations (Solmi, Hatch, Hotopf, Treasure, & Micali, 2014); the respective lifetime prevalence rates for AN, BN and BED are reported to be between 0.3 and 0.9%, 0.9 and 1.5%, and 1.9 and 3.5% respectively (Smink, van Hoeken, & Hock, 2012). However, research indicates that ED prevalence studies do not capture the true extent due to the often- secretive nature of an ED and the reluctance to seek treatment (Smink et al., 2012).

An ED, depending on the presentation, can manifest in life threatening physical complications, such as Bradycardia in AN (Mehler & Brown, 2015) and electrolyte imbalances in BN (Mehler & Rylander, 2015). EDs have a high mortality rate (Harris & Barraclough, 1998), with Anorexia Nervosa having the highest mortality rate of any mental health condition (BEAT, 2019), highlighting the importance of further research in this area.

Despite the physical complications associated with ED behaviours, the ED pathology remains an important aspect of the illness. The DSM-V defines those experiencing AN and BN as having an intense fear of weight gain and self-worth is impacted due to their perception of their weight and shape (Substance Abuse and Mental Health Services Administration, 2016). Research indicates those experiencing an ED are likely to experience feelings of shame and stigma (Thapliyal, Hay, & Conti, 2018) whilst identifying that the ED enables a numbing of emotions and fills a void of loneliness (Levine, 2012). Furthermore, an ED can provide an individual with a sense of control and they come to understand it as part of their identity (Eaton, 2019).

Eating Disorders in Men

Whilst there is a reported prevalence of EDs it is believed these are hugely under reported, especially in men. Men are estimated to account for between 10 to 25% of reported ED cases (BEAT, 2019).

Additionally, research highlights the role of gender in help seeking, as females are more likely to seek contact with a GP than males (Hunt, Adamson, Hewitt, & Nazareth, 2011). The stigma attached to mental health is likely to further impact male help seeking; research highlighted males are less likely to exhibit help seeking behaviours in relation to mental health support (Mackenzie, Gekoski, & Knox, 2006). Further gender disparity is apparent when considering the diagnosis given. Females are twice as likely as males to receive a diagnosis of depression (Call & Shafer, 2018) yet men are more likely to die from suicide (Oquendo et al, 2002). Females are more likely to get a diagnosis of depression than males even when presenting with the same scores on a standardised measure (Afifi, 2007). Whilst there are apparent biological, genetic and personality trait differences amongst males and females, there is a wealth of evidence to indicate these cannot always account for the differences in mental health diagnoses different genders receive (Paris, 2007).

There are numerous factors that are believed to contribute to the underreporting of males experiencing an ED. Research has highlighted that men present with a less severe ED pathology (Thapliyal et al., 2018), and this may account for the limited number of males reported to be experiencing an ED. The less severe psychopathology observed in males might result in a lack of recognition by professionals. However, the role of societal norms may further impact the detection of EDs in males by professionals; if a society does not believe males experience EDs then it may prevent professionals from asking questions or undertaking investigations, attributing ED symptomology to another cause. Furthermore, there is a difference in the way males and females present as men may be striving to attain muscle mass (Strother, Lemberg, Stanford, & Turbeville, 2012), which may be viewed as normal and acceptable by society and again hinder recognition of an ED.

Societal acceptance of men striving for a particular body type in the context of building muscle mass may be a contributing factor to the underreporting of males experiencing and ED. Modern Western society floods males with messages about their appearance and body (Duggan & McCreary, 2008), in the way that it has for many more years with females. Due to the long-standing pressures placed upon females it is felt that females have become more adept at challenging societal ideals (Pope, Pope, Phillips, & Olivardia, 2002), whereas males may feel more pressured to conform which could lead to an experience of low self-esteem and a lack of sense of self-worth. Society reinforces the notion that males do not talk about emotions, let alone body dissatisfaction (Pope et al., 2002) which further intensifies, not only the secrecy, but prevents males from challenging societal norms amongst peers.

In today's society there is an expectation that men 'man up' and manage their vulnerabilities (Real, 2003), which could impact on male reporting of ED symptoms as it is highlighted there is an underreporting of symptomology in men (Strother et al., 2012). It is believed that societal norms relating to EDs act as a barrier to help seeking in males, as they are less likely to discuss what is felt to be a female illness (Thapliyal et al., 2018). EDs are often seen to be a female illness and therefore the experience of stigma relating to an ED is greater in males (Strother et al., 2012). This may further account for the under representation of males, not only in prevalence, but in research also.

Despite the difference in presentation, the lack of recognition and the barriers men experience with regards to help seeking, it is believed that males do not have a poorer prognosis than females with regards to treatment (Strother et al., 2012). However, the major underreporting of males with an ED highlights the need for further research to challenge societal expectations and barriers to help seeking, and to enable research to be undertaken on a truer representation of males with an ED. A systematic review was undertaken in 2014 exploring males’ experiences of treatment (Thapliyal & Hay, 2014), which included four studies. Since this time, there have been developments in the literature, which when combined with a question with a wider scope for male experiences, provides sufficient literature to enable synthesising of the available research.

Qualitative Evidence Synthesis

Meta-Ethnography is a seven-phased approach to synthesising qualitative data, developed by Noblit and Hare in 1988 (France et al., 2019). Synthesising of qualitative data is growing not only in popularity but also in credence as it informs policies and provides information on treatment acceptability (France et al., 2014).

The existing literature provides a Meta-Synthesis exploring the role of gender in treatment for EDs (Thapliyal et al., 2018) and a systematic review of male experiences of treatment (Thapliyal & Hay, 2014). Whilst the latter explores solely male experiences, it is confounded by treatment experiences and only included four studies. The majority of research available explores female experiences of EDs, which is often due to the difficulty in recruiting males to studies (Cibralic & Conti, 2018).

It is felt that due to the often small numbers of males recruited to studies that there is not enough known about their experience of an ED on a wider level. It is therefore felt a Meta-Ethnographic approach to synthesising the qualitative data exploring males' experiences was not only warranted but also needed to provide greater understanding of the male experience.

Aims of the review

The aim of this review is to explore male experiences of an ED. A qualitative evidence synthesis provides a greater comprehension of the area being investigated as it enables the synthesising of individual insights, generating a broader understanding of an area, which can propose implications for therapeutic input (Lachal, Revha-Levy, Orri, & Moro, 2017). Therefore, this review aims to synthesis the existing literature regarding male experiences of an ED to enable a more global understanding of this under represented population.

Method

Type of review

A Meta-Ethnographic approach to synthesising the literature was undertaken, informed by Noblit and Hare (1988). Meta-Ethnography is proposed to enable rigorous development of interpretations through the comparison and analysis of a data set, arriving at new interpretations (Noblit & Hare, 1988).

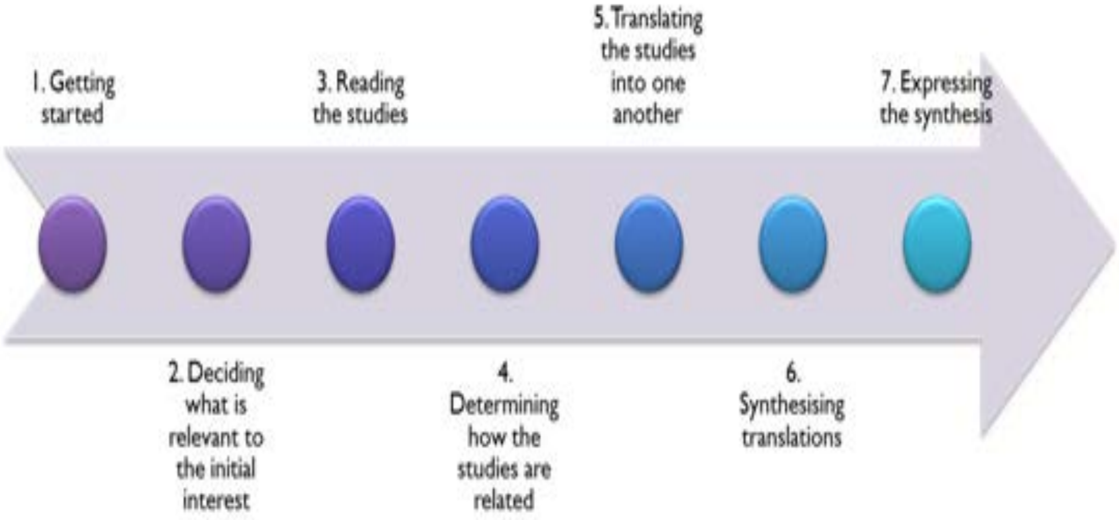

Figure 1. Outlining the Seven Phases of Meta-Ethnography (Noblit & Hare, 1998)

Research highlights the benefits of synthesising qualitative data to enable a more generalisable and comprehensive understanding of existing data (Atkins et al., 2008). A Meta-Ethnographic approach enables the development of conceptual understandings of individual experience, even in areas of established research (France et al., 2015). Meta-Ethnography allows for interpretations made in the studies being synthesised to be treated as new data, enabling the development of original concepts to answer a specific research question (Britten et al., 2002). Thus a Meta-Ethnographic approach was felt to be of particular relevance in the under-researched area of male experience of an ED. Furthermore, research highlights the importance of synthesised qualitative data in informing healthcare policy (Cahill, Robinson, Pettigrew, Galvin, & Stanley, 2018). Meta-Ethnography is believed to usefully enable the synthesising of an individual’s experience of an illness (Atkins et al., 2008) through a robust method that enables the development of interpretations at a transcendent level (Cahill et al., 2018).

Noblit and Hare’s (1988) seven phases of Meta-Ethnography are presented in Figure 1 above. A more detailed outline is provided in Table 1 and how the phases were undertaken will be discussed throughout the method section.

Table 1

Outlining the Seven Phases of Meta-Ethnography (Noblit & Hare, 1988)

Phase	**Description**
1. Getting Started	Identify an area of interest whilst considering if a synthesis of the topic is required.
2. Deciding what is relevant	Selecting studies for inclusion in the synthesis. Making decisions regarding inclusion, exclusion and assessing quality.
3. Reading the studies	Repeated reading of the studies whilst extracting key concepts.
4. Determining how the studies are related	Exploring the relationship between the extracted key concepts to enable an understanding of how the studies are interconnected.

Phase	**Description**
5. Translating the studies into one another	Exploring the key concepts across all studies, looking for presence or absence of key concepts.
6. Synthesising translations	Creating concepts across studies. Exploring the relationship between studies and deciding if synthesis is refutational, reciprocal or line of argument.
7. Expressing the synthesis	Compiling the synthesis and delivering it to the intended audience.

Phase 1 commenced with identifying an area of interest, which came ‘naturally’ as the researcher had spent many years working with people with an ED. From exploratory reviews of the literature, it was apparent that there was a distinct lack of research, related to males and EDs. Furthermore, clinical experience had informed the researcher’s desire to explore experiences due to the rich, qualitative data that is often lost when completing routine outcome measures. Initial searches of the literature identified one systematic review focused on male experiences of treatment by Thapliyal & Hay in 2014, which included four papers. It was therefore felt that exploring research developments in the past five years would be worthwhile. However, further initial searches of the literature highlighted that there was not sufficient research to expand the question of male experiences of treatment, and so a decision was made to expand the focus of the review to explore male experiences of having an ED more broadly. A Meta-Ethnographic approach was felt to be an appropriate, and worthy means of exploring male experiences of an ED. As there is currently limited research into male experiences and difficulty in recruiting males to research (Cibralic & Conti, 2018), making large scale studies almost impossible, a Meta-Ethnographic approach to synthesising data was felt to be a useful contribution to the research base. Meta-Ethnography enables a deeper analysis (Atkins et al., 2008) and interpretation across data (Britten et al., 2002) thus providing a greater understanding of male experiences of an ED.

Systematic Literature search

On developing a research question, phase 2 of Noblit and Hare's (1988) approach was implemented by undertaking a systematic search of the literature.

Search strategy

The search strategy was developed in order to detect relevant papers that could support the answering of the research question. The decision was made to not restrict the search to peer reviewed journals as initial searches highlighted few papers and identified 'grey literature' provided research studies that contributed significantly to answering the proposed research question. The search strategy was influenced by a previous a Meta Synthesis (Thapliyal et al., 2018) and systematic review exploring gendered experiences (Thapliyal & Hay, 2014).

Table 2

Database Search Terms

Search	**Description** [1]
1	“ED*”
2	Male* OR Men
3	Experience OR “Lived Experience”
4	1 AND 2 AND 3
5	LIMIT 5 to “Qualitative (best balance of sensitivity and specificity)”[2]

* Indicates a truncation

The search strategy was applied to the following databases: PsycINFO, MEDLINE, SCOPUS, Web of Science, ASSIA, EMBASE, and CINAHL Plus. A search of theses was undertaken using the same search strategy on the following databases: Open Access, Pro Quest and EThoS. Limits were applied to the search strategy results to ensure the abstracts screened were of relevance to the study (Appendix B). A wide range of databases were used to maximise the number of papers found as there appeared to be limited information relating to male experiences of EDs available. All papers found from the searches were exported into REFWORKS; reference management software.

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[1] The only variation to this search strategy was for the database Web of Science where the search term ‘NOT rats’ was included to reduce the number of results relating to rat studies

[2] This search item was only applied to PsycINFO, MEDLINE and EMBASE

Inclusion / Exclusion Criteria

A number of inclusion and exclusion criteria were applied to the literature identified during the systematic search strategy as outlined below in Tables 3 and 4.

Table 3

Inclusion criteria applied to identified literature

Number	**Inclusion Criteria**
1	Participants were male
2	Participants over the age of 18[3]
3	Participants had an experience of an ED that was defined by a diagnosis
4	Qualitative research exploring experiences
5	English language

Table 4

Exclusion criteria applied to identified literature

Number	**Exclusion Criteria**
1	Not focused on EDs
2	Not qualitative
3	Not focused on male experiences
4	Not clear if it was male participants
5	Experience of someone other than the person experiencing an ED
6	Literature reviews including systematic reviews and Meta Syntheses

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[3] One study included two 17-year-old male participants but was included as the majority of participants were over the age of 18 and the paper contributed effectively to answering the research question.

Number	Exclusion Criteria
7	Reports including case studies or case reviews
8	Books as they were not peer reviewed
9	Research below Masters level

Systematic screening process

The systematic screening process is detailed below in Figure 2.

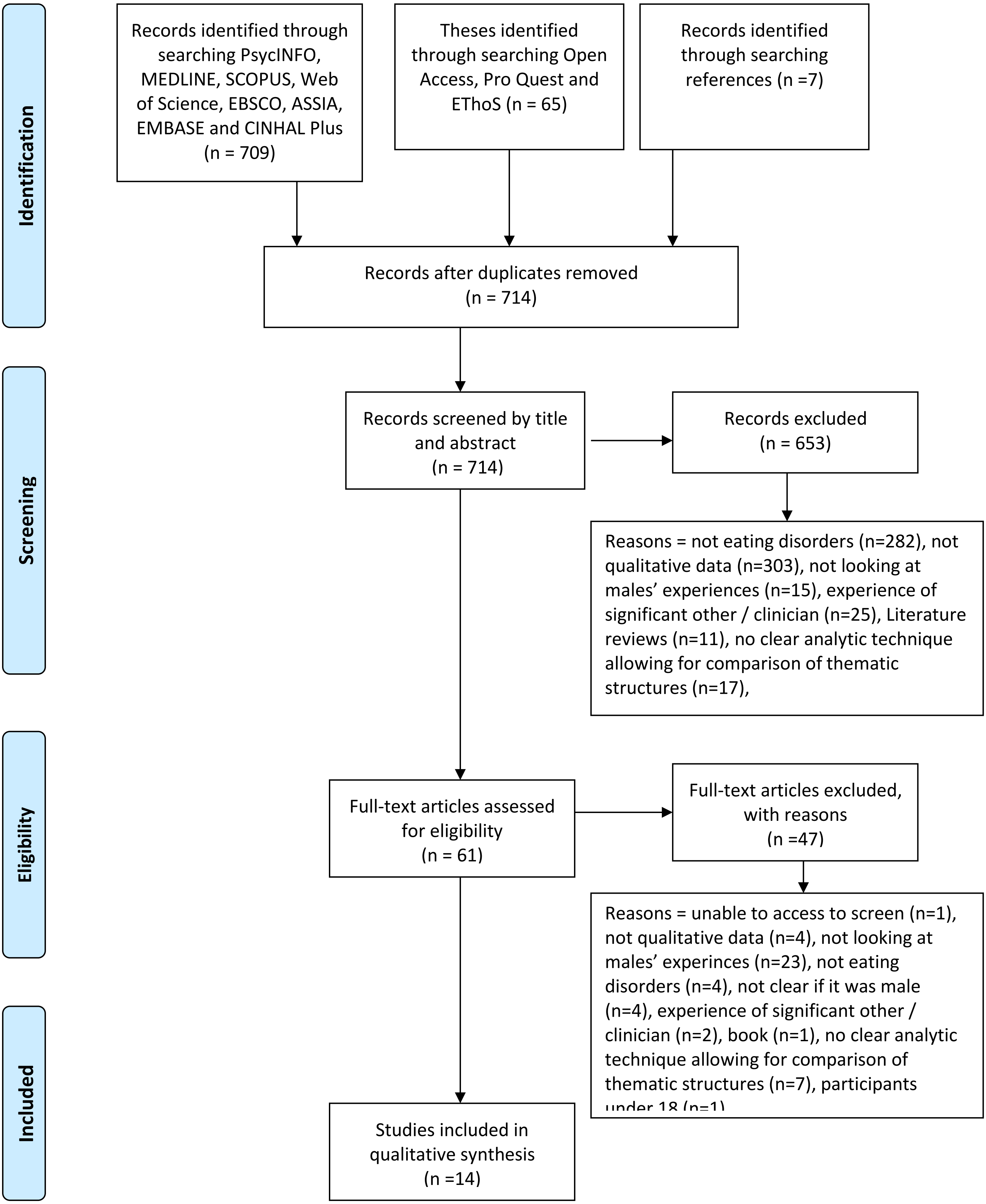

Figure 2. PRISMA diagram displaying systematic screening process (Moher, Liberati, Tetzlaff, & Altman, 2009)

The systematic screening process resulted in 14 papers to be included in the synthesis via the process of Meta-Ethnography. Where there was uncertainty regarding the inclusion of a paper discussions were held with research supervisors and peers to arrive at a conclusion. On occasion additional details were sought from authors to help inform the decision process. An overview of the 14 papers to be included is provided below in Table 5.

All of the studies were conducted in westernised countries including, the United Kingdom, Australia, Canada, America and Scandinavia. A total of 89 participants are included in the review. Some of the studies listed below used the same data set (2 & 3 and 7, 11 & 12). The author of papers 2 and 3 used the same participant interviews to produce two papers presenting different themes. Papers 7, 11 & 12 used the same participant interviews but to answer different research questions. Paper 12 reported that this was the intention and therefore all participants were asked questions to enable the three differing research questions to be answered, and researchers focused on aspects of the interview relating to their research question when it came to analysis. All participants were either diagnosed with an ED or believed to meet the diagnostic criteria by the researchers. The age range of participants was predominantly 18 – 65. However, as discussed previously, two participants were 17 years of age. The predominate approach used by the studies was Interpretative Phenomenological Analysis but a variety of approaches were used: Inductive analysis, Qualitative Phenomenographic Approach, Narrative Research, Grounded Theory, Content Analysis and

Thematic Analysis. Although there is variation in the methodological approaches used it is felt that all of the included papers contribute significantly to answering the research question. The majority of researchers were female with only four of the papers having a male primary author. This may reflect the numbers of females who work clinically with EDs, which is likely to be associated with the larger percentage of females experiencing an ED compared to males.

Table 5

Overview of the articles to be included

Author(s) and year of publication[4]	**Study Title**	**Key research question / aim(s)**	**Participants**	**Analysis**
1. Oickle, 1998	A needs assessment: Resources for males with EDs	What is the nature of the experiences with available resources for males with EDs and associated health care professionals?	8 male participants, aged 18-42, diagnosed with an ED	Inductive analysis
2. Drummond, 1999	Life as a Male 'Anorexic'	To highlight the significance of EDs amongst men.	8 male participants, aged 18-42, all had contact with South Australia Anorexia Bulimia Nervosa	Inductive approach

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[4] The numbers assigned to studies in this table will be used throughout the document from this point forward.

Author(s) and year of publication[4]	Study Title	Key research question / aim(s)	Participants	Analysis
			Association for ED presentation	
3. Drummond, 2002	Men, Body Image, and EDs	To explore issues relating to masculinity and men's health with respect to eating-disordered men.	8 male participants, aged 18-42, all had contact with South Australia Anorexia Bulimia Nervosa Association for ED presentation	Inductive approach
4. Ashuk, 2004	Narratives of Males with EDs	What is the nature of the experiences of males who have an ED?	2 males over 18, diagnosed with an ED and accessing ED services.	Narrative Research
5. Wertheimer, 2006	Gay Men With EDs and Food, Body Image and Exercise Concerns: A Group Treatment Approach	Explore the participants' experiences in the group and the features of the group that may have contributed to its impact.	10 males, aged 18-65, who met diagnostic criteria for an ED	Grounded Theory
6. Robinson, Mountford, &	Being men with EDs: Perspectives of male ED service-users	What is it like for men to live with an ED? What is it like for men to seek	8 males, aged 24 - 56, all with a diagnosed ED and receiving treatment for the ED.	Interpretative Phenomenological Analysis

Author(s) and year of publication[4]	Study Title	Key research question / aim(s)	Participants	Analysis
Sperlinger, 2012		treatment for an ED? What is it like for men to receive treatment for an ED?		
7. Björk, Wallin, & Petterson, 2012	Male Experiences of Life After Recovery From an ED	To explore adult males experience of recovery from an ED	15 males, aged 19-52, with a previous diagnosed ED	Qualitative Phenomenographic Approach
8. Markham, 2013	Exploring Men's Accounts of Understanding and Seeking Help for Problems with Eating	To explore how men (in the UK) made sense of the development of an 'ED' and their experiences of living with and seeking help for the 'ED'	8 males, aged 22 – 53, involved with an ED Charity with self-identified ED	Interpretative Phenomenological Analysis
9. Räisänen, & Hunt, 2014	The role of gendered constructions of EDs in delayed help-seeking in men: a qualitative interview study	How do men make sense of their early (and later) signs and symptoms of disordered eating? How do they realise something might be wrong and require intervention? Are there perceived barriers to accessing primary care (or other) services for men with EDs?	10 males, aged 17-25, 8 diagnosed with an ED and 2 self-identified.	Interpretative Phenomenological Analysis

Author(s) and year of publication[4]	Study Title	Key research question / aim(s)	Participants	Analysis
		What are men’s experiences of health professionals’ responses to their initial presentations of ED signs and symptoms?		
10. Spyrou, 2014	Exploring men’s experiences and understanding of binge ED: An interpretative phenomenological analysis	How do men experience and understand BED? How do men with BED experience and understand the process of seeking, accessing and receiving treatment(s).	6 males, aged 22-50, with a formal diagnosis of Binge ED	Interpretative Phenomenological Analysis
11. Wallin, Pettersen, Björk, & Råstam, 2014	A Qualitative Study of Males’ Perceptions about Causes of ED	How former male patients perceived causes of onset of their ED	15 males, aged 19-52, who had been diagnosed with an ED. Had received treatment and deemed to be in recovery	Qualitative Phenomenographic Approach
12. Pettersen, Wallin, & Björk, 2016	How do males recover from EDs? An interview study	To investigate what males experience as helpful in their recovery process from an ED.	15 males, aged 19-52, with a formal diagnosis of an ED. Deemed to have completed treatment.	Content Analysis

Author(s) and year of publication[4]	**Study Title**	**Key research question / aim(s)**	**Participants**	**Analysis**
13. Thapliyal, Mitchison, & Hay, 2017	Insights into the Experiences of Treatment for An ED in Men: A Qualitative Study of Autobiographies	To explore the experiences of men who ever had any form of treatment for an ED.	6 males, aged 25 – 50, with a diagnosis of an ED. Various stages of recovery. Accounts taken from autobiographical books.	Thematic analysis
14. Tresca, 2018	An Exploration of Men's Experiences of Motivation to Change in Relation to their Journey with Anorexia Nervosa.	Participants' experiences of Motivation to Change including but not limited to what drives, impedes and challenges their journey with AN.	8 males, aged 20 – 44, defined by researcher to meet criteria for an ED. 6 were classed as recovered and 2 were in recovery.	Interpretative Phenomenological Analysis

Quality Appraisal

The quality of the studies included were appraised using The National Institute for Health and Care Excellence (NICE) recommended Methodology Checklist for qualitative studies (NICE, 2012). The checklist was amended to meet the research question and an adaptation regarding the definition of an ED was included to further assess the quality of the papers and the relevance to the proposed research question (Appendix C).

The checklist was applied systematically to each study whereby each study was considered in light of the questions in Table 6 and a rating was applied; a tick if it was present (**✓**), a cross if the information was absent (*X*) and a question mark if there was insufficient information to enable a decision to be made (**?**). An overall assessment rating was then given regarding the quality of the study and the study either awarded a **++**, **+** or a **–**. An overview of the findings is presented in Table 7 and a more detailed overview can be located in Appendix D.

Table 6

The Methodology Checklist for qualitative studies (NICE, 2012)

Section	**Checklist Question**
Theoretical Approach	1. Is a qualitative approach appropriate? 2. Is the study clear in what it seeks to do?
Study Design	3. How defensible/rigorous is the research design/methodology? 4. How is an ED defined?
Data Collection	5. How well was the data collection carried out?

Section	**Checklist Question**
Trustworthiness	6. Is the role of the researcher clearly described? 7. Is the context clearly described? 8. Were the methods reliable?
Analysis	9. Is the data analysis sufficiently rigorous? 10. Is the data 'rich'? 11. Is the analysis reliable? 12. Are the findings convincing? 13. Are the findings relevant to the aims of the study? 14. Conclusions – are they plausible and coherent?
Ethics	15. How clear and coherent is the reporting of ethics?
Overall Assessment	16. How well was the study conducted? ++ = All or most of the checklist criteria fulfilled. + = Some of the checklist criteria fulfilled. – = Few or no checklist criteria fulfilled.

The majority of the studies assessed were deemed to be of good quality in that they met most or all of the checklist criteria. Two studies were deemed to have met some of the criteria (9 and 13) and were therefore deemed to be of a fair quality and two papers (2 and 3) were deemed to be of poor quality as they met few of the checklist criteria. However, despite the poor-quality rating it was felt that these two papers contributed to the research question and were therefore included in the synthesis whilst being mindful of the quality criteria outcome when considering their contribution to themes.

For the majority of studies assessed, it was a lack of reporting of information that contributed to a reduction in their scores on the quality criteria checklist. The areas where there appeared to be a distinct lack of information related to ethics, data collection and trustworthiness. It is questioned if the word limits applied to journal submissions impact on the amount of information authors can report relating to these areas, as the theses appeared to be provided greater information in the areas of ethics, data collection and trustworthiness, enabling them to score more highly

To enhance the validity of implementing the quality criteria, as many of the questions could be deemed to be subjective, ratings were compared with the research supervisors ratings and a sample were rated by a second rater. Any inconsistencies in the ratings were discussed until an agreement was reached.

Table 7

Overview of findings from the Methodology Checklist for qualitative studies (NICE, 2012).

		Theoretical Design			Study Design	Data Collection		Trustworthiness				Analysis				Ethics	
Author	**Year of publication**	**Is a qualitative approach appropriate?**	**Is the study clear in what it seeks to do?**	**How defensible/rigorous is the research design/methodology?**	**How is an ED defined?**	**How well was the data collection carried out?**	**Is the role of the researcher clearly described?**	**Is the context clearly described?**	**Were the methods reliable?**	**Is the data analysis sufficiently rigorous?**	**Is the data 'rich'?**	**Is the analysis reliable?**	**Are the findings convincing?**	**Are the findings relevant to the aims of the study?**	**Conclusions**	**How clear and coherent is the reporting of ethics?**	**Overall Assessment rating**
1. Oickle	1998	✓	?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	++
2. Drummond	1999	✓	?	?	✗	?	✗	?	?	✓	✓	?	✓	?	✗	?	–
3. Drummond	2002	?	✓	✓	✗	?	✗	✗	✗	?	✓	?	✓	?	✗	?	–
4. Ashuk	2004	✓	✓	✓	✓	?	✓	?	✗	✓	✓	?	✓	✓	✗	✓	++
5. Wertheimer	2006	✓	?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	?	++

Author	Year of publication	Theoretical Design			Study Design	Data Collection		Trustworthiness			Analysis					Ethics	
		Is a qualitative approach appropriate?	Is the study clear in what it seeks to do?	How defensible/rigorous is the research design/methodology?	How is an ED defined?	How well was the data collection carried out?	Is the role of the researcher clearly described?	Is the context clearly described?	Were the methods reliable?	Is the data analysis sufficiently rigorous?	Is the data 'rich'?	Is the analysis reliable?	Are the findings convincing?	Are the findings relevant to the aims of the study?	Conclusions	How clear and coherent is the reporting of ethics?	Overall Assessment rating
6. Robinson, Mountford, & Sperlinger	2012	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	++
7. Björk, Wallin, & Petterson	2012	✓	✓	✓	✓	✓	✗	?	✓	✓	✓	✓	✓	✓	✓	✓	++
8. Markham	2013	✓	✓	✓	✗	✓	✓	✓	✓	✓	✓	✓	✓	?	✓	✓	++
9. Räisänen, & Hunt	2014	✓	✓	?	✗	✓	?	✓	✓	✓	✓	?	✓	✓	?	?	++
10. Spyrou	2014	✓	?	✓	✓	?	✓	✓	✓	?	✓	?	✓	✓	✓	✓	++
11. Wallin, Pettersen, Björk, & Råstam	2014	✓	?	✓	✓	?	?	✓	✓	✓	✓	✓	✓	✓	✗	✓	++

		Theoretical Design			Study Design	Data Collection		Trustworthiness			Analysis					Ethics	
Author	Year of publication	Is a qualitative approach appropriate?	Is the study clear in what it seeks to do?	How defensible/rigorous is the research design/methodology?	How is an ED defined?	How well was the data collection carried out?	Is the role of the researcher clearly described?	Is the context clearly described?	Were the methods reliable?	Is the data analysis sufficiently rigorous?	Is the data 'rich'?	Is the analysis reliable?	Are the findings convincing?	Are the findings relevant to the aims of the study?	Conclusions	How clear and coherent is the reporting of ethics?	Overall Assessment rating
12. Pettersen, Wallin, & Björk	2016	✓	✓	✓	✓	?	?	✓	✓	✓	✓	✓	✓	✓	✓	✓	++
13. Thapliyal, Mitchison, & Hay	2017	✓	✓	?	✓	✓	N/A	✓	✓	✓	✓	✓	✓	✓	✓	?	++

Data Extraction

Noblit and Hare (1988) recommend repeated reading of the studies for Phase 3 to enable the extraction of key concepts (Appendix E), which was undertaken. To extract key concepts the researcher mapped out the studies themes into a spreadsheet and then began to add quotes and extracts to enable the researcher to create her own understanding of the theme being presented by the study. This was felt to be an important step in preparation for the next phases of the Meta-Ethnographic approach as it might start to highlight key concepts that had not been captured in individual studies but were present across studies.

Data Analysis and Synthesis

Noblit and Hare (1988) propose three further phases to analysing and synthesising the data, which are phase 4: determining how the studies are related, phase 5: translating the studies into one another and phase 6: synthesising the translations. Whilst these are presented as independent phases the researcher's experience was moving between the phases to enable synthesising and the creation of the themes that will be presented. Appendices E to H provide an example of the development of the themes which have become known as 'Striving to Maintain a Masculine Identity' and 'Societal Construction of the Perfect Male' throughout the three phases.

As previously stated, enabling the researcher to immerse herself in the themes presented by the studies was a preparatory step for phases four to six. Once the key concepts and associated data had been extracted into a spreadsheet (Appendix I) the researcher was able to explore the interconnectedness of the studies (Appendix J), looking for the presence or absence of key concepts to synthesise the data in either a reciprocal, refutational or line of argument manner (Noblit & Hare, 1988). This process involved the researcher reading over key concepts and quotes and grouping existing or new concepts with a colour coding system, enabling the start of the development of themes. As the researcher began to produce new themes, her understanding and interpretation of the data progressed.

Once the researcher had developed a theme, phases five and six were repeated to re-examine the data with the theme in mind to ensure the synthesising was thorough, looking for additional data to confirm or dispute the researcher’s interpretation. At this point the researcher started to document her understanding of an emerging theme, highlighting key concepts, emerging themes and discussion points. Discussions were held with research supervisors and peers through the latter phases of Noblit and Hare’s Meta-Ethnographic approach to enhance the validity of the process, and enable an in-depth and fresh review of the data and emerging themes. To further reduce subjectivity and bias due to the researcher’s immersion in the data, a fellow trainee clinical psychologist looked at the researcher’s spreadsheet with the extracted key concepts and associated data and undertook phases 5 and 6. The researcher then compared this to her own themes, and held discussions with the trainee clinical psychologist around their findings in relation to the researchers.

Results

The completion of the Meta-Ethnographic approach to synthesising the data resulted in the creation of four themes, which will be presented in turn.

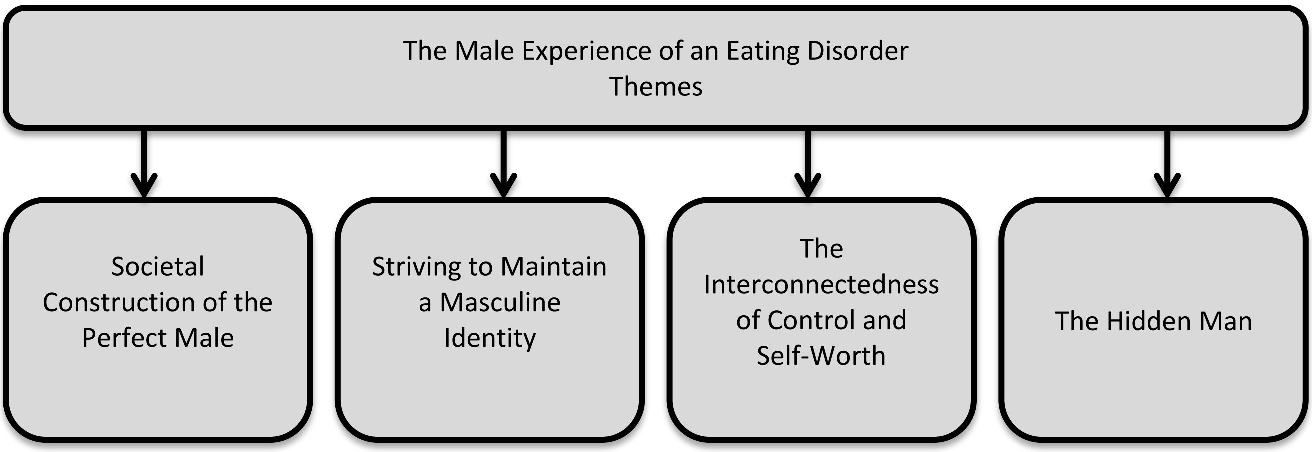

Figure 3. An overview of the themes

Each theme encapsulates elements of the experience of males living with an ED. The themes will be discussed below in the context of the wider literature and theoretical underpinnings, whilst presenting original quotes that contribute to the development of the theme. Throughout the themes there appears to be an underlying conflict of being male with what is perceived to be a female illness and how this challenges an individual's masculinity, but also challenges wider societal concepts. This will be explored in more detail during the discussion.

Societal Construction of the Perfect Male

Table 8

A sample of participant quotes that support the theme ‘Societal Construction of the Perfect Male’

Quote	Paper details	Quality rating of paper
"And I have these obligations to them… And I won't be able to hold my role in society."	1. Oickle, 1998, p.137	++
"It's because we're brought up with the whole "macho" image. For men, it's strong. It doesn't really reveal anything. It just kind of gets handed down."	1. Oickle, 1998, p.138	++
“I don't fit the cultural model of masculinity because I'm not very muscular.”	3. Drummond, 2002, p.8	–
“It's a masculine image, which is impossible for some of us to have.”	3. Drummond, 2002, p.9	–
“Guys would suffer longer because they won’t come forward, they won’t seek therapy because of the stigma”	10. Spyrou, 2014, p. 69	++

The quotes in the table above highlighted the importance of the impact of societal norms on the male participants. Oickle, 1998, stated “Participants expressed feeling the need to live up to an unbreakable image for men set by society” (p.136) and this idea was supported by a number of papers (1, 3, 4, 8, 9, 10, 11, 13). It appeared that the men were acutely aware of a male ideal, the “ideal male physique…combines thinness and muscularity, which they associate with a masculine stereotype of being a man” (Spyrou, 2014, p. 62). Yet participants felt that their appearance contrasted with this and they did not fit the societal norms, “I don't fit the cultural model of masculinity” (Drummond, 2002, p. 8). Furthermore, male characteristics were also deemed important by society, “that nothing can hurt men, that they are not emotional, and that they can handle all problems without help” (Oickle, 1998, p. 136), reinforcing this notion of a perfect male “which is impossible for some of us to have” (Drummond, 2002, p. 9). The idea that men should not need to seek help appeared to be reinforced by societal constructs as Oickle (1998, p. 138) highlighted “the "strong man" image was expressed as one of the reasons men may not seek treatment or information to help them deal with their ED”.

Ashuk, 2004, highlighted the role of the media in overemphasising “physical strength, force, aggressiveness, competitiveness and independence in males” (p. 95), with participants noting the pressure of societal norms was reinforced by the media (Ashuk, 2004; Markham, 2013). Furthermore, there was a sense that although the males struggled to fit with societal norms that this should not impact upon them, yet some males attributed the pressure to conform as a contributing factor to the development of their ED (Drummond, 2002; Wallin, 2014). Whilst others highlighted male norms influenced a lack of internal (Räisänen, & Hunt, 2014) and external (Markham, 2013) recognition of the ED.

The societal expectations for males seemed to create an impossible position for the participants whereby they experienced an external pressure to act and behave in a certain way yet “Admitting to low self-esteem and distorted body image goes against the expectations of what men are supposed to feel and think about” (Oickle, 1998, p. 139). Markham (2013) highlighted that males experience a “paradox of an increased pressure to conform to a certain image of toughness and strength, yet it being considered unacceptable for men to talk about, or express any form of concerns around, diet or body image” (p. 43). This impossible situation seems to maintain the stuckness of males who experience something that does not fit within the societal constructs of a male, namely an ED.

Striving to Maintain a Masculine Identity

Table 9

A sample of participant quotes that support the theme ‘Striving to Maintain a Masculine Identity’

Quote	**Paper details**	**Quality rating of paper**
“I get worried that they might now see me as less of a man. Flawed. Not as strong”.	2. Drummond, 2002, p. 8	**–**
“Back to the males, we ought to be able to sort our problems out for ourselves”	8. Markham, 2013, p. 44	**++**
“But it conflicts the whole sort of masculine ideal of being strong and, you know, not really admitting to going through any issues 'cos that’s seen as being slightly effeminate, you know, weak perhaps.”	8. Markham, 2013, p. 49	**++**
“Thinking about my body and what is expected from a boy or a man”	10. Wallin, Pettersen, Björk, & Råstam, 2014, p. 1816	**++**
“Every... guys want to say, ‘Oh, I've got my life under control. I, you know, I do everything on my own. I'm independent’".	1. Oickle, 1998, p. 113	**++**
“I don’t want to be seen as a weak… it’s a symptom of not being able to cope”	6. Robinson, Mountford, & Sperlinger, 2012, p. 181	**++**

A key concept emerged relating to the experience of being a male and trying to maintain masculine ideals whilst admitting to needing help. Drummond (2002) highlighted participants believed their “masculinity” to be “flawed”(p.8) and many papers contributed to this idea that males did not want to be seen as flawed (3, 6, 8, 10, & 11). There was a sense that being flawed was not judged by individuals but related to the wider societal constructs as highlighted by Markham (2013) “expectations of what it meant to be a *‘boy’s boy’* and the participant’s positioning in the boyhood network” (p.38). The impact of societal constructions of males and what males expect of themselves needs to be considered in light of help seeking and how this may impact on males.

Moreover, striving to maintain a masculine identity appeared to be situated within a sense that the males felt they did not fit in, and therefore, maintaining a perception of a masculine identity was important (1, 3, 8, 10, and 11). These papers contributed to the concept that men worried about a sense of de-masculinisation. Robinson, Mountford, and Sperlinger, (2012), highlighted “many felt there was something unacceptable about them which had to be compensated for” (p. 181), which reinforced the notion that males may be trying to strive for an “ideal male physique that combines thinness and muscularity, which they associate with a masculine stereotype of being a man.” (Spyrou, 2014, p.62). The notion that participants needed to live up to masculine stereotypes was highlighted as the males shared a sense that they felt a burden to live up to expectations, yet experiencing an ED meant they could not live up to ideals which ultimately reinforced the notion that they did not fit in; “my ideal body for a masculine guy is a white T-shirt that fits and a pair of blue jeans that fit” (Drummond, 2002, p.8). The very thing that they felt might have helped them achieve a male ideal in terms of physical attributes was now the very thing preventing them from connecting with their sense of masculinity.

Furthermore, it was felt that the masculine ideals placed upon men referred to the notion that men should not be seen as weak or unable to cope, with several papers contributed to this idea that males should not be seen as weak (1, 2 & 11). Markham (2013) highlighted one participant spoke “of his ‘need’ to carry out certain activities” indicating the “pressure he feels to perform as a man”, such as “consistently earn a wage” (p. 48). Further reinforcing the conflicting experience of having an ED and upholding masculine roles and ideals. Spyrou (2014) focused on male experiences of Binge ED and presented the notion that binge eating could be seen as more acceptable for males as eating large quantities of food is often seen as manly and in society it is widely accepted that men eat more than women. It therefore needs considering how this impacts on males identification of their difficulties, their understanding of EDs as an illness, and consequently help seeking when their behaviour could reinforce their identity as a male and be deemed acceptable by society. Furthermore, how does this fit for a male who feels they do not fit in and is striving to achieve a masculine ideal whilst binge eating; a conflicting sense of feeling as if you are fitting one external ideal whilst failing to achieve another, reinforcing the difficulty males face in trying to achieve a masculine ideal in the context of societal constructions.

The Interconnectedness of Control and Self-Worth

Table 10

A sample of participant quotes that support the theme 'The Interconnectedness of Control and Self-Worth'

Quote	**Paper details**	**Quality rating of paper**
"So I do see it as a part of me, something that I was proud of and I guess something that I'm still pretty proud of, that I can control my eating"	2. Drummond, 1999, p. 84	–
"Nothing else I could really control as well ... it was a sense of control."	6. Robinson, Mountford, & Sperlinger, 2012, p. 181	++
"I don't want to go through the process of fixing it because I know that's going to involve probable weight gain, it's going to involve just releasing that control".	14. Tresca, 2018, p. 105	++
"Deep down I think that I wanted to be hospitalized. It was a relief. Again it was a control issue."	13. Thapliyal, Mitchison, & Hay, 2017, p. 13	++
"It never seemed to have an end goal. You were never good enough."	11. Wallin, Pettersen, Björk, & Råstam, 2014, p. 1817	++
"For me, perfection was being the perfect anorectic, the perfect employee, the perfect student and the perfect family member – all at the same time."	4. Ashuk, 2004, p. 90	++

The quotes in the table above highlight participants needing a sense of control, which fitted within a wider sense of internal personal standards in line with perfectionism (2, 3, 4, 5, 6, 7, 11, 12, 14). This theme appeared to largely embody an internal standard that participants were aiming for, yet there was an element of achieving this internal standard for external recognition (2, 4, 8, 11). It was felt that achieving internal and external standards enabled the participant to achieve a sense of self and self-worth.

Ashuk (2004) highlighted participants were required to maintain a “discipline [that] required determination and fortitude” (p. 97), and the males knew “how to successfully compete within the context of their own personal illness” (Drummond, 2002, p. 13), reinforcing the notion that participants were aiming to achieve an internal standard that helped shape their identity and self-worth. The men were able to improve low self-esteem by achieving the high standards they set themselves but this in turn seemed to fuel the internal standards set (Wallin, 2014). Striving for perfection in the form of an ED provided an additional benefit in the form of disconnect with their emotions, as Wertheimer (2006) reported the ED enabled “a way to cope with or disconnect from difficult emotions” (p. 176), as one participant described, “if I’m not doing it, I have to feel my feelings, which is difficult” (p. 176). Feelings such as “disdain and disgust were often levelled at their personal appearance, heavily impacting on individual masculine identity” (Drummond, 2002, p. 8). The dislike of oneself further reinforces the notion that achieving internal standards for external validation may enhance ones sense of self and therefore means of measuring self-worth.

One aspect of the personal standards of perfectionism related to having to maintain control as “controlling the amount of food he put in his mouth was important in being successful at what he does as a man” (Drummond, 1999, p. 84). It felt that maintaining control was central to the ED and appeared in a number of papers. This was reinforced by the idea that the men were relinquishing control in order to recover (Drummond, 1999;

Thapliyal, Mitchison, & Hay, 2017) and by recovering Ashuk (2004) indicated, "to ask for help, [which] would have been to admit failure" (p. 102). The notion of conflict between having an ED or recovering further reinforced the ambivalence the men felt in relinquishing control as there was a duel "desire to "fix" their bodies and other perceived flaws and the desire to accept themselves as they were" in order to recover (Wertheimer, 2006, p. 199). It is questioned if the idea of maintaining control was central to the males' experiences yet as they entered recovery was there a realisation that they were never in control; they were controlled by the ED.

A smaller number of papers (2, 4, 8, 11) contributed to the notion that participants' internal standards were driven by their need for external validation. Markham (2013) highlighted participants "felt the need to achieve and be good at something… he needed to be successful himself to affect others' perception of him" (p. 66). Despite the internal drive to succeed there remained an element of needing validation from others as one participant reflected, "being perfect meant being a better person. I wanted for others to see me as perfect" which ultimately led to a desire to not fail (Ashuk, 2004, p. 90). Males appeared to use comparison to measure their success; with one participant claiming to feel a sense of achievement as "no-one trains as hard" (Drummond, 1999, p. 85) whilst another highlighted the comparison drove the desire to achieve (Wallin, 2014). The need for external validation appears to fit with the notion of creating a sense of self and measuring self-worth, yet it remains interconnected with the internal standards as achieving internal standards enabled external validation which appeared to impact on the individuals' sense of self. Self-worth is believed to be determined by internal and external perceptions of an individual's ability and linked with success (Simmons et al., 1999). It is further questioned how an experience of an ED impacts on the male sense of self and how this infiltrates the need to be in control and succeed.

The Hidden Man

Table 11

A sample of participant quotes that support the theme 'The Hidden Man'

Quote	**Paper details**	**Quality rating of paper**
"but that was the hardest thing for me, to.. to understand that I wasn't the only guy that.. that was going through this."	1. Oickle, 1998, p. 117	++
"there is a big male elephant in the room."	8. Markham, 2013, p. 43	++
"something that only I did"	9. Räisänen, & Hunt, 2014, p. 3	++
"I feel kind of like I'm looking in a mirror, which is unusual because I typically feel terminally unique"	5. Wertheimer, 2006, p. 184	++
"I think that people probably just don't think that guys do have.... EDs"	1. Oickle, 1998, p. 135	++
"A lot of people are surprised if you, you know, if you are male with an ED"	6. Robinson, Mountford, & Sperlinger, 2012, p. 180	++
"You haven't got bulimia, you're just depressed"	9. Räisänen, & Hunt, 2014, p. 5	++

A key theme of males being hidden emerged from the literature (1, 2, 3, 4, 5, 6, 8, 9). It became apparent that the feelings associated with the men wanting to remain hidden centred on shame, which connected to a sense of feared stigma. It was felt that participants carried the ED as a “burdensome, shameful secret” (Wertheimer, 2006, p. 189) and a “lack of communication and feelings of isolation were noted by the men as prominent difficulties” (Oickle, 1998, p. 141). Robinson et al. (2012) highlighted that fear of how others would perceive them acted as a barrier for help seeking in the men. Men were concerned about how they would be perceived by both peers and professionals (Ashuk, 2004). Feelings of isolation impacted on help seeking for the males, not only preventing them from accessing help but their knowledge and awareness of available help (Oickle, 1998).

It was felt that the men remained hidden, as they believed they were the only ones feeling “alone as a man with an ED, as if they were the only ones” (Robinson et al., 2012, p. 180). One participant remained hidden as he was not sure a man could have an ED, “I wasn’t even sure that men got it... There were no role models... so maybe then this is an abnormal thing...maybe this isn’t what I’ve got” (Markham, 2013, p. 45), which is further reinforced by the lack of male ED coverage in the media (Robinson et al., 2012). Yet “learning that they were not alone in their concerns about food, body image, and exercise” (Wertheimer, 2006, p. 60) proved to be important in enabling steps towards recovery. Furthermore, Wertheimer (2006) highlighted the importance of reducing feelings of isolation during the process of recovery for males, indicating isolation is a maintaining factor for males experiencing an ED. EDs in men appeared to remain hidden due to life shrinking, leaving the individual with not much but the ED (Drummond, 2002) thus enabling the individual to keep their behaviours and psychopathology a secret. The very cyclic nature of being a male who keeps his ED hidden and therefore remains hidden is further impacted by societal expectations and normative behaviour as highlighted by the challenge of being “open about [the ED] when you are not getting messages that it’s ok to be open about it” (Markham, 2013, p. 47).

There appears to be a wider, overarching contributing factor to males remaining hidden in the context of societal norms and how these influence external individuals. It appeared that others did not consider the male to have an ED or they did not consider it to be serious (Drummond, 2002; Robinson et al., 2012; Räisänen, & Hunt, 2014); this resonated with friends and family (Markham, 2013; Räisänen, & Hunt, 2014) and professionals reinforced the idea that only females get an ED (Robinson et al., 2012). Research highlighted “when professionals are not recognizing an ED, the men…get better at "hiding" their condition” (Oickle, 1998, p. 129), emphasising the cyclic nature. There was a sense that men were assessed in terms of their physical presentation as opposed to their psychological distress (Drummond, 2002; Räisänen, & Hunt, 2014), which is in keeping with normative experiences of accessing primary care with an ED (Lask et al., 2005; Waller, Micali, & James, 2014). Furthermore, societal norms relating to males and male behaviour impacted on the men’s motivation to seek help (Oickle, 1998), with men fearing how they would be perceived (Robinson et al., 2012) and if they would be viewed as weak (Drummond, 2002).

Further to a lack of recognition, there was also the concept of a missed diagnosis or an incorrect diagnosis (Räisänen, & Hunt, 2014), which further supports the role of gender bias in mental health diagnosis; with females being more likely to have a diagnosis of depression and males being more likely to receive a diagnosis of alcohol dependency (World Health Organisation, n.d.). When considering the increased rates of depression in females a contributing factor could be help seeking behaviours that are more typical of females (Hunt et al., 2011). However when considering there was a "clear theme of stigmatisation associated with increased isolation and disconnect from the real world" (Markham, 2013, p. 57) it is likely these feelings of isolation, stigma and shame contribute to reduced levels of help seeking behaviours in men. The lack of recognition of male EDs further reinforces societal expectations that men do not get EDs.

Discussion

The qualitative evidence synthesis highlighted a number of themes identifying the challenging experience of being male with an ED. The male experience was compounded by societal constructions and there was either an internal or external conflict in relation to societal expectations and gender norms in the context of experiencing an ED as a man.

Societal assumptions

The research synthesised indicated the male experience of an ED occurred in the context of societal assumptions, which contributed to the illness to remain hidden. Throughout there was an overarching sense that the male experience existed in, and could not be separated from, societal expectations of what it means to be male and how this contributed to the hidden nature of male experiences of an ED. Men are commonly viewed in society as the dominant gender (Covington, 2008) promoting the notion that females are born unequal (McNeish & Scott, 2014); gender identity development therefore appears enmeshed in societal norms. The role of societal norms in male experiences of an ED are complex and multifaceted; the theme of ‘Societal Construction of the Perfect Male’ highlighted how men were encouraged to strive to look a certain way (Drummond, 2002; Spyrou, 2014; Strother, 2012) yet when they experienced an ED in the context of striving, their presentation was at odds with what society stipulated about male behaviours and emotions (Markham, 2013; Oickle, 1998; Pope et al., 2002), which was reinforced by the theme ‘Striving to Maintain Masculine

Identify’. Conversely, whilst EDs remain under reported in both genders (Hudson, Hiripi, Harrison, Pope, & Kessler, 2007; Strother et al., 2012), female illness behaviours are celebrated and encouraged by society and their body dissatisfaction normalised, whilst for men there is an expectation that they do not have body dissatisfaction, they do not diet and most importantly they do not discuss this with others (Pope et al., 2002). An ED is wider than body dissatisfaction; it can be a means of managing difficult and unwanted emotions (Eaton, 2019; Levine, 2012; Thapliyal et al., 2018) yet the synthesis highlighted men are not expected, and subsequently not encouraged, to discuss their emotional and mental wellbeing. The notion of not discussing emotions and mental health was highlighted in the theme ‘Striving to Maintain Masculine Identity’ as the men did not wish to be seen as weak or unable to cope. Thus highlighting that being male with an ED becomes more of a problem because it is not seen as a problem by society as discussed in the theme of ‘The Hidden Man’.

Societal norms enable behaviours to remain hidden if they do not fit with a gendered stereotype, which was highlighted throughout the theme of ‘The Hidden Man’ as it emphasised the diagnostic difficultly encountered by males with an ED (Räisänen, & Hunt, 2014). The notion of behaviour remaining hidden due to societal expectations is multifaceted, for example male and female acts of violence are viewed differently; women who commit violent crimes are extradited and dehumanised (Motz, 2009), yet this does not happen for males. It is suggested male perversion stems from difficult early attachments with the maternal figure, which raises questions as to why this would not occur for females (Welldon, 1988), reinforcing the notion that societal norms set parameters around acceptable behaviours based on gender. The males described being acutely aware of societal norms highlighted in the theme ‘Societal Construction of the Perfect Male’ and the challenges faced when not fitting with gender based behaviours in ‘The Hidden Man’.

The concept of female perversion is described in the literature yet it is highlighted that there is a lack of acknowledgement that it exists as societal norms do not allow the consideration of females as capable of perversion (Motz, 2009; Welldon, 1988). Denying female perversion exists is denying female agency yet societal norms leading to a lack of acknowledgement around male experiences of EDs enables the experience, and the males, to remain hidden; denying their individualised choice and action as discussed in the theme ‘The Hidden Man’. When considering how widely distributed and entrenched societal norms are, it becomes apparent the battle men have to firstly understand their own experience as having an ED (Markham, 2013; Robinson et al., 2012) and secondly to seek help (Ashuk, 2004; Robinson et al., 2012). If as a society we do not accept males as experiencing an ED then this will further impact on our understanding of the male process of help seeking, treatment and recovery.

Gendered norms

An overarching concept from the qualitative evidence synthesis was the experience of being male with a female illness; the notion of an ED being a female illness and gendered norms further compounded the experience of the males. Whilst the impact of ‘gendered norms’ is interconnected with ‘societal assumptions’, this overarching concept was situated in the conflict the males experienced when believing to be engaging in behaviours that are normative for females. It was felt that the ED provided men with a maladaptive means of achieving control (Ashuk, 2004; Drummond, 1999) and addressing self-worth (Wallin, 2014), as highlighted in the theme ‘The Interconnectedness of Control and Self-Worth’. Yet the overarching sense of the difficulties encountered by the males related to their experience of a ‘female illness’. When attempts to maintain a sense of masculinity were made through ED symptomology they were confounded by the awareness that the behaviours were stereotypically female (Markham, 2013). The notion of females gaining a sense of control from an ED is supported by the literature (Eaton, 2019) highlighting gender does not play a role in this particular experience.

The experience of men having a ‘female illness’ was further intensified when considering the external pressure experienced by men to behave in line with gendered norms (Markham, 2013; Oickle, 1998; Pope et al., 2002), as discussed in the theme ‘Striving to Maintain a Masculine Identity’. As the men struggle to live up to a gendered norm, they engage in behaviours associated with a female illness yet their gender roles reinforce that they should not engage in those behaviours, let alone talk about those behaviours, enabling the male ED experience to remain invalidated. Wertheimer (2006) highlighted the ED enabled a disconnect from emotions, further highlighting the functionality for men as they are stuck between striving to achieve a sense of self as a male whilst being mandated by society to cope (Real, 2003). It was felt showing signs of weakness was deemed effeminate yet there is an expectation about the performance of a male (Markham, 2013). When considered in the context of a lack of internal recognition (Räisänen, & Hunt, 2014) and external recognition (Markham, 2013) of an ED, both of which are most likely influenced by gendered norms, it can be understood why men fear help seeking (Robinson et al., 2012), as highlighted in the theme ‘The Hidden Man’. It is questioned how different the male experience of an ED would be if it was not situated within the parameters of a female illness; if men experiencing an ED were not caught in a paradox of conforming to gender norms as highlighted in the research regarding help seeking (Hunt et al., 2011; Mackenzie et al., 2006; Paris, 2007). Markham (2013) described the men needing to belong to a male network, presenting the idea that they are caught in a paradox of conforming to gendered norms and societal expectations regarding appearance yet it is deemed unacceptable for men to discuss their body image. This notion that men should not talk about body image is present, so how do men make sense of engaging in ED behaviours to achieve a desired body image; “you are not allowed to be concerned… there is a big male elephant in the room” (Markham, 2013, p. 43).

Comparison to other Qualitative Evidence Syntheses

This qualitative evidence synthesis aimed to review male experiences of an ED as there is limited existing research exploring the male experience and the synthesising of existing literature aimed to provide a greater understanding. The findings can be considered in light of the existing literature relating to male experiences of treatment and the literature exploring female experiences. Female experiences of recovery highlighted similarities in experiences as the females described the ED becoming part of their identity and lacking a sense of self (Stockford, Kroese, Beesley, & Leung, 2019) and developing a sense of identity as part of their recovery (Duncan, Sebar, & Lee, 2015). Duncan et al. (2015) highlighted females experienced a loss of control with the increase in ED symptomology and many papers highlighted the need for the men to maintain control (Drummond, 1999; Robinson et al., 2012; Thapliyal et al., 2017; Tresca, 2018) and the relinquishing of control related to recovery (Ashuk, 2004; Drummond, 1999; Thapliyal et al., 2017). Thapliyal et al. (2018) explored gendered experiences of treatment for an ED, highlighting how treatments for EDs challenged male identity, which is in keeping with the findings of this Meta-Ethnographic approach to synthesising data; males experiences of an ED impacted on their sense of self and masculinity. Furthermore, males and females responded differently to experiences within treatment, which was believed to relate to the gendered response to power dynamics (Thapliyal et al., 2018).

Critique of the review

A qualitative evidence synthesis is subjective in that it relies on interpretations, not only of the researcher synthesising, but also those of the original authors of the studies included in the review. To minimise the subjectivity of this Meta-Ethnographic approach to synthesising, triangulation was implemented in a variety of forms to minimise researcher bias. The researcher attended regular peer workshops where findings and interpretations were discussed with peers and research supervisors. Additionally, findings of themes were peer reviewed and differences were discussed until a mutual understanding was reached. Throughout the process the researcher regularly reviewed findings independently and with her research supervisor to minimise subjectivity and enhance the findings.

There were a small number of studies included in the qualitative evidence synthesis. However, the majority of the papers were deemed to be of good quality when they were appraised, although some of the studies were focused on a particular diagnosis or aspect of the treatment pathway, which limited the contribution they could make to the wider research question.

Whilst qualitative evidence syntheses enable qualitative studies to be drawn together to enable broader interpretations to be made, the generalisation of the interpretations made remain limited due to the small sample.

Clinical Implications

This qualitative evidence synthesis highlighted the importance of societal assumptions and gendered norms in the understanding and treatment of males with an experience of an ED. The theme ‘The Hidden Man’ highlighted that men reported having an experience of not being heard or their difficulties not being understood as an ED at the first point of help seeking. To support recognition of EDs in men, training and information for primary care staff, including GPs, could be beneficial. Research has highlighted GPs report a low incidence of ED cases presenting to GP services (Reid, Williams, & Hammersley, 2009). Research has also highlighted the need for training and better liaison between GP services and specialist ED services (Reid et al., 2009). Improving understanding of EDs at the first help seeking experience could make a huge impact on the cyclic nature presented in the theme ‘The Hidden Man’.

Gendered norms that men felt compelled to maintain and achieve impacted not only their disordered eating in striving to achieve perceived norms, but also on their sense making of their experience and their help seeking, as highlighted by the themes presented in this Meta-Ethnographic approach to data synthesising. The promotion of how men should look and act needs to be challenged by society as a whole as western societies overwhelm men with appearance related ideals (Duggan & McCreary, 2008). Whilst there is a recognition of the need to challenge societal pressures regarding female appearance (Pope et al., 2002) and an understanding of the impact this has on a female sense of self and worth (Clay, Vignoles, & Dittmar, 2005; Yamamiya, Cah, Melnyk, Posavac, & Posavac, 2005), as a society we are yet to realise the impact societal pressures have upon a male and their sense of self-worth. Societal norms would assume that men are not affected by body ideals and the messages portrayed in society (Pope et al., 2002), therefore if their sense of self and worth is not affected, then there is no drive to change the way men are portrayed in society. Challenging the norms presented in the themes ‘Striving to Maintain a Masculine Identity’ and ‘Societal Construction of the Perfect Male’ would enable males to have a different experience to those reported in the theme ‘The Interconnectedness of Control and Self-Worth’

The male experience of an ED remains hidden due to the gendered norms that exist; their illness is not recognised by professionals (Oickle, 1998; Robinson et al., 2012), they are experiencing isolating feelings (Oickle, 1998; Robinson et al., 2012), and they fear stigma (Ashuk, 2004; Wertheimer, 2006). These combined create a maintaining cycle of the male experience of an ED being invalidated, as emphasised in the theme ‘The Hidden Man’. There is a drive to address these challenges with regards to EDs (Secretary of State for Health and Social Care, 2019), yet men are still largely unaccounted for in ED services (BEAT, 2019). Further work is needed to challenge gendered and societal norms, as presented in the themes, in relation to male experiences of an ED alongside societal ideals and pressures.

Further research into male experiences of an ED would be warranted to enable the synthesising of treatment experiences and diagnoses specific experiences. Recruitment of males to ED research has been historically problematic (Cibralic & Conti, 2018), which is understandable in the context of societal norms and gendered norms. However, to enable further research into male experiences of an ED, and therefore enhance understanding, the problems with recruitment need to be considered and addressed.

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Chapter 2: Empirical Paper

Exploring the Experience of Young People Receiving Treatment for an Eating Disorder: Family Therapy for Anorexia Nervosa and Multi-Family Therapy in an Inpatient Setting

Abstract

Introduction

Research indicates that Family Therapy for Anorexia Nervosa (FT-AN) and Multi-Family Therapy (MFT) are effective treatments for adolescents experiencing Anorexia Nervosa (AN). However, less is known about young people's experiences of these two treatments, as there is limited qualitative research. Furthermore, to date there is no qualitative research exploring their experience of these two treatments in an inpatient setting.

Method

Five young people were recruited to the study from an inpatient unit who were receiving treatment on the AN pathway which included both FT-AN and MFT. Semi structured interviews were undertaken and analysed using Interpretative Phenomenological Analysis (IPA).

Results

Four superordinate themes and twelve subthemes were developed from the data. The four superordinate themes were: *'Process of Understanding', 'Reviving Connection', 'Emerging from the Eating Disorder and 'Development of I'*.

Discussion

There appeared to be two overarching concepts: the role of the individual and the role of others. The superordinate themes 'Emerging from the Eating Disorder' and 'Development of I' focussed on the development of the individual. Conversely, the superordinate themes 'The Process of

Understanding’ and ‘Reviving Connection’ were centred on the familial relationships existing within the family system.

Introduction

Anorexia Nervosa

The core psychopathology associated with an Eating Disorder (ED) is a preoccupation with weight, shape and food and is a commonality across the varying ED diagnoses (American Psychiatric Association, 2013). Anorexia Nervosa (AN) is categorised by restrictive dietary intake that leads to a low body weight, combined with an intense fear of weight gain, behaviours that interfere with weight gain and a disturbance in how an individual experiences their body (American Psychiatric Association, 2013). AN is a serious and dangerous mental illness associated with severe physical (Mehler & Brown, 2015) and psychological complications (Eaton, 2019), with one fifth of deaths associated with AN due to completed suicides (Arcelus, Mitchell, Wales, & Nielsen, 2011). AN is believed to have the highest mortality rate of all mental health conditions (BEAT, 2019) and a higher mortality rate than physical health conditions such as asthma or diabetes (Kahki & McCann, 2016).

Anorexia Nervosa in Young People

AN is predominately associated with adolescence, and prevalence studies have shown the median age of onset for AN to be 12.3 years (Swanson, Crow, Le Grange, Swendsen, & Merikangas, 2011), with incidence rates being highest amongst the 15-19 age range (Kahki & McCann, 2016). In keeping with the above figures from Swanson et al. (2011), AN is more common amongst adolescent females than males (Kahki & McCann, 2016). However, prevalence studies struggle to capture the true extent of Eating

Disorders (EDs) in society due to variation in measurement and cross-cultural variation (Swanson et al., 2011). Furthermore, the often secretive nature of an ED impedes treatment seeking (Smink, van Hoeken, & Hock, 2012) and therefore also prevents a clear understanding of the magnitude of the problem. AN is reported as the third most chronic illness amongst adolescents (Kahki & McCann, 2016), highlighting the importance of effective treatment to enable recovery. The chronicity and severity of AN highlights the importance of effective and early treatment as lower age and reduced duration of illness are factors associated with better treatment outcomes (Jewell, Blessitt, Stewart, Simic & Eisler, 2016). The ‘Access and Waiting Time Standard for Children and Young People with an Eating Disorder’ document states that young people should have access to National Institute for Health and Care Excellence (NICE) compliant treatment within 4 weeks of assessment, and 1 week in urgent cases (NHS England, 2015), further reinforcing the necessity for early intervention to aid recovery. Furthermore, the document highlighted the importance of commissioners understanding the experiences of young people to improve access to services (NHS England, 2015).

Treatment for Anorexia Nervosa in Young People

Family Therapy for Anorexia Nervosa[5] (FT-AN) is the first line intervention for adolescents experiencing AN, as defined by NICE guidance (NICE, 2017). FT-AN is a treatment that supports parents to re-feed their child

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[5] Family Therapy for Anorexia Nervosa can also be referred to as Maudsley Family Therapy or Family Based Treatment.

and is most commonly an outpatient treatment, delivered weekly to a single family and young person. Despite evaluation of this therapy within the literature, not all adolescents respond to FT-AN (Eisler, Simic, Hodsoll et al., 2016), which led to the development of Multi-Family Therapy (MFT) (Dare & Eisler, 2000). MFT is a group treatment that sees multiple families and adolescents come together for their treatment. FT-AN and MFT have many similarities, especially in that the overarching goal is to enable recovery from AN for the young person whilst supported by their family. However, community treatments are not always successful in enabling a young person to recover and inpatient treatment can be required. Research indicates that inpatient treatment for an adolescent is no more effective than outpatient treatments (Lock, 2010) but it is sometimes necessary due to the severe presentation requiring physiological rehabilitation (Kezelman et al. 2016). However, the evidence to support the effectiveness of inpatient treatment is variable and largely inconclusive (Colton & Pistrang, 2004). Hospital admission for the treatment of AN in young people is often associated with relapse and readmission (Offord, Turner, & Cooper, 2006).

Research reviewing the existing literature highlights the efficacy of FT-AN and MFT (Jewell et al., 2016); FT-AN was deemed to be significantly better than the comparison treatment at six and twelve month follow ups (Lock et al., 2010) and MFT resulted in significantly better treatment outcomes (Eisler et al., 2016). However, there remain a limited number of randomised control trials (RCTs) exploring the effectiveness of both treatments; a meta-analysis exploring adolescent treatment only included seven randomised control trials including FT-AN (Vall & Wade, 2015) and only two RCTs exploring MFT (Carrot et al., 2019; Eisler et al., 2016) have been published to date.

There is also limited qualitative research available into adolescents' experience of FT-AN. The qualitative research looking at FT-AN is all conducted in outpatient community settings (Chan & Ma, 2006; Chen et al., 2010; Krautter & Lock, 2004; Lindstedt, Neander, Kjellin & Gustafsson, 2015; Wallis et al., 2017). FT-AN is primarily an outpatient community intervention, hence the majority of the research being conducted in this area; however, there are a number of inpatient facilities that deliver FT-AN as an inpatient treatment. Furthermore, there is an even smaller body of qualitative research into MFT as it is a newer treatment option; one paper investigated parents' experiences (Engman-Bredvik, Carballeria, Levi, & Nillson, 2016), one investigated adults' experiences (Tantillo, Sanftner McGraw, Hauenstein, & Groth, 2015) and only one focused on adolescents' experiences and only after the first four sessions of the treatment intervention (Voriadaki, Simic, Espie, & Eisler, 2015); all of these were conducted in an outpatient setting.

The majority of qualitative research into EDs is with adults, and the qualitative research with adolescents is primarily focused on treatment and recovery (Bezance & Holliday, 2013), with the majority in the context of inpatient treatment (Boughtwood & Halse, 2009; Hedlund & Landgren, 2017; Kezelman et al., 2016; Offord et al., 2006; Ramjan & Gill, 2012; Tierney, 2008; Van Ommen, Meerwijk, Kars, Van Elburg, & Van Meijel, 2009) focussing on the overall experience of being an inpatient. It is believed to be important to explore adolescents' experiences of treatment, as previous research has highlighted the benefit of obtaining detailed descriptions of how adolescents view their treatment (Colton & Pistrang, 2004) to inform service development (Tierney, 2008). Having a better understanding of an adolescent's experience of their treatment could provide a rich insight into treatment acceptability and complexity (Medway & Rhodes, 2016), and thus enabling treatment providers to have a better informed knowledge of the treatment options available. Furthermore, NHS England recognise the benefit in exploring young people's experiences of treatment to enable service improvements (NHS England, 2015).

Aims of the project

The principal objective of the research is to explore a young person's experience of FT-AN and MFT in an inpatient setting to enable a greater understanding of their experiences in order to better understand the treatments provided and the treatment acceptability from the young person's perspective. Following a systematic review of the literature, none of the published qualitative research has examined an adolescent's experience of FT-AN and MFT in an inpatient setting. Therefore, the aim of this research is to focus on adolescents' experience of FT-AN and MFT whilst in an inpatient setting with a view to gaining a better understanding of their experiences of the treatment and the sense they make of the relational, familial and individual changes that occur for them. The theoretical background of the theory of change in relation to FT-AN proposes that FT-AN is focused on the interconnectedness of how an individual experiences change, the change in significant relationships and the shared meaning of those changes (Eisler, Simic, Blessitt, & Dodge, 2016). Therefore, the question of how an adolescent makes sense of the changes they experiences in themselves and their family relationships in the context of FT-AN and MFT whilst residing in an inpatient unit and not their family home requires consideration. It is felt that adolescents can help shape services (Tierney, 2008), and therefore, future developments in treatment through qualitative research (Bezance & Holliday, 2013), highlighting the importance of qualitative research. This is felt to be of particular importance in the context of EDs when the available treatments are not always successful.

Method

Interpretative Phenomenological Analysis

Interpretative Phenomenological Analysis (IPA) is a qualitative research method that focuses on examining how people make sense of their lived experiences (Smith, Flowers, & Larkin, 2009). Three key areas of philosophy have informed IPA: phenomenology, hermeneutics and ideography (Smith et al., 2009). Phenomenology is concerned with the study of experience and hermeneutics is the theory of interpretation, which in the context of IPA can be understood as an individual's understanding of their experience, whilst the idiographic nature focuses on the particular; the context in which the experience occurred (Smith et al., 2009). A double hermeneutic process occurs in IPA as the researcher attempts to make sense of a participant's sense making of their lived experience in a given context (Smith et al., 2009). IPA is focused on the individual sense making and the meaning associated with their own personal experience, focusing on the individual expression of experience as opposed to defining an experience by pre-existing categories (Smith et al., 2009). It was felt that IPA was suited to this particular study as the study is concerned with the sense young people make of their experience of FT-AN and MFT whilst in an inpatient unit; exploring an individual's understanding of their lived experience in a given context.

Recruitment

As IPA is concerned with the individual experience a small sample of participants was deemed appropriate (Smith et al., 2009). Purposive sampling was used to recruit participants to the study to enable the identification of young people who could provide a detailed account of their experience of FT-AN and MFT in an inpatient setting.

Once ethical approval had been sought and granted by the Health Research Authority (Appendix K) participants were recruited from an NHS inpatient facility for EDs. To ensure homogeneity of participants the following inclusion and exclusion criteria were implemented when assessing the eligibility of participants for the study.

Table 12

Inclusion Criteria

Number	Inclusion Criteria
1	Diagnosis of Anorexia Nervosa
2	Received treatment at the inpatient unit that includes FT-AN and MFT
3	Have been deemed to have completed treatment by the clinical team
4	Have capacity to consent to participate in the research
5	Aged 10 to 18

Table 13

Exclusion Criteria

Number	Exclusion Criteria
1	Receiving treatment that does not include both FT-AN and MFT
2	Ceased treatment before clinical team deemed them to have completed treatment
3	Non-English speaking

The clinical team at the inpatient unit identified potential participants and assessed their suitability in line with Tables 12 and 13. Once they were deemed eligible for the research the clinical team approached the young person to ask if they were interested in participating in the study. If they were interested in taking part, then they were given a ‘Participant Information sheet’ and ‘Data Protection Additional Information’ Sheet (Appendix L - O) and allowed five days to consider their involvement. If a young person was under 16, their legal guardian was also provided with an information sheet (Appendix P). After five days the clinical care team approached the young person again to see if they wished to participate. If they wished to participate the young person completed a ‘Consent to Contact’ form (Appendix Q). Once the Chief Investigator received the form contact was made with the young person, and their legal guardian if under 16, to arrange completion of the relevant written consent / assent forms (Appendix R - T), answer any questions regarding the research and organise a time for the interview. If the young person had recently been discharged from the inpatient unit then contact was made with their GP and if applicable their Care Coordinator in their community team to assess eligibility and capacity (Appendix U).

Participants

A total of five participants were recruited to the study from the AN treatment pathway at the inpatient unit which included them having FT-AN and MFT as part of their inpatient treatment. As the participants had accessed the AN treatment pathway they had either a diagnosis of AN or a diagnosis largely characterised by features of AN, such as Other Specified Feeding or Eating Disorder[6]. Four participants were female and one was male and their ages ranged from 10-18 with a mean age of 14.6 years. Three of the participants were coming to the end of their inpatient stay and were deemed to have completed MFT and FT-AN by the clinical team and the other two had recently been discharged. The clinical team would deem individuals has having completed treatment when they had engaged in a cycle of MFT and completed all components of FT-AN delivered in the inpatient unit.

Table 14

Participant demographics

Participant Number	Name[7]	Gender
1	Morty	Male
2	Lilly	Female
3	Meghan	Female
4	Lucy	Female
5	Molly	Female

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[6] A diagnosis of Other Specified Feeding or Eating Disorder was included as this participant had a diagnosis that was characterised by features of AN and eligible for the AN treatment pathway.

[7] Pseudonyms have been allocated to maintain confidentiality.

Data collection

Participants engaged in semi-structured interviews, which were audio recorded to enable transcription post interview. At the start of the interview participants were reminded of their right to withdraw and consent to undertake the research was either obtained or checked. The interviews were either held at the inpatient unit or the participant’s home. The interviews followed a semi structured interview guide (Appendix V) exploring themes relating to the young persons experience of treatment and experience of change. The young person guided the duration of the interview and they varied in duration, ranging from 24 to 76 minutes with a mean duration of 37 minutes. At the end of the interviews the wellbeing of participants was checked and if the young person was still an inpatient at the inpatient unit it was handed over to nursing staff on shift that they had completed a research interview. If the participant had recently been discharged then they were provided with a ‘Participant Debrief Sheet’ (Appendix W).

Data analysis

The transcripts were transcribed verbatim with identifiable information amended to maintain confidentially. The steps outlined in Table 15 were followed to enable IPA of the transcripts.

Table 15

Overview of the stage of IPA (Smith et al., 2009)

Step	Description
Step 1	**Reading and re-reading** This step enables the researcher to become familiar with the data and begin to immerse oneself in the data. Initial notes might be made during this step.
Step 2	**Initial coding** This step sees the researcher making notes on the transcript, noting things of interest. There are three processes: a. Descriptive comments – describing content of the narrative b. Linguistic comments – exploring the participants use of language c. Conceptual comments – exploring the narrative from an interpretive approach
Step 3	**Developing emergent themes** This step involves working with the researchers coding notes to summarise and capture the meaning of the participant's narrative.
Step 4	**Searching for connection across emergent themes** This step requires the researcher to start to explore how emergent themes map on to one another. Finalising this process by displaying the findings in a coherent thematic structure. The researcher employed a number of techniques including: • ***Abstraction*** (identifying patterns between emergent themes and creating a superordinate theme), • ***Subsumption*** (an emergent theme becomes a superordinate theme to group a number of emergent themes), • ***Polarisation*** (identifying differences between emergent themes that link), • ***Numeration*** (looking at the frequency with which a theme is supported).

The steps outlined in Table 15 were followed systematically for participant one until a thematic structure was created at the end of step 4 (See Appendix X – Y for a worked example). On completion of a thematic structure for participant one, the steps were repeated for each subsequent participant, one at a time. On completion of participant five, all five thematic structures were explored for connections across these to enable the creation of the final themes presented in the results section (see Appendix Z).

Reflexivity

Due to the interpretative nature of IPA and the existence of a double hermeneutic in the process of the researcher making sense of the participants own sense making, it is important to engage in reflexive processes. Many processes were incorporated throughout the progression of IPA to enable reflexivity and to enable consideration of biases. Research supervision enabled the researcher to discuss her experience of interviewing the participants, coding and creating thematic structures. Furthermore, triangulation was enabled via IPA tutorial groups whereby coding, the development of emergent themes and creation of thematic structures were explored with research supervisors and peers. In addition, the researcher kept a reflective diary throughout the process. The researcher remains enthusiastic about the field of EDs and the developing understanding of the available treatments. However, at times the researcher needed to be mindful of making assumptions about participant’s narrative based on her understanding of EDs and treatment processes. The researcher had a preconceived idea that the young people would feel as if treatment was being done to them and therefore not value it; the researcher was also aware of the differences between the researcher and the participants and held in mind differences in age, gender, social class and lived experiences at all stages, from conducting the interviews to writing the results. Because of these pre-conceptions, the researcher needed to utilise reflexive methods when analysing the data. At these times it was helpful to utilise supervisors and peers to check their sense making; discussions were held until an agreement was reached. Furthermore, an awareness of the researcher's epistemological and ontological stance was imperative in applying a reflexive stance to the interpretations made. The researcher would describe herself as having a 'Critical Realist' stance as she believes a reality exists independent of an individual's experience yet the reality can only be fully understood by an individual experiencing that reality (Coyle, 2015). Due to the researcher's previous experience of working with people with an ED and ongoing interest, it was important for the researcher to remain mindful of her experiences to ensure that she did not map her understanding of reality on to those of the participants. Ensuring that the researcher was able to bracket off assumptions and understanding was central to preventing assumptions being made regarding participants experiences.

Results

Four superordinate themes arose from the analysis of the data: ‘Process of Understanding’, ‘Reviving Connection’, ‘Emerging from the Eating Disorder’ and ‘Development of I’. Each superordinate theme had a number of subthemes (Table 16) and will be presented in further detail, with associated quotes to support the development of the theme.

Table 16

Overview of themes

Superordinate Theme	Subthemes	Participants contributing
1.Process of Understanding	1.1. Understanding you are not alone	All participants
	1.2. Understanding the why	All participants
	1.3. I am understood	All participants except Meghan
2. Reviving Connection	2.1. Disconnection	All participants
	2.2. Altering the system	All participants
	2.3. Taking it forward	All participants
3. Emerging from the Eating Disorder	3.1.Understanding the immersion	All participants except Molly
	3.2. The Eating Disorder as damaging	Lily, Meghan and Molly
4. Development of I	4.1. Adapting to the new norm	All participants except Lilly
	4.2. The process of evolving	All participants
	4.3. Finding my voice	All participants except Lilly

1. Process of Understanding

The superordinate theme of ‘Process of Understanding’ related to the young people’s experience that once others understood more, they were then able to better understand the ED, which connected to the young person’s experience of being understood.

1.1. Understanding you are not alone

The theme ‘Understanding you are not alone’ arose from the sense that being with others, either professionals or peers, facilitated learning as Lilly made sense of her experience of MFT; "I think it was nice to talk to other people, other parents, er, they knew they weren't alone and they gave them the tools to progress". Morty reflected on the impact of the groups on his parents understanding, "groups and stuff for like parents to understand and stuff … it helps like with my parents and stuff to understand and helps me to like try and deal with things a bit better”. Meghan went on to explain:

> *My dad only went to one Multi-Family Therapy cause he works a lot [yeah] and it was a bit awkward to get out, but I think my mum used to always sort of find it really helpful, sort of speaking to the other parents [yeah] and the other families, and I think [pause] sort of especially with like the foster thing as well, cause I found it quite, I think my mum found it quite helpful, sorta seeing how other parents support me (Meghan)*

Throughout this theme there was an overarching sense that the young people attributed the benefit of the treatment to the impact it had on their parents understanding, as described by Molly, “it was almost Multi-Family Therapy was less for us, more for our parents, or at least that’s what we felt.” Despite the usefulness of connecting with others there was a sense that at times it could be unhelpful as Lucy explored:

> *Erm I think listening to [pause] other people, like especially if they’re people who got re-admitted because [pause] it was my – it’s a bit different now, but when I first got admitted into [ward name], I hadn’t [pause] it hadn’t really been going on for that long. So to hear people who had got re-admitted, it was something we didn’t know about cos it was completely new to us, you know. (Lucy)*

Notwithstanding the apparent difficult nature of learning about relapse described by Lucy, it is questioned if this experience enabled a greater understanding of the ED for Lucy and her parents. It was felt that aiding understanding in others was seen as beneficial to the young people.

1.2. Understanding the why

When the young people talked about their experiences there was a sense that understanding more about the eating disorder, or the “why” as Morty described it, was central to their treatment experience, and this was enabled through the processes described in ‘Understanding you are not alone'. This notion related largely to parents having a better understanding of the ED, "I think that they'd say that [pause] their [pause] view of anorexia has changed probably … They see it as more a mental illness … Er, they still saw it as a mental illness but not as severe" as described by Lilly. There was a sense that the parents had gained a greater understanding of the illness itself but also the severity of the illness. The enhanced understanding appeared to sit within the context of supporting parents as described by Lucy, "it's helped them" to understand the ED but Lucy still felt that her parents would never be able to fully understand her experience, "obviously you can never be 100%, but it's helped them understand [pause] the illness".

'Understanding the why' remained important but for Meghan there was a sense that her understanding had developed as she never anticipated her experience of treatment to focus on her mental wellbeing. It appeared that Meghan expected her treatment to centre around weight restoration and as if this would be the primary focus:

> *Yeah, I thought it'd be more focussed on sort of the physical side of sort of helping you to start eating again instead of [pause] sort of [pause] the, just like the emotional than physical side [yeah], so mental side as well. (Meghan)*

Although Meghan described the benefits of her increased understanding this subtheme largely related to the young person valuing their parent having a greater awareness and understanding of the illness, which it felt enabled the young person to be better understood~~.~~

1.3. I am understood

The subtheme ‘I am understood’ was created through the interpretation of the data which conveyed a sense that the young people were better understood as a result of their parents increased grasp of the ED. Lucy described her parents as having a greater understanding of the emotional impact, “Erm [pause] helped them understand the emotions associated with it [pause] and how it’s not one-sided ever. It’s always two sides”. Thus sharing a sense that she is better understood and implying parental responses to her have been modified. The notion of modified parental responses was highlighted by Lilly who felt that her parents now knew how to support her, “Er, they know how to manage my meltdowns... and they know how to properly support me at mealtimes” and Molly described them as “a lot more accepting”.

Morty described the idea that now his parents’ understanding had changed so had the way they made sense of his previous behaviour:

> *Er, it was just a bit – it was just a bit, not sure, just a bit like, er, annoying because it was like I think she also thought like, about like I was choosing to be unwell and stuff but yeah. (Morty)*

Morty’s experience created a sense that his past behaviours were better understood in the context of the ED and raised the question as to whether there would be an improved interaction between Morty and his parents going forward due to this greater understanding of the young person. The increased understanding of the young person in the context of the ED appeared to highlight an improved interaction between the parents and young person.

2. Reviving Connection

The superordinate theme of ‘Reviving Connection’ centred around the notion that there was a newness in the connection the young people and their families were experiencing. There was a process through which disconnection had occurred, but by altering the system through treatment this enabled the system to act differently and thus revive the connection.

2.1. Disconnection

The young people talked of a disconnection in the family system, which appeared situated within the context of the ED, as Meghan explored:

> *I feel like you don’t really mention about the effect it has on us unless we’re sort of having a really stressful time, so we don’t actually ever end up talking about it because I don’t really like talking about it, so [yeah] we don’t really talk about it, but… (Meghan)*

It appeared as if for Meghan’s family there had been an impact on their system associated with the ED, which was almost too much to bear in that it was not articulated within the family. The idea of the effect of the ED was supported by Lilly who explained that “so much has had an impact on the family” in the context of the ED. Furthermore, Molly described a disconnect in the way the familial system managed conflict, “But if I’m screaming at you, scream back at me because then at least there’s some emotion behind it”, and this appeared to lead to a disconnected relationship.

Whilst there appeared to be a universal acknowledgment amongst the young people that the ED had impacted their familial relations, for some it appeared to be in the context of entering an inpatient system as Lilly described the difficulties she experienced, "It's hard because it's no longer the family environment … And they're not there to support you when you need their support, especially when you're upset, it's hard"; reinforcing the idea that hospital admission, as a result of the ED, created a disconnect. Conversely, whilst it appeared hospital further contributed to the experience of disconnect by either creating a disconnect or exacerbating it, it is questioned how treatment received in hospital altered the disconnect.

2.2. Altering the system

The subtheme of ‘Altering the system’ centred around the idea that in order for the disconnect experienced to change then the system needed to be altered, with the alteration occurring via the input of others, mainly through the interventions of FT-AN and MFT. The idea that someone external entering the system could facilitate change was presented:

> *Er, and having someone a third party label all of those makes it much easier to have conversations where I can use massive metaphors with the family and them still understand what's going on. Because I think the key kind of way of dealing with it was I'd make really elaborate metaphors and actually having someone translate those to my family means that I don't sometimes have to say what I really think but they still understand what's going on (Molly).*

Lucy further supported the sense that an external voice entering the system was of benefit:

> *Erm [pause] I think positive was having a voice from someone else, erm because even though my family are [pause] quite a close family, erm in the hard situation you need someone else to kind of have an input. (Lucy)*

The role of an external entering the system seemed to centre on the benefit of an outside voice as well as the role of FT-AN and MFT:

> *But, [pause] oh yeah, we did a role play … we were the parents [okay] and I think that sort of opened it up for a lot of us, sort of*

> *actually seeing sort of what it must be like in your parents' perspective [yeah]. We notice ourselves sort of being like you know, 'stop repeating all the things all the time', but then when you actually get in that situation so this is probably what they feel like instead of just seeing it from your point of view (Meghan)*

The value in the role of treatment was situated in the context of enabling an alternative perspective. Meghan talks of understanding the situation from her parent's perspective, which is likely to have facilitated increased empathy, whereas Molly talked of her family becoming "a lot more aware of each other". Morty described a change as a result of the therapy:

> *Er, yeah it's helped quite a lot of people cause just now that like, now that I'm sort of having therapy with … and my family it helps because like, er, talking about like what's, er, been hard over the past like time period or what, like something like that. Or like how, or what, something that's been good and stuff and they've kind of, er, yeah just helped with everything really (Morty)*

Supporting the notion that therapy has helped shift perspectives which has enabled the family system to act differently, as if the family scripts the family hold are starting to become more fluid due to the input of others.

2.3. Taking it forward

The shifts in family systems as a result of altered perspectives and increased understanding were acknowledged by the young people as they started to make sense of what this meant for their families in a longer term capacity, figuring out taking the changes forward with them. The role of an external voice entering the system and shifting perspectives led to the familial systems acting differently. Young people talked of improvements in their relationships with significant others as Lilly describes “getting closer again” to her sibling, which was supported by Meghan’s experience:

> *I think we’ve got closer as well [yeah], not just like me and my family, my family’s got closer with each other as well [okay], probably cause we’re spending a lot of time together [pause]. At first, that was awful, spending a lot of time together [laugh], so it’s like I’m not used to it [yeah], it was too much and we’d all keep like going moody with each other cause we just get like sort of fed up all the time, constant. But now, it’s, [pause] I think it’s quite good (Meghan)*

Meghan described the challenges experienced in attending therapy as a family unit, but was able to reflect on the positive outcome. Molly further explored the changes that had occurred for her family:

> *Yeah key ones are being able to have more conversations, have like brother as an ally rather than someone to compete against. Er, I think we have gone back to being more of a normal brother, sister relationship now. There was a while where he wouldn't say boo to a goose and he was really scared of triggering me (Molly)*

Highlighting the revival of a sibling relationship and a sense that there is a version of normality returning, although returning to the former is not possible due to the lived experiences and the changes that have occurred for the family unit.

Although the young people reflected on these changes as positive there was an experience that these changes were challenging and required effort and still needed embedding in the altered family scripts. Molly described:

> *Er, kind of building on creating almost a new element of family is really difficult and still is. You know my mum will talk more and I think up until the point where someone said you have conversations but they're not really conversations (Molly)*

Molly highlighted the challenges faced by the family and the use of the word 'building' supports the notion that this process of change is hard work and takes effort and thought. There was a sense that despite the hard work implemented by the families there were times when the new way of doing things was ineffective. Lucy further highlighted the idea of ineffective communication; making sense of it as her family becoming stuck:

> *I think [pause] a bit. That can still happen now, us going round in circles. Erm I think before we went in [pause] before we went in I just remember, [pause] I think there was quite a lot of fear in those like two months. Erm and I think even now things might actually go around in circles more now (Lucy)*

There were further difficulties with embedding change within the family as highlighted by Morty who suggested that although talking was happening outside of therapy it was only “sometimes” and “not that much outside though”, highlighting the role of therapy in facilitating relational shifts. There was a sense that the young people wanted to take the changes forward but it was a complex process. The impact of the individual on the shifts in the relational changes is important to consider and as this research was exploring the experiences of the young people their experiences of individual change will be explored further.

3. Emerging from the Eating Disorder

The superordinate theme of ‘Emerging from the Eating Disorder’ resonated with the sense that at some point in the illness trajectory the young people experienced being consumed by the ED but as they progressed through treatment they came to understand the ED as damaging.

3.1. Understanding the immersion

The young people shared experiences of the ED, which were understood in the context of being immersed in the illness, as Lilly came to realise the need for inpatient treatment: “it got to a point where I wanted to get better and I knew I couldn’t do that at home”. Lilly describes feeling “upset” by the experience of hospital but it feels as if she came to a realisation that she was so immersed in the ED that she had no other option; she could not recover at home implying the ED was too strong. The idea of struggling to progress was shared by Lucy who explained “I wasn’t really making enough progress in the community. So it was, yeah, I was sent there”, implying inpatient treatment enabled her to emerge from the ED. There was a sense that the young people were fighting to return to a previous way of being, as Morty described “they've helped with like, er, trying to get, er, back into like eating different foods.” The sense that Morty needed help to ‘try’ reinforces the gravity of the challenge the young people faced when trying to regain a sense of normality in the context of eating. Meghan used eating as a measurement of change:

> *I think so, I think sometimes I look back and realise how bad I used to actually be before sort of getting my treatment [okay][pause], to the point where it's like I'm eating now, but like a couple of months ago, I probably wouldn't eat anything at all (Meghan)*

The striking feature of Meghan's account is the power in her realisation of how immersed she was; the young people needed facilitated recovery to enable them to reflect and realise the impact of the eating disorder on themselves. There is a sense that the ability to reflect on the past is key to their understanding and that the young people would not have understood the immersion at the time. The subtheme feels centred around the realisation of where one was in terms of the illness as opposed to evaluating the impact of the immersion.

3.2. The Eating Disorder as damaging

There was a unanimous experience that the young people came to understand the illness as damaging; Lilly described it, "I just kind of thought what it would look like, it would be like spikey and…" when trying to make sense of how she would externalise the ED. The word spikey is suggestive of causing harm to those on the exterior but perhaps harmful to the internal as it ensures others are repelled and keep a distance to maintain their safety. The notion of distance was supported by Lilly as she reflected an impact of the ED on her relationships, "We're definitely not as close, we don't see each other anymore and beforehand I was, she was, I really took it out on her." Lilly highlighted the lasting impact it had on her sibling relationship whilst indicating she felt a sense of responsibility for these changes. Molly further contributed to this sense of damage caused to others and self as she described, “just the relief you feel where it’s like you’re not forcing your parents into that situation anymore is incredible and you’re not lying anymore. You’re, it’s really difficult because you’re constantly lying”, this is suggestive of damage incurred due to the coercive nature of the ED but there is also a reinforcement of the responsibility or guilt that is experienced by the young people.

Molly further described the damage experienced by the ED in the context of damage to self:

> *I feel like I chose it because I did it to myself. It’s not like cancer where you suddenly, you know, you’ve grown a tumour. And my parents say, it’s like cancer but I still don’t, I can’t see that, I don’t know whether I ever will, maybe I will at some point in the future. But I can still remember going [inaudible] shall I choose or not and that to me is a choice where you can’t choose but I think that’s probably still slightly an anorexic thought (Molly)*

Molly describes her experience as believing she made a choice in terms of her actions and it is felt that this is experienced as guilt for the impact of the ED; therefore providing an alternative stance on the ED as damaging as it appears to be damaging from an internal stand point for Molly. Interestingly, Molly questions if her beliefs about choice are “an anorexic thought”, implying time might enable a shift away from her experience of responsibility. There was a sense that the young people experienced the eating disorder as damaging due to the impact it had on others and the emotional impact on themselves because of the perceived sense of responsibility for the damage. However, there was a sense this could shift over time and this had occurred during their inpatient experience.

4. Development of I

The superordinate theme of ‘Development of I’ was focused on experiences of individualised change for the young people. Throughout the theme there appeared to be a sense of questioning and almost hesitance in identifying and naming changes for them as individual. It is important to consider the impact of individualised change on the system. Yet the value placed on change for the individual appeared less than that of the value placed on others changing and the systems changing.

4.1. Adapting to the new norm

There was a sense that the young people experienced adjusting to a new sense of normal. Their experience of entering hospital was described as difficult and in a way that made it feel as if the young people were entering the unknown, as described by Lucy “It was hard. I think now I don’t like thinking about that part cos I just think being like take away from your home is really difficult”. Molly reiterates the idea of the unknown:

> *Yeah, a bit, when I first got here cause I sort of, obviously cause you've just suddenly moved into like a new place and you're living with people [inaudible], so I was very scared when I first got here (Molly)*

Despite the sense that coming into hospital was challenging, Molly appears to be suggesting that this was her initial experience and it changed over time. The changes in an individual's experience was attributed to the connection with others by Meghan "so, yeah, but I think sort of getting used to it now, at the start, it was scary but sorta, then you make friends and different, like close relationships with people, [pause] it's not as bad" whereas Morty seemed to make sense of it as "it just feels a bit more like, just a bit more like you get used to it more." Thus there was an overarching awareness of the role of time that appeared to facilitate adaption, Lucy explained "I think, as time went on, it became more and more valuable and different activities we did", reinforcing the idea that time enabled the individual to develop to a point where they valued the input. The young people reflected on the challenging experience of entering an inpatient facility and how time enabled a shift in the way they felt, enabling an adaption.

4.2. The process of evolving

The subtheme 'The process of evolving' related to the idea that there had been change for the young person as an individual and they experienced a process of change. Lucy recognised that over time her contribution to therapy evolved, "I think in terms of family therapy or generally, probably throughout my stay I became more [pause] involved in the session", it is questioned how the sense of involvement facilitated change for Lucy. Other young people noticed an emotional shift in themselves as Morty reflected:

> *Er, mmm, maybe, er, [pause 5 seconds] I've [pause], umm, I'm not, er, I've got more, er, calm with, er, sort of being in hospital I guess. And er, [pause] yeah the therapy like sort of changed how like I sort of felt as well a bit. So yeah, I'm not too sure what else (Morty)*

Although Morty recognised a shift in his internal state, he highlights the hesitance that surrounded the young people when discussing the evolution of themselves. It is questioned if this relates to a difficultly in expressing oneself or a reluctance to prioritise the role of I in this process. The idea of a change in one's internal state is supported by Lilly, "My mental state is much different to the state it was in, feeling less upset, less tearful", highlighting a positive evolution in her mental state.

Furthermore, the young people described a sense of evolving to be in a position where they better understood themselves as described by Meghan:

> *Umm, yeah, I feel like it's not just figuring out my problems, I think it's in general, like sort of [pause] become sort of more social than I was beforehand [yeah], cause like before, I didn't really like to speak to that many people to be honest, but here,*

> *you end up meeting a lot of new people and seeing a lot of, [pause] you know, different things. So, I feel like [pause] I'm more confident, just as a social [yeah] person as well as before I came in here as well (Meghan)*

Meghan highlighted the benefits of her experience of treatment as not solely focused on the problem but a wider impact on the development of her as an individual, reflecting on how she evolved and how this differed from her former self. The young people reflected on an experience of evolving in their understanding of themselves, which led to a change in their internal states, and how they acted.

4.3. Finding my voice

The final subtheme to be presented further explores the process of self-development and how the young people emerged from the process as an evolved version of their former selves. The idea that the young people had found a voice arose from the interpretation of the data as Meghan describes a change in how she approaches things:

> *I don't really say anything, sort of I don't really mention anything to them so, now, I think it's sort of helping and like cause I wouldn't dare to say anything before [yeah], I was very a keep to myself type of person, I can't really do that here [laugh] (Meghan)*

There is a sense that Meghan was previously hesitant to use her voice and it feels as if the change in using her voice is associated with her sense of self-development. It is questioned if there was a sense of fear regarding using her voice and perhaps the power it held. There was a sense that practicing using their voices enabled them to find their voice:

> *Erm and then in terms of seeing friends and stuff, one of the things we did talk about in family therapy was how to deal with other people and erm I think by the time I left [ward name], there was still quite a lot of family we hadn't seen. But erm now I've seen them all and I can deal with it. So I think that – talking about it definitely did help (Lucy)*

There is a sense that by practicing to use her voice it enabled it to become the norm and perhaps this impacted on the previously perceived repercussions of using your voices. Morty reinforces the notion that finding his voice, and subsequently using it, became the norm, "maybe it's just because, er, I've been with loads of people on the ward and talking to them, maybe I'm a bit more used to talking." It is suggestive that through a process of finding their voices and talking, the young people had developed a sense of who they were and thus enabled them to share their lived experience of FT-AN and MFT in an inpatient setting.

Discussion

The analysis of the data resulted in the development of four superordinate themes, which are presented above. There appeared to be two overarching concepts: the role of the individual and the role of others. The Superordinate themes ‘The Process of Understanding’ and ‘Reviving Connection’ were centred on the familial relationships existing within the family system. ‘Process of Understanding’ was embedded in others understanding; better understanding of the ED enabled the young person to feel understood. ‘Reviving Connection’ explored how altering of the system through treatment, enabled a system alteration and thus reviving a previous disconnection. The superordinate themes ‘Emerging from the Eating Disorder’ and ‘Development of I’ focussed on the development of the individual. ‘Emerging from the Eating Disorder’ highlighted a process of the young people feeling consumed by the ED and coming to understand the ED as damaging and ‘Development of I’ explored the young peoples’ experiences of their individualised change. The themes generated from this research highlighted that young people valued others understanding and the revival of interrupted connection, they placed less emphasis on their experiences of change and the role of the individual within this experience.

The role of the individual

The researcher felt that the individual change was of most importance when considering the often unheard voice of young people, in particular in ED treatment approaches which often put the parents in charge of the recovery process (Eisler, Simic, Blessitt, & Dodge, 2016).

The themes ‘Emerging from the Eating Disorder’ and ‘Development of I’ appeared to centre around the experience for the individual. The young people acknowledged the damaging nature of the ED in the theme ‘Emerging from the Eating Disorder’; the notion of individuals coming to realise the negative impact of the ED is supported by the literature (Eaton, 2019). Eaton (2019) described the individuals as having a pivotal moment of realisation regarding the damage. The notion of a defining moment did not transpire from the transcripts; perhaps the admission to an inpatient unit facilitated the realisation of the severity of the situation. Furthermore, Eaton’s Meta-Ethnography is focused on the experiences of adult females and therefore it is possible that young people have a different experience. Research highlights differences between adults and young people with EDs; young people were found to not have impaired mentalisation[8] when compared to adults (Jewell et al., 2017). It is possible the young people did not have a defining moment of realisation due to their ability to make sense of their own and others mental states. They were able to reflect upon the damage to significant others, which appeared centred in feelings of guilt and responsibility in the theme of ‘Emerging from the Eating Disorder’, further highlighting the mentalising abilities of the young people. Existing research reported a deterioration in interpersonal relationships in the context of damage (Eaton, 2019; Jenkins &

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[8] Mentalising relates to the ability to make sense of one’s own mental states and the mental states of other (Bateman, Fonagy, & Allen, 2009).

Ogden, 2012; Lindgren, Enmark, Bohman, & Lundström, 2015; Pettersen, Wallin, & Björk, 2016), as opposed to damage to significant others and the impact on the individual in terms of responsibility for the damage caused to others as was evident in this research.

More covertly, the young people explored the impact the ED had on their self-development, giving consideration to how they had evolved through the process during their reflections in the theme 'Development of I'. Research supports the notion of an individual losing their sense of identity in an inpatient context (Bezance & Holliday, 2013; Colton & Pistrang, 2004; Offord et al., 2006), highlighting that inpatient settings can foster dependency (Bezance & Holliday, 2013). However, the unique nature of the inpatient unit in terms of the use of FT-AN, which sees the final stages of treatment returning responsibility of eating to the adolescent (Eisler, Simic, Blessitt, & Dodge, 2016), combined with the encouraged parental involvement, may have prevented a sense of dependency developing and supports the creation of a theme centred on the development of the individual.

The themes of 'Development of I' and 'Emerging from the Eating Disorder' were centred around the individual. The role of individual change on the system is questioned; which changed first is not known but the young people participating in this research placed an emphasis on a shift in parental understanding, which is suggestive, that parental shift enabled individual change. It is believed systemic change, in the context of parental containment in FT-AN is needed in order to support individual change (Wallis et al., 2017), reflecting the experience of the young people in this research. It is noteworthy that this still occurs for the individuals when undertaking FT informed treatments whilst removed from the family environment.

The role of others

Reflecting on the development of the themes the most prominent theme related to ‘The Process of Understanding’, followed by ‘Reviving Connection’. Both of these themes centred around others and focussed less on the individual. Within Family Therapy it is felt that an individual can be understood in the context of the familial system and this system is utilised to facilitate change (Minuchin, 1985), supporting the development of the themes to firstly centre on others before exploring the individual. Little is known about how change arises in FT interventions, including FT-AN and MFT, yet the mechanisms that facilitate change are felt to be key (Vilaca & Relvas, 2014).

The themes ‘The Process of Understanding’ and ‘Reviving Connection’ were embedded in the young people’s relation to others and how they as an individual existed within their family system. As previously discussed, young people are believed to experience a loss of identity in the context of an inpatient admission for an ED (Bezance & Holliday, 2013; Colton & Pistrang, 2004; Offord et al., 2006). The sense of a lost identity centred around the role of staff defining AN ways of thinking or being (Bezance & Holliday, 2013), yet the experience of the young people in this research project focused on the positivity of staff in general but also appeared to benefit from the role of professionals in facilitating learning and understanding in family members, leading to the individual feeling more understood.

A disconnect within the family was described by the young people in the theme ‘Reviving Connection’, which is supported by the literature. Research highlights the anxiety provoking nature of an ED and how this impacts on parents and consequently interconnection within the family (Wallis et al., 2017). Whitley and Eisler (2005) reported the family adapt to centre around the illness, causing disruption to family life and magnifying existing patterns of family functioning. Therefore, the removal of the individual from the system in the context of an inpatient admission may influence the changes experienced in terms of reviving familial connections as described by the young people. Inpatient treatment may prevent the centralisation of the illness and therefore provide a space to facilitate and enable change to occur.

The themes ‘The Process of Understanding’ and ‘Reviving Connection’ were interconnected in the idea of learning and altering actions facilitated by the treatments. A Meta-Synthesis exploring young people’s experiences of FT-AN in community settings highlights the improvement in familial relationships via the process of therapy (Medway & Rhodes, 2016). The notion of improved relationships was apparent in the experiences described by the young people in this research, highlighting similarities in the young people’s experiences of FT-AN in an inpatient context when compared with the existing literature. If young people detail a similar experience it is questioned if this supports the efficacy of the treatment outcomes as FT-AN and MFT are only researched in community settings.

Limitations

There are a number of limitations that need to be considered in the context of this research project. The sample size was small, with a total of five participants, and whilst recruitment issues were unavoidable due to the service constraints and the Covid-19 pandemic, it does limit the findings and the potential for missing important experiences. However, qualitative research is typically associated with small sample size enabling rich, detailed accounts to be obtained through semi structured interviews providing insight into lived experience in a way that is unattainable in quantitative research. Furthermore, recruitment was carefully considered to ensure a homogenous group of participants were recruited to enhance the understanding of this particular group. The value in a homogenous sample in qualitative research is that it enables an in-depth exploration of a particular group of people sharing a particular experience in a given context.

The homogeneity of the group, whilst it has advantages, further limits the research project as all participants were deemed to have completed treatment by the clinical team. By including only participants who were deemed to have completed treatment it is therefore highly likely they would be deemed ‘recovered’ and this could have influenced the data. It would have been valuable to explore the experiences of those who were deemed to have not completed FT-AN and MFT yet they may still have been physically compromised which could raise concerns about capacity to consent. A number of potential participants declined to take part and it is questioned what valued and rich accounts would have been obtained from them and how they may have influenced the data.

Additionally, the use of IPA needs considering in light of limitations, IPA is idiographic and interpretive in its approach (Smith et al., 2009), which enables the researcher to make sense of the participants' sense making. Due to the double hermeneutic process it is necessary for the researcher to engage in reflexive practices to minimise the impact of the researchers own lived experience on their interpretation of the data. Whilst the researcher implemented a number or reflexive practices during the process it is not possible to completely remove the researchers own lived experience from her sense making during the interpretive stages of IPA.

The researcher was particularly interested in young people's experience of MFT, as at the time of designing this research project there was very little qualitative research available in this areas due to it being a relatively new therapeutic approach. Furthermore, the uniqueness of the inpatient unit interested the researcher further. However, by undertaking research into specific therapeutic approaches in the context of an inpatient setting it may have made it hard for the young people to make sense of the impact of specific therapeutic approaches when experienced in a collective treatment approach of an inpatient unit. Conversely, the very nature of therapeutic approaches that normally happen in a community setting taking place in an inpatient setting felt important to explore.

Clinical Implications

A number of recommendations have arisen from the completed research project regarding service provision. The young people appeared to place value in others learning and understanding about the ED in terms of them feeling understood. Research has highlighted the benefits of providing containment to significant others to foster positive therapeutic outcomes (Wallis et al, 2017). Furthermore, there is widespread literature highlighting the hidden nature of an ED as it is not recognised or understood by others (BEAT, 2019; Smink, van Hoeken, & Hock, 2012). It is therefore felt that further training and education to professionals would be of benefit. Individual ED services could provide training to primary care and third sector services to enhance recognition, understanding and signposting. Training could take place as part of continued professional development events to all professionals in a service to prevent only those who are interested attending. In addition to supporting the understanding of professionals. Improving the wider societal understanding of EDs is important; if society better understood EDs then this may reduce the lack of understanding about it as an illness in parents when experiencing a child with an ED for the first time. In addition, ongoing support to parents was deemed valuable in this data set, which is supported by research evidence highlighting the acceptability of online support platforms (Binford Hopf, Grange, Moessner & Bauer, 2013) and anecdotal reports of the value of face-to-face support groups for parents.

The outcome of the research highlights treatment acceptability for young people in an inpatient setting. The researcher's personal experience of working with young people, combined with manualised approaches placing parents in charge of re-feeding, led the researcher to feel as if treatment is often done to the young people. However, the young people appeared to value the treatments offered, and even when they did not value them for the benefit to themselves, they identified the value to parents; a greater parental understanding of an ED appeared to benefit the young people as parents appeared to better understand their young person as a result.. Furthermore, as the inpatient unit offer a novel way of delivering inpatient treatment the findings support the notion that young people benefit from this approach and value the support offered. Further research into FT-AN and MFT in an inpatient setting could be of value to inform service provisions.

Future Research

Future research into the area of FT-AN and MFT in an inpatient setting would be of value, enhancing the understanding of young people's experiences and acceptability of treatment modalities available to them. The current study would have benefited from a larger sample size to add credence to the findings that have arisen from this data set. It would have been advantageous to look at the individual experiences of both FT-AN and MFT in an inpatient setting. At the time of running the research the way the treatments were delivered meant this was not possible, however this has since changed and would enable a focus on FT-AN or MFT. Although careful consideration would need to be given to the fact that young people may experience both treatments so it may limit the clarity that could be obtained regarding the individuals experience of a particular treatment.

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Chapter 3: Press Release

Chapter 1: Literature Review

“The male elephant in the room”: A Qualitative Evidence Synthesis Exploring Male Experiences of Eating Disorders.

Men have eating disorders too, research shows

An eating disorder is typically associated with women and has become known as a female illness, so much so that as a society we do not seem to even contemplate that men may experience similar problems. To date, there has been limited research into the male experience of eating disorders and this appears to be related to the difficulty with getting men involved in studies; there are generally fewer men who experience an eating disorder but also men are reluctant to come forward due to perceived feelings of shame. Men are also less likely to recognise their own behaviour as being symptomatic of an eating disorder and are less likely to have their eating disorder identified by professionals, again making it hard to research this area. Men are also less likely to identify as having an eating disorder or be seen to have an eating disorder by others as their behaviours can often be normalised as simply ‘what men do’; striving to change their body by building muscle or eating large amounts of food can be seen as normal. However, feelings of shame and guilt are often present as the men struggle to manage body image concerns and emotional wellbeing independently; society discourages men from talking about their feelings.

This research project combined the existing literature exploring men’s experiences of an eating disorder to enable a better understanding of their experience. It was hoped that combining the existing literature and looking at 89 male experiences would provide greater insight.

Four themes were generated from analysing the data. The first theme highlighted the impact of societal norms on men; they were stuck between striving to act and behave in a certain way while appearing to be able to handle life and not admit to any difficulties with emotional wellbeing. The second showed the men struggled to fit in and tried to do so by striving to achieve masculine ideals while not being seen as weak. The third theme presented the idea that the men achieved a sense of control, which was facilitated by the eating disorder, thus enabling them to achieve internal and external standards, which gave them a sense of self-worth. And lastly, the final theme indicated the men wanted to remain hidden due to shame, which was affected by their belief that they were the only ones. Additionally, they were not recognised by either society or professionals.

The results highlighted that the male experience was complex and influenced by societal assumptions and gender norms. These experiences affected the male experience in many ways but most importantly it prevented help seeking and recognising eating disorders in men. Eating disorders have the highest mortality rate of all mental health disorders and men are more likely to complete suicide, therefore as a society we need to change the expectations we place upon men; enabling them to ask for help when needed and struggle with body image in the way we allow women.

Research has highlighted that women have had such a long-standing relationship with societal messages that they are now able to challenge these ideals but we have a long way to go until we achieve that for men.

Chapter 3: Press Release

Chapter 2: Empirical Paper

Exploring the Experience of Young People Receiving Treatment for an Eating Disorder: Family Therapy for Anorexia Nervosa and Multi-Family Therapy in an Inpatient Setting

Young people share their experience of in-patient therapy for eating disorders

The most widely used and recognised treatment for Anorexia Nervosa in young people is Family Therapy for Anorexia Nervosa. An alternative treatment is Multi-Family Therapy, which has many similarities to Family Therapy for Anorexia Nervosa in the overarching principles but happens in a group setting.

Both of these treatments are deemed to be effective and are usually treatments that happen in the community. However, some hospitals provide these treatments while the young people are in-patients. There is no research exploring young people's experiences of these two treatments while in an in-patient unit. Gaining an insight into young people's experiences is helpful because it can help shape future service provisions and help us to understand how young people feel about the treatment. Understanding this is important because there is limited research but also because these treatments put parents in control of the recovery.

Young people who had received both Family Therapy for Anorexia Nervosa and Multi-Family Therapy in an inpatient setting were asked to share their experiences of these two treatments. Their stories were analysed by a researcher.

The analysis identified four themes. The first theme highlighted that once others understood more they were better able to understand the eating disorder and therefore the young person felt more understood. The second theme indicated how altering the way the family worked through treatment enabled the family to reconnect. The third theme showed that as the young people progressed through treatment they felt as if they emerged from the eating disorder and reflected on this. Finally, the fourth theme centred around the young people's own self-development as a result of treatment.

The results highlighted that the young people's experiences fell into two categories: the role of the individual and the role of others. The young people appeared to place more value on the role of others but perhaps others changing allowed them to change. The research highlighted the benefit in others' understanding and therefore how improving society's understanding as a whole would be advantageous.

The young people valued the treatment, and even if there were specific aspects they did not personally value, they recognised the benefit it provided to their parents. As the young people reflected that both themselves and their parents benefited from Family Therapy for Anorexia Nervosa and Multi-Family Therapy in an inpatient setting this could help inform future service developments regarding inpatient provision.

Appendix

Appendix A: DSM V Eating Disorder Diagnostic Criteria (American Psychiatric Association, 2013).

ED	Abbreviation	DSM V Diagnostic Criteria
Anorexia Nervosa	AN	A) Restriction of energy intake relative to requirements, leading to a significantly low body weight in the context of age, sex, developmental trajectory, and physical health. *Significantly low weight* is defined as a weight that is less than minimally normal or, for children and adolescents, less than that minimally expected. B) Intense fear of gaining weight or of becoming fat, or persistent behavior that interferes with weight gain, even though at a significantly low weight. C) Disturbance in the way in which one's body weight or shape is experienced, undue influence of body weight or shape on self-evaluation, or persistent lack of recognition of the seriousness of the current low body weight.
Bulimia Nervosa	BN	A) Recurrent episodes of binge eating. An episode of binge eating is characterized by both of the following: i) Eating, in a discrete period of time (e.g., within any 2-hour period), an amount of food that is definitely larger than what most individuals would eat in a similar period of time under similar circumstances. ii) A sense of lack of control over eating during the episode (e.g., a feeling that one cannot stop eating or control what or how much one is eating). B) Recurrent inappropriate compensatory behaviors in order to prevent weight gain, such as self-induced vomiting; misuse of laxatives, diuretics, or other medications; fasting; or excessive exercise. C) The binge eating and inappropriate compensatory behaviors both occur, on average, at least once a

ED	Abbreviation	DSM V Diagnostic Criteria
		week for 3 months. D) Self-evaluation is unduly influenced by body shape and weight. E) The disturbance does not occur exclusively during episodes of anorexia nervosa.
Binge Eating Disorder	BED	A) Recurrent episodes of binge eating. An episode of binge eating is characterized by both of the following: i) Eating, in a discrete period of time (e.g., within any 2-hour period), an amount of food that is definitely larger than what most people would eat in a similar period of time under similar circumstances. ii) A sense of lack of control over eating during the episode (e.g., a feeling that one cannot stop eating or control what or how much one is eating). B) The binge-eating episodes are associated with three (or more) of the following: Eating much more rapidly than normal. i) Eating until feeling uncomfortably full. ii) Eating large amounts of food when not feeling physically hungry. iii) Eating alone because of feeling embarrassed by how much one is eating. iv) Feeling disgusted with oneself, depressed, or very guilty afterward. C) Marked distress regarding binge eating is present. D) The binge eating occurs, on average, at least once a week for 3 months. E) The binge eating is not associated with the recurrent use of inappropriate compensatory behavior as in bulimia nervosa and does not occur exclusively during the course of bulimia nervosa or anorexia nervosa.

ED	Abbreviation	DSM V Diagnostic Criteria
Other Specified Feeding or Eating Disorder	OSFED	This category applies to presentations in which symptoms characteristic of a feeding and Eating Disorder that cause clinically significant distress or impairment in social, occupation- al, or other important areas of functioning predominate but do not meet the full criteria for any of the disorders in the feeding and Eating Disorders diagnostic class Examples of presentations that can be specified using the “other specified” designation include the following: 1. **Atypical anorexia nervosa:** All of the criteria for anorexia nervosa are met, except that despite significant weight loss, the individual’s weight is within or above the normal range. 2. **Bulimia nervosa (of low frequency and/or limited duration):** All of the criteria for bulimia nervosa are met, except that the binge eating and inappropriate compensatory behaviors occur, on average, less than once a week and/or for less than 3 months. 3. **Binge Eating Disorder (of low frequency and/or limited duration):** All of the criteria for binge-eating disorder are met, except that the binge eating occurs, on average, less than once a week and/or for less than 3 months. 4. **Purging disorder:** Recurrent purging behavior to influence weight or shape (e.g. self- induced vomiting; misuse of laxatives, diuretics, or other medications) in the absence of binge eating.

Appendix B: Limitations Applied to Search Strategy Results

Database	Limitations applied
SCOPUS	Limited to exact key words: Eating Disorder, Male, Human Limited to: English Language Limited to: Article Excluded areas: BIOC, ARGI, DENT, PHAR, COMP, IMMU, CENG, ENGI
PsycINFO	Limited to: Human
MEDLINE	Limited to: English, Male, Full text, Human
EMBASE	Limited to: Full text, Human, Male
ASSIA	Filters applied: Eating Disorder, Male, English
Web of Science	Limited to: Articles

Appendix C: Blank Checklist for Methodology Checklist for qualitative studies (NICE, 2012).

Study identification: Include author, title, reference, year of publication		
Guidance topic:	**Key research question/aim:**	
Checklist completed by:		
Theoretical approach		
1. Is a qualitative approach appropriate? For example: • Does the research question seek to understand processes or structures, or illuminate subjective experiences or meanings? • Could a quantitative approach better have addressed the research question?	Appropriate Inappropriate Not sure	Comments:
2. Is the study clear in what it seeks to do? For example: • Is the purpose of the study discussed – aims/objectives/research question/s? • Is there adequate/appropriate reference to the literature? • Are underpinning values/assumptions/theory discussed?	Clear Unclear Mixed	Comments:
Study design		

3. How defensible/rigorous is the research design/methodology? For example: • Is the design appropriate to the research question? • Is a rationale given for using a qualitative approach? • Are there clear accounts of the rationale/justification for the sampling, data collection and data analysis techniques used? • Is the selection of cases/sampling strategy theoretically justified?	Defensible Indefensible Not sure	Comments:
4. How is an Eating Disorder defined? For example: • Use of a measure • Receiving treatment in service.	Clearly defined Not clearly defined Missing data	Comments:
Data collection		
5. How well was the data collection carried out? For example: • Are the data collection methods clearly described? • Were the appropriate data collected to address the research question? • Was the data collection and record keeping systematic?	Appropriately Inappropriately Not sure/inadequately reported	Comments:
Trustworthiness		
6. Is the role of the researcher clearly described?	Clearly described	Comments:

For example: • Has the relationship between the researcher and the participants been adequately considered? • Does the paper describe how the research was explained and presented to the participants?	Unclear Not described	
7. Is the context clearly described? For example: • Are the characteristics of the participants and settings clearly defined? • Were observations made in a sufficient variety of circumstances • Was context bias considered	Clear Unclear Not sure	Comments:
8. Were the methods reliable? For example: • Was data collected by more than 1 method? • Is there justification for triangulation, or for not triangulating? • Do the methods investigate what they claim to?	Reliable Unreliable Not sure	Comments:
Analysis		
9. Is the data analysis sufficiently rigorous? For example: • Is the procedure explicit – i.e. is it clear how the data was analysed to arrive at the results? • How systematic is the analysis, is the procedure reliable/dependable?	Rigorous Not rigorous Not sure/not reported	Comments:

• Is it clear how the themes and concepts were derived from the data?		
10. Is the data 'rich'? For example: • How well are the contexts of the data described? • Has the diversity of perspective and content been explored? • How well has the detail and depth been demonstrated? • Are responses compared and contrasted across groups/sites?	Rich Poor Not sure/not reported	Comments:
11. Is the analysis reliable? For example: • Did more than 1 researcher theme and code transcripts/data? • If so, how were differences resolved? • Did participants feedback on the transcripts/data if possible and relevant? • Were negative/discrepant results addressed or ignored?	Reliable Unreliable Not sure/not reported	Comments:
12. Are the findings convincing? For example: • Are the findings clearly presented? • Are the findings internally coherent? • Are extracts from the original data included? • Are the data appropriately referenced? • Is the reporting clear and coherent?	Convincing Not convincing Not sure	Comments:

13. Are the findings relevant to the aims of the study?	Relevant Irrelevant Partially relevant	Comments:
14. Conclusions For example: • How clear are the links between data, interpretation and conclusions? • Are the conclusions plausible and coherent? • Have alternative explanations been explored and discounted? • Does this enhance understanding of the research topic? • Are the implications of the research clearly defined? **Is there adequate discussion of any limitations encountered?**	Adequate Inadequate Not sure	Comments:
Ethics		
15. How clear and coherent is the reporting of ethics? For example: • Have ethical issues been taken into consideration? • Are they adequately discussed e.g. do they address consent and anonymity? • Have the consequences of the research been considered i.e. raising expectations, changing behaviour? • Was the study approved by an ethics committee?	Appropriate Inappropriate Not sure/not reported	Comments:
Overall assessment		

As far as can be ascertained from the paper, how well was the study conducted? (see guidance notes)	++ + −	Comments:

Notes on the use of the qualitative studies checklist

Section 1: theoretical approach

This section deals with the underlying theory and principles applied to the research.

1. Is a qualitative approach appropriate?
A qualitative approach can be judged to be appropriate when the research sets out to investigate phenomena which are not easy to accurately quantify or measure, or where such measurement would be arbitrary and inexact. If clear numerical measures could reasonably have been put in place then consider whether a quantitative approach may have been more appropriate. This is because most qualitative research seeks to explain the meanings which social actors use in their everyday lives rather than the meanings which the researchers bring to the situation.

Qualitative research in public health commonly measures:

- personal/lives experiences (for example, of a condition, treatment, situation)
- processes (for example, action research, practitioner/patient views on the acceptability of using new technology)
- personal meanings (for example, about death, birth, disability)
- interactions/relationships (for example, the quality of the GP/patient relationship, the openness of a psychotherapeutic relationship)
- service evaluations (for example, what was good/bad about patients experiences of a smoking cessation group).

2. Is the study clear in what it seeks to do?
Qualitative research designs tend to be theory generative rather than theory testing; therefore it is unlikely that a research question will be found in the form of a hypothesis or null hypothesis in the way that you would expect in conventional quantitative research. This does not mean however that the paper should not set out early and clearly what it is that the study is investigating and what the parameters are for that. The research question should be set in context by the provision of an adequate summary of the background literature and of the study's underpinning values and assumptions.

Section 2: study design

Considers the robustness of the design of the research project.

3. How defensible is the research design?
There are a large number of qualitative methodologies, and a tendency in health to 'mix' aspects of different methodologies or to use a generic qualitative method. From a qualitative perspective, none of this compromises the quality of a study as long as:

- The research design captures appropriate data and has an appropriate plan of analysis for the subject under investigation. There should be a clear and reasonable justification for the methods chosen.
- The choice of sample and sampling method should be clearly set out, (ideally including any shortcomings of the sample) and should be reasonable. It is important to remember that sampling in qualitative research can be purposive and should not be random. Qualitative research is not experimental, does not purport to be generalisable, and therefore does not require a large or random sample. People are usually 'chosen' for qualitative research based on being key informers.

Section 3: data collection

5. How well was the data collection carried out?
Were the method of data collection the most appropriate given the aims of the research? Was the data collection robust, are there details of:

- how the data were collected?
- how the data were recorded and transcribed (if verbal data)?
- how the data were stored?
- what records were kept of the data collection?

Section 4: trustworthiness

Assessing the validity of qualitative research is very different from quantitative research. Qualitative research is much more focused on demonstrating the causes of bias rather than eliminating them, as a result it is good practice to include sections in the report about the reflexive position of the researcher (what was their 'part' in the research?), about the context in which the research was conducted, and about the reliability of the data themselves.

6. Is the role of the researcher clearly described?
The researcher should have considered their role in the research either as reader, interviewer, or observer for example. This is often referred to as 'reflexivity'. It is important that we can determine: a clear audit trail from respondent all the way through to reporting, why the author reported what they did report, and that we can follow the reasoning from the data to the final analysis or theory.

The 'status' of the researcher can profoundly affect the data, for example, a middle aged woman and a young adult male are likely to get different responses to questions about sexual activity if they interview a group of teenage boys. It is important to consider age, gender, ethnicity, 'insider' status (where the interviewer/researcher is part of the group being researched or has the same condition/illness, for example). The researcher can also profoundly influence the data by use of questions, opinions and judgments, so it is important to know what the researchers' position is in that regard and how the researcher introduced and talked about the research with the participants.

7. Is the context clearly described?
It is important when gauging the validity of qualitative data to engage with the data in a meaningful way, and to consider whether the data are plausible/realistic. To make an accurate assessment of this it is important to have information about the context of the research, not only in terms of the physical context – for example, youth club, GP surgery, gang headquarters, who else was there (discussion with parents present or discussion with peers present are likely to cause the participant to position himself very differently and thus to respond very differently) – but also in terms of feeling that the participants are described in enough detail that the reader can have some sort of insight into their life/situation. Any potential context bias should be considered.

8. Were the methods reliable?
It is important that the method used to collect the data is appropriate for the research question, and that the data generated map well onto the aims of the study. Ideally, more than 1 method should have been used to collect data, or there should be some other kind of system of comparison which allows the data to be compared. This is referred to as triangulation.

Section 5: analysis

Qualitative data analysis is very different from quantitative analysis. This does not mean that it should not be systematic and rigorous but systematicity and rigour require different methods of assessment.

9. Is the data analysis sufficiently rigorous?
The main way to assess this is by how clearly the analysis is reported and whether the analysis is approached systematically. There should be a clear and consistent method for coding and analysing data, and it should be clear how the coding and analytic strategies were derived. Above all, these must be reasonable in light of the evidence and the aims of the study. Transparency is the key to addressing the rigour of the analysis.

10. Are the data rich?
Qualitative researchers use the adjective 'rich' to describe data which is in-depth, convincing, compelling and detailed enough that the reader feels that they have achieved some level of insight into the research participants experience. It's also important to know the 'context' of the data, that is, where it came from, what prompted it and what it pertains to.

11. Is the analysis reliable?
The analysis of data can be made more reliable by setting checks in place. It is good practice to have sections of data coded by another researcher, or at least have a second researcher check the coding for consistency. Participants may also be allowed to verify the transcripts of their interview (or other data collection, if appropriate). Negative/discrepant results should always be highlighted and discussed.

12. Are the findings convincing?
In qualitative research, the reader should find the results of the research convincing, or credible. This means that the findings should be clearly presented and logically organised,

that they should not contradict themselves without explanation or consideration and that they should be clear and coherent.

Extracts from original data should be included where possible to give a fuller sense of the findings, and these data should be appropriately referenced – although you would expect data to be anonymised, it still needs to be referenced in relevant ways, for example if gender differences were important then you would expect extracts to be marked male/female.

13–14. Relevance of findings and conclusions
These sections are self-explanatory.

Section 6: ethics

15. How clear and coherent is the reporting of ethics?
All qualitative research has ethical considerations and these should be considered within any research report. Ideally there should be a full discussion of ethics, although this is rare because of space limitations in peer-reviewed journals. If there are particularly fraught ethical issues raised by a particularly sensitive piece of research, then these should be discussed in enough detail that the reader is convinced that every care was taken to protect research participants.

Any research with human participants should be approved by a research ethics committee and this should be reported.

Section 7: overall assessment

- Is the study relevant?
- Does the study cast light on the review being undertaken?

- How well was the study conducted?

Grade the study according to the list below:

++ All or most of the checklist criteria have been fulfilled

+ Some of the checklist criteria have been fulfilled

– Few or no checklist criteria have been fulfilled.

Appendix D: Overview of the findings of the Methodology Checklist for qualitative studies (NICE, 2012) applied to the included paper

Author(s)	**Year of publication**	**Overall Assessment rating**	**Comments to support Overall Assessment Rating**[9]
1. Oickle	1998	🟩 ++	Question 1 – Appropriate Question 2 – Clear Question 3 – Defensible Question 4 – Clearly defined Question 5 – Appropriately Question 6 – Clearly described Question 7 – Clear Question 8 – Reliable Question 9 – Rigorous Question 10 – Rich Question 11 – Reliable Question 12 – Convincing Question 13 – Relevant Question 14 – Adequate Question 15 – Appropriate
2. Drummond	1999	🟥 –	Question 1 – Appropriate Question 2 – Mixed - Lacks clarity around the parameters of the research Question 3 – Not sure - Lack of detail to enable me to define as defensible Question 4 – Not clearly defined - Does not clearly define ED diagnosis Question 5 – Not sure / Inadequately reported– Data collection methods are unclear Question 6 – Not described – Role of the researcher not described Question 7 – Unclear - Context lacking Question 8 – Not sure - Reliability unclear Question 9 – Rigorous

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[9] Where a paper has been deemed to be lacking in an area a justification for this will be provided otherwise just the score given will be reported.

Author(s)	Year of publication	Overall Assessment rating	Comments to support Overall Assessment Rating[9]
		🟥	Question 10 – Rich Question 11 – Not reported – No information to determine analysis is reliable Question 12 – Convincing Question 13 – Partially relevant – Aims unclear at the start so hard to assess Question 14 – Inadequate – no reference made to limitations of the research or implications for future research Question 15 – Not reported - Ethics information not provided
3. Drummond	2002	🟥 –	Question 1 – Appropriate Question 2 – Clear Question 3 – Defensible Question 4 – Not clearly defined – researcher felt all to have an ED but only two completed a diagnostic questionnaire. Question 5 – Not sure / Inadequately reported – no information regarding storage of data / records Question 6 – Not described – Role of the researcher not described Question 7 – Unclear – not enough information provided Question 8 – Unreliable – no reference to triangulation Question 9 – Not reported – not enough detail provided to determine rigour Question 10 – Rich Question 11 – Not reported – not enough detail provided to determine reliability Question 12 – Convincing Question 13 – Relevant Question 14 – Inadequate – no reference made to limitations of the research or implications for future research Question 15 – Not reported - Ethics information not provided
4. Ashuk	2004	🟩 ++	Question 1 – Appropriate Question 2 – Mixed – not clear for the empirical aspect of the paper Question 3 – Defensible Question 4 – Clearly defined

Author(s)	Year of publication	Overall Assessment rating	Comments to support Overall Assessment Rating[9]
			Question 5 – Not sure / Inadequately reported – clearly described but no information about record keeping. No justification for small number (n=2) participants Question 6 – Clearly described Question 7 – Not sure – Little reporting of demographics Question 8 – Unreliable – no mention of triangulation Question 9 – Rigorous Question 10 – Rich Question 11 – Not reported - unclear how discrepancies were resolved. Question 12 – Convincing Question 13 – Relevant Question 14 – Inadequate - doesn't talk about limitations of this research. Question 15 – Appropriate
5. Wertheimer	2006	++	Question 1 – Appropriate Question 2 – Clear Question 3 – Defensible Question 4 – Clearly defined Question 5 – Appropriately Question 6 – Clearly described Question 7 – Clear Question 8 – Reliable Question 9 – Rigorous Question 10 – Rich Question 11 – Reliable Question 12 – Convincing Question 13 – Partially relevant – aims unclear Question 14 – Adequate Question 15 – Not reported - Ethics information not provided.
6. Robinson, Mountford, & Sperlinger	2012	++	Question 1 – Appropriate Question 2 – Clear Question 3 – Defensible

Author(s)	Year of publication	Overall Assessment rating	Comments to support Overall Assessment Rating[9]
			Question 4 – Clearly defined Question 5 – Appropriately Question 6 – Clearly described Question 7 – Clear Question 8 – Reliable Question 9 – Rigorous Question 10 – Rich Question 11 – Reliable Question 12 – Convincing Question 13 – Relevant Question 14 – Adequate Question 15 – Appropriate
7. Björk, Wallin, & Petterson	2012	++	Question 1 – Appropriate Question 2 – Clear Question 3 – Defensible Question 4 – Clearly defined Question 5 – Appropriately Question 6 – Unclear – no information about the reflexive position Question 7 – Not sure - is clear but did not consider context bias Question 8 – Reliable Question 9 – Rigorous Question 10 – Rich Question 11 – Reliable Question 12 – Convincing Question 13 – Relevant Question 14 – Adequate Question 15 – Appropriate
8. Markham	2013	++	Question 1 – Appropriate Question 2 – Clear Question 3 – Defensible

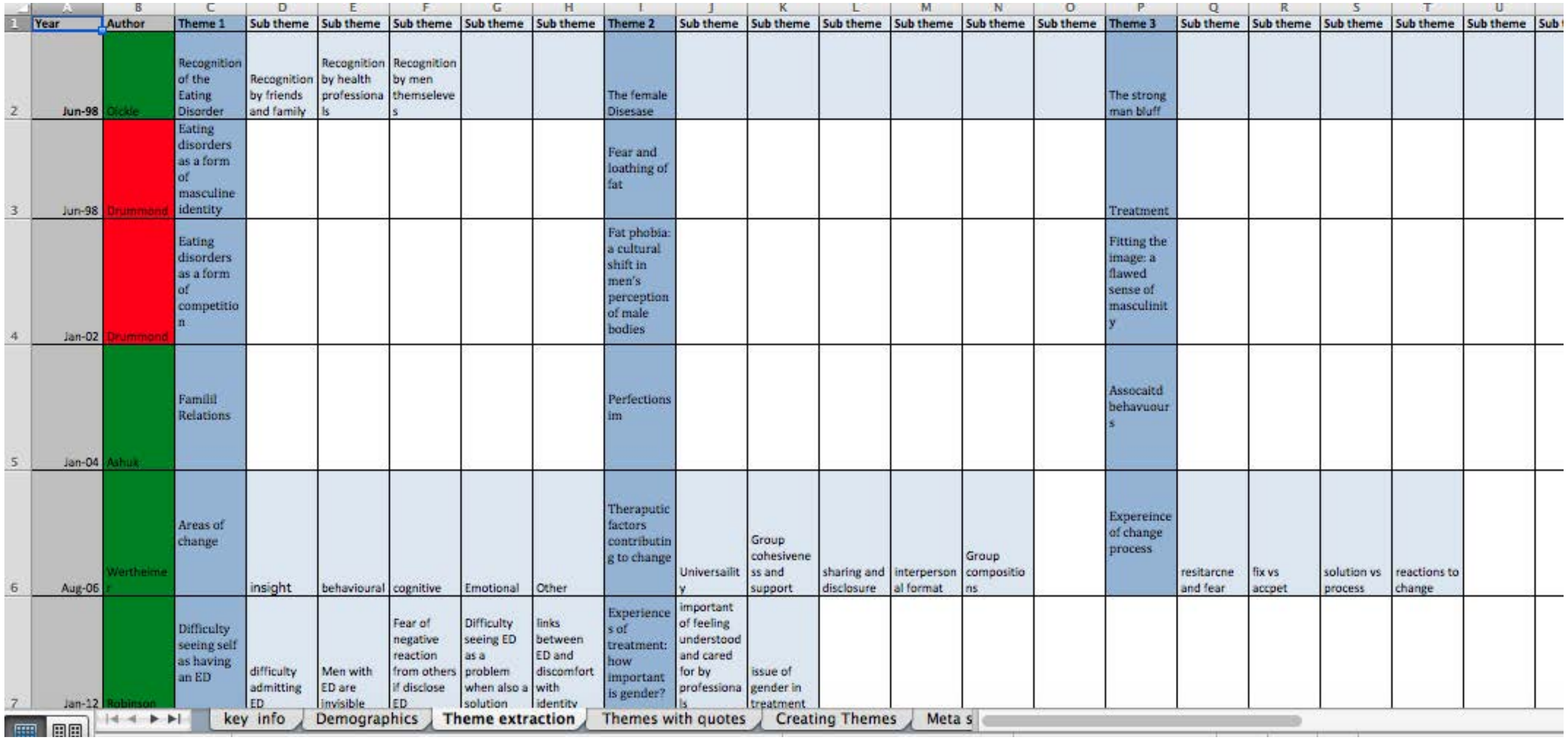
Author(s)	Year of publication	Overall Assessment rating	Comments to support Overall Assessment Rating[9]
		🟩	Question 4 – Not Clearly defined - self report of an ED but all stating an ED diagnosis Question 5 – Appropriately Question 6 – Clearly described Question 7 – Clear Question 8 – Reliable Question 9 – Rigorous Question 10 – Rich Question 11 – Reliable Question 12 – Convincing Question 13 – Partially relevant - don't feel like the themes cover all of the aims Question 14 – Adequate Question 15 – Appropriate
9. Räisänen, & Hunt	2014	🟩 ++	Question 1 – Appropriate Question 2 – Clear Question 3 – Not sure – states 'qualitative interpretive approach' Question 4 – Missing data - defines 8 out of 10 as having an ED but 2 as self-diagnosed Question 5 – Appropriately Question 6 – Not described - Role of the researcher not described Question 7 – Clear Question 8 – Reliable – despite methodology being unclear a coherent description of the process is outlined with further detail in another paper Question 9 – Rigorous Question 10 – Rich Question 11 – Not sure - talks about both authors but not clear that both were involved in that process or how differences were resolved. Question 12 – Convincing Question 13 – Relevant Question 14 – Not sure – only refers to one limitation Question 15 – Not reported - Ethics information not provided
10. Spyrou	2014	🟩 ++	Question 1 – Appropriate

Author(s)	Year of publication	Overall Assessment rating	Comments to support Overall Assessment Rating[9]
		🟩	Question 2 – Clear Question 3 – Defensible Question 4 – Clearly defined Question 5 – Not sure / Inadequately reported - no information regarding storage of data / records Question 6 – Clearly described Question 7 – Clear Question 8 – Reliable Question 9 – Not reported – clear process but no reference to a second rater Question 10 – Rich Question 11 – Not reported – no information reported regarding reliability of analysis Question 12 – Convincing Question 13 – Relevant Question 14 – Adequate Question 15 – Appropriate
11. Wallin, Pettersen, Björk, & Råstam	2014	🟩 ++	Question 1 – Appropriate Question 2 – Mixed – minimal information provided Question 3 – Defensible Question 4 – Clearly defined Question 5 – Not sure / Inadequately reported - no information regarding storage of data / records Question 6 – Not described – Information regarding role of research is not provided Question 7 – Clear Question 8 – Reliable Question 9 – Rigorous Question 10 – Rich Question 11 – Reliable Question 12 – Convincing Question 13 – Relevant Question 14 – Inadequate – no discussion of limitations Question 15 – Appropriate

Author(s)	Year of publication	Overall Assessment rating	Comments to support Overall Assessment Rating[9]
12. Pettersen, Wallin, & Björk	2016	++	Question 1 – Appropriate Question 2 – Clear Question 3 – Defensible Question 4 – Clearly defined Question 5 – Not sure / Inadequately reported - no information regarding storage of data / records Question 6 – Not described – Information regarding role of research is not provided Question 7 – Clear Question 8 – Reliable Question 9 – Rigorous Question 10 – Rich Question 11 – Reliable Question 12 – Convincing Question 13 – Relevant Question 14 – Adequate Question 15 – Appropriate
13. Thapliyal, Mitchison, & Hay	2017	++	Question 1 – Appropriate Question 2 – Clear Question 3 – Not sure - no rationale given for choice of qualitative approach Question 4 – Clearly defined Question 5 – N/A Question 6 – Clearly described Question 7 – Clear Question 8 – Reliable Question 9 – Rigorous Question 10 – Rich Question 11 – Reliable Question 12 – Convincing Question 13 – Relevant Question 14 – Adequate

Author(s)	Year of publication	Overall Assessment rating	Comments to support Overall Assessment Rating[9]
			Question 15 – Not reported - Ethics information not provided
14. Tresca	2018	++	Question 1 – Appropriate Question 2 – Clear Question 3 – Defensible Question 4 – Not clearly defined – not clear how the ED was defined Question 5 – Inadequately reported – no information related to records of data collection. Question 6 – Clearly described Question 7 – Clear Question 8 – Not sure – information not reported regarding reliability of methods. Question 9 – Rigorous Question 10 – Rich Question 11 – Not reported – no information relating to the reliability of the analysis reported Question 12 – Convincing Question 13 – Relevant Question 14 – Adequate Question 15 – Appropriate

Appendix E: Phase 3 of Meta-Ethnography (Noblit & Hare, 1988) - Reading the studies

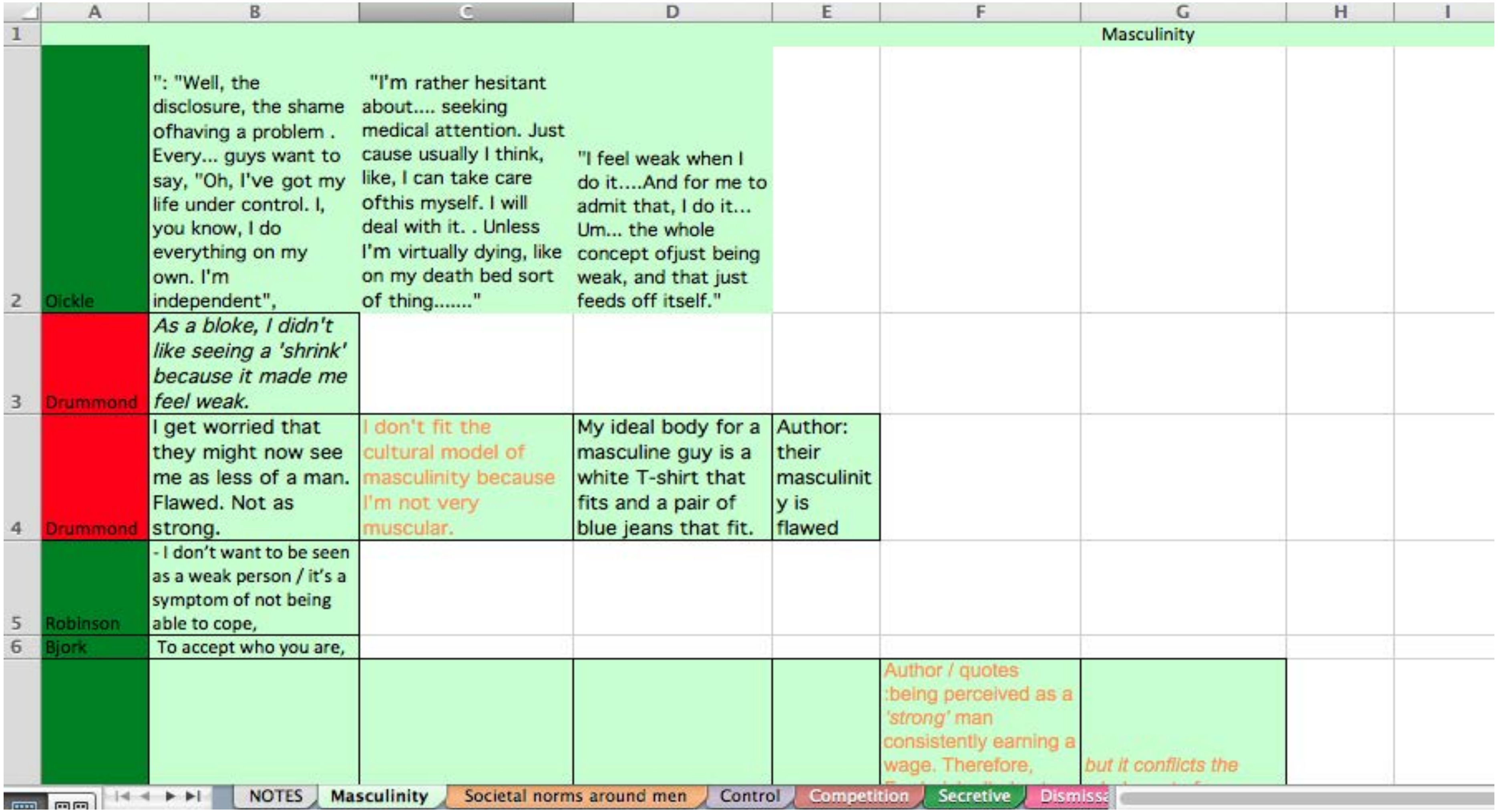


	Year	Author	Theme 1	Sub theme	Sub theme	Sub theme	Sub theme	Sub theme	Theme 2	Sub theme	Sub theme	Sub theme	Sub theme	Sub theme	Sub theme	Theme 3	Sub theme	Sub theme	Sub theme	Sub theme	Sub theme	Sub
2	Jun-98	Dickie	Recognition of the Eating Disorder	Recognition by friends and family	Recognition by health professionals	Recognition by men themseleves			The female Disesase							The strong man bluff						
3	Jun-98	Drummond	Eating disorders as a form of masculine identity						Fear and loathing of fat							Treatment						
4	Jan-02	Drummond	Eating disorders as a form of competition						Fat phobia: a cultural shift in men's perception of male bodies							Fitting the image: a flawed sense of masculinity						
5	Jan-04	Ashuk	Familil Relations						Perfectionsim							Assocaitd behavuours						
6	Aug-06	Wertheimer	Areas of change	insight	behavioural	cognitive	Emotional	Other	Theraputic factors contributing to change	Universaility	Group cohesiveness and support	sharing and disclosure	interpersonal format	Group compositions		Expereince of change process	resitarcne and fear	fix vs accpet	solution vs process	reactions to change		
7	Jan-12	Robinson	Difficulty seeing self as having an ED	difficulty admitting ED	Men with ED are invisible	Fear of negative reaction from others if disclose ED	Difficulty seeing ED as a problem when also a solution	links between ED and discomfort with identity	Experiences of treatment: how important is gender?	important of feeling understood and cared for by professionals	issue of gender in treatment											

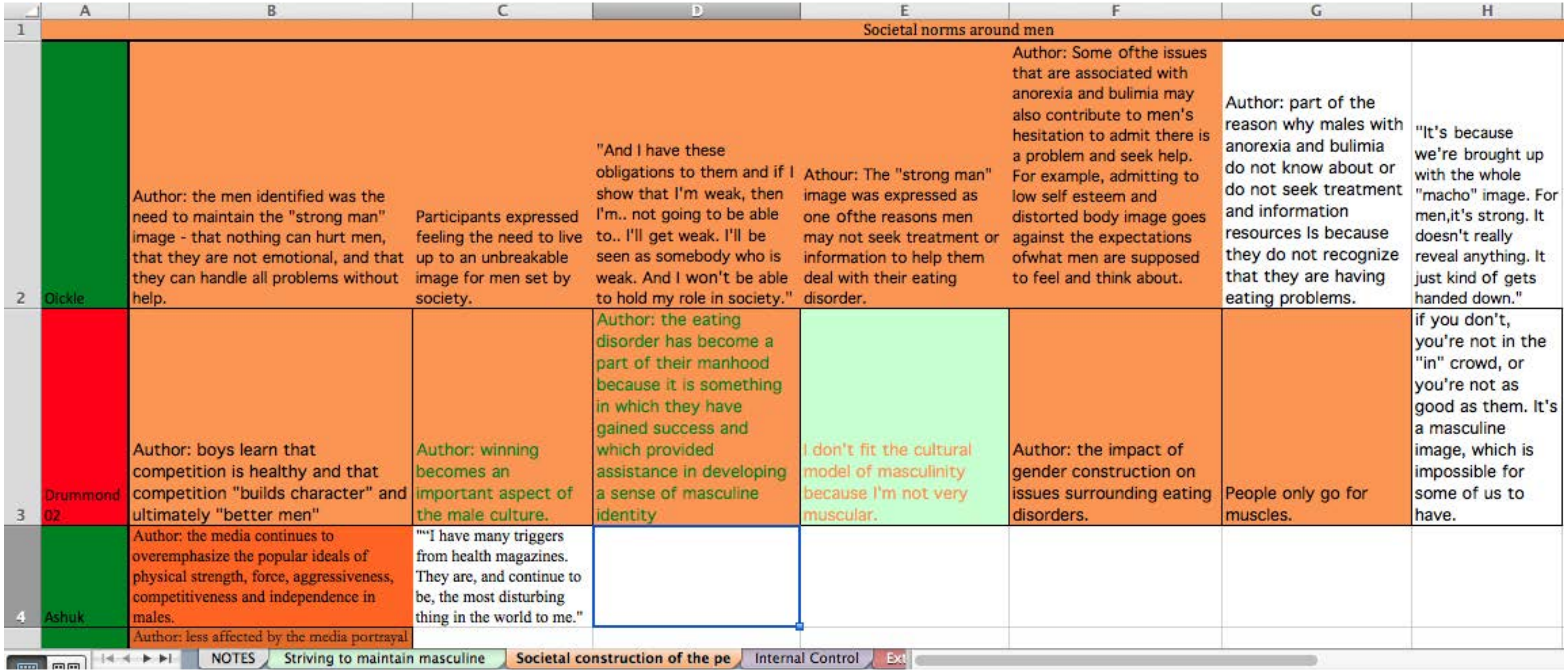
Appendix F: Phase 4 of Meta-Ethnography (Noblit & Hare, 1988) - Determining how the studies are related

	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	Q	R	S	T	U	V	W	X
1	Year	Author																						
7	Jan-12	Robinson	THEME 1: Difficulty seeing self as having an ED	Sub theme: difficulty admitting ED	was just a bit ashamed / I thought I was being ridiculous.	Author: Admitting the existence of the ED was an ongoing process	Author: The more they understood about the ED, the more they realized the seriousness of the ED and the more they were able to admit that they had a problem	Author: Many were proactive about seeking help to make sure they got what they needed.	Sub theme: Men with ED are invisible	[illegible]	Author: They felt there is a lack of visibility of male EDs in the media:	Author: Participants felt alone as a man with an ED, as if they were the only ones	Author: Some questioned if there was something wrong with them for them to have an ED as a man:	Author: There was a sense that this makes the ED even harder to talk about than it already is. literature being aimed towards women	Author: The idea that only women get EDs was reinforced by professional	Sub theme: Fear of negative reaction from others if disclose ED	- I don't want to be seen as a weak person / it's a symptom of not being able to cope,	Author: Many found it difficult talking about problems generally but telling people about the ED was particularly difficult because of the fear of how they would respond	Author: Some also worried that loved ones would blame themselves. Some had told people about the ED and were met with disbelief and rejection:	Sub theme - Difficulty seeing ED as a problem when also a solution	- nothing else I could really control as well ... it was a sense of control.	Author: Although initially a solution, the ED then became a problem in itself but was difficult to give up due to the benefits it was providing	sub theme: links between ED and discomfort with identity	people reacted to me in a different way, people wanted to get to know me better, wanted to get to know me full stop./ whole maintaining it and trying to look a certain way.

Appendix G: Phase 5 of Meta-Ethnography (Noblit & Hare, 1988) - Translating the studies into one another

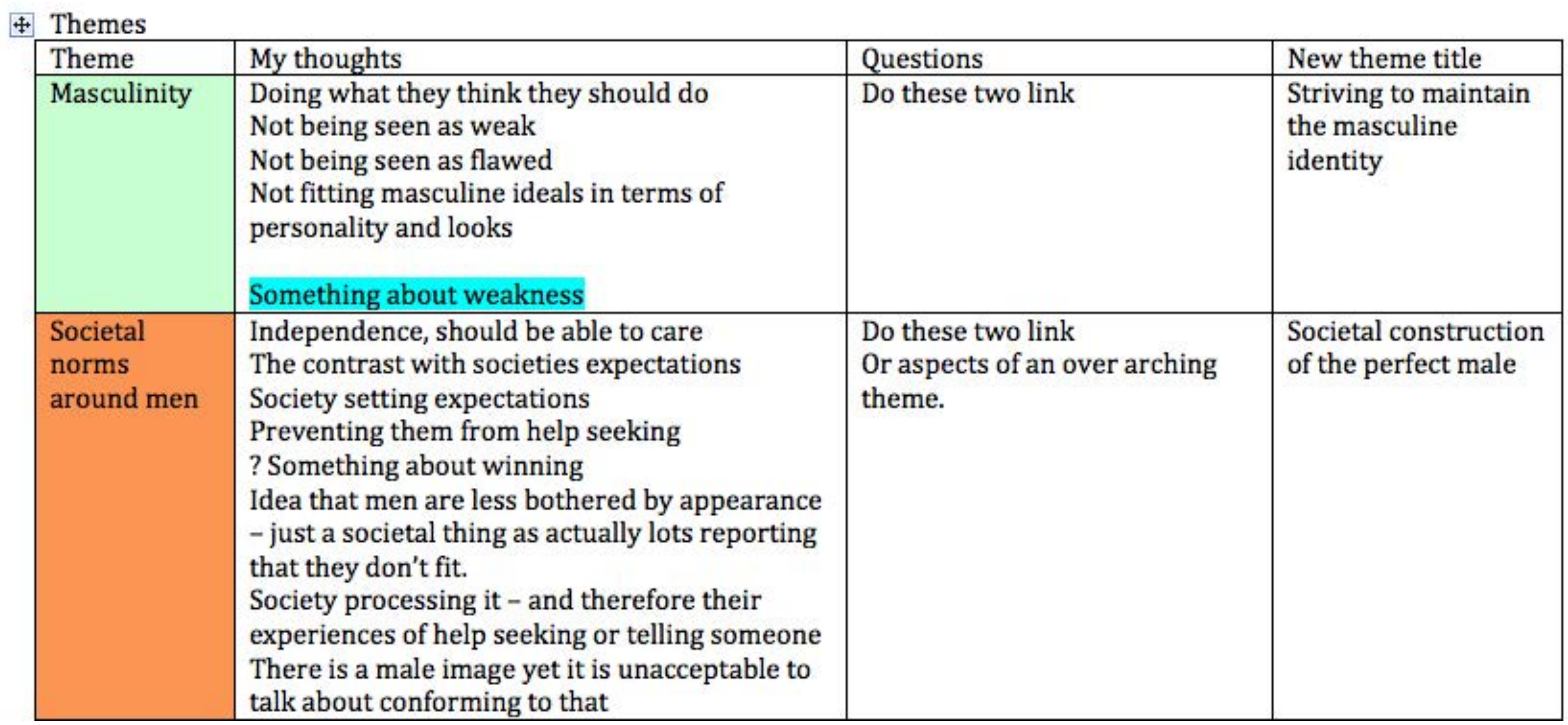


	A	B	C	D	E	F	G	H	I
1							Masculinity		
2	Oickle	": "Well, the disclosure, the shame ofhaving a problem . Every... guys want to say, "Oh, I've got my life under control. I, you know, I do everything on my own. I'm independent",	"I'm rather hesitant about.... seeking medical attention. Just cause usually I think, like, I can take care ofthis myself. I will deal with it. . Unless I'm virtually dying, like on my death bed sort of thing......."	"I feel weak when I do it....And for me to admit that, I do it... Um... the whole concept ofjust being weak, and that just feeds off itself."					
3	Drummond	*As a bloke, I didn't like seeing a 'shrink' because it made me feel weak.*							
4	Drummond	I get worried that they might now see me as less of a man. Flawed. Not as strong.	I don't fit the cultural model of masculinity because I'm not very muscular.	My ideal body for a masculine guy is a white T-shirt that fits and a pair of blue jeans that fit.	Author: their masculinity is flawed				
5	Robinson	- I don't want to be seen as a weak person / it's a symptom of not being able to cope,							
6	Bjork	To accept who you are,							
						Author / quotes :being perceived as a *'strong'* man consistently earning a wage. Therefore,	*but it conflicts the*		



	A	B	C	D	E	F	G	H
1					Societal norms around men			
2	Oickle	Author: the men identified was the need to maintain the "strong man" image - that nothing can hurt men, that they are not emotional, and that they can handle all problems without help.	Participants expressed feeling the need to live up to an unbreakable image for men set by society.	"And I have these obligations to them and if I show that I'm weak, then I'm.. not going to be able to.. I'll get weak. I'll be seen as somebody who is weak. And I won't be able to hold my role in society."	Athour: The "strong man" image was expressed as one ofthe reasons men may not seek treatment or information to help them deal with their eating disorder.	Author: Some ofthe issues that are associated with anorexia and bulimia may also contribute to men's hesitation to admit there is a problem and seek help. For example, admitting to low self esteem and distorted body image goes against the expectations ofwhat men are supposed to feel and think about.	Author: part of the reason why males with anorexia and bulimia do not know about or do not seek treatment and information resources Is because they do not recognize that they are having eating problems.	"It's because we're brought up with the whole "macho" image. For men,it's strong. It doesn't really reveal anything. It just kind of gets handed down."
3	Drummond 02	Author: boys learn that competition is healthy and that competition "builds character" and ultimately "better men"	Author: winning becomes an important aspect of the male culture.	Author: the eating disorder has become a part of their manhood because it is something in which they have gained success and which provided assistance in developing a sense of masculine identity	I don't fit the cultural model of masculinity because I'm not very muscular.	Author: the impact of gender construction on issues surrounding eating disorders.	People only go for muscles.	if you don't, you're not in the "in" crowd, or you're not as good as them. It's a masculine image, which is impossible for some of us to have.
4	Ashuk	Author: the media continues to overemphasize the popular ideals of physical strength, force, aggressiveness, competitiveness and independence in males.	""I have many triggers from health magazines. They are, and continue to be, the most disturbing thing in the world to me."					
		Author: less affected by the media portrayal						

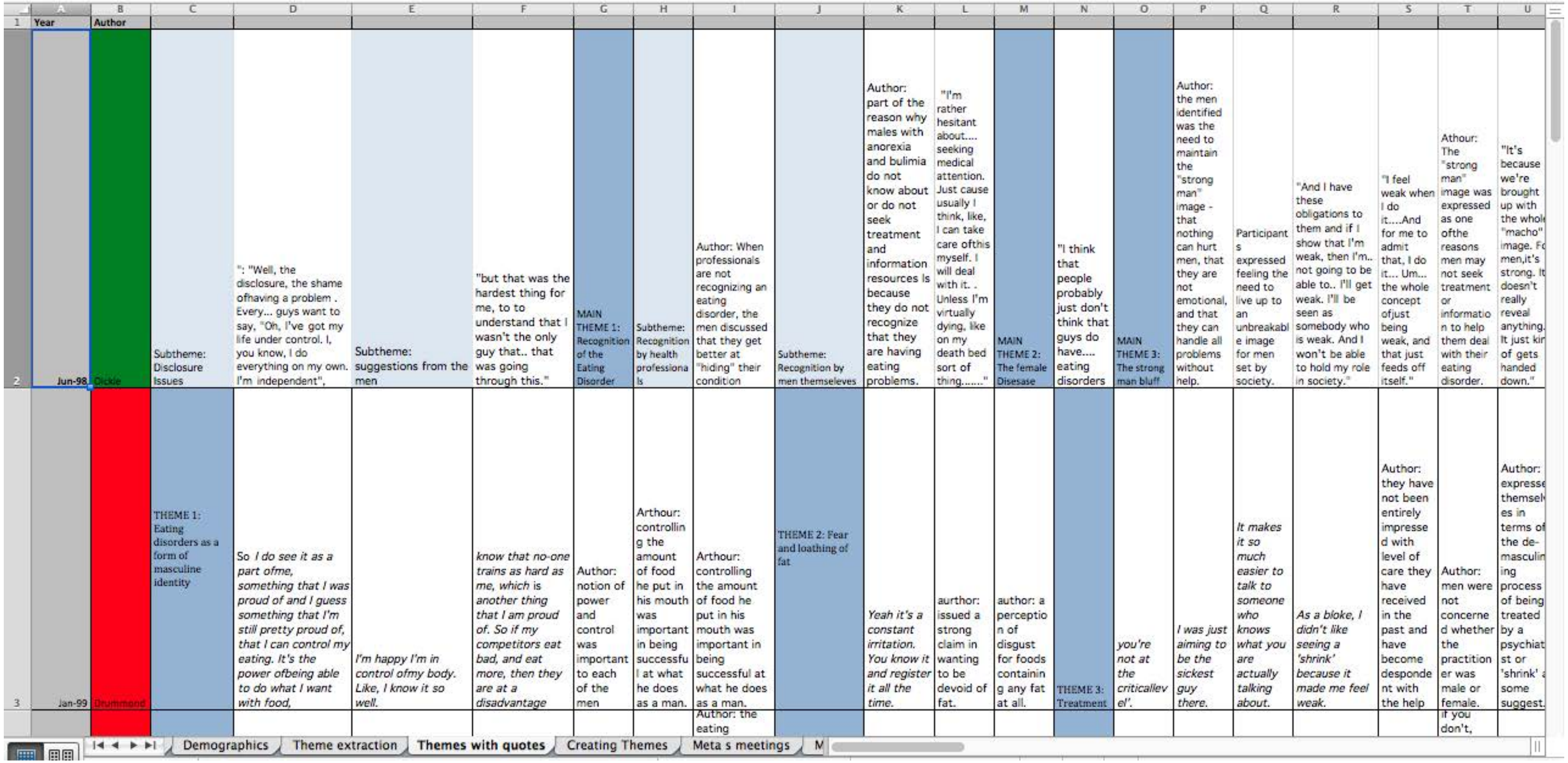
Appendix H: Phase 6 of Meta-Ethnography (Noblit & Hare, 1988) – Synthesising translations



Themes

Theme	My thoughts	Questions	New theme title
Masculinity	Doing what they think they should do Not being seen as weak Not being seen as flawed Not fitting masculine ideals in terms of personality and looks Something about weakness	Do these two link	Striving to maintain the masculine identity
Societal norms around men	Independence, should be able to care The contrast with societies expectations Society setting expectations Preventing them from help seeking ? Something about winning Idea that men are less bothered by appearance – just a societal thing as actually lots reporting that they don't fit. Society processing it – and therefore their experiences of help seeking or telling someone There is a male image yet it is unacceptable to talk about conforming to that	Do these two link Or aspects of an over arching theme.	Societal construction of the perfect male

Appendix I: Spreadsheet with extracted data



	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	Q	R	S	T	U
1	Year	Author																			
2	Jun-98	Dickie	Subtheme: Disclosure Issues	": "Well, the disclosure, the shame ofhaving a problem . Every... guys want to say, "Oh, I've got my life under control. I, you know, I do everything on my own. I'm independent",	Subtheme: suggestions from the men	"but that was the hardest thing for me, to to understand that I wasn't the only guy that.. that was going through this."	MAIN THEME 1: Recognition of the Eating Disorder	Subtheme: Recognition by health professionals	Author: When professionals are not recognizing an eating disorder, the men discussed that they get better at "hiding" their condition	Subtheme: Recognition by men themseleves	Author: part of the reason why males with anorexia and bulimia do not know about or do not seek treatment and information resources Is because they do not recognize that they are having eating problems.	"I'm rather hesitant about.... seeking medical attention. Just cause usually I think, like, I can take care ofthis myself. I will deal with it. . Unless I'm virtually dying, like on my death bed sort of thing......"	MAIN THEME 2: The female Disesase	"I think that people probably just don't think that guys do have.... eating disorders	MAIN THEME 3: The strong man bluff	Author: the men identified was the need to maintain the "strong man" image - that nothing can hurt men, that they are not emotional, and that they can handle all problems without help.	Participants expressed feeling the need to live up to an unbreakable image for men set by society.	"And I have these obligations to them and if I show that I'm weak, then I'm.. not going to be able to.. I'll get weak. I'll be seen as somebody who is weak. And I won't be able to hold my role in society."	"I feel weak when I do it....And for me to admit that, I do it... Um... the whole concept ofjust being weak, and that just feeds off itself."	Athour: The "strong man" image was expressed as one ofthe reasons men may not seek treatment or information to help them deal with their eating disorder.	"It's because we're brought up with the whol "macho" image. Fo men,it's strong. It doesn't really reveal anything. It just kir of gets handed down."
3	Jan-99	Drummond	THEME 1: Eating disorders as a form of masculine identity	So *I do see it as a part ofme, something that I was proud of and I guess something that I'm still pretty proud of, that I can control my eating. It's the power ofbeing able to do what I want with food,*	*I'm happy I'm in control ofmy body. Like, I know it so well.*	*know that no-one trains as hard as me, which is another thing that I am proud of. So if my competitors eat bad, and eat more, then they are at a disadvantage*	Author: notion of power and control was important to each of the men	Arthour: controlling the amount of food he put in his mouth was important in being successful at what he does as a man.	Arthour: controlling the amount of food he put in his mouth was important in being successful at what he does as a man.	THEME 2: Fear and loathing of fat	*Yeah it's a constant irritation. You know it and register it all the time.*	aurthor: issued a strong claim in wanting to be devoid of fat.	author: a perception of disgust for foods containing any fat at all.	THEME 3: Treatment	*you're not at the criticallevel'.*	*I was just aiming to be the sickest guy there.*	*It makes it so much easier to talk to someone who knows what you are actually talking about.*	*As a bloke, I didn't like seeing a 'shrink' because it made me feel weak.*	Author: they have not been entirely impressed with level of care they have received in the past and have become despondent with the help	Author: men were not concerned whether the practitioner was male or female.	Author: expresse themsel es in terms of the de-masculin ing process of being treated by a psychiat st or 'shrink' a some suggest.
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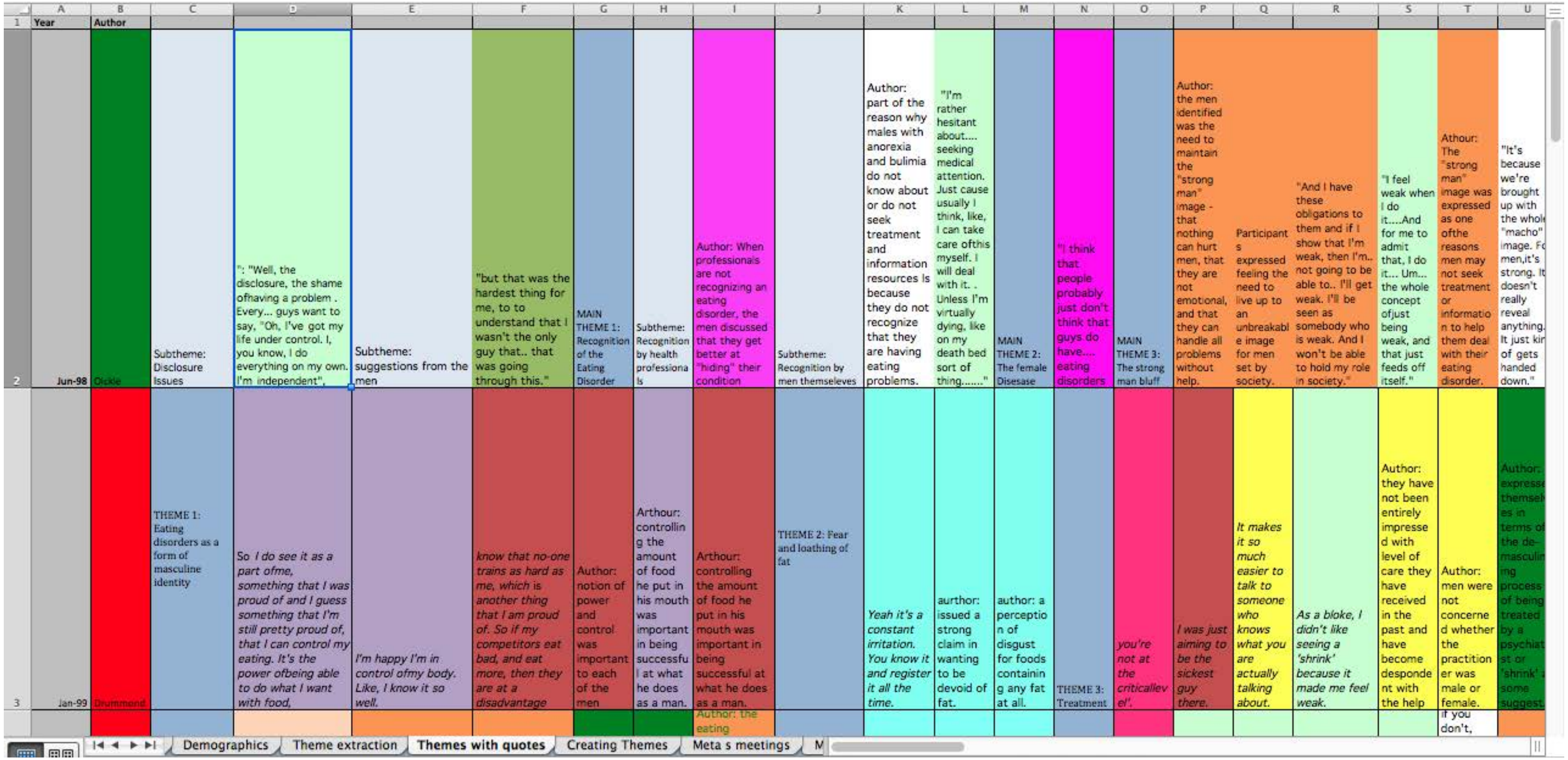
Appendix J: Exploring the interconnectedness of the studies



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1	Year	Author																			
2	Jun-98	Oickle	Subtheme: Disclosure Issues	": "Well, the disclosure, the shame ofhaving a problem . Every... guys want to say, "Oh, I've got my life under control. I, you know, I do everything on my own. I'm independent",	Subtheme: suggestions from the men	"but that was the hardest thing for me, to to understand that I wasn't the only guy that.. that was going through this."	MAIN THEME 1: Recognition of the Eating Disorder	Subtheme: Recognition by health professionals	Author: When professionals are not recognizing an eating disorder, the men discussed that they get better at "hiding" their condition	Subtheme: Recognition by men themseleves	Author: part of the reason why males with anorexia and bulimia do not know about or do not seek treatment and information resources Is because they do not recognize that they are having eating problems.	"I'm rather hesitant about.... seeking medical attention. Just cause usually I think, like, I can take care ofthis myself. I will deal with it. . Unless I'm virtually dying, like on my death bed sort of thing......"	MAIN THEME 2: The female Disesase	"I think that people probably just don't think that guys do have.... eating disorders	MAIN THEME 3: The strong man bluff	Author: the men identified was the need to maintain the "strong man" image - that nothing can hurt men, that they are not emotional, and that they can handle all problems without help.	Participants expressed feeling the need to live up to an unbreakable image for men set by society.	"And I have these obligations to them and if I show that I'm weak, then I'm.. not going to be able to.. I'll get weak. I'll be seen as somebody who is weak. And I won't be able to hold my role in society."	"I feel weak when I do it....And for me to admit that, I do it... Um... the whole concept ofjust being weak, and that just feeds off itself."	Athour: The "strong man" image was expressed as one ofthe reasons men may not seek treatment or information to help them deal with their eating disorder.	"It's because we're brought up with the whol "macho" image. F men,it's strong. It doesn't really reveal anything. It just ki of gets handed down."
3	Jan-99	Drummond	THEME 1: Eating disorders as a form of masculine identity	So *I do see it as a part ofme, something that I was proud of and I guess something that I'm still pretty proud of, that I can control my eating. It's the power ofbeing able to do what I want with food,*	*I'm happy I'm in control ofmy body. Like, I know it so well.*	*know that no-one trains as hard as me, which is another thing that I am proud of. So if my competitors eat bad, and eat more, then they are at a disadvantage*	Author: notion of power and control was important to each of the men	Arthour: controlling the amount of food he put in his mouth was important in being successful at what he does as a man.	Arthour: controlling the amount of food he put in his mouth was important in being successful at what he does as a man.	THEME 2: Fear and loathing of fat	*Yeah it's a constant irritation. You know it and register it all the time.*	aurthor: issued a strong claim in wanting to be devoid of fat.	author: a perception of disgust for foods containing any fat at all.	THEME 3: Treatment	*you're not at the criticallevel'.*	*I was just aiming to be the sickest guy there.*	*It makes it so much easier to talk to someone who knows what you are actually talking about.*	*As a bloke, I didn't like seeing a 'shrink' because it made me feel weak.*	Author: they have not been entirely impressed with level of care they have received in the past and have become despondent with the help	Author: men were not concerned whether the practitioner was male or female.	Author: expresse themsel es in terms o the de-masculin ing process of being treated by a psychiat st or 'shrink' some suggest.
									Author: the eating											if you don't,	

Appendix K: Health Research Authority Approval

Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Miss Emily Coopey
Trainee Clinical Psychologist
Birmingham and Solihull Mental Health Trust
52 Pritchatts Road
Birmingham
England
B15 2TT

Email: hra.approval@nhs.net
Research-permissions@wales.nhs.uk

12 June 2019

Dear Miss Coopey

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title: **Exploring the Experience of Young People Receiving Treatment for an Eating Disorder: Family Therapy for Anorexia Nervosa and Multi Family Therapy in an Inpatient Setting.**
IRAS project ID: **257778**
Protocol number: **RG_18-260**
REC reference: **19/WM/0112**
Sponsor **University of Birmingham**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **257778**. Please quote this on all correspondence.

Yours sincerely,
Rekha Keshvara

Approvals Manager

Email: hra.approval@nhs.net

Copy to: *Dr Birgit Whitman*

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	*Version*	*Date*
Costing template (commercial projects) [Signed Insurance Letter]	V1.0	04 March 2019
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Public and Product]		16 July 2018
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Generic]		03 July 2018
GP/consultant information sheets or letters [GP letter]	V1.0	26 April 2019
HRA Schedule of Events	2	29 April 2019
HRA Statement of Activities	2	29 April 2019
Interview schedules or topic guides for participants [Interview Topic Guide]	v1.0	05 February 2019
Interview schedules or topic guides for participants [Semi Structured interview guide]	v1.1	06 May 2019
IRAS Application Form [IRAS_Form_13032019]		13 March 2019
IRAS Checklist XML [Checklist_15052019]		15 May 2019
IRAS Checklist XML [Checklist_20052019]		20 May 2019
IRAS Checklist XML [Checklist_07062019]		07 June 2019
Letter from sponsor [Signed Sponsor Letter]	V1.0	04 March 2019
Other [Consent for Researcher Contact]	v1.0	24 January 2019
Other [CI Agreement Form]	v1.0	08 January 2019
Other [Additional data protection information]	v1.2	06 May 2019
Other [Debrief sheet]	v1.0	26 April 2019
Other [REC response table]	V1.0	08 May 2019
Participant consent form [Participant Consent Form_O16]	v1.6	26 February 2019
Participant consent form [Participant Assent Form]	v1.6	26 April 2019
Participant consent form [Carer Consent Form]	v1.7	26 April 2019
Participant information sheet (PIS) [Participant Information Sheet_10-12]	v1.0	26 April 2019
Participant information sheet (PIS) [Participant Information Sheet_13-15]	v1.1	06 May 2019
Participant information sheet (PIS) [Carer Information Sheet]	v1.7	26 April 2019
Participant information sheet (PIS)		
Participant information sheet (PIS) [Participant Information sheet_o16]	1.9	05 June 2019
Research protocol or project proposal [Research Protocol]	1.8	08 May 2019
Summary CV for Chief Investigator (CI) [CI CV]	v1.0	02 November 2018
Summary CV for student [Research CV_Emily Coopey]	v2.0	02 November 2018
Summary CV for supervisor (student research) [Research CV_George Johnson]	v2.0	01 December 2018

Information to support study set up

The below provides all parties with information to support the arranging and confirming of capacity and capability with participating NHS organisations in England and Wales. This is intended to be an accurate reflection of the study at the time of issue of this letter.

Types of participating NHS organisation	Expectations related to confirmation of capacity and capability	Agreement to be used	Funding arrangements	Oversight expectations	HR Good Practice Resource Pack expectations
There is only one NHS organisation taking part in the study, there is therefore one type of participating organisation undertaking the research activity as detailed in the study protocol.	Research activities should not commence at participating NHS organisations in England or Wales prior to their formal confirmation of capacity and capability to deliver the study.	A statement of activities has been submitted and the sponsor is not requesting and does not expect any other site agreement to be used.	No application for external funding has been made	A Local Collaborator is expected to be in place at the participating NHS site.	Use of identifiable patient records held by an NHS organisation to identify potential participants should be undertaken by a member of the direct care team for the patient, so it would not normally be acceptable for this to be done by staff not employed by that organisation. A Letter of Access (or equivalent) would be expected for any external NHS/research staff undertaking all of the other activities for the study once consent from the participant is in place. The pre-engagement checks should include a standard DBS check and Occupational Health Clearance.

Other information to aid study set-up and delivery

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales in study set-up.
☐ The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

Appendix L: Participant Information Sheet ages 10-12

Information Sheet for participants aged 10-12

Study title: Exploring the Experience of Young People Receiving Treatment for an Eating Disorder: Family Therapy for Anorexia Nervosa and Multi-Family Therapy in an Inpatient Setting.

Why have I been asked to do this research study?

You have been asked to talk to us because we want to know more about how you feel about being in hospital.

What do I have to do?

We would like you to do an **interview.** An interview is talking about something with another person.

Why do you want me to an interview?

We would like to know what it is like for you being in hospital. This interview will let you explain what it was like. You can say *whatever you like* – we want to hear about the *good and the bad* things about being in hospital.

What you tell us will help us find the best way of helping children and young people who have an eating disorder

What happens in the study?

We want to talk with you about being in hospital. This talking is called an "interview". The interview will be all about what your time in hospital. How long it takes depends on how much you say!

We will record the interview so that we can listen to it listen and think carefully about everything you said.
We will give you a £10 voucher to say thank you for your time. We will give this to your parents to look after for you.

Who is taking part?
We are asking 6-10 children and teenagers who have been in hospital.

Do we have to take part?
No, it is up to you and your family!
You can decide to leave the study at any point and *you do not have to tell us why*. You will not be treated any differently by any hospital or doctor if you decide you want to leave the study.

Who will know I am taking part in this study?
No one else will know about you taking part in this study. We won't tell anyone anything about you, unless we think that you or someone else is at risk of being hurt.

We will write some reports about these interviews, so that other people can learn from everything people tell us. We might use some of your words in these reports, but **no one** will be able to tell it was *you* who said those words.

Who is running this study?
The study is a project run by the University of Birmingham.

The interview will be with a member of the study team.

Has this research study been checked by an ethics committee?
Yes, this study has been checked by lots of people. The group of people who checked this study is called an "ethics committee". The West Midlands - Solihull Research Ethics Committee checked this study and they are happy for the study to take place.

I have some questions about this study, who do I contact?
You can speak to the person who told you about this study. You can also contact Emily Coopey [redacted] or George Johnson [redacted] at the University of Birmingham.

***REMEMBER*:**
You don't have to take part in this study

You can leave the study any time you like, up until the researcher starts to think carefully about your interview.

Thank you very much for reading this information sheet!

Appendix M: Participant Information Sheet ages 13-15

Information Sheet for participants aged 13-15

Project title: Exploring the Experience of Young People Receiving Treatment for an Eating Disorder: Family Therapy for Anorexia Nervosa and Multi-Family Therapy in an Inpatient Setting.

You are invited to take part in a research project at the Irwin Unit. We are inviting young people with an experience of an Eating Disorder, who are at the Irwin Unit to take part.

Why are we doing this research?
There is not much research about young people's experiences of Family Therapy for Anorexia Nervosa and Multi-Family Therapy, especially in an inpatient setting so we would like to learn more about your experience.
Understanding young people's experiences of treatment can help clinicians and researchers to have a better understanding of how the treatment does and doesn't work.

What is the study about?

We are interested in understanding your experience of your inpatient stay. We would like to explore your experience of your treatment whilst in hospital.

Do I have to take part?

It is completely up to you whether or not to take part.
If you do not take part, it won't affect your time in hospital at all.
You can also change your mind and leave the research. If you leave the study, we will keep the information about you that we have already obtained. Leaving from the study will not affect your treatment.

What do I have to do?

We would like you to complete one interview with a member of the research team. This will last anywhere from 45 minutes to 90 minutes. The interview will be completed with just you and the Chief Investigator so it will be confidential. If the interviewer is worried about your safety, they will talk to you about sharing this with your clinical team to help you. The interview will be audio recorded on a Dictaphone but will be deleted as soon as it is typed up.

Extracts of your data may be used in the form of quotes, but **no one** will be able to tell it was *you* who said those words.

What happens next?

Now you have this sheet, you will be given time to decide whether or not to take part. If you do decide to take part then you can complete a consent to contact form and the Chief investigator will contact you. This will be an opportunity to explain the study and answer any questions you have.

If you then decide you want to take part, you and your parent/carer will be asked to sign a form with a researcher.

Is there anything to be worried about if I take part?
You will need to give some of your time to complete the interview. We do not expect the questions to be upsetting, but if you become upset or worried at any point during the research please speak to the researcher or your clinical team. Taking part is up to you and you do not have to answer any questions you don't want to.

What are the possible benefits of taking part?
The information we get from this study will help us to improve our understanding of treatments for others in the future. You will receive a £10 voucher to reimburse you for your time spent completing the interview. This is our way of saying thank you for taking the time to help us out with the research. We will give the voucher to your parents to look after for you.

What will happen if I don't want to carry on with the study?
You are free to leave at any time, without giving a reason. This will not affect your treatment in any way.

Will anyone else know I'm doing this?
Only researchers on the study and your clinical team will know you are taking part. We will not share any information that can identify who you are, so no one will be able to know that you were involved or find out anything about you.
The only time a researcher would need to share information would be if they are worried that you or someone else is at risk of being hurt. In this case they will need to tell someone like your therapist. This is very rare and we would normally talk to you about this first.

Who has reviewed the study?
The research is being undertaken as part of the Chief Investigator's clinical doctorate in psychology and is sponsored by the University of Birmingham.
This research has been reviewed by West Midlands – Solihull Research Ethics Committee, a Research Ethics Committee, who make sure that the research is fair.

Further information and contact details

For further information, or if you have any questions, please contact Emily Coopey (Chief Investigator) by email. You can also talk to the care team looking after you who can contact Emily for you. Emily will be happy to speak to you and explain more about the research.

Email address: [redacted]

Thank you for taking the time to read this. Please ask any questions you may have.

Appendix N: Participant Information Sheet ages 16+

Information Sheet for Participants aged 16+

Project title: Exploring the Experience of Young People Receiving Treatment for an Eating Disorder: Family Therapy for Anorexia Nervosa and Multi-Family Therapy in an Inpatient Setting.

You have been invited to take part in a research project at the [hospital name]. The research is being undertaken as part of the Chief Investigator’s clinical doctorate in psychology and is sponsored by the University of Birmingham. We are inviting young people with an experience of an Eating Disorder, who are residing at the [hospital name] to take part in the research.

Why are we doing this research?

There is not much research about young people’s experiences of Family Therapy for Anorexia Nervosa and Multi-Family Therapy, especially in an inpatient setting so we would like to learn more about your experience of these two treatments whilst in an inpatient setting. Understanding young people’s experiences of treatment can help clinicians and researchers to have a better understanding of the treatment and therefore how it works.

What is the study about?

We are interested in understanding your experience of your inpatient stay. We would like to explore your experience of the treatment you have received and think about how this has impacted on you.

Do I have to take part?

It is up to you as to whether or not to take part. Taking part will not affect your treatment in any way. You can also change your mind and withdraw from the research. If you withdraw from the study, we will keep the information about you that we have already obtained. Withdrawing from the study will not affect your treatment.

What the research involves

We are asking you to complete one interview with a member of the research team. This will last anywhere from 45 minutes to 90 minutes. The interview will be completed with just you and the Chief Investigator so it will be confidential. If the Chief Investigator is worried about your safety, they will talk to you about sharing this with your clinical team to help you. The interview will be audio recorded on a Dictaphone but will be deleted as soon as it is transcribed. A university approved transcribing service will transcribe your interview. Extracts of your data may be used in the form of quotes, but these will be anonymised so that you cannot be identified.

Who has reviewed the study?

This research has received a favourable opinion from West Midlands – Solihull Research Ethics Committee.

What happens next?

Now you have this sheet, you will be given time to decide whether or not to take part. If you do decide to take part then you can complete a consent to contact form and the Chief investigator will contact you. This will be an opportunity to explain the study and answer any questions you have.

If you then decide you want to take part, you will be asked to sign a form with a researcher.

What are the possible disadvantages of taking part?

You will need to give some of your own time to complete the interview. We do not expect the questions to be upsetting, but if you do become upset or worried at any point during the research, please speak to the researcher or your clinical team. Taking part is optional and you do not have to answer any questions you don't want to.

What are the possible benefits of taking part?

Taking part in the study will not benefit you directly, but the information we get from this study will help us to improve our understanding of treatments for others in the future. You will receive a £10 voucher to reimburse you for your time spent completing the interview. This is our way of saying thank you for taking the time to help us out with the research. If you are under 18 we will give the voucher to your parents to look after for you.

What will happen if I don't want to carry on with the study?

You are free to stop at any time, without giving a reason. This will not affect your treatment.

Will my taking part in this study be kept confidential?

All your information will be stored securely and anonymously so that you cannot be identified personally. All identifiable personal information such as names and addresses will be stored securely and separately and will only be accessible to authorised researchers.

All identifiable personal information will be destroyed securely on the completion of the study, which includes publication of reports and papers. [NHS Trust Name] will store consent forms securely for ten years in order to comply with data management guidance. Anonymised research data from which you cannot be identified will be kept securely by the University of Birmingham for ten years in order to comply with data management guidance. After this time it will be disposed of securely.

On rare occasions the researcher may need to pass on confidential information if they are concerned that there is a serious risk of harm to participants or others. In this case it is standard practice for the researcher to speak to a relevant healthcare professional, in order to keep participants safe. Situations where this might be necessary include participants reporting plans to harm themselves or others, and are very rare

What will happen to the results of the research study?

The results of the study are intended to be published in a scientific journal, and as part of the Chief Investigator's PhD Thesis. You will also be asked if you want to hear about the results of the study. You will not be personally identified in any report or publication.

What if there is a problem?
If you have a concern or complaint about any aspect of this study, please speak to the researcher who will do their best to answer your questions. If you remain unhappy and wish to complain formally you can contact the NHS Trust's Patient Advice and Liaison Service (PALS). You can contact PALS on [redacted] [redacted]. You can also contact PALS via email on [NHS Trust Name].pals@nhs.net.

How will my data be looked after?
The University of Birmingham is the sponsor for this study based in the United Kingdom. We will be using information from you and your medical record in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Birmingham will keep identifiable information about you for 10 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally identifiable information possible.

Please see Data Protection Additional Information sheet for further information.

You can find out more about how we use your information by contacting Emily Coopey [redacted] or George Johnson [redacted].

Further information and contact details

For further information, or if you have any questions, please contact Emily Coopey (Chief Investigator) by email. You can also talk to the care team looking after you who can pass on your details for Emily to contact you. Emily will be happy to speak to you and explain more about the research.

Email address: [redacted]

Thank you for taking the time to read this.

Please ask any questions you may have.

Appendix O: Data Protection Additional Information Sheet

Data Protection Additional Information Sheet

Project title: Exploring the Experience of Young People Receiving Treatment for an Eating Disorder: Family Therapy for Anorexia Nervosa and Multi-Family Therapy in an Inpatient Setting.

In order to carry out the research project described on the Participant or Parent / Carer information sheet, we will need to collect information about you / your young person, and some of this information will be your / your young person's personal data. Under data protection law, we have to provide you with very specific information about what we do with your / your young person's data and about your / your young person's rights. We have set out below the key information you need to know about how we will use your / your young person's personal data.

More information on how the University processes personal data can be found on the University's website on the page called 'Data Protection - How the University Uses Your Data' https://www.birmingham.ac.uk/privacy/index.aspx

Who is the Data Controller?

The University of Birmingham, Edgbaston, Birmingham, B15 2TT re the data controllers for the personal data that we process in relation to you.

What data are we processing and for what purpose will we use it?

We will collect and process your personal data to conduct the research project, as explained in the Participant or Parent/ Carer Information Sheet.

What is our legal basis for processing your data?

The legal justification we have under data protection law for processing your personal data is in the public interest. These data will not be used to make decisions about you.

Who will my personal data be shared with?

For the purposes of the research project, we may need to share your personal data with a transcribing service so that they can transcribe the audio recordings. They will not have access to any additional personal identifiable information however, an audio recording is deemed as personally identifiable data. We have appropriate agreements in place with them to protect and safeguard your data.

Sometimes, external organisations assist us with processing your information, for example, in providing IT support. These organisations act on our behalf in accordance with our instructions and do not process your data for any purpose over and above what we have asked them to do. We make sure we have appropriate contracts in place with them to protect and safeguard your data. If your personal data are transferred outside the European Union (for example, if one of our partners is based outside the EU or we use a cloud-based app with servers based outside the EU), we make sure that appropriate safeguards are in place to ensure the confidentiality and security of your personal data.

How will my personal data be kept secure?

The University and [NHS Trust Name] takes great care to ensure that personal data is handled, stored and disposed of confidentially and securely. Staff receive regular data protection training, and organisational and technical measures are in place so that personal data is processed in accordance with the data protection principles set out in data protection law.

The University has an Information Security Management System based on ISO27001 with a range of controls covering the protection of personal information. Annual security awareness training is mandatory for staff and the University is accredited under the NHS Information Governance Toolkit, the Payment Card Industry Data Security Standard and is in the process of gaining Cyber Essentials Plus for defined services.

In relation to this project, hard copies of consent forms will remain on site at the [hospital name] and then be transferred to [NHS Trust Name] Research department on completion of the study in line with trust policies and procedures regarding information governance and safe storage and disposal of personally identifiable information.

There will be an electronic database to store personal data and create unique identifier codes. This will be stored on an NHS computer system.

No personally identifiable information will be published, as any extracts used in the write up will have pseudonyms to maintain confidentiality.

Electronic research data will be sorted using unique identifier codes on a secure password protected University of Birmingham computer system in the long term. The research supervisor will retain this for a period of approximately ten years.

All other personal identifiable information will be securely deleted once the research is completed, including publication of reports and papers.

Access to personally identifiable information will be restricted to that of the Chief Investigator, Emily Coopey, and Research Supervisor, George Johnson.

How long will my personal data be kept?

Your data will be retained for 10 years after the publication of the research outcomes.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the project, we will keep the information we have already obtained but, to safeguard your rights, we will use the minimum personally identifiable information possible.

If you would like more information on your rights, would like to exercise any right or have any queries relating to our processing of your personal data, please contact:

> The Information Compliance Manager, Legal Services, The University of Birmingham, Edgbaston, Birmingham B15 2TT
> Email: dataprotection@contacts.bham.ac.uk Telephone: +44 (0)121 414 3916

If you wish to make a complaint about how your data is being or has been processed, please contact our Data Protection Officer.

> Mrs Carolyn Pike, OBE, The Data Protection Officer, Legal Services, The University of Birmingham, Edgbaston, Birmingham B15 2TT
> Email: dataprotection@contacts.bham.ac.uk Telephone: +44 (0)121 414 3916

You also have a right to complain to the Information Commissioner's Office (ICO) about the way in which we process your personal data. You can make a complaint using the ICO's website.

Appendix P: Carer Information Sheet

Information Sheet for Parents / Carers

Project title: Exploring the Experience of Young People Receiving Treatment for an Eating Disorder: Family Therapy for Anorexia Nervosa and Multi-Family Therapy in an Inpatient Setting.

Your young person has been invited to take part in a research project at the [hospital name]. The research is being undertaken as part of the Chief Investigator's clinical doctorate in psychology and is sponsored by the University of Birmingham. We are inviting young people with an experience of an Eating Disorder, who are residing at the [hospital name] to take part in the research.

Why are we doing this research?
There is not much research about young people's experiences of Family Therapy for Anorexia Nervosa and Multi-Family Therapy, especially in an inpatient setting so we would like to learn more about your young person's experience of these two treatments whilst in an inpatient setting. Understanding young people's experiences of treatment can help clinicians and researchers to have a better understanding of the treatment and therefore how it works.

What is the study about?
We are interested in understanding your young person's experience of their inpatient stay. We would like to explore their experience of the treatment they have received and think about how this has impacted on them.

Do I have to take part?
It is up to your young person as to whether or not to take part. Taking part will not affect their treatment in any way. They can also change their mind and withdraw from the research at any stage. If you withdraw from the study, we will keep the information about you that we have already obtained. Withdrawing from the study will not affect their treatment.

What the research involves
We are asking your young person to complete one interview with a member of the research team. This will last anywhere from 45 minutes to 90 minutes. The interview will be completed with just the young person and the interviewer, the Chief Investigator, so it will be confidential. If the interviewer is worried about their safety, they will talk to them about sharing this with their clinical team to help them. The interview will be audio recorded on a Dictaphone and then uploaded to a University of Birmingham server but will be deleted as soon as it is transcribed. A university approved transcribing service, who will have signed a confidentiality agreement, will transcribe your young person's interview. Extracts of their data may be used in the form of quotes, but these will be anonymised so that they cannot be identified.

Who has reviewed the study?

This research has received a favourable opinion from West Midlands – Solihull Research Ethics Committee, a Research Ethics Committee.

What happens next?

Now you have this sheet, you will be given time to decide whether or not you are happy for your young person to take part. If you and your young person do decide your young person will take part then you can complete a consent to contact form and the Chief investigator will contact you. This will be an opportunity to explain the study and answer any questions you have.

If you and your young person decide they want to take part in the interview and are over 16 they will need to sign a consent from with a researcher. If your young person is under 16 they will need to sign an assent form and their parent or guardian will need to sign a consent form on their behalf.

What are the possible disadvantages of taking part?

Young people will need to give some of their own time to complete the interview. We do not expect the questions to be upsetting, but if they become upset or worried at any point during the research, they are advised to please speak to the researcher or their clinical team. Taking part is optional and your young person does not have to answer any questions they don't want to.

What are the possible benefits of taking part?

Taking part in the study will not benefit you or your young person directly, but the information we get from this study will help us to improve our understanding of treatments for others in the future. Your young person will receive a £10 voucher to reimburse them for their time spent completing the interview. This is our way of saying thank you for taking the time to help us out with the research. If your young person is under 18 years of age then we will give the voucher to you to look after for them.

What will happen if my young person doesn't want to carry on with the study?

Young people are free to stop at any time, without giving a reason. This will not affect their treatment or on-going care.

Will taking part in this study be kept confidential?

All your young person's information will be stored securely and anonymously so that they cannot be identified personally. All identifiable personal information such as names and addresses will be stored securely and separately and will only be accessible to authorised researchers.

All identifiable personal information will be destroyed securely on the completion of the study. Completion of the study is indicated by the publication of reports and papers. [NHS Trust Name] will store consent forms securely for ten years in order to comply with data management guidance. Anonymised research data from which your young person cannot be identified will be kept securely by the University of Birmingham for ten years in order to comply with the Universities Code of Practice. After this time it will be disposed of securely. On rare occasions the researcher may need to pass on confidential information if they are concerned that there is a serious risk of harm to participants or others. In this case it is standard practice for the researcher to speak to a relevant healthcare professional, in order to keep participants safe. Situations where this might be necessary include participants reporting plans to harm themselves or others, and are very rare.

What will happen to the results of the research study?
The results of the study are intended to be published in a scientific journal, and as part of the Chief Investigator's PhD Thesis. You will also be asked if you want to hear about the results of the study. Your young person will not be able to be personally identified in any report or publication.

What if there is a problem?
If you have a concern or complaint about any aspect of this study, please speak to the researcher who will do their best to answer your questions. You can also speak with the research supervisor, George Johnson. If you remain unhappy and wish to complain formally you can contact the NHS Trust's Patient Advice and Liaison Service (PALS). You can contact PALS on [redacted]. You can also contact PALS via email on [NHS Trust Name].pals@nhs.net

How will yours and your young person's data be looked after?
The University of Birmingham is the sponsor for this study based in the United Kingdom. We will be using information from you and your young person and their medical records in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after yours and your young person's information and using it properly. The University of Birmingham will keep identifiable information about you and your young person for 10 years after the study has finished.

Your rights to access, change or move yours or your young person's information are limited, as we need to manage yours and your young person's information in specific ways in order for the research to be reliable and accurate. If your young person withdraws from the study, we will keep the information about you and them that we have already obtained. To safeguard yours and your young person's rights, we will use the minimum personally identifiable information possible.

Please see Data Protection Additional Information sheet for further information

You can find out more about how we use your information by contacting Emily Coopey [redacted] or George Johnson [redacted].

Further information and contact details

For further information, or if you have any questions, please contact Emily Coopey (Chief Investigator) by email. You can also talk to the care team looking after your young person who can pass on your details for Emily to contact you. Emily will be happy to speak to you and explain more about the research.

Email address: [redacted]

Thank you for taking the time to read this.

Please ask any questions you may have.

Appendix Q: Consent to Contact Sheet

CONSENT FOR RESEARCHER CONTACT

The **"**Exploring the Experience of Young People Receiving Treatment for an Eating Disorder: Family Therapy for Anorexia Nervosa and Multi-Family Therapy in an Inpatient Setting" study has been explained to me by the clinical care team and I have been given the Participant or Parent /Carer Information Sheet. I agree to the researcher contacting me to discuss the study in more detail.

Please provide the information below, including your signature and today's date.

Full name: ____

Signature: _____________________________________ Date: ___________________

Participant or Parent / Carer contact details:

How is it best for the researcher to contact you? Please tick all the ones that apply to you.

Method of contact	Y/N	Contact details
On the ward		
Phone		Phone number:
Email		Email address:

This form will be sent to the researcher so that s/he can contact you to arrange to visit you to discuss your possible involvement in the Study. If you decide not to take part in the study, this form will be destroyed and no one else will see it.

Thank you for your interest

Once signed, please send to Emily Coopey as soon as possible:

[redacted]

Appendix R: Assent Form under 16

Participant Assent Form – Ages 10-15

Title of the Project: Exploring the Experience of Young People Receiving Treatment for an Eating Disorder: Family Therapy for Anorexia Nervosa and Multi-Family Therapy in an Inpatient Setting.

Name of Researcher:

Participant Identification Number:

Please circle 'Yes' if you agree:

Has somebody else explained this project to you?	Yes	No
Do you understand what this project is about?	Yes	No
Have you asked all the questions you want?	Yes	No
Have you had your questions answered in a way you understand?	Yes	No
Do you understand it's OK to stop taking part at any time?	Yes	No
Do you understand that we will need to share information if we are worried about your safety?	Yes	No
Do you understand you will be audio recorded?	Yes	No
Are you happy to take part in this study?	Yes	No
Do you want to hear about the results of the research? If you answer yes, we will ask your carer for contact details to write to you once the study is complete.	Yes	No

If any answers are 'no' or you don't want to take part, don't sign your name!

- If you do want to take part, please write your name below

Your name ______________________
Date ______________________

- The researcher who explained this project to you needs to sign too:

Print Name ______________________
Sign ______________________
Date ______________________

Appendix S: Consent Form over 16

Participant Consent Form – Over 16

Title of the Project: Exploring the Experience of Young People Receiving Treatment for an Eating Disorder: Family Therapy for Anorexia Nervosa and Multi-Family Therapy in an Inpatient Setting.

Name of Researcher:

Participant Identification Number:

Instructions: *Please initial each item if you agree, or leave blank if you do not, and then sign below.*

	Initial Here
1. I have read the participant information sheet version number…………………………… dated……………………………………. for the above study. I have had the opportunity to consider the information, ask questions and have these answered satisfactorily.	
2. I understand my participation is voluntary and I can withdraw at up until the analysis of my interview, and that this will not affect my care in any way.	
3. Researchers may access healthcare notes for information directly relevant to this study.	
4. I understand that the research interview will be audio recorded. I agree to take part in a research interview	
5. I understand extracts of my data may be used but will be fully anonymised.	
6. I am not currently involved in any other research / my involvement in other research has been discussed with the researchers.	
7. I agree to take part in this study	
8. I would like hear about any results of the research	
If you answered yes to Question 8 please provide contact details:	

PARTICIPANT SIGNATURE	**SIGNATURE OF RESEARCHER**

Name:
Date:
Signature:

Name of person taking consent:
Date:
Signature:

Appendix T: Carer Consent Form

Parent / Carer Consent Form – for participants under 16

Title of the Project: Exploring the Experience of Young People Receiving Treatment for an Eating Disorder: Family Therapy for Anorexia Nervosa and Multi-Family Therapy in an Inpatient Setting.

Name of Researcher:

Participant Identification Number:

Instructions: *Please initial each item if you agree, or leave blank if you do not, and then sign below.*

	Initial Here
1. I have read the information sheet for the above study. I have had the opportunity to consider the parent / carer information sheet version number date , ask questions and have these answered satisfactorily.	
2. I understand my young person's participation is voluntary and they can withdraw up until the analysis of their interview, and that this will not affect their care in any way.	
3. Researchers may access my young person's healthcare notes for information directly relevant to this study.	
4. I understand extracts of my young person's data may be used but will be fully anonymised.	
5. My young person is not currently involved in any other research / their involvement in other research has been discussed with the researchers.	
6. I agree for my young person to take part in this study	
7. I would like hear about any results of the research	
If you answered yes to Question 7 please provide contact details:	

PARENT/ CARER SIGNATURE	**SIGNATURE OF RESEARCHER**
Name:	Name of person taking consent:
Date:	Date:

Signature:	Signature:
Relationship to young person:	

Appendix U: GP Contact Letter

[day] [month] [year]

Psychology Department
52 Pritchatts Road
University of Birmingham
Birmingham
B15 2SA
Tel: [redacted]
Email: [redacted]

Private and Confidential
Dr ______
Address
Address
Address
Address

Dear Dr __________

[Participant name] D.O.B. [DOB]
[Participant address]

Project title: Exploring the Experience of Young People Receiving Treatment for an Eating Disorder: Family Therapy for Anorexia Nervosa and Multi-Family Therapy in an Inpatient Setting.

I am writing to inform you of the above patient’s participation in a research study. This study is exploring young people’s experiences of inpatient treatment for Eating Disorders. [PP name] has consented to take part in an interview with the chief investigator, lasting anywhere from 45 minutes to 90 minutes. To take part in the study, participants must have capacity to consent. If there is anything that you feel the research team need to be aware of, or if you feel that [pp name] is not suitable for the study, then please do not hesitate to get in contact with myself using the contact details above.

Yours sincerely

Emily Coopey (Chief Investigator)
Trainee Clinical Psychologist
University of Birmingham

Appendix V: Semi Structured Interview Guide

Semi structured interview topic guide

The below is a guide as to the type of questions that will be asked during the interview. However, the interview will be semi-structured, meaning the interviewer may ask additional questions for the participant to elaborate to ensure themes and sub themes are explored during the interview.

Setting up the interview
Introductions – check consent Process – up to 90 minutes, determined by you, say as much or as little as you like Right to withdraw, Distress - breaks at any time, pause, terminate, don't have to answer Confidentiality – harm to self or others need to pass on

Theme	Sub themes	Example questions
- Experiences of treatment	- Overall treatment experiences - Feedback on treatments - Feedback on treatment acceptability	- What has been your overall experience of treatment? - What has been positive about your treatment? - What has been negative about your treatment? - What changes have you noticed during treatment? - What has been your experience of being away from your family? - How does your experience differ to your expectations? - If applicable, does this differ from any other inpatient experience you have had?
- Experience of change	- Perspectives on change - Perceptions of others views on change	- What do you think have been the pivotal / key moments in your treatment?

Theme	Sub themes	Example questions
		- Have there been changes for you as an individual? - Have there been changes for you and your family? - Have there been changes in your relationships? - How do you think being in an inpatient unit has affected changes for you, your family and your relationships? - What do you think others (family / significant others) think of the changes that have happened?

Appendix W: Participant Debrief Sheet

Participant Debrief Sheet

Project title: Exploring the Experience of Young People Receiving Treatment for an Eating Disorder: Family Therapy for Anorexia Nervosa and Multi-Family Therapy in an Inpatient Setting.

Thank you for participating in an interview to help us gain an understanding of what it was like for you whilst in hospital. We hope that you have found it interesting and have not been upset by any of the topics discussed. However, if you have found any part of this experience to be distressing and you wish to speak to one of the researchers, please contact:

Emily Coopey (Chief Researcher)
Tel: [redacted]
Email: [redacted]
Post: Emily Coopey, School of Clinical Psychology, Department of Psychology, 52 Pritchatts Road, University of Birmingham, Edgbaston, Birmingham, B15 2TT

There are also a number of organisations listed below that you can contact for support.

If you need mental health support now:

- **NHS 111** (Phone 111)
- **Samaritans** (Phone 116 123, Email: jo@samaritans.org)
- If you are still accessing mental health services in your local area, you should contact them.
- If you are not currently accessing mental health services, contact your GP.
- **Call 999 if someone is seriously ill or injured, and their life is at risk.**

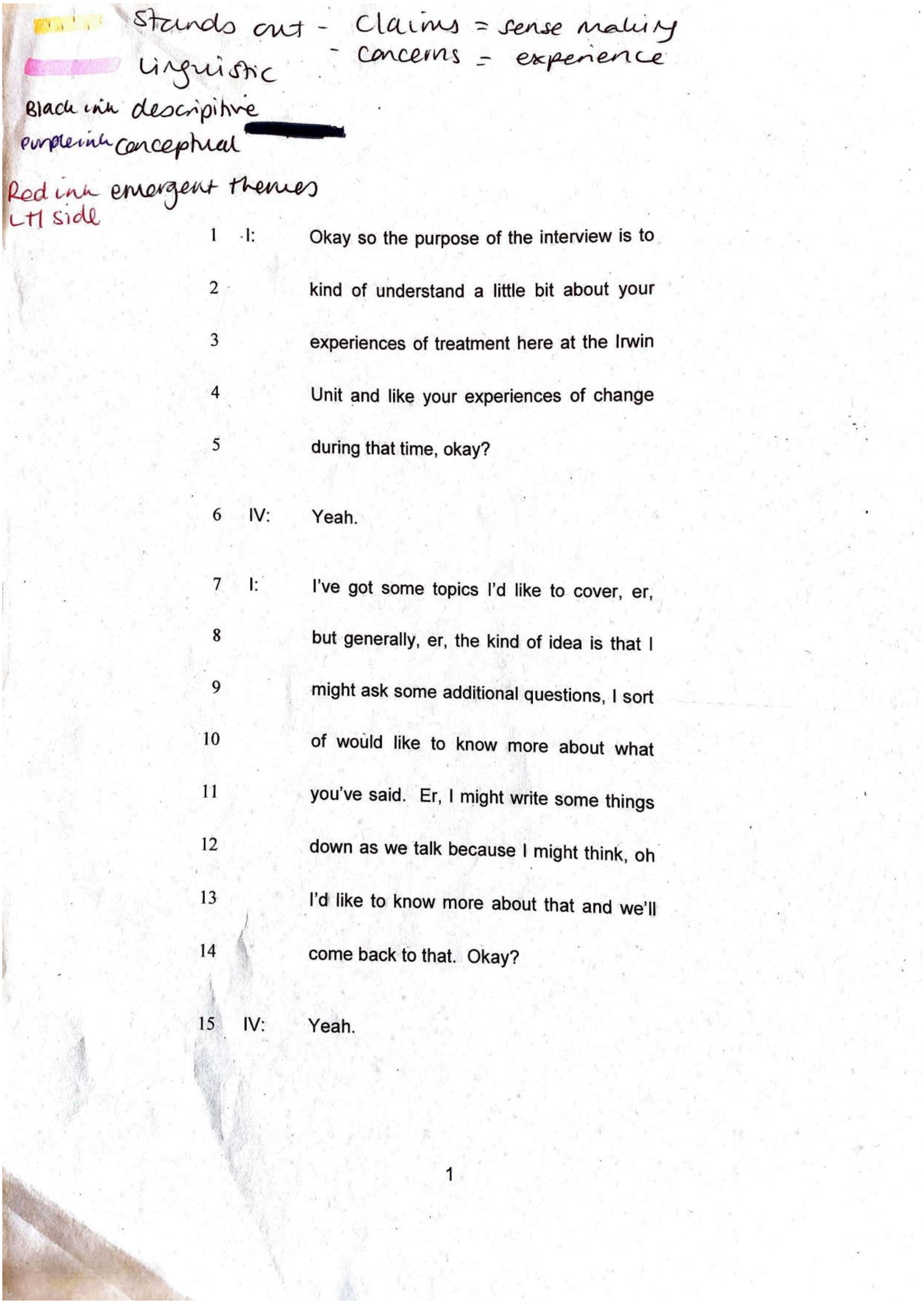
For support and more information on mental health and eating disorders:

- BEAT (https://www.beateatingdisorders.org.uk)
- Mind (https://www.mind.org.uk)
- Young Minds (https://youngminds.org.uk)
- Health for Teens (https://www.healthforteens.co.uk)

If you wish to make a complaint regarding your experience of your treatment you can contact Patient Advice & Liaison Service (PALS) using the below details:

- Telephone: [redacted]
- Email: [NHS Trust Name].pals@nhs.net.

Appendix X: A worked example of IPA steps 2 and 3



🟨 Stands out - Claims = sense making
- Concerns = experience

🟪 Linguistic

Black ink descriptive [redacted]

purple ink conceptual

Red ink emergent themes LH side

I: Okay so the purpose of the interview is to kind of understand a little bit about your experiences of treatment here at the Irwin Unit and like your experiences of change during that time, okay?

IV: Yeah.

I: I've got some topics I'd like to cover, er, but generally, er, the kind of idea is that I might ask some additional questions, I sort of would like to know more about what you've said. Er, I might write some things down as we talk because I might think, oh I'd like to know more about that and we'll come back to that. Okay?

IV: Yeah.

1

[redacted]

I: So do you want to start off by telling me a bit like, kind of your overall experience of treatment here, kind of about the multi family therapy and the family therapy for anorexia nervosa?

IV: Er, so am I telling you about just like how I feel?

I: Yeah what's it like being part of those …

IV: Oh okay, er, the family therapy was quite good because like I got to draw out like different things and listen to all the other parents and what they thought about everything.

- ?dont want to own it
- something about hesitance
- form of expression
- enjoyment | creativity
- evaluating - positive
- shared exp | learning from others
- now way of communicating
- engagement | exp
- value of this - others views
- global
- massive - level of info

Novel learning from others

I: Was that when you did the group sessions?

[redacted]

-checking in

remembers the name

IV: Yeah – yeah like normal multi family therapy [yeah]. And then, er, yeah I thought that was quite good. And, er, we did like got to have like an, like a meal with somebody else's parent, that's one of the things in MFT as well so like we kind of chose, er, we put them like to choose each other, like in different groups. And then, er, yeah we did like a supported meal with someone else's parents but in the same room, so like yeah. And then we did, er, we had to do this like thing about like a big piece of paper you had to put like different, er, things about what it's been like from the start before going in hospital and then in hospital. And kind of at the end like what you think it's going to be like kind of [okay] so yeah. And then, er, in like hospital, er,

> linguistic = ? hesitance

claim

- recall of this

-importance
- ? making sure I understand

importance of this

- power of choice

power of choice

-repeating this
-power of choice

whats that like different to norm

- stands out

difference - change to norm

- element of safety to it

'my experience

- levels of transition

suggestive of change

change of environment

- moving through a process

- mapping the future

- mapping future

power for ind

c hope

? hesitant
difficult to articulate

3

[redacted]

- Importance of experience in hospital

- Sharing difficult emotions

- changing to surroundings

- new normal.

making sense of new experiences

- making new connections

- loosing choice

hard to say - less coherent

? minimising

hospital is upsetting

it's kind of, er, it's kind of like upsetting at first.

names it i can't being asked

suggesting it changes

I: What being in hospital?

- explaining

IV: Yeah because like, er, you're not really used to it or anything. And then, er, then

- different / new experience

unlike anything experienced before.

yea, after a bit it kind of it doesn't get that much easier but it just feels a bit more like

- still hard

change

a feeling you get

small change

- just a bit more like you get used to it more [that makes sense] yeah. And, er,

- adapt to your surroundings

new normal

- ff - ? too much

you had to make friends with all the different people I guess yeah on the ward,

? lack of choice - forced

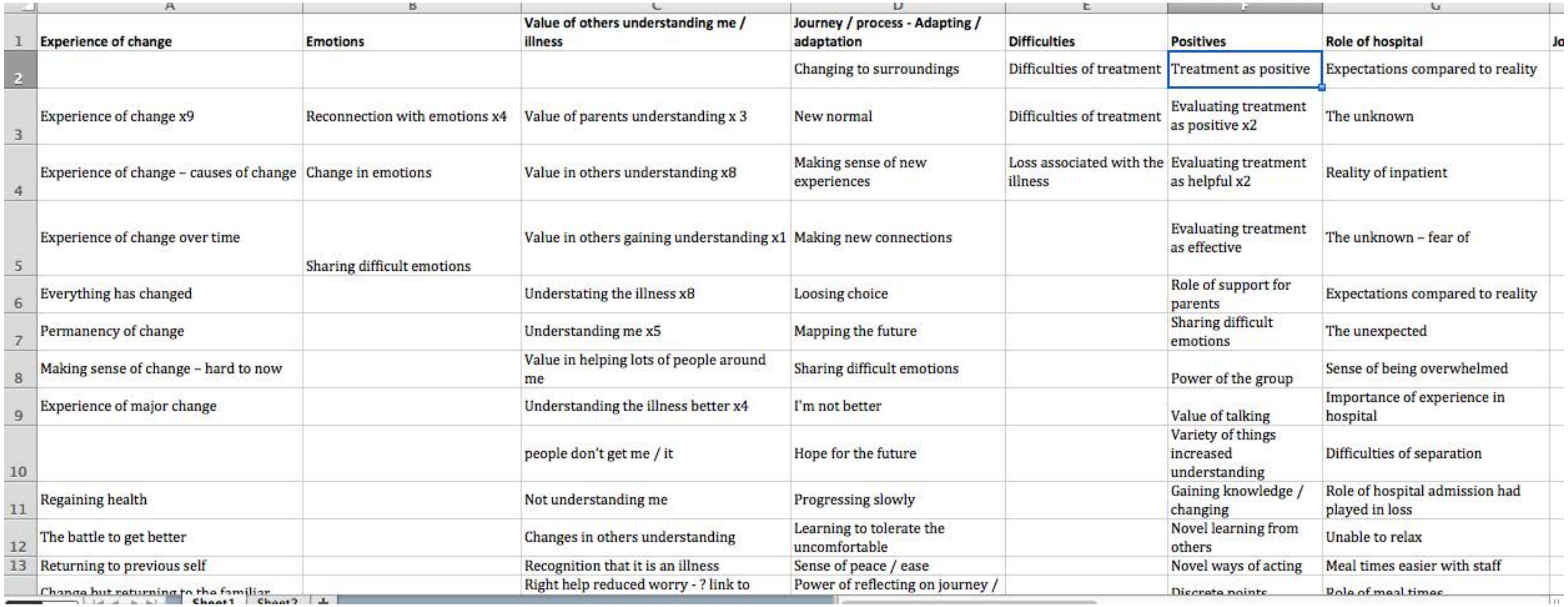
connections - gaining something

new exp - difference - making sense of this new exp

er, and yeah.

I: So thinking about those treatments kind of multi family therapy and the family therapy for anorexia nervosa, er, and when you meet with just kind of the family therapist [3:28]. What's been positive about those

Appendix Y: A worked example of IPA step 4



	A	B	C	D	E	F	G	
1	**Experience of change**	**Emotions**	**Value of others understanding me / illness**	**Journey / process - Adapting / adaptation**	**Difficulties**	**Positives**	**Role of hospital**	**Jo**
2				Changing to surroundings	Difficulties of treatment	Treatment as positive	Expectations compared to reality	
3	Experience of change x9	Reconnection with emotions x4	Value of parents understanding x 3	New normal	Difficulties of treatment	Evaluating treatment as positive x2	The unknown	
4	Experience of change – causes of change	Change in emotions	Value in others understanding x8	Making sense of new experiences	Loss associated with the illness	Evaluating treatment as helpful x2	Reality of inpatient	
5	Experience of change over time	Sharing difficult emotions	Value in others gaining understanding x1	Making new connections		Evaluating treatment as effective	The unknown – fear of	
6	Everything has changed		Understating the illness x8	Loosing choice		Role of support for parents	Expectations compared to reality	
7	Permanency of change		Understanding me x5	Mapping the future		Sharing difficult emotions	The unexpected	
8	Making sense of change – hard to now		Value in helping lots of people around me	Sharing difficult emotions		Power of the group	Sense of being overwhelmed	
9	Experience of major change		Understanding the illness better x4	I'm not better		Value of talking	Importance of experience in hospital	
10			people don't get me / it	Hope for the future		Variety of things increased understanding	Difficulties of separation	
11	Regaining health		Not understanding me	Progressing slowly		Gaining knowledge / changing	Role of hospital admission had played in loss	
12	The battle to get better		Changes in others understanding	Learning to tolerate the uncomfortable		Novel learning from others	Unable to relax	
13	Returning to previous self		Recognition that it is an illness	Sense of peace / ease		Novel ways of acting	Meal times easier with staff	
	Change but returning to the familiar		Right help reduced worry - ? link to	Power of reflecting on journey /		Discrete points	Role of meal times	

	A	B	C	D	E	F	G
1	**Experience of change**	**Quotes**	**Value of others understanding me / illness**	**Quotes**	**Journey / process - Adapting / adaptation**	**Quotes**	**Role of hospital**
2		"er, like more, er... like getting better" L94-95		"my family know how to support be better" L-68-69	Changing to surroundings	"what its been like from the start, beofre going in hpsital and then in hospital" L- 44-46	Expectations compared to reality
3	Experience of change x9	"it just makes it a bit easier" L101	Value of parents understanding x 3	"for like parents to understand and stuff" L70-71	New normal	"At the end like what you think it's going to be like" L -46-47	The unknown
4	Experience of change – causes of change	"it's a bit like upsetting and scray and stuff" L 116-117	Value in others understanding x8	"it helps like with my parents and stuff to undertand and helps me to like try and deal with things a bit better" L 72-75	Making sense of new experiences	"you're not really used to it or anything" "-52-53	Reality of inpatient
5	Experience of change over time	"I've got better with it over, um, like over time I guess" L 117-118	Value in others gaining understanding x1	"my family's got more of understanding of like how it feels" L97-98	Making new connections	"yea, after a but it kind of, it doesn't get that much easier" L54-55	The unknown – fear of
6	Everything has changed	"it's got a bit easier" L 119	Understating the illness x8	"they can help me a bit better" L102-103	Lose of choice / agency	"it just feels... like you get used to it" L-55-57	Expectations compared to reality
				"before it felt like, er		"you had to make	

Participant One

Narrative

What are you taking? What do you know? What are the themes? What have they told you?

[redacted]

Superordinate Theme	Notes / Thoughts
The value in creating understanding **Or** **Valuing understanding**	I feel like these are all linked – like others gain an understanding / knowledge which enables them to understand the illness which means they get the participant. Is it something about understanding me? I think it is that the participant values that others gained an understanding – there is less about what changed for them but more about the others around them

Sub theme	Quotes	Notes / Thoughts
-Development of external understanding	"for like parents to understand and stuff" L70-71 "it helps like with my parents and stuff to understand and helps me to like try and deal with things a bit better" L 72-75	Non blaming Value of parents understanding Value in others gaining understanding Value in others understanding Value in helping lots of people around me

	"they go to MFT and... learn different skills and stuff so then they can" L211-212 "They didn't really understand as much as they do now" L220 -221 "I don't know if they thought it was like a choice or something" L221-223 "she just, er, understands kind of a bit more from going to different groups"L314-316 "it's helped quite a lot of people cause ... having therapy...helps because like, er, talking about like what's, er, been hard... Or...something that's been good... yeah just helped with everything really" L412-421	Changes in others understanding The role of treatments in gaining an understanding Enabled talking Helped a lot of people – they key thing is it helped others Something about the external world gaining an understanding
- Understanding the why	"my family know how to support me better" L-68-69 "She understands a lot more, before maybe she didn't understand about the eating disorder as much but now she does" L272-274 "because like its before it might have been like she didn't really understand that much about why" L279-281 "but now she doesn't really because she understands so she doesn't ask me, like why wouldn't I eat this or why wouldn't I eat that" L311-314	It is the why that is important to understand Recognition that it is an illness How understanding the illness has changed the experience for the participant

- Understanding the internal experience	"my family's got more of understanding of like how it feels" L97-98 "before it felt like, er, nobody really understood that much but now" L185 -186 "the help of the therapists and stuff It kind of helps other people to understand so they understand more" L187-189 "understand more about how I feel" I: "so maybe it changed..." P1: how they, yeah, how they react" L213-214 "it was just a but... annoying because it was like I think she also though like, about, like I was choosing to be unwell" L320-323	Understanding me Understanding the illness better People don't get me / it Not understanding me Role of treatment in helping Changes peoples reactions because the better understand the drive behind the persons behaviour
Superordinate Theme	Notes / Thoughts	
The new norm	Change to surroundings New normal Making sense of new experiences The reality of their experiences Will this theme come through with me? Is it telling me anything new? Is there something about making sense of familial change when external to that setting / group? Adapting?	
Sub themes	Quotes	Notes / Thoughts

Participant One

Narrative

What are you taking? What do you know? What are the themes? What have they told you?

[redacted]

.

Superordinate Theme	Notes / Thoughts	
Valuing Understanding	I feel like these are all linked – like others gain an understanding / knowledge which enables them to understand the illness which means they get the participant. Is it something about understanding me? I think it is that the participant values that others gained an understanding – there is less about what changed for them but more about the others around them	
Sub theme	Quotes	Notes / Thoughts
-Development of external	"groups and stuff for like parents to understand and stuff" L70-71	Non blaming Value of parents understanding

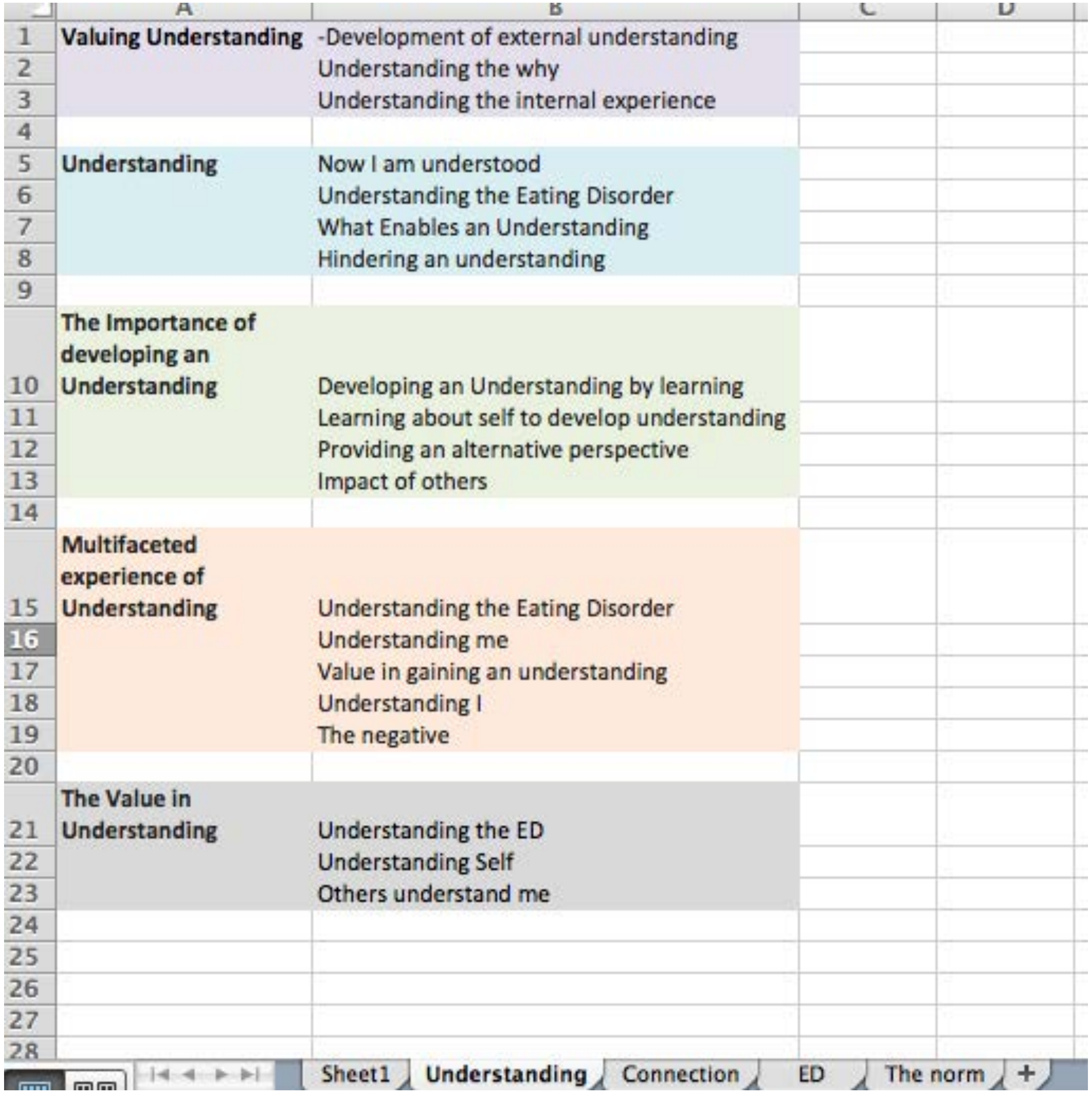
understanding	"it helps like with my parents and stuff to understand and helps me to like try and deal with things a bit better" L 72-75 "they go to MFT and... learn different skills and stuff so then they can" L211-212 "They didn't really understand as much as they do now, they kind of just, er, I don't know if they thought it was like a choice or something" L220 -223 "[they] just, er, understands kind of a bit more from going to different groups"L314-316 "it's helped quite a lot of people cause ... having therapy...helps because like, er, talking about like what's, er, been hard... Or...something that's been good... yeah just helped with everything really" L412-421	Value in others gaining understanding Value in others understanding Value in helping lots of people around me Changes in others understanding The role of treatments in gaining an understanding Enabled talking Helped a lot of people – they key thing is it helped others Something about the external world gaining an understanding
- Understanding the why	"my family know how to support me better" L-68-69 "[they] understand a lot more, before maybe [they] didn't understand about the eating disorder as much but now [they] do" L272-274 "because like its before it might have been like [they] didn't really	It is the why that is important to understand Recognition that it is an illness How understanding the illness has changed the experience for the participant

	understand that much about why" L279-281 "but now [they] don't really because [they] understand so [they] don't ask me, like why wouldn't I eat this or why wouldn't I eat that" L311-314	
- Understanding the internal experience	"my family's got more of understanding of like how it feels" L97-98 "before it felt like, er, nobody really understood that much but now that with like the help of the therapists and stuff but it kind of helps other people to understand so they understand more" " L185 -189 "Yeah, understand more about how I feel and stuff" L194-195 I: "so maybe it changed..." P1: how they, yeah, how they react" L213-214 "it was just a bit... annoying because it was like I think she also though like, about, like I was choosing to be unwell" L320-323	Understanding me Understanding the illness better People don't get me / it Not understanding me Role of treatment in helping Changes peoples reactions because the better understand the drive behind the persons behaviour

Superordinate Theme	Notes / Thoughts
The Norm	Change to surroundings New normal Making sense of new experiences The reality of their experiences

Appendix Z: Development of an across participant Thematic Structure

2	**Valuing Understanding**	-Development of external understanding		**I am the Eating Disorder but I am not**	Immersed in the ED		**The Importance of developing an Understanding**	Developing an Understanding by learning		**Changing the dynamic / system**	Creating ripples
3		Understanding the why			The Eating Disorder as damaging			Learning about self to develop understanding			Systems alter
4		Understanding the internal experience			Role of I in recovering			Providing an alternative perspective			The complexity of taking t forward
5								Impact of others			
6	**The Norm**	The reality of the new norm		**The Power of Connection**	Disconnection with Family					**Multifaceted experience of Understanding**	Understanding the Eating
7		The process of adapting to the new norm			Repairing connections		**Connection**	Valuing Connection			Understanding me
8		Evolving through the adaptation			Repositioning within family relationships			Disconnection			Value in gaining an unders
9		Integration of norms			New connections			The Enabling of Connection through Expression of Emotions			Understanding I
10								Moving forward with the connection			The negative
11	**The Power of Choice**	Misunderstanding Choice		**Understanding**	Now I am understood						
12		Regaining Choice			Understanding the Eating Disorder		**I am the Eating Disorder but I am not**	Immersed in the ED		**The Power of Talking**	Finding my voice
13					What Enables an Understanding			The Eating Disorder as damaging			Others finding their voice
14	**??**	Facilitating talking to enable a relational shift			Hindering an understanding			Development of I			Changing family scripts
15								Recovering losses by returning to a previous existence			
16								Reality of recovery		**The Norm**	The unknown
17								Or Recovery is hard			Moving from the unknow



	A	B	C	D
1	**Valuing Understanding**	-Development of external understanding		
2		Understanding the why		
3		Understanding the internal experience		
4				
5	**Understanding**	Now I am understood		
6		Understanding the Eating Disorder		
7		What Enables an Understanding		
8		Hindering an understanding		
9				
10	**The Importance of developing an Understanding**	Developing an Understanding by learning		
11		Learning about self to develop understanding		
12		Providing an alternative perspective		
13		Impact of others		
14				
15	**Multifaceted experience of Understanding**	Understanding the Eating Disorder		
16		Understanding me		
17		Value in gaining an understanding		
18		Understanding I		
19		The negative		
20				
21	**The Value in Understanding**	Understanding the ED		
22		Understanding Self		
23		Others understand me		
24				
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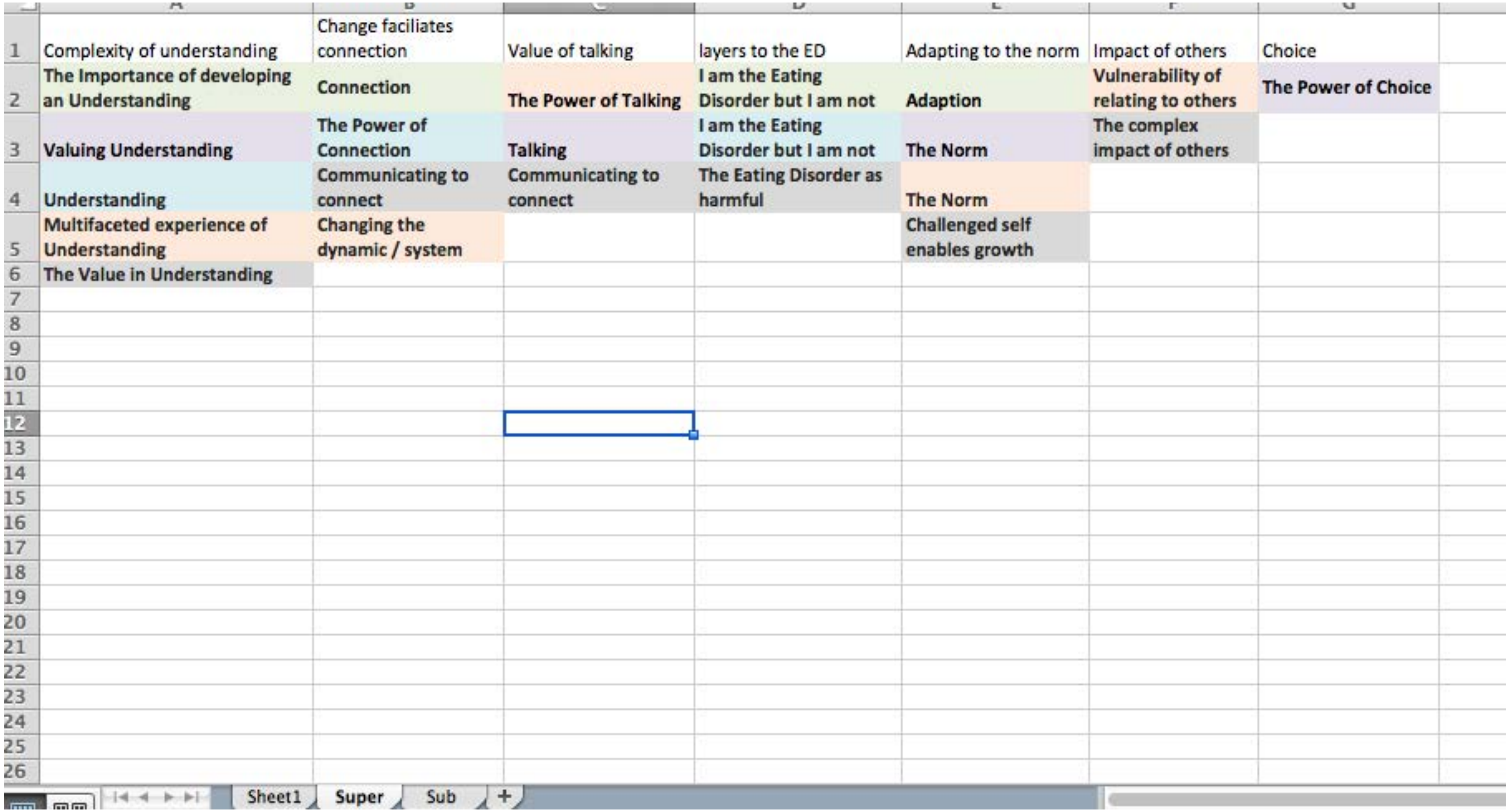
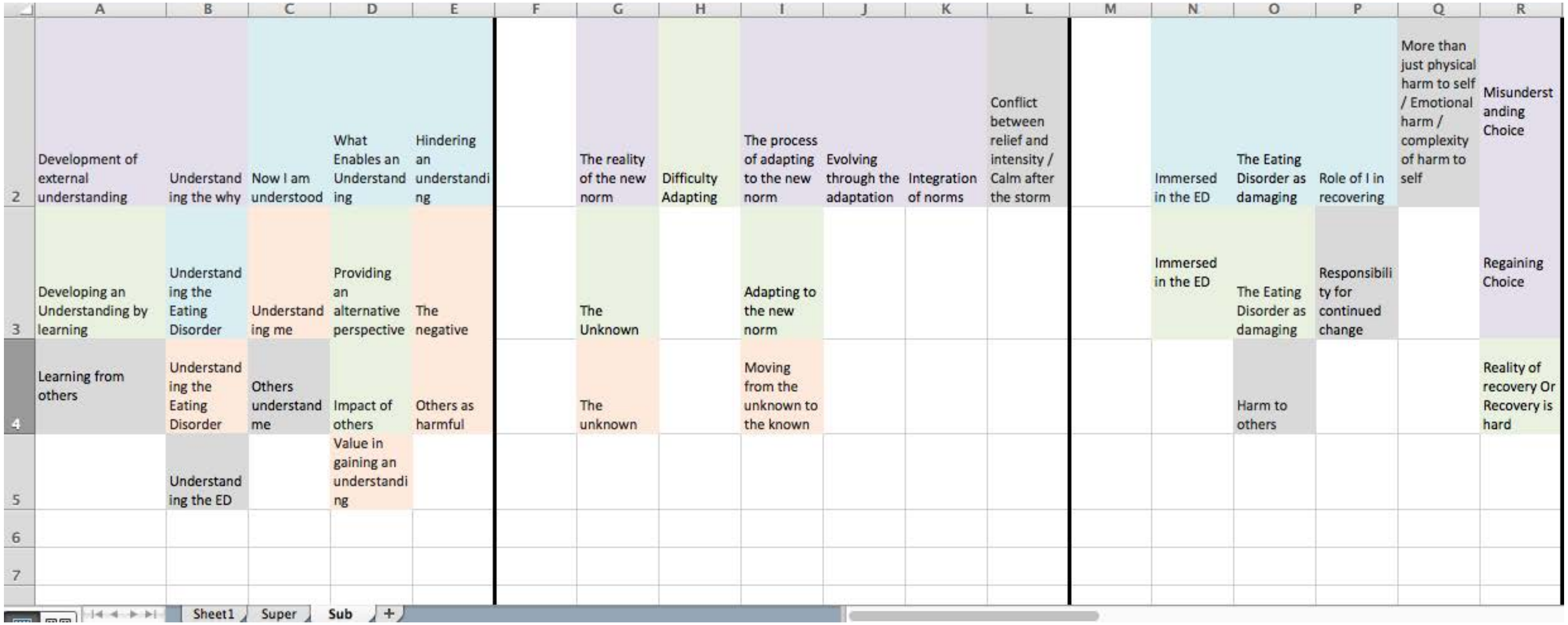


1	Complexity of understanding	Change faciliates connection	Value of talking	layers to the ED	Adapting to the norm	Impact of others	Choice
2	**The Importance of developing an Understanding**	**Connection**	**The Power of Talking**	**I am the Eating Disorder but I am not**	**Adaption**	**Vulnerability of relating to others**	**The Power of Choice**
3	**Valuing Understanding**	**The Power of Connection**	**Talking**	**I am the Eating Disorder but I am not**	**The Norm**	**The complex impact of others**	
4	**Understanding**	**Communicating to connect**	**Communicating to connect**	**The Eating Disorder as harmful**	**The Norm**		
5	**Multifaceted experience of Understanding**	**Changing the dynamic / system**			**Challenged self enables growth**		
6	**The Value in Understanding**						



	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	Q	R
2	Development of external understanding	Understanding the why	Now I am understood	What Enables an Understanding	Hindering an understanding		The reality of the new norm	Difficulty Adapting	The process of adapting to the new norm	Evolving through the adaptation	Integration of norms	Conflict between relief and intensity / Calm after the storm		Immersed in the ED	The Eating Disorder as damaging	Role of I in recovering	More than just physical harm to self / Emotional harm / complexity of harm to self	Misunderstanding Choice
3	Developing an Understanding by learning	Understanding the Eating Disorder	Understanding me	Providing an alternative perspective	The negative		The Unknown		Adapting to the new norm					Immersed in the ED	The Eating Disorder as damaging	Responsibility for continued change		Regaining Choice
4	Learning from others	Understanding the Eating Disorder	Others understand me	Impact of others	Others as harmful		The unknown		Moving from the unknown to the known						Harm to others			Reality of recovery Or Recovery is hard
5		Understanding the ED		Value in gaining an understanding														
6																		
7																		

Super Ordinate Theme	Notes/ Thoughts	
Understanding	There is something about the process of understanding – others understand, I understand and it seems to be about the illness more than anything. But also an element of understanding me The idea that others gain an understanding and then they get the ED which means I am able to be understood more.	
Subtheme	Quotes	Notes / Thoughts
Process of understanding	"groups and stuff for like parents to understand and stuff" L70-71 "it helps like with my parents and stuff to understand and helps me to like try and deal with things a bit better" L 72-75 "they go to MFT and... learn different skills and stuff so then they can" L211-212 "They didn't really understand as much as they do now, they kind of just, er, I don't know if they thought it was like a choice or something" L220 -223 "[they] just, er, understands kind of a bit more from going to different groups"L314-316 "it's helped quite a lot of people cause ... having therapy...helps because like, er, talking about like what's, er, been hard... Or...something that's been good... yeah just helped with everything really" L412-421	I think this link with the two below and also thing this is a bit too much answering my question??

Exploring the Experience of Young People Receiving Treatment for an Eating Disorder: Family Therapy for Anorexia Nervosa and Multi Family Therapy in an Inpatient Setting.

Superordinate Themes	Sub Themes	Participants contributing
Process of Understanding	Understanding you are not alone	5
	Understanding the why	5
	I am understood	4 (Not 3)
Reviving Connection	Disconnection	5
	Shifting the perspective / Altering the system	5
	Taking it forward	5
Emerging from the Eating Disorder	Immersed	4 (not 5)
	The eating disorder as damaging	3 (2 3 5)
Development of I	Adapting to the new norm	4 (not 2)
	The process of evolving	5
	Finding my voice	4 (not 2)

Superordinate Theme	Sub Theme	Quotes	Thoughts / Notes
Process of understanding	There is something about the process of understanding – others understand, I understand and it seems to be about the illness more than anything. The idea that others gain an understanding and then they get the ED which means I am able to be understood more		
	Understanding you are not alone 5	"groups and stuff for like parents to understand and stuff ... it helps like with my parents and stuff to understand and helps me to like try and deal with things a bit better" L 70-75 P1 "I think it was nice to talk to other people, other parents, er, they knew they weren't alone and they gave them the tools to progress" L53-56 P2 My dad only went to one multi family therapy cause he works a lot [yeah] and it was a bit awkward to get out, but I think my mum used to always sort of find it really helpful, sort of speaking to the other parents [yeah] and the other families, and I think [pause] sort of especially with like the foster thing as well, cause I found it quite, I think my mum found it quite helpful, sorta seeing how other parents support me L596-605 P3 But they gave our parents kind of structure and it was almost multi family therapy was less for us, more for our parents, or at least that's what we felt. L247-251 P5 Erm I think listening to [pause] other people, like especially if they're people who got re-admitted because [pause] it was my – it's a bit different now, but when I first got admitted into [ward name], I hadn't [pause] it hadn't really been going on for that long. So to hear people who had got re-admitted, it was something we didn't know about cos it was completely new to us, you know. L136-144 P4	Is this a bit too much answering my question?? Learning from others through groups via professionals or ex patients / parents or just by being with others and learning you are not alone. But this can have a negative impact also