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Doctoral Thesis:

Lived Long-Term Experience of Eating Disorders: A Narrative Exploration

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Word Counts

| | Abstract | Main Text | Appendices (including tables, figures and references) | Total |
|--------------------|----------|-----------|---|-------|
| Thesis Abstract | 291 | --- | --- | 291 |
| Literature Review | 148 | 7756 | 3879 | 11783 |
| Research Paper | 141 | 7800 | 27931 | 35872 |
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Abstract

This thesis explores the narratives of people with long-term experience of eating disorders and the wider socio-political, psycho-medical discourses that surround these presentations. It comprises a narrative literature review, a research article and a critical appraisal. The literature review provides a social constructivist critique of the limiting nature of language in the case of anorexia nervosa. By reviewing diagnostic criteria, historical accounts and dominant explanations of anorexia, this article explores their epistemological underpinnings, and the consequent impact of these on research, policy and service-user experience in a neo-liberal political context.

The research paper applies a narrative analytic approach to the accounts of eight participants with long-term experience of eating disorders and specialist service provision. The findings are presented in six cinematic style scenes across three acts, which illustrate participants' first contact with specialist services, a brief overview of what had happened to get them to this point, the context and quality of their current relationship with services, and their needs and hopes for the future. The contributions of these narratives are discussed in relation to the role specialist services play in the construction of participants' sense of self, and the implications of this for clinical practice and service development going forward.

Finally, the critical appraisal adopts a narrative approach to the exploration of my experience undertaking this research. Using a similar process to the analysis of participants' narratives in the research article, I reflect on my introduction to eating disorder services and the reason I became interested in this research, what had happened in my life story to influence this decision and approach, before providing an overview of the challenges, strengths and limitations of the process, and reflecting on what I have learned from researching this topic in this way.

Declaration

This thesis records work undertaken for the Doctorate in Clinical Psychology at the Division of Health Research in Lancaster University from September 2014 to August 2017.

The work presented here is the author's own, except where due reference is made.

The work has not been submitted for the award of a higher degree elsewhere.

Name: Ciara Joyce

Signature:

Date:

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Firstly, I would like to thank all of the participants who made this research possible. I feel honoured that you chose to share your stories, and your courage, with me.

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Table of Contents

| | |
|---|-------------|
| SECTION ONE: LITERATURE REVIEW | 1-1 |
| ABSTRACT | 1-2 |
| AIMS AND OBJECTIVES | 1-3 |
| METHODOLOGICAL RATIONALE | 1-4 |
| THE DILEMMA OF ANOREXIA NERVOSA: THE CURRENT SITUATION | 1-5 |
| LANGUAGE IN PRACTICE AND SERVICE DEVELOPMENT | 1-8 |
| LIMITATIONS OF THE POSITIVIST PARADIGM | 1-10 |
| POLITICS, POWER AND KNOWLEDGE | 1-13 |
| HISTORICAL OVERVIEW OF “SELF STARVATION” AND EVIDENCE BASED MEDICINE | 1-14 |
| CONSTRUCTING A DOMINANT NARRATIVE | 1-16 |
| EXPLORING THE CONSEQUENCES OF PREVAILING CONSTRUCTIONS | 1-20 |
| LANGUAGE AND STIGMA | 1-21 |
| LEGITIMISING AND EXPORTING DISTRESS | 1-24 |
| UNDERSTANDING THE ROLE OF LANGUAGE TO INFORM FUTURE DIRECTIONS | 1-27 |
| CONCLUSION | 1-29 |
| REFERENCES | 1-30 |
| APPENDICES | 1-47 |
| APPENDIX A: HOW DIAGNOSTIC CRITERIA FOR ANOREXIA NERVOSA HAD CHANGED OVER TIME | 1-47 |
| APPENDIX B: GUIDELINES FOR SUBMISSION TO TARGET JOURNAL (THEORY AND PSYCHOLOGY) | 1-49 |
| SECTION TWO: RESEARCH PAPER | 2-1 |
| ABSTRACT | 2-2 |
| INTRODUCTION | 2-3 |
| THE CURRENT STUDY | 2-6 |
| METHOD | 2-7 |
| DESIGN | 2-7 |

| | |
|--|-------------------|
| REFLEXIVITY STATEMENT | 2-7 |
| ETHICAL CONSIDERATIONS | 2-8 |
| PARTICIPANTS | 2-8 |
| PROCEDURE | 2-9 |
| ANALYSIS | 2-10 |
| FINDINGS | 2-13 |
| PROLOGUE | 2-14 |
| ACT ONE: INTRODUCING SPECIALIST SERVICES | 2-16 |
| ACT TWO: IN RELATIONSHIP WITH SERVICES | 2-22 |
| ACT THREE: CLIMAX AND RESOLUTION; NEEDS AND HOPES | 2-26 |
| DISCUSSION | 2-31 |
| IMPLICATIONS FOR SERVICE DEVELOPMENT | 2-33 |
| STRENGTH AND LIMITATIONS | 2-38 |
| CONCLUSION | 2-39 |
| REFERENCES | 2-40 |
| FIGURES | 2-49 |
| APPENDICES | 2-54 |
| APPENDIX A: NARRATIVE STATEMENT | 2-54 |
| APPENDIX B: SUMMARY STORIES | 2-54 |
| APPENDIX C: ANALYSIS | 2-85 |
| APPENDIX D: NARRATIVE MAPS | 2-98 |
| APPENDIX E: GUIDELINES FOR TARGET JOURNAL (QUALITATIVE HEALTH RESEARCH) | 2-106 |
| <u>SECTION THREE: CRITICAL APPRAISAL</u> | <u>3-1</u> |
| ABSTRACT | 3-2 |
| ACT ONE: AN INTRODUCTION TO EATING DISORDER SERVICES AND NARRATIVE ANALYSIS | 3-2 |
| ACT TWO: IN RELATIONSHIP WITH RESEARCH, OBSTACLES AND ALLIES | 3-9 |

| | |
|---|-----------------------|
| ACT THREE: CLIMAX AND RESOLUTION | 3-13 |
| EPILOGUE | 3-16 |
| REFERENCES | 3-17 |
| SECTION FOUR: ETHICS SECTION | <u>4-1</u> |
| IRAS FORM | 4-4 |
| LETTER OF APPROVAL FROM NHS REC | 4-41 |
| LETTER OF APPROVAL FROM HRA | 4-44 |
| IRAS AMENDMENT FORM | 4-45 |
| LETTER OF APPROVAL FOR AMENDMENT FROM NHS REC | 4-54 |
| EMAIL CONFIRMATION OF AMENDMENT APPROVAL FROM HRA | 4-56 |
| RESEARCH PROTOCOL | 4-57 |
| INTRODUCTION | 4-57 |
| METHOD | 4-62 |
| PROPOSED ANALYSIS | 4-65 |
| PRACTICAL ISSUES | 4-66 |
| ETHICAL CONSIDERATIONS | 4-66 |
| PLANS FOR DISSEMINATION | 4-67 |
| PROPOSED TIMETABLE OF KEY MILESTONES | 4-67 |
| APPENDICES | 4-68 |
| APPENDIX A: RECRUITMENT EMAIL TO SERVICES | 4-68 |
| APPENDIX B: RECRUITMENT LEAFLET | 4-69 |
| APPENDIX C: PARTICIPANT INFORMATION SHEET | 4-70 |
| APPENDIX D: CONSENT FORM | 4-73 |
| APPENDIX E: DEBRIEFING SHEET | 4-74 |
| REFERENCES | 4-75 |



Section 2: Research Paper

Long-Term Lived Experience of Eating Disorders and Specialist Service Provision: A Narrative Analysis

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Abstract

This study undertook a narrative analysis of participants' long-term lived experience of eating disorders and specialist service provision. Eight participants were recruited with service experience across five National Health Service Trusts in the UK. All participants had a minimum of 10 years self-reported experience living with an eating disorder. The data is presented across three Acts to demonstrate the development of participants' self-construct in relation to their first contact with specialist services, what had happened in their lives for this to become necessary, and their current relationships with services, before gaining an appreciation for what they need from services to help them feel heard going forward. Findings suggest current methods of service delivery result in delayed and inappropriate supports, and a consequent "battling" against professionals, which can provide an obstacle to compassionate and collaborative working, and promote "revolving door" experiences.

Keywords

Anorexia/bulimia; eating disorders; narrative inquiry/analysis; service delivery; psychology; research; qualitative

Introduction

Long-term, severe and enduring experiences of eating disorders (EDs) provide a significant challenge to the individuals affected, their families and professionals alike (Robinson, 2009; Robinson, Kukucska, Guidetti, & Leavey, 2015; Strober, 2004). While EDs are associated with stigmatised attitudes (Bannatyne & Abel, 2015) considerable physical health and psychosocial consequences (Jenkins, Hoste, Meyer, & Blissett, 2011), they generate a lot of interest in the general public and the scientific community (Fairburn & Harrison, 2003). Described as “serious and often fatal illnesses that cause severe disturbances to a person’s eating behaviours” by the National Institute of Mental Health (NIMH, 2016, para. 1), EDs are characterised by intense preoccupation with food, body weight and shape.

Historically EDs have been considered a “nervous disease” (Striegel-Moore & Bulik, 2007, p. 182) located in the individual and psychological research focused on quantitative measurement of individual factors like body image satisfaction (Malson, Riley, & Markula, 2009). More recently, researchers are drawing attention to how distress that manifests in body concerns is socially constructed within socio-political, cultural and service contexts (Brooks, 2009; Eivors, Button, Warner, & Turner, 2003; Orbach, 1986; Riley, Rodham, & Gavin, 2009; Wiggins, 2009). Standardised “causes” of EDs remain elusive within the interplay of complex social, psychological and biological processes, and there is a call for “fresh perspectives” (Botha, 2015, p.328) and “a new paradigm” (Touyz & Hay, 2015, p. 1) in the way we conceptualise, research and develop interventions for these presentations.

Such recommendations are driven by the recognition that there has been minimal improvement in ED treatment outcomes over the last 50 years (Botha, 2015; Steinhausen, 2002) with high drop-out rates (Fassino, Pierò, Tomba, & Abbate-Daga,

2009) and low levels of service-user satisfaction (Botha, 2015). Nevertheless, despite their association with topical discourses around “treatment resistance” and low “recovery” rates (Botha, 2015; Hay & Touyz, 2015), long-term experiences of EDs have received relatively little attention in research to date (Hay & Touyz, 2015; Hay, Touyz, & Sud, 2012; Schmidt et al., 2016).

The medicalised conceptualisation of EDs as a spectrum of severity was incorporated towards the end of the last century (American Psychiatric Association, 2013; Hay & Touyz, 2015), and with the recent introduction of the term severe and enduring eating disorders (SEED) to classify those with 10 or more years of experience (Robinson, 2009) research has started to consider this group. Nevertheless, this focus has been largely restricted to studies of Anorexia Nervosa (AN) (Hay & Touyz, 2015) which some consider to represent the most “risky” of the ED presentations (Arcelus, Mitchell, Wales, & Nielsen, 2011).

EDs have been contextualised in the literature as existing on a continuum of control with AN being understood as the manifestation of over-control and abstinence, and Bulimia Nervosa (BN) representing a lack of control or even greed (Burns, 2004). In this way, constructions of EDs can inadvertently convey AN in a more “positive” light as an achievement, which can leave people with experience of BN feeling less worthy, and like “failures” in comparison (Burns, 2004, p.276). Such comparisons are arguably reinforced in the broader literature, which prioritises research and discussion around SEED-AN (Fassino & Abbate-Daga, 2013; Geppert, 2015; Robinson et al., 2015) despite the fact that, in practice, diagnoses are not always clear. Consequently, some theorists have argued for a “transdiagnostic” approach to understanding EDs, where eating too much or too little are seen as conceptually inseparable ways of managing emotional distress (Fox & Power, 2009).

Current lifetime prevalence estimates, garnered from international research, predict that approximately 5% of the general population will experience an ED at some point in their lives (Treasure, Claudino, & Zucker, 2010). Some 20% of those may go on to develop long-term, severe and enduring presentations (Arkell & Robinson, 2008), for which there are few efficacious approaches to intervention (Hay & Touyz, 2015; Hay et al., 2012; Stephen Touyz & Hay, 2015). These include family therapy interventions for adolescents (Botha, 2015), and cognitive behavioural therapy (CBT) for adults with long-term experience of AN (Touyz et al., 2013). From an etic (outsider or researcher) perspective, longer follow-up periods have been associated with more positive outcomes (Arcelus et al., 2011; Keel & Brown, 2010; Steinhausen, 2002), while older age at first engagement with services has been associated with more negative outcomes (Arcelus et al., 2011).

Thus, while there is low quality evidence for particular treatment approaches to intervention in EDs, high dropout (Fassino et al., 2009) and low satisfaction rates (Botha, 2015), little professional guidance or academic research has considered these findings from service-user perspectives. Such a dearth in the literature arguably contributes to researchers' perspective of treatment 'resistance', which is said to accompany the 'ego-syntonic' features of EDs (Fassino & Abbate-Daga, 2013) and is considered one of the main culprits in the increasing chronicity of ED presentations (Strober, 2004) and the "revolving door" phenomenon of relapse rates in EDs (BEAT, 2015, p. 35). Qualitative research, has found that disengaging from ED services can be related to disappointment, in not finding the desired insight and understanding through their therapeutic engagement, and feeling like treatment was superficial and self-perpetuating in focusing on physical health symptoms rather than the deeper emotional causes (Eivors et al., 2003).

Although discussion around treatment “resistance” and “medical futility” in SEEDs continues in the psychiatric literature, recent papers have cited the need for critical challenges to such pessimistic conversations (Fassino & Abbate-Daga, 2013; Geppert, 2015) and have made recommendations that treatment protocols move beyond targeting core areas of physical health risk associated with EDs, and focus on developing ways of managing the personal and social costs of long-term presentations (Hay et al., 2012). More recent qualitative research has looked to establish an understanding of the lived experience of SEEDs (Robinson, Kukucska, Guidetti, & Leavey, 2015) and has challenged the negative narratives around outcomes by finding that full recovery from SEED-AN is possible where hope, support, motivation and self-efficacy can be nurtured (Dawson, Rhodes, & Touyz, 2014).

In light of such findings, it is important to listen to service-users’ experience and get a sense of what they hope for. Therefore, the aim of this research is to further our understanding of what it is like to live with long-term eating difficulties and receive input from specialist services.

The Current Study

A narrative approach was employed to explore participants’ long-term lived experience of EDs and service provision. This approach assumes that events become meaningful because of their placement in an individual’s narrative, and that while stories do not represent a mirror of reality, they compose a creatively authored, constructed account complete with personal assumptions and interpretations (Riessman, 1993). By focusing on participants’ accounts in this way, an interpretist paradigm may be adopted. Understanding events and the meanings attached to them is gained by analysing beyond a description of individuals’ past actions and experiences. By valuing and understanding the subjective nature of personal experience, in terms

of how it is grounded within a particular time, place and perspective (Personal Narratives Group, 1989) we can acknowledge such experiences, and hopefully learn from them.

Method

Design

Narrative research provides methods for examining and relating meaning across the ideational (content-specific), interpersonal (relational) and textual (structural) qualities implicit within the stories people tell about their lives (Riessman, 1993). This approach to data collection and analysis directly relates to how people make sense of their experiences (Crossley, 2000), and can be useful in exploring the impact of dominant societal discourses, culture and self (Weatherhead, 2011).

Other disciplines and feminist approaches have explored the social and cultural meanings associated with EDs, and advocate a more thorough understanding of how cultural practices, gender roles and embodiment inform the development and experience of living with these diagnoses (Gelo, Vilei, Maddux, & Gennaro, 2015; Gremillion, 1992; Malson et al., 2009; Orbach, 1986, 2009). Narrative analysis preserves accounts shared by participants within their social and cultural context (Riessman, 2008) and therefore allows for the exploration of these, with the aim of understanding them better (Patton, 2002).

Reflexivity Statement

In qualitative research in general, and narrative approaches in particular, the researcher's professional, personal and epistemological positioning is important. The researcher is considered a co-creator of meaning (Riessmann, 1993; 2008). In

acknowledging the same story will never be told twice, sharing narratives comprise a social function for both narrator and listener (Squire, 2008).

I have an interest in systemic, narrative and compassion-focused approaches to clinical work, and use their social constructionist leanings to enable the deconstruction of my own understanding of EDs and my experience of working clinically in this area. I argue that there is an overemphasis on a medicalised understanding and treatment of EDs, which has been derived from structuralist approaches to healthcare and language (see Section One).

Ethical Considerations

Ethical approval was gained from the NHS Research Ethics Committee and the Health and Research Authority in England (see Section Four). Participants provided written consent to be included in the research, and for their data to be published. The field supervisor was the Clinical Lead for one of the recruitment sites, and an academic supervisor was chair of the special interest group that recruitment invitations were circulated through. Consideration was given to how this might affect recruitment and confidentiality. Supervisors' involvement in the project was made transparent, and where supervisors may have known participants they were not permitted to access their transcripts or interviews. This protocol was explained to participants.

Participants

Participants were invited to take part in the study if they were 18 years or older, had self-reported experience of specialist ED services, and living with an ED for 10 years or more. This is consistent with Robinson's (2009) description of SEED. In keeping with a "transdiagnostic" approach to EDs (Fox & Power, 2009),

participants were not excluded based on any particular diagnostic category. They were recruited directly through two NHS Trusts and by sharing an advertisement within a special interest group formed to collaboratively develop understanding of EDs from service-user, carer and professional perspectives.

Fifteen people expressed an interest in participation. Five people ceased responding to correspondence, and two people were excluded for not having experience of specialist services. A total of eight participants (seven female), across five NHS Trusts volunteered to take part. Table 1 provides demographic information including age, diagnoses, employment status, and length of self-reported experience of living with an ED and receiving input from specialist services. Participants' ages ranged from 20-64 years. The average age was 44 years. Average length of experience living with an ED and receiving input from specialist services was 25 and 10 years, respectively.

Procedure

Recruitment leaflets and emails were circulated. Participants expressed interest in the project with the researcher directly, or through their service. They were then sent a link to access the participant information sheet, a copy of the consent form and some demographic questions. Participants were invited to bring images or objects that felt meaningful to their experience to interviews, where photographs of these could be taken with permission. Consent was gained in person before each interview, and participants were given the choice of using their own name or a pseudonym. Section 4 contains reference to all research materials.

Individual, biographical interviews took place at a variety of locations depending on the preference of participants and feasibility for the researcher. All interviews began with the same open-ended narrative statement to explain the

boundaries of the interview and encourage a natural starting point (see Appendix A). Clarifying questions and additional prompts were included where necessary to facilitate the expansion of the narrative (Riessman, 1993). Participants were encouraged to share their stories at a comfortable pace, and in a way that facilitated a consideration of how they viewed and understood their experiences (Josselson, 2011).

Interviews lasted 90-180 minutes, and were transcribed verbatim. To enhance trustworthiness of the data, the researcher created summary stories (Appendix B1-8), which were offered to participants with an option of meeting again to review these. One participant declined this offer, three took part in face-to-face conversations, three chose to review these by email, and one discussed theirs over the phone.

Analysis

Narrative analysis (NA) is grounded in principles of narrative psychology (Howitt, 2010) which aims to explore and understand the narrator's construction of self and identity in relation to their cultural contexts (Weatherhead, 2011). There is no definitive framework for conducting NA, and this can be considered a strength of the approach in promoting creativity over limiting procedures (Crossley, 2007). This research was guided by several narrative methods and frameworks including Crossley (2007; 2000), Howitt (2010), Riessman (1993; 2008) and Weatherhead (2011).

Each interview was listened to, transcribed and read through a number of times to enhance familiarisation and engagement with the data (Crossley, 2007). Summary stories were created for each participant by highlighting and reflecting on events that the researcher deemed salient and emotive to the participants. Any requested changes, or additional reflections deemed pertinent to the participant or researcher, were incorporated into the final version of these stories, which give an interesting overview of each participant's narrative (see Appendix B1-8).

Table 1. Participant's Demographic Information

| Preferred Name | Gender | Age | Length of self-reported experience of living with an ED | Aprx Length of time known to specialist ED services | Number of inpatient admissions | Current ED Diagnosis | Additional diagnoses | Currently Working or Studying |
|----------------|--------|-----|---|---|--------------------------------|----------------------|--|-------------------------------|
| Angie | F | 41 | 20 years | >10 | 6 | Anorexia Nervosa | None disclosed | Yes |
| Sue | F | 46 | 30 years+ | >20 | 1 | Anorexia Nervosa | Depression, Anxiety, Obsessive Compulsive Disorder, Underactive Thyroid. | No |
| Emma | F | 32 | 15/20 years | <5 | n/a | Anorexia Nervosa | None disclosed | Yes |
| Diane | F | 64 | 25 – 30 years | <5 | 3 | Anorexia Nervosa | Reynaud's, Osteoporosis | Yes |
| Rachel | F | 56 | 20 years+ | >10 | 3 | Anorexia Nervosa | None disclosed | Yes |
| Mark | M | 54 | 40 years | <10 | 2 | Anorexia Nervosa | Osteoporosis, Query Autism Spectrum Disorder | Yes |
| Lisa | F | 42 | 20 years+ | <5 | n/a | Bulimia Nervosa | Bi-Polar Disorder | No |
| Rosie | F | 20 | 10 years | <10 | 3 | Anorexia Nervosa | Irritable Bowel Syndrome, General Anxiety Disorder | Yes |

Each transcript was then reviewed in depth by identifying important concepts, characters, recurring themes and imagery as well as ascertaining their overall narrative tone (Crossley, 2007; Howitt, 2010). Tables C1 and C2 provide an example of how data was organised for each narrative (see Appendix). While the interviews elicited life history or biographical narratives, the method of analysis focused on a more categorical, content approach to identifying and constructing a coherent narrative around the central research question (Hiles & Cermak, 2008 in Howitt, 2010). Correspondingly, particular attention was given to plots and themes that were situated in the social service context.

This focus was aided by the use of a visual map to plot the location of themes and images across individual, familial, social, political and societal levels for each participant. Figures D1-8 are scanned versions of these maps and are included for reference in the Appendix. Given the use of the data in this way, the findings are presented in terms of acts and scenes (explained below). This has been done to respect the fact they represent a narrow subsection of the available data, and that the participant's individual life stories continue behind these scenes. To increase the trustworthiness, reflexivity and rigour in the analytical process, supervisors were invited to listen to interviews, provide feedback and remain involved in the analytic process throughout.

Findings

Within film and screenplay, Act One orientates the audience to the narrative tone, plot and main characters, Act Two should help identify challenges and allies the characters embrace in their journey, and Act Three typically houses the main climax and narrative resolution (Industrial Scripts, 2014). In following this format, each scene presented here is comprised of interconnected images, plots and themes across different temporal and spatial locations. Scenes emerged from the data as a way to unify the diversity of participants' interactions with services and elicit the consequent impact of these on the development of their self-constructs. They are intended to illustrate fluidity across narratives, while maintaining a sense of each participant.

Act One introduces the character of specialist ED services. The opening scene depicts the point and context around participants' first contact, and the second scene explores participants' accounts of what had happened in their lives to get them to this point. Act Two scene one captures what services have conveyed to the participants' through their interactions, and Act Two scene two depicts the battling nature that characterises these interactions. Act Three exposes the "villains" behind services' perceived malice, and explores what participants need from services to feel heard, as well as their hopes for the future. For a diagrammatical overview of these scenes, and the themes and imagery they contain see Figure 1.

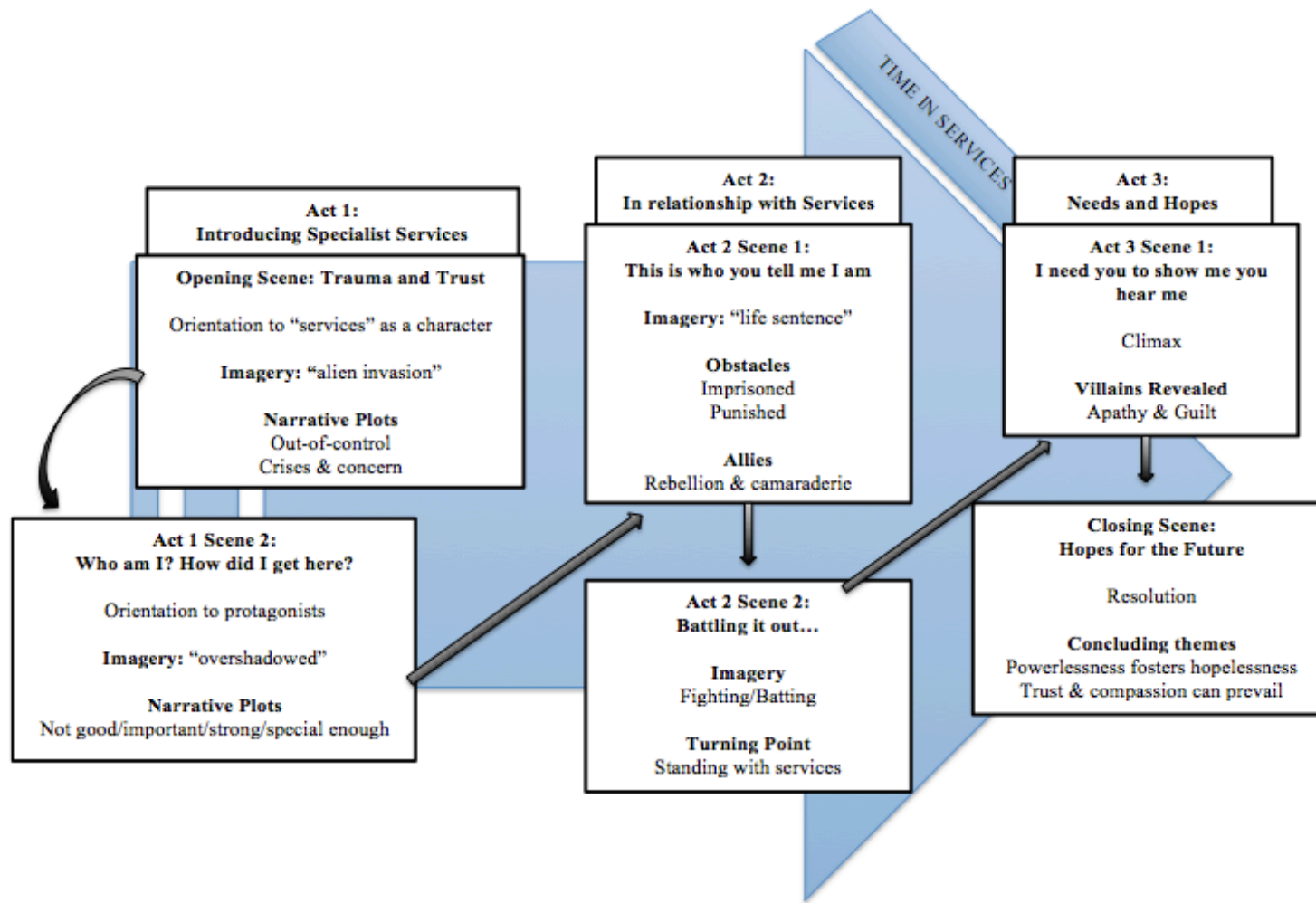


Figure 1. Diagrammatical overview of acts, scenes and the narrative plots and imagery they contain.

Prologue

n.b. INT. (Internal scene location) EXT. (External scene location)

MONTAGE - VARIOUS SCENES - PRESENT DAY

A) INT. PRIVATE ROOM INPATIENT WARD - DAY - POST LUNCH - Angie sits at her laptop working and catches a glimpse of a nurse looking at her through the circular glass window in her door.

B) INT. SITTING ROOM - DAY - PRE DINNER - Sue sits on the armchair leafing through old family photos she extracts from a plastic bag.

C) INT. OFFICE - DAY - LUNCHTIME - Emma sits at her desk eating her salad. Her gaze rests on the screen of her monitor resolutely.

D) EXT. CARPARK - DAY - LUNCHTIME - Rachel sits in her car and unwraps her plain cheese sandwich with a sigh.

E) INT. KITCHEN - EVENING - PRE DINNER - Lisa prepares food for her son and explains she'll eat hers when she's back from her evening class.

F) INT. ART STUDIO - MID MORNING - PRE LUNCH - Mark stands at his easel lost in the strong charcoal strokes on the page. His phone alerts him to a text. He reaches for the forgotten fortisip nutrition drink on the table.

G) INT. BAR - EVENING - PRE DINNER - Rosie sits around a table with friends. A bowl of chips arrive for the table. At the gentle encouragement of a friend she picks one and brings it to her mouth.

H) EXT. GARDEN - DAY - POST LUNCH - Diane stands smoking a cigarette. She blows the smoke at the sky.

END OF MONTAGE

FLASHBACK TO:

INT. HOSPITAL ROOM - EVENING 1971

The room is quiet except for bleeping of hospital machines and sound of distant footsteps in the corridor. Diane lays in a hospital bed eyes closed softly. Her father sits by her side. His hand in hers.

FATHER

Squeeze my hand if you can hear me Diane.

Diane remains silent and still. The merest hint of a smile plays on her lips.

BACK TO THE PRESENT.

Act One: Introducing Specialist Services

“It is our nature, as humans, to be nurtured” (O’Toole, 2015, p.3)

Opening Scene: trauma and trust

Picture an old, grand, red-brick building set amongst a mature modest garden and old-fashioned turning circle for cars to pull up and drop people off. It feels quite warm here on a bright sunny day, but as you get closer to the entrance the smell of hospital and the dank, chill of uncirculated air runs out to meet you. Most of the participants made their initial contact with ED services on inpatient wards like this. They used vivid and emotive language to describe how “horrific” (Angie), “dehumanising” (Diane) and “agonising” (Sue) it was:

INT. HOTEL FUNCTION ROOM – DAY (INTERVIEW)

We sat opposite one another, across the dark wooden table. Sue reached for her glass of water as her pace quickened.

SUE

...They just fed me from morning until night (emphasis) and I couldn’t cope with it. You had like a breakfast, and then you had to have a mid-morning snack – this is true! and then you had to have lunch, and then you had to have a mid afternoon snack, and then you had to have dinner, and then you had to have a supper. And for someone whose stomach has shrunk so much I couldn’t cope with all this food, and it got so so bad (volume fades softly) but they were feeding me up because they thought ‘well she’s gonna die’ but they were going to kill me anyway – the shock of the body – I didn’t think I could cope with it.

Angie’s experience had been similarly terrifying, causing her to question her identity, without any therapeutic input to understand why she found eating so difficult, and how she could manage the resulting distress: “I gained weight quite quickly – they really piled it on thick and fast...this sort of alien invasion...my body had just been taken over it was almost like it wasn’t me in the mirror”.

In contrast, Mark found that it was a relief to have the control taken away:

INT. ART STUDIO – DAY (INTERVIEW)

We sat across from one another in the brightly lit space. Some of Mark's artwork spread out on the table between us.

MARK

I was suddenly admitted, and I knew I was in trouble. My immune system was packing up; every time I got a cut I got cellulitis, and freezing! coats on in bed... I went to see the consultant and he was good and he admitted me to the first available bed, which was at [REDACTED] though I didn't realise it was compulsory until after they showed me around and I suddenly thought – well said actually, 'I might prefer to try it as an outpatient' because like seeing nine girls sort of sat around and you know (pauses) and [REDACTED] the nurse said oh that's fine you can try it as an outpatient you just need to put on a pound in the next week I said what!? I can't do that! Which is when I realised yeah they had sectioned me I think.

INTERVIEWER

So that hadn't been communicated to you before then?

MARK

They do their best not to.

INTERVIEWER

So what did it feel like?

MARK

A relief at the time because I knew how bad it was and I knew I couldn't do anything about it...

Although Mark similarly expressed the need for more therapy he explained how when choice is removed in a trusting environment it helped finally dissolve the “invisible barrier” between him and food, albeit temporarily.

All but two participants did not choose to engage with services but were strongly encouraged like Sue, coerced like Angie, or sectioned like Mark. Lisa had been already known to mental health (MH) services and found her general practitioner (GP) responsive to her request, while Emma did not. Having been referred for support to a non-specialist dietician in the past, Emma had a diagnosis of AN on her medical

record, but her later request for support was declined by her GP, whom she described as asserting her weight was not “low enough” to qualify. She attempted again a couple of years later:

INT. FRONT ROOM – EVENING (INTERVIEW)

We sit on the couch, beside one another but angled so that we are facing each other. Both sipping cups of steaming camomile tea.

EMMA

...At that point I kind of just thought well there mustn't be anything wrong with me then because I kind of I was better than I had been at my worst – I think I kind of thought I must be too well to get help kind of thing... I had a couple of experiences like that with GPs but that was the only time I asked for help until I took my own referral form.

Concerned managers, families, partners and professionals featured prominently as reasons participants sought help. For Diane it was her manager, and for Mark it was his orthopaedic consultant. Having conveyed concerns about low mood (Diane) and an inability to eat (Mark) to their GPs, their relationship with food was not explicitly addressed until they were so severely underweight it was affecting Diane's ability to work, and had resulted in osteoporosis for Mark.

Similarly, half of the participants were already known to MH services before any concern about an ED was identified. For example, Rachel was transferred from a general MH ward into a specialist ED unit after a second attempt to end her life and Rosie's contact with services was also precipitated by a suicide attempt. Thus, many participants were in quite a raw, and fragile condition by the time they first encountered services.

Act One, Scene Two: Who am I? How did I get here?

All participants expressed the sense of feeling *not good enough*, and were able to relate this to early life experiences and relationships. Sue, Lisa and Rachel shared experiences of trauma and abuse, objectification, exploitation, and struggling to feel safe in the world. For example, Rachel grew up “in the shadow” of her brother, and became resigned to her place as a woman and a “second-class citizen” to all of those more deserving. She was “the good girl” that could “never quite fit in”. While trying to ensure the needs of others were always met, hers were silenced, and love and joy remained perpetually out of reach (see Figure 2).

INSERT FIGURE 2 HERE

Similarly, Angie felt “unloved” and “unnoticed” all her life and, having been accustomed to a controlling and punitive home environment, restricting her food intake initiated a way to impart some “control” on her newfound independence from an abusive mother when she left home. Diane related the development of her ED to her first memory of feeling “powerful” and “in control” of her father (see Prologue), after feeling overshadowed by his “Victorian” attitude, and the need to always do “the right thing”. In the context of feeling unimportant and not “special enough”, she found a sense of achievement and control in restricting her food intake and exercising excessively.

Sue’s lifelong on-and-off relationship with services started when she reached puberty, and began to experience depression. Four decades later she remains affected

by chronic low mood, and a need to feel empty to be comfortable. Exercise helped her manage the “tension and anger” of self-hatred that accompanied the unwanted attention she received from men, and restricting helped her “cut off” from the more difficult feelings. Similarly, Emma described her ED as serving a protective function:

EMMA

My dad was an alcoholic - he's dead now - but he was also quite violent so that was all going on, and there's just me and my [REDACTED] so I think I was very much the responsible one who sorted things out. And my mum didn't cope particularly well, and it was in that context that things developed so I think there was a lot of stuff going on around me that felt very difficult - and emotionally felt very difficult - to cope. And then when my parents split up, which was a good thing and I was happy about that, things didn't really settle as you would have - as I certainly hoped they would - that's when things actually became more difficult for a while, and that's what was going on really so you know it's not rocket science I suppose is it you know? That was just how I coped.

Like Diane, things went “downhill” for Emma after leaving University without a sense of direction and purpose, and she “got really hooked on the sense of achievement - that sense of doing something”.

Lisa felt controlled, put down and abused in many of her early relationships with men: “it was almost like I wasn't strong enough”. Like Sue, she has “always hated” herself, and “seemed to be always battling and didn't know how to eat normally”. Lisa has experienced being both significantly under, and over-weight: “it was kind of like me rebelling against myself”. Similarly for Mark his experience related to demonstrating strength, and an ability to protest against internalised gender norms and social expectations. He spent his life doing more than others on less: “be

big and macho and yea no I'm not really (gently laughs), and I'm stronger than you anyway, I can out do you all! and I generally could".

All but two participants spoke about how "food was always an issue" (Rachel) even "from a young age" (Lisa). For example, having grown up with stories about how "different" and "faddy" she was from a young age, Rosie found it difficult to feel like she was "in a comfortable skin". She did not "want to take up space", and felt trapped in childhood but also "terrified" of becoming an adult. For many participants EDs became a way of acknowledging and understanding the consequences of their early life experiences, but this happened at various stages sometimes with, and sometimes without, the help of services.

Feeling like she was "failing" at life, and at her ED, meant that Emma only recently came to terms with having "a problem" in her relationship with food, which was hampered by her GP's ambivalence around securing her further professional support. Similarly, Lisa felt "embarrassed" and "stupid" that she managed to get to her 40's and "never admit it", although she reflected how this didn't feel intentional, but rather it took her that long to appreciate that the difficulties she was experiencing could be understood in ED terms, particularly when this had not been considered by the MH professionals she was already engaged with.

Overall, all participants' narratives referred to how their ED developed in the context of managing unmet need for psychological security and autonomy, self-worth and purpose in the context of feeling powerless, and overlooked by others. Thus, while no two stories were the same, there were many overlapping themes and narrative plots that made sense of the courage, and the vulnerability with which participants approached services for help.

Act Two: In Relationship with Services

“There is nothing harder to convince someone of than an unfamiliar truth”

(Rothfuss, 2011, p. 566)

Act Two, Scene One: This is who you tell me I am

Inpatient services were experienced as “prison-like” (Mark), recreating the critical and controlling conditions from which EDs emerged (Angie), and reinforcing the rigidity that accompanies them (Diane). Seemingly punitive rules and absurd circumstances (see Figure 3), contributed to a sense of injustice and oppression, where participants felt they were “being punished for having an illness” (Angie). Mark spoke about how such punitive measures escalated distress, and highlighted staff’s inability to manage this by imposing their own agenda rather than demonstrating compassion or understanding: “The worst bit though is explaining and not being listened to... I’m used to staying in situations where I’m not actually heard, or [I’m] told what I’m saying” (Mark).

Lisa, Sue, Rosie, Mark, Diane and Angie all spoke about how critical, malicious and consuming an ED is, which services can then collude with when they restrict focus to weight management, adhering to rigid rules, arbitrary weight thresholds and mealtime routines (see Figure 4): “patients are told not to focus on the numbers and weight yet your progress is judged purely on what you weigh” (Angie). Success and worthiness became explicitly defined in terms of “numbers” (Lisa), reinforcing a sense of objectification, and reflecting wider socio-cultural values about there being a “right” weight. Consequently, “there probably is an atavistic sense of self-punishment and lack of worth associated with ED, that the structure and nature of inpatient treatment exacerbates” (Mark).

INSERT FIGURE 3 HERE

INSERT FIGURE 4 HERE

Many participants felt inpatient experience did them “more harm than good” (Angie), contributing to their “revolving door” admissions (Angie) where they “came out worse” (Rosie) than when they went in: “I was not helped I was drugged” (Rosie). Angie lost hope after her first inpatient stay because she had seen the “experts” and nothing had changed. Similarly, Diane spoke about how AN felt like a “life sentence” to her, providing her with a label that simultaneously undermined hope and her sense of self-worth, while offering an identity she felt the need to defend against losing:

INT. SITTING ROOM – DAY (INTERVIEW)

We sit perpendicular to one another on separate couches.

DIANE

I think I was incredibly depressed you know this idea of a life sentence of anorexia of struggling.

INTERVIEWER

Where had that come from?

DIANE

Well it came from seeing the patients go in and out.

INTERVIEWER

Yeah.

DIANE

So the idea was that you can't recover, you know? you spend your life going in and out. And I couldn't see that they had helped me at all, they'd put weight on me but they hadn't done anything else... that idea of categorising may feel good for the professional, but actually what that gives the patient is a sense of 'I'm not important enough' 'I'm not special enough' 'I'm just you know another one' you know - doctors not reading notes and asking questions that they've asked before - it just all sets up this anger really. And when you haven't got the words I mean you know I really didn't understand what was wrong with me so having this label that said I was anorexic well you're not going to bloody take that away from me! It's the only thing I'm good at.

Participants felt like they were being set up to fail. Rosie, Rachel and Angie spoke about how there was little support in preparing for transitioning into the outside world and to thinking beyond their ED: “it’s like you can be in hospital and fed or then you come into the community where you get some therapeutic input but you’re not getting the same food support so you’re kind of getting one or the other all the time – you’re never getting them kind of hand in hand” (Angie).

Conversely, Lisa and Emma - who only engaged with ED services on an outpatient basis - described finding their therapists supportive, even if the work itself is “frustrating” (Emma), and at times “confusing” (Lisa). Rosie, Diane, Sue and Rachel spoke similarly of the benefit, and hope that could come from working with interested and understanding professionals. However, for Mark, Sue and Rachel this compassion, and validation was only found initially amongst the other service-users: “you can see in their eyes that they are feeling exactly the same” (Mark). The professionals were less informed, which led to feelings of frustration:

INT. ROOM G18. - DAY (INTERVIEW)

We sat across from one another in the bare clinical room. The sound of the air conditioning a back drop to Rachel’s change in tone; becoming more assertive.

RACHEL

I started to get a bit indignant then - you know - I thought well why don’t they understand - they are looking after us - why don’t they read up on it you know but again there wasn’t much understanding of it.

Act Two, Scene Two: Battling it out

Having approached services with a fragile sense of self, and expending the last of their courage exposing their vulnerability in looking for help from others, participants found punishment where they had hoped to find care. This led to

indignation and frustration as participants started to use “fighting” language, “battling” metaphors, and descriptive imagery around not receiving any help to “tackle the problem” of eating in the outside world (Angie); “the battle I’ve been up against” with professionals to get them to stop solely focusing on “the physical” experience (Sue), and the “struggle” with holding on to hope in this relationship with ED and services (Diane). Consequently, participants and other service-users banded together, with stories of camaraderie (Figure 5) and “rebellling against” (Rosie) the professionals.

Similarly, Diane shared how her third inpatient stay had “allowed us to be the children that we’d never been...we laughed we joked we were told off we didn’t care”. This experience however, was different to the others because it was accompanied by the more compassionate, benevolent figures of the ward sister as the fond disciplinarian “while we would go ‘bloody her’ we loved it as well...she created the boundaries so it was a very safe place”, and the psychiatrist who “was very much like the father that I never had... he would sit down on the bed and talk to me”.

INSERT FIGURE 5 HERE

Compassion featured prominently in the narratives that depicted more positive relationships with services, where participants and services battled together *against the ED* rather than each other. Rachel, Emma and Lisa all spoke about turning points in terms of learning that “compassion [for oneself] is the key” (Rachel), developing “powerful tools” (Lisa) to support this outlook, and shared, credible weight goals with

the service that made long-term sense. For example, Emma spoke about how “the service set target weight at a BMI of 20 is so helpful - it’s difficult but it’s so helpful because there is no way that my natural weight is less than that”.

Emma also spoke about the benefits of the service “holding their line”, and giving her “the push” she needed but doing this at her pace that allowed her to develop trust. With weight gain came an increase in distress and anxiety from feeling physically uncomfortable and psychologically out of control. But because of her rapport with her therapist, and the service’s flexibility to offer alternative therapeutic models, this facilitated “formulating things in that way [which] really helped me to start to put the pieces together a bit more” (Emma). Similarly for Lisa, the turning point came when she stopped looking at her life, her MH diagnosis and the ED as *separate* experiences, and found a supportive space within services to help her make sense of this as a whole.

Act Three: Climax and Resolution: Needs and Hopes

“Death is not the opposite of life, but the opposite of choice.” (Hobb, 2008, p.212)

Act Three, Scene One: I need you to show me you hear me

Services could be experienced as maliciously indifferent, where “cold”, “clinical” and “corrupt” experiences of professionals (Rosie) reinforced participants’ sense they were worthless, unimportant and *not* good (Rosie, Sue), strong (Mark, Lisa), special (Diane), important (Rachel, Angie) or low weight (Emma) *enough*. But services were also depicted in a warmer more compassionate light, when particular staff had been perceived as supportive (Mark), encouraging (Rosie), nurturing (Diane), caring (Angie, Rachel and Lisa), and patient (Emma). Diane explained how

the wider social and healthcare systems' apparent lack of understanding could promote such indifference, and undermine such compassion:

INT. SITTING ROOM - DAY (INTERVIEW)

DIANE

They see it as an eating problem while that's the symptom...the person gets forgotten and we sit there and talk collectively about ED or SEED as opposed to the person who struggles for so many years with this illness and how can we support them to move forward - there's a kind of an apathy...

Consequences of such perceived apathy were considered in two, seemingly self-serving, threads. One was the limited availability of appropriate, understanding services and the capacity for GPs to appropriately assess and refer into these. The second reflected the participants' own understanding of EDs, which, similarly to the unhelpful professionals they encountered, were based on very "stereotypical" (Emma, Angie) media portrayals. Consequentially, participants did not consider themselves "bad" (Sue, Emma, Lisa), "young" (Diane, Rachel), or in Mark's case female, enough, to be legitimately considered as experiencing an ED, which resulted in delayed opportunities to receive specialist input.

INT. FRONT ROOM - DAY (INTERVIEW)

LISA

Once somebody says 'it's that' I can go and fuel myself, and I can educate myself on what that is. I'm not saying I can get myself out of it but I can understand it better ... it's an eating disorder it's a label and I didn't ask to have this. It makes it better - a lot better - because you feel like you're not the only one, your not a freak, you're not abnormal it's just my brain is wired a bit differently... knowledge is power really.

However, even when participants had been signposted in the right direction, some ended up avoiding services due to frightening first experiences of the professionals involved:

INT. THERAPY ROOM 2 – DAY (INTERVIEW)

We sit opposite one another. Angie has her papers in her lap, but puts them to one side.

ANGIE

...she showed me one of the patient bedrooms and she was talking about the spy hole in the bedroom... and supervision after meals... and I remember saying something about 'Oh well I don't do that I don't make myself sick I just restrict' and she said well 'by the time we are finished feeding you might start' and I drove off from [REDACTED] like a scene out of the dukes of hazard there was like dust coming out of from behind (laughs. pauses). And I do actually blame that woman for my problems being as bad as they are because she put the fear of God into me. Needless to say I didn't get admitted, I didn't go for a voluntary admission because I was absolutely petrified. [I] basically went underground and I must have had another couple of years before I did actually get admitted but I'm a strong believer that if you kind of tackle these things as soon as you can you stand a better chance.

Similarly, Sue's experiences had made her very "suspicious" and untrusting of professional support. She was no longer in direct contact having experienced a number of inappropriate interactions with staff, which were triggering in terms of early life experiences of powerlessness and objectification: "the male doctors they've been very abusive and you know in a sexual way and that doesn't help...they've let me down". Such direct accounts of malice were thought about in terms of how certain professionals could be drawn into these positions of power, with opportunities to "exploit the vulnerable", or "get away with" indifference (Sue).

Correspondingly, it was believed that from a political and economic standpoint there is a vested interest in maintaining the status quo, where in a culture of “stretched” NHS resources (Emma), there is no safeguard against the prioritising of “profits over people” (Angie) when services are put out to tender “under pressure” (Sue). Angie argued that it would be more cost effective to invest more in services, and by positioning herself as a taxpayer she sought to assert her legitimacy to this viewpoint beyond her service-user role:

INT. THERAPY ROOM 2 – DAY (INTERVIEW)

ANGIE

Yet because it [the current system] guarantees repeat income and if you invest in what people need...it costs money and I'm not saying an NHS funded option would have a bottomless pit of money but at least it's not for profit - it's about meeting patient need and it's a huge frustration to me because I'm a taxpayer at the end of the day.

Rosie spoke about the consequent “guilt” associated with receiving on-going support from community services when everyone is aware of the lack of funding, and the blaming social narratives around ED “being a choice” not an illness. Sue too spoke about feeling others were more worthy of services’ limited resources. This sense of “judgement” (Lisa) and “stigma” (Sue) was also experienced in the wider social narratives that participants reflected on, such as social media (Lisa and Rosie) and employment benefit (Sue). Participants felt vilified, and noticed how this left them vulnerable to internalising the blame they heard about in their wider social contexts.

Closing Scene: Hopes for the future

All participants shared concern about how a “one size fits all” (Angie) approach promotes a sense of disempowerment (Rosie), and undermines trust (Sue), compassion (Rachel) and hope (Diane), which were considered fundamental to living beyond this diagnosis (see Figure 6). Similarly, Mark, Angie and Rachel reflected how the high turnover rate of inpatient staff, particularly in the private services they had attended most commonly, acted as a barrier to consistency and compassionate understanding, as staff were not provided with necessary training.

Rosie and Sue described their hopes that regardless of what someone’s first contact with services looks like it is meaningful and considerate, where trust can be fostered, unlike their own experiences. Rosie believes this depends on changing attitudes in service delivery, which currently maintain an “us and them” culture, where rigidity and powerlessness promotes dependency and hopelessness:

INT. UNIVERSITY OFFICE – DAY (INTERVIEW)

We sit beside one another.

ROSIE

Because if someone, say I do want to recover it’s them who is doing it and it’s not anyone else. You’re not treating them and giving them a packet of pills and saying take these and you will be better or take food six times a day and you will be better. They have to want to do it, but they need motivation and they need emotional support and they need some guidance, even those of us who don’t want to recover. Like I need support to keep me on track. Because at one point they were questioning to even keep me in services and I was like well if you don’t do that then I just won’t eat because no one is telling me I need to... It’s not that I’m being treated, it’s that I’m being allowed to reflect and be guided to solve things my own way (pause) and it’s not a cure because it’s not making me better in that sense of the word. But it’s allowing me to keep living.

Participants emphasised how they wanted to share their experiences in the hope it would help others receive timelier, or more appropriate support. Through art (Mark) and online blogs (Emma); sharing their stories with advocacy initiatives and NHS representatives (Angie, Lisa); becoming involved in service development and practice (Diane) “one day” (Rosie); or being involved in this research (Sue, Rachel); all participants wanted to play their part in promoting better understanding of EDs and encourage a more compassionate consideration of this experience.

INSERT FIGURE 6 HERE

Discussion

In collecting and analysing the narratives of eight individuals with long-term lived experience of EDs and specialist service provision, the findings presented here offer much to consider for professionals, service commissioners, and the public. Act One conveys an understanding of the fragility and the vulnerability with which our protagonists first encountered services. In Act Two, however, we learn that instead of finding the care they required, a majority found punishment, and violent assault on their already tenuous identities. This understandably led to indignation, and frustration, which fuelled a battle between participants and professionals. Only a lucky few were able to find themselves on services’ more benevolent side where they could make sense of their experiences in the compassionate light of another’s respect. We witness a climactic Act Three where participants described the dichotomised aspect of services. They were all consuming, malicious and indifferent

to some, while individual professionals and allies within this structure held others in a more considerate and encouraging place. This was explained in terms of systemic apathy and social stereotyping, which fuelled limited understanding, a likelihood of delayed access to care, and a lack of respect. This led to an understandable fear and avoidance of services by our protagonists, which was acknowledged in the context of socio-political vested interest in generating repeat income for private inpatient services, and venerating the power of guilt and self-blame to assure this.

Similar to findings from previous qualitative research in EDs, these participants shared a strong sense of unworthiness and self-hatred at various points in their narratives (Godier & Park, 2014; Robinson et al., 2015; Thiel, Brooks, Ohlmeier, Jacoby, & Schussler, 1995). Expanding on this literature, these findings were able to root this sense of “not good enough” in the context of participants’ life stories, and in an understanding of the impact of abuse, trauma and feeling overshadowed by the “more worthy other”. Moreover, there was recognition of how these feelings were reinforced in early, and some on-going, interactions with services. This led to insight around the role that professionals have to play in maintenance of participants’ negative self-image.

Many participants recognised the protective role of their ED in serving to provide a sense of achievement, focus and control that felt necessary for survival through difficult life circumstances. However, they also recognised its life limiting aspects, and sought therapeutic input and help to make sense of the function of these. These findings are echoed in previous research, which found more positive attributes of ED being acknowledged by individuals in earlier stages of a relationship with AN compared to the later stages where individuals became more ambivalent and

distressed by the compulsive and addictive behaviours they associated with the “anorexic voice” (Tierney & Fox, 2010, p. 243).

Nevertheless, participants’ initial contact with services appeared to set the tone for the development of subsequent relationships with professionals, and the consequent opportunity they had to develop and convey such ambivalence. While some were able to overcome negative experiences to continue a relationship with service providers, the sense of value and trust they imparted into the process was shaped by how sensitive and understanding professionals were perceived to be. In line with other research, notions of rigidity and flexibility were discussed in terms of the unhelpful aspects of a “one size fits all” approach (Turton et al., 2011), and the need to foster hope above all other treatment outcomes (Dawson et al., 2014a).

Implications for Service Development

Barriers to participants receiving supportive care were experienced at a political, social, service and individual level. Participants alluded to a sense of systemic apathy whereby stereotypical representations in the mainstream media, and flippant communications on social media, reflect and perpetuate misguided assumptions about ED as an extreme “psychiatric syndrome” (Williamson 1990, p. 8 in Way, 1995), promoting oversimplified, stigmatising attitudes, and egocentric discourse around their development being “a choice” (Bannatyne & Abel, 2015).

Such discourses may be viewed as situated within a neo-liberal political context which asserts that autonomy and material success at an individual level should be valued above all else, and consequently that society can be divided into those who are more deserving of care, consideration and remuneration and those who are not (Ramon, 2008). Treating EDs as a problem within an individual is consistent with the prevailing psycho-medical narratives, and neoliberal logic that downplays the

importance of the social components of MH by pathologising experiences that deviate from what is considered “functional, productive or desirable” to the market economy (Esposito & Perez, 2014, p.414).

Arguably, politics are a symptom of wider societal unease and may reflect the current identity crises that is accompanying a global paradigm shift in how we access knowledge and information (Tippett, 2017). Nevertheless, wider political discourses collude with a diminished sense of social accountability, and place the burden of improvement and compassionate care on overwhelmed services (Cambell, 2015), unsupported staff (Crawford, Gilbert, Gilbert, Gale, & Harvey, 2013) and disenfranchised service-users. Correspondingly, growing prevalence and poor outcome rates associated with EDs, and the disproportionate amount being spent on research, reflect how services have become glaringly under-resourced compared to the level of need (Schmidt et al., 2016).

Similar to previous findings from qualitative research, inpatient services were depicted as an environment with the power to create the conditions from which EDs emerged and are exasperated, or an opportunity to provide the safe and nurturing environment necessary for healing, with service-users’ experiences commonly shifting along this continuum (Eli, 2014; Gremillion, 2003). However, while austerity measures and budget cuts create cultures of threat where employees do not feel secure or valued in their own roles, which can promote compassion fatigue (Bhutani, Bhutani, Balhara, & Kalra, 2012; Rothschild, 2006) the likelihood of staff being experienced less positively by patients is arguably increased.

Nevertheless, it is the individuals within the system that continue to be vilified instead of the Government and organisations responsible for promoting such cultures (Crawford, 2012). Compassion requires motivation and ability to engage with,

understand and alleviate suffering, and it can rarely be born from a “doing more for less” culture (Crawford et al., 2013, p. 719), which has become the norm in UK healthcare services (Seddon, 2008).

In the apparent interest of ensuring better health outcomes, neoliberal policies in the UK have identified a preference for managerial approaches to health and social care, modelled on private industry, which grant more power to service managers at the expense of individual workers’ autonomy by increasing the amount of “paper accountability” (Ramon, 2008, p. 117). Research has found an unintended and unhelpful impact of this on staff in acute MH contexts, where a production line, institutional mentality promotes emotional distancing practices between practitioners and patients over more compassionate consideration (Crawford et al., 2013).

This is a disturbing trend considering that inpatient MH services remain the main area of health provision in the UK run by private organisations (Ramon, 2008). Thus, local NHS trusts and taxpayers continue to fund expensive placements in services that seemingly prioritise “profit over people”, and undermine the potential for more compassionate approaches to the support of people with EDs, which when formalised, have been found to significantly improve social functioning and well-being in standard treatment programmes within specialist service delivery (Gale, Gilbert, Read, & Goss, 2014).

In the community context participants also described missed opportunities, and examples of inadequate care that delayed people’s access to appropriate supports, reinforcing the sense that they were not yet “worthy” of care. Such findings are echoed by others who report feeling like they were “not good enough”, and needing to “get better at [their ED]” in order to be worthy of care and support (McCubbin, 2016). Thus, when services are not supported with the necessary funding, training and insight

to provide an appropriate level of care, these findings demonstrate how they begin to play an active role in creating “revolving door” cases (BEAT, 2015, p.35).

Figure 7 contains a visual representation of the hypothesised relationships between political ideology, stigmatising social narratives, and service-level apathy in staff and service-users described above. These relationships are conveyed as taking place within a triad of vilification (consistent with current political ideologies, and participants’ perception of stigmatising social discourses), vulnerability (consistent with themes from participants’ life experiences) and violence (consistent with the “battling” language and imagery participants used when describing their relationship with services). This process arguably undermines hope in those who work in MH settings, as it does with those who experience EDs, and perpetuates a “them and us” culture between practitioners and service-users (Richards, 2010, p.40). This in turn likely reinforces the “us and them” experience the participants described in this study.

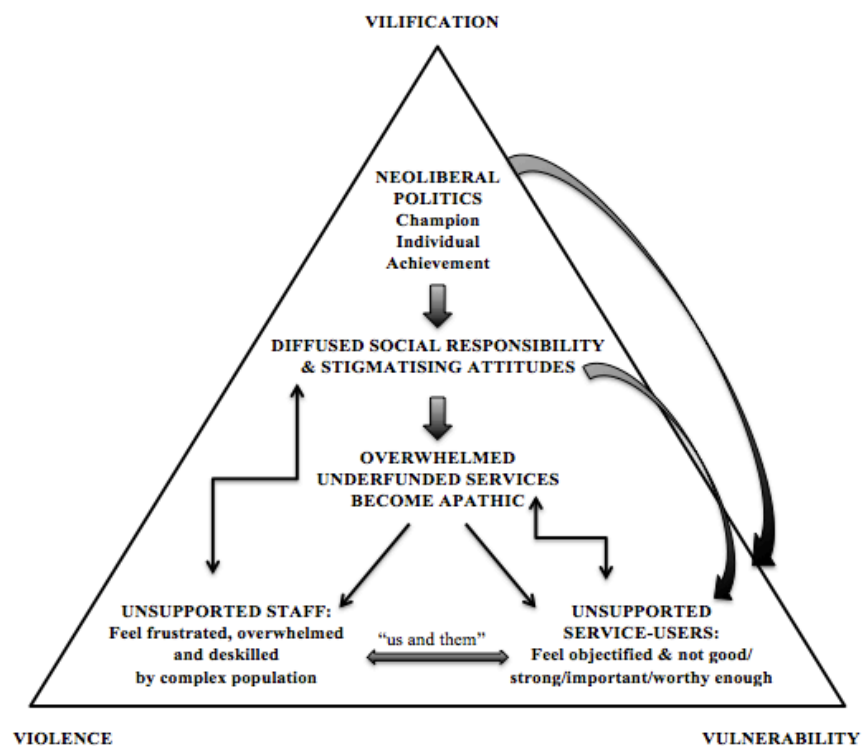


Figure 7: Triad of vilification, vulnerability and violence.

Specialist ED services have a long way to go yet to provide equitable, and timely, care and support (BEAT, 2015; HM Government, 2014). Services should be encouraged by research which has found some evidence of effectiveness in intensive psychological interventions for long-term experience of EDs (Touyz et al., 2013) and in the consistent application of compassionate, psychosocial principles (Dawson et al., 2014a; Gale et al., 2014). However, this research highlights concern about the feasibility of compassionate ED service delivery in the current socio-political context, and the wealth of information that is readily available when those, the service-users, with the most extensive and relevant experiences are invited to contribute. Table 2 outlines some suggestions about how we can use this information in practice to ensure these findings are responded to.

Table 2. MAKE A CHANGE: What we need to do to show we are listening

| At an individual level: | At a service level: |
|---|---|
| Maintain an awareness about the understandable influence of eating disorder stereotypes on prejudicial attitudes | Challenge current practice when we know it is no longer fulfilling the role it was designed to undertake |
| Ask rather than assume how to behave and communicate with someone in distress to ensure we empower rather than offend | Have recruitment, training and supervision processes in place that can foster compassionate approaches to service delivery |
| Kindly report practices where we are not adequately supported or trained to work in a way that respects the people we work for | Acknowledge the role that services can play in the maintenance of psychological distress & the promotion of safe, therapeutic spaces |
| Educate ourselves in an understanding of eating difficulties from service-user perspectives | Negotiate intervention outcomes in meaningful collaboration with service-users |
| Act with compassion towards ourselves and others; it is a difficult job we do | Generate quality benchmarks with service-user guidance |
| | Evaluate service delivery with these in mind to ensure cost-effective care is fairly assessed |

Strengths and Limitations

To my knowledge this is the first study to explore and analyse the narratives from long-term lived experience of EDs, with a focus on the role of specialist service provision across inpatient and community contexts. In line with previous findings that people with long-term experience of ED often find it difficult to trust and engage in research (Robinson et al., 2015) the recruitment strategy was amended to include members of an ED special interest group when recruitment through specialist services did not yield enough interest (see Section 4). Therefore, this study may be limited by the predominance of participants who were actively interested and involved in sharing their experiences outside of the clinical context.

The group of participants who took part in this research can be considered “ecologically” representative of a larger picture of ED service delivery for those with long-term ED experiences in the UK. A population based sample of twins in Sweden found the gender ratio of men to women for AN to be 1:4 (Bulik et al., 2006). One of the eight participants in this research was male, which is broadly in line with this finding. Participants had experience of five different NHS Trusts, and were recruited nationally with a good mix of people with multiple (5), single (1) and no inpatient experience (2). Similarly, there was a range of ages across participants.

Correspondingly, we were able to gain insight into inpatient and community service experience from 20 years ago until very recently, where for example Angie was experiencing her sixth inpatient admission during our research interview. Future research should continue using different methods of inclusion, recruitment, and analysis of service-users’ experience at different stages of interaction with services, so that these can authentically drive policy and service improvements.

Conclusion

“The big issue” in ED literature has been portrayed as disproportionate funding compared to the seriousness of the presentations, prevalence rates and poor treatment outcomes (Schmidt et al., 2016). However, this research contests this assertion by highlighting the active role of psychiatric and psychological services in shaping the experience of those who live with long-term eating difficulties for better, and for worse. A blind injection of funds, without a radical rethinking of how they should be employed, could cause more harm than good. Increasing detection rates, while continuing to promote excluding practices and an unhelpfully medicalised and hopeless view of these experiences (see Section One) consistent with demonising and commercially profitable political ideologies (Esposito & Perez, 2014; Ramon, 2008) is not the way forward.

Findings presented here paint a timely revision to the picture of the wilful, defiant ED patient “resisting” the benefits of effective treatment approaches (Eli, 2014; Fassino & Abbate-Daga, 2013; Hebebrand & Bulik, 2011). Instead they support the depiction of a healthcare system unable to connect and collaborate with the patients it ultimately seeks to serve. Similar to findings in Robinson et al.'s (2015) thematic analysis of people with experience of SEED-AN, the findings from this study suggest that individuals with long-term experience of ED are ready to work collaboratively with services to optimise care for themselves, and for others. The question remains, are we, the professionals, willing to acknowledge our failings and build on our strengths in a meaningful collaboration with service-users, and with the necessary awareness about the role our political and organisational contexts have played in the harm that has already been caused.

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Figures to be inserted in Main Text

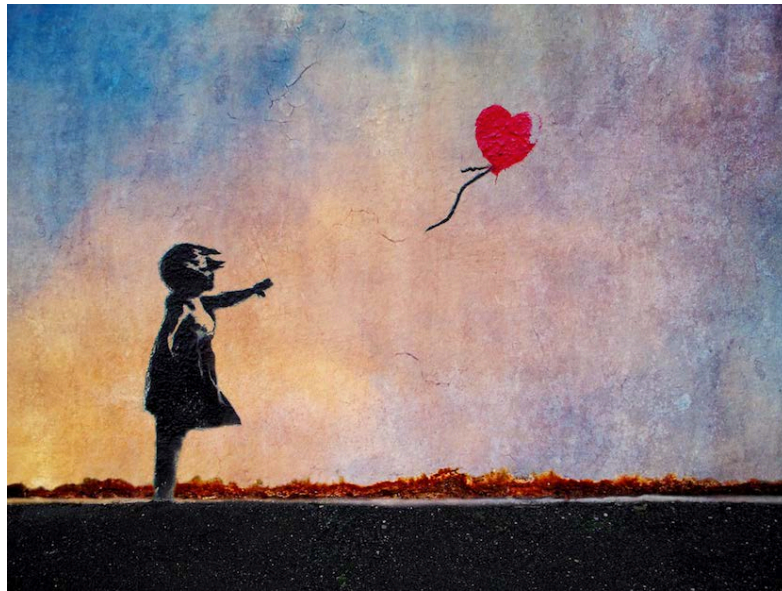


Figure 2. Rachel's chosen image at interview.

The Commandments

(Mass Exodus? 2, Verse 1)

Thou shalt be assumed to be stereotypical.
 Thou shalt eat a yoghurt with a dessert spoon, not a tea spoon, even though it is too big to fit in the pot!
 Thou shalt only eat Bran Flakes on Tuesdays & Fridays.
 Thou shalt walk, at a snail's pace, the same route at the same time every single day.
 Thou shalt not go for a walk if it is windy.
 Thou shalt be treated like a five year old at all times.
 Thou shalt be reminded to wear a coat whenever you venture out.
 Thou shalt have nobody to talk to even if you are crying your heart out.
 Thou shalt receive no TLC however bad a day you are having.
 Thou shalt not have a serviette, even if you have food round your mouth & all over your hands.
 Thou shalt not have a caffeinated cup of tea or coffee.
 Thou shalt only have one sachet of source, salt & pepper.
 Thou shalt ask permission to use the laundry (lest you should set the place on fire).
 Thou shalt be regularly woken in the middle of the night & forced to stand out in the cold, due to false fire alarms.
 Thou shalt never receive an apology if the staff make a mistake.
 Thou shalt be woken up by strangers staring at you in bed in the middle of the night (supposedly checking you are still breathing).
 Thou shalt do the same routine seven days a week, no matter how mundane & bad for your well being.
 Thou shalt not be trusted to take so much as a vitamin tablet without supervision.
 Thou shalt not be trusted with nail clippers or tweezers, let alone a pair of scissors.
 Thou shalt spread marmalade on toast with a spoon.
 Thou shalt display notices on the notice board with Sellotape, not drawing pins.
 Thou shalt eat all the food on the plate, even if the quantity is completely abnormal.
 Thou shalt eat cold custard & porridge, lest you should burn yourself.
 Thou shalt be surrounded by obese staff at all times.
 Thou shalt have all aspects of your personality attributed to your condition, to further boost your self esteem.
 Thou shalt not be deemed capable of using a hole punch or stapler without supervision.
 Thou shalt eat in silence, regardless of how hard you try to spark conversation.
 Thou shalt have your yoghurt lid removed by staff, as if you were a toddler & incapable of doing this for yourself.
 Thou shalt begin to smoke like a chimney in order to cope with the anxiety & insanity of all of the above!

The "professionals" say I am mentally ill?????????? Is it any wonder???????????

Figure 3. "The commandments" a poem written by Angie.



Figure 4. Image from “Newspaper Piece” (Mark). Bottom left writing reads: “NO patients allowed in this dining room at all except at mealtimes” Caption on the bottom of image on the right reads “Yay! Getting out for the weekend and party!”



Figure 5. Image from “Newspaper Piece” (Mark). Caption reads: “Hey, How are you doing? xxx They don’t like us happy in here do they? x bye bye! Not normal, but fuck ‘em! xxx”

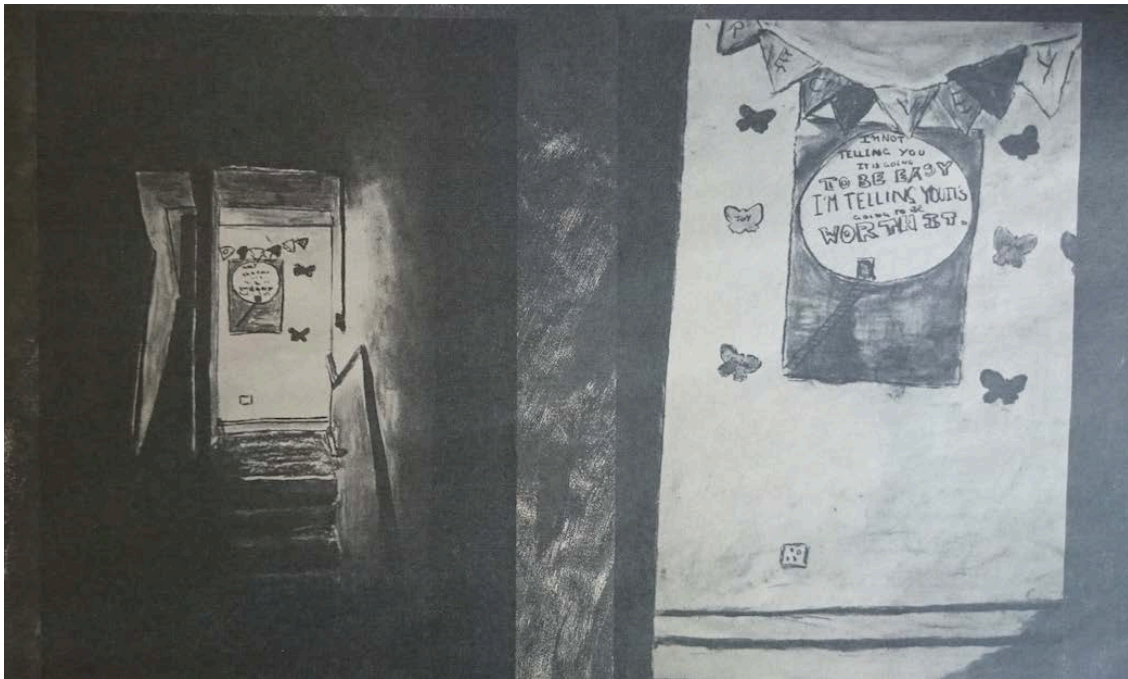


Figure 6. Image from “Newspaper Piece” (Mark). Sign reads: “I’m not telling you it’s going to be easy, I’m telling you it’s going to be worth it”.

Appendices

Appendix A: Narrative Statement to Initiate Interviews

We're here to think and talk about your experience of living with an eating disorder. I'm interested in hearing about experiences from childhood right up to where you are now, so please include any events or relationships that are important to you, but only share what you feel comfortable sharing. Does that sound ok? Where would you like to start?

Appendix B: Summary Stories

Appendix B1: Angie's Summary Story

Angie spoke about her first experience of developing eating difficulties was when she was 21. It was seemingly triggered by a very ordinary experience during a very stressful time in her life. She had started her job as a teacher and had been off sick from work for a week. When she returned she described feeling noticed when a colleague mentioned that it was obvious that she had been off work sick as she had lost a good bit of weight. She described how someone sharing their observation and concern with her had given her a sense of being noticed and cared for. At this time Angie had no contact with her parents and was going through a difficult time with her partner, having recently bought a house together. She felt unhappy and unloved, and believes that this experience of being noticed created the need for her to maintain a low weight in order to sustain this consideration.

Angie reflected that although she did not develop eating difficulties in her childhood her early experiences had created the foundation from which they emerged. Her mother was 'mentally abusive', never showed her affection and encouraged a need to achieve and be the best even though she would never celebrate achievements. She sounded like a very controlling woman, where the same meals had to be eaten at the same time, same day every week. Angie was punished for eating between meals and would only ever have been allowed a square of chocolate at a time. Angie wasn't allowed friends around the house, which made them difficult to sustain. She had a positive relationship with her father but he seemed unable to challenge her mother, and when Angie left home and the relationship with her mother broke down, she did not hear from her Dad again until very recently.

So, feeling like she needed to maintain a lower weight to feel cared for, Angie became more aware of what she was eating and started experiencing more intrusive thoughts about food. It was not a conscious decline from here but rather an intention to stay in control of food when her emotions felt so out of control. This process became about control for Angie, and specifically about the need to find control in a newer and freer environment. Because rigidity was what she had been used to in her early life it now became a way for her to manage difficult feelings during a difficult period where she was starting to navigate a new found sense of autonomy. During this phase the changes in her body were not that noticeable to others because she had always been slim and sporty, and they didn't seem that obvious at first.

Angie broke up with her partner and bought her own house. She expected things to improve now that she was out of this difficult relationship but it didn't, and her relationship with food and exercise deteriorated; exercise became a daily occurrence, diet became more restricted and she experienced more guilt around consuming food and 'breaking' the ever-increasing rules she would set for herself. She went to see a psychotherapist and this made her feel better about things on the surface but she never brought up her relationship with food and doesn't know exactly why. On reflection she feels this might have been about not wanting that way of coping to be taken away from her. So her routine around food and exercise continued for the next 5 years or so without her obviously looking 'anorexic' and without anyone noticing that she was struggling in this way. Even when she went to a gynaecologist to investigate her loss of periods they never 'twigged'.

Then Angie met [REDACTED], and this became the happiest time in her life. Feeling better in herself the reason behind her needing to control her life diminished, she started to feel loved and valued in her own right, and had a new focus, new feelings and so was able to unintentionally relax her relationship with food. It also just wasn't as easy to maintain anymore now that she was regularly eating with someone else, which was a great 'excuse' not to have to stick to the rules anymore. But about 6 months into the relationship she started to doubt that she was deserving of this happiness, and the honeymoon period of the relationship ended. She started restricting and over exercising again and things 'spiralled'. She knew that she had a problem at this stage but didn't know how to get help and didn't want to tell her partner, partially because of the sense of stigma that surround mental health difficulties and a worry that he would leave her. But also because feelings and emotions were not a conversation he was comfortable with. So it became something they both knew about but just couldn't talk about.

Then [REDACTED] went behind Angie's back to her GP and was referred to have a look around the [REDACTED] in [REDACTED]. She described meeting the team leader (who is *affectionately* known as Cruella Deville) who put 'the fear of god into her' about what an inpatient experience would be like. Angie left that place as fast as she good and still looks back at this experience as a missed opportunity. She blames the team leader for stopping her from feeling like she could have gotten help at this stage. Angie opted to go for private therapy over an inpatient stay but it was not very successful. She didn't have a great relationship with the therapist, doubted their expertise, and was not ready to give up her ED yet. Things were also deteriorating with her partner, and they were constantly fighting over meals. Her performance in sport started deteriorating as well, as she became physically weaker. This was a massive blow to her self-esteem because this was an area that she had always done well in.

So Angie continued to 'comfort starve' over the next while, and her memory of this time is vague. She was monitored by her GP but this felt quite 'hit and miss' and eventually was referred for a specialist assessment in [REDACTED] and very quickly found herself as an inpatient, without much choice in the matter or time to prepare. Angie hated the institutionalisation of the inpatient context as for her it replicated the controlling early home environment that she felt had provided a foundation for her current difficulties. It was incredibly difficult to have no say in her daily life, but she stuck with it and did everything they asked of her. She started gaining weight quickly and this change to her body felt like an 'alien invasion'. She asked for help from staff to make sense of the feelings this left her with but they never delivered on this. She felt out of control with no one to talk to so she discharged herself because it was so unbearable and went back to restricting.

Angie felt lost and confused after discharge. She was criticised by her partner for losing weight again but did not know what else to do. She had been to a specialist service and nothing had changed. She blames this experience of [REDACTED] for trying to make her want something she didn't want – weight gain (as it was only through this process that she was able to leave), rather than help her process and manage the difficult experiences she was going through. There followed a pattern of multiple admissions (6 in total) and she felt like she had no one to turn to. Even the GP was expressing their frustration with her, claiming they couldn't understand why she just wouldn't eat more. She wanted things to change but just didn't know how, she felt like a failure and didn't trust being able to share her concerns with others for fear that they would put her back into [REDACTED].

Angie felt hopeless, numb & confused and after another difficult holiday with her partner they broke up. She felt trapped as she couldn't move to another job without them knowing about her eating difficulties and she didn't want to leave a job she loved... but breaking up with the boss wasn't easy! Looking back over this relationship she can see that their ups and downs were not good for her illness and they were as much a consequence of her partner's demons as they were not helped by her ED. At the time however, everything was blamed on her and she was struggling to feel heard or understood.

More recently Angie has reconnected with her father and is hopeful that this renewed relationship will help her feel like she has a positive relationship in her life again; help her feel loved and valued. She also speaks about the importance of fostering compassion towards herself and her experiences as a way of helping her in her recovery. She reflects that her illness is about punishing herself through rigidity, restriction and control because when she was a child she felt punished and unloved, and with this as the foundation to her current experiences it's very difficult to be nice to, and possibly even love, herself. She was able to speak to her father more when she was an inpatient in [REDACTED] recently but she knows this relationship will be a hard balance between wanting answers from him and being able to forgive him, and leaving the past in the past.

Angie choose to share with me her more recent experiences of feeling like a revolving door patient which has been overwhelmingly negative and unhelpful – being just “fed” without any therapy, or receiving therapy in the community without support around meals; just never getting both at the same time. She feels this process has even contributed to her sense of body image concerns as she feels so large and uncomfortable by the time she leaves to go home she just wants a break from that feeling and will immediately revert back to her old way of managing things.” You eat to get out, not to feel better” and “anybody in their vaguely right mind wouldn't want to be in that environment”... and it is this cycle that perpetuates a sense of hopelessness.

Before Angie was diagnosed with AN she identified the problem she experienced as ‘knowing that she had to eat but finding it really difficult to do’ (as she would be feeling guilty every time), and also finding it really difficult to not do because she was thinking about food constantly. She knew what was going on in her head wasn't normal. Things had changed for her and exercise wasn't the fun and the release it used to be. She knew generally about ED and AN but didn't seem to be able to think about them in relation to her own experience. Angie can't really remember when this officially happened for her, but she thinks she felt quite embarrassed when it did. The stigma around MH was worse 10 years ago when she would have received her diagnosis of AN.

Angie spoke about having had good therapy in the community both 1:1 and group, where they were able to take a more holistic approach and put her at the centre of the process. She spoke about the difference between CBT as a logic based approach and CFT as a more emotion and belief based approach that helped her start to work on some of the core difficulties she was experiencing without just being told she should try and think differently. Unfortunately though she never had any support around eating, which she could access at the same time as therapy, which has left her feeling stuck with things.

Angie has two sets of friends – ones who “know” and ones who don’t. Sometimes she just wants normalcy and not to have to think or talk about it for awhile but she experiences a tension between wanting to feel normal and not talk about it with anybody and feeling frustrated that others don’t get it. On the one hand it’s understandable they can’t understand what it’s like but it’s irritating when people don’t try to make more of an effort and ending up making more of an issue out of it by changing over the channel if something about food comes on. Some people who have known her for years seem to just think it’s about eating more and can’t understand why that’s so difficult for her.

Although Angie had probably received a diagnosis on that first visit to the [REDACTED] it was the 2nd or 3rd admission where she had the worst experience with it. One of the consultants she had been working with just turned around to her one day and said “so you know you’ll have this for the rest of your life” which left Angie struggling to understand what that actually means in terms of what she should be doing, what she should be hoping for and the kind of support she should be receiving. Naming it didn’t change anything, it didn’t provide any answers or solutions but rather perpetuated a sense of hopelessness, and a frustration that no one seems to be questioning the regular readmissions, no one seems to understand that something needs to change.

Angie believes the reasons behind this come down to politics and money (PHP – profits before patients). Because the inpatient facilities in her catchment area are private organisations so it’s not the patient that is the top priority but rather making a profit; and by ensuring a revolving door effect with patients they are actually ensuring a regular income. This makes the initial investment it would take to get the service up to scratch, less interesting or valuable to them and [REDACTED] don’t have enough money for their own inpatient service so they seem powerless in this too. The [REDACTED] just seems to have a monopoly on the area and Angie is not quite sure why.

For Angie this sense of hopelessness often leads to depression because AN is life limiting and ‘you just can’t do all of the things you would like to be doing’. Motivation is so hard to achieve because you are constantly battling in the community about having to try and make yourself eat without support, and constantly having to battle with your emotions in hospital, you just never seem to get a break to recuperate. It’s so difficult to engage in therapy when you’re so uncomfortable in your own body and it’s so hard to gain weight because feelings so “stuffed” is so triggering. Angie feels like she is at a dead end because she has done everything she can to ask for additional support when in hospital and to ask for additional support when she is in the community but no one seems to do anything about it. No one seems to care, and those that do don’t have the money to do anything meaningful about it.

There is a sense of stigma that surrounds EDs, about EDs being perceived as a choice, and although this has improved somewhat over the years Angie feels there remains a public bias to be more understanding of those overweight because being somewhat overweight is probably the norm now. There is also a deep grained

assumption that fatter people are jollier and cuddly while underweight individuals are a bit miserable and unpleasant. So with all this going on thin people stand out more and are thought to perhaps be less acceptable.

When I asked about weight Angie explained that it becomes a measure of control. For Angie it's more about her body shape than weight and she feels at the mercy of needing that control - it's not something she can switch off. She finds that staff misunderstanding about this is really frustrating and patronising. She knows she has an illness but it doesn't render her useless but the way that staff on the ward interact with her it's hard not to feel like that's what they think. There are lots of assumptions about AN that aren't true; for example, that you believe you are overweight. So weight becomes something that you are judged against and what your incentivised against. No other progress or health outcomes are acknowledged so it skews the focus in line with the intrusive thoughts about eating, food planning, and weight – clearly highlighting this mismatch between treatment aims and practice. Weighing the right number doesn't resolve the problem it actually keeps it going, especially when it's heralded as an isolated achievement.

Angie also spoke about the secondary consequences of institutionalisation; the heightened anxiety about doing things independently leaves people less motivated to leave. And a fortisip culture that promotes dependence on liquids over moving towards the objective of eating solid food. Angie feels like she, and others she has met, are treated like bodies to feed and not valued as people with an illness that deserve compassion. There is also a distinct lack of comradery with no social or therapy groups, and they are not allowed to talk about food (to anyone!). While the lack of choice over food takes the guilt away temporarily it's a short-lived reprieve that doesn't actually translate into any real world objectives. This whole system makes Angie feels punished for having an illness and she would love to see there being more therapy being made available for her and others. She believes that this is not an unsurmountable challenge but that she has done everything that is within her power to do to try and change things, she feels unheard and her challenges to services have not yet been responded to.

Appendix B2: Sue's Summary Story

Sue's body began changing at a young age, and when she started her period aged 11, she believed that the associated changes in hormones affected her moods, and lead to her feeling depressed. This started to affect her in school, and at home, and at the age of 14 her GP sent her to hospital for an assessment. When the nurses tried to examine her, Sue started to shout at them and wouldn't let them near her. Consequently, they felt she might benefit from a referral to a psychiatrist. Sue remembers this psychiatrist as a very stern older woman, who put the "fear into her". Her mental health deteriorated after this point, which led to Sue's doctor sending her to a number of psychiatrists, psychologists and psychotherapists throughout her life. Sue believes that the depression she experienced led to another health problem in her 20's when she was diagnosed with Anorexia.

Sue reflected that there were main early signs that she was struggling with her body image, which had not been picked up on when she was younger. For example Sue would ask new friends at school if they thought she was fat, and she used to regularly study her stomach, thinking she was fat. She was fearful of eating a whole

biscuit, and very rarely ate chocolate or sweets, and she remembers finding Sunday dinners particularly difficult as she was expected to eat most of the roast dinner and she wasn't keen on eating much of the meat and preferred to just eat vegetables. Sue had a variety of jobs throughout her adolescence, but her mental health was still declining. Sue began exercising in between her day jobs, before going on to her evening jobs, and her weight started to fall. She felt this wasn't an intentional drive to lose weight but that she noticed exercising made her feel good in herself; she would get a "buzz" from it and started to become quite "obsessive". Sue was in a difficult relationship with an ex-partner at the time, who was very controlling of her. In this context, she didn't feel worthy of food but she did feel comforted by her exercise regime.

Sue talked about how she had a number of jobs during her teenage years that made her feel very objectified by others, and very unsafe. She explained that she had learned to stand up for herself after receiving the "wrong kind of attention" from older men from a young age. Sue recognised how these experiences of unwanted attention made her hate herself and feel unworthy. She felt like an object rather than a person and believes that unconsciously this affected how she wanted to become less sexual in her own appearance and less attractive to others.

She felt her relationship to exercise helped get rid of all that tension and anger that she felt. And she felt that restricting food helped her "cut off" from her feelings because she wanted to feel numb. Sue reflected on how for her these patterns of behaviour - restricting her food intake and exercising regularly - were kind of like a slow suicide.

She spoke about moving around a variety of jobs, and described a number of roles where she felt taken advantage of by her employers. It was around this time her panic attacks started as her body's way of responding to the weight loss. She remembers vividly the first time this happened driving back from her job where she had to pull into someone's driveway and simply lie down in the back seat hoping that it would pass, but as she struggled with her breathing she felt she was going to die.

Sue described how after this point she just started getting thinner and thinner and having more and more panic attacks. She remembers feeling so sick, weak and overwhelmed because this seemed to be happening all the time. It got to the point, in her early 20s, where her psychiatrist told her that she needed to go and spend time in hospital. She found this difficult because as an inpatient she felt like she was constantly being fed first breakfast and mid-morning snack, then lunch in the mid-afternoon, another snack, dinner and supper. It felt intolerable both physically and emotionally.

Her mum stuck up for her during this period and became angry with the doctors about how she was being treated. They were able to organise a specialist consultant to assess her, who recommended the use of the dietician informing the meal plans in the inpatient ward. Sue remembers how the nurses ripped up this diet plan after the dietician left, and how disappointing and frustrating this felt that they couldn't respect how painful and difficult the process was for her.

Sue described how while being an inpatient she felt very disrespected by the staff. They would taunt her about having to eat every crumb on her plate while they could just get away with eating an apple. She became very suspicious of the care she was receiving and would never take the medication that they prescribed but only the tablets that her own doctor outside of the hospital had been prescribing. She described an incident where a male nurse walked in on her while she was getting dressed after she had asked him to wait outside and about how this made her feel yet

again like there was another man treating her like an object. She didn't feel safe and she didn't feel supported.

Sue spoke about how during this impatient visit there were people in positions of power that offered her inappropriate treatment, broke their promises of confidentiality, and behaved unprofessionally in appointments. She gave the example where the staff used to have parties in the ward and would turn up the following morning to appointments, still drunk from the night before, falling asleep during a session.

Sue reflected on the specific incident where she was seeing a psychiatrist who was offering her family therapy. On a day where her father, mother and her brother were attending a clinic with her, he betrayed her confidence and shared information with her family that she did not feel ready to discuss yet. This ended up in an escalation between the psychiatrist and her father and it broke down any remaining trust she had for the service and her relationship with them.

She felt very let down by this experience reflecting on how the services didn't really listen to her, the patient, but rather treated every one as having the same problem that food was the only cure for. She reflected on how although there were some therapeutic activities offered like music or art therapy these were done in a very impersonal way, and didn't feel like an appropriate support at the time. She talked about how for her it made sense of why people leave hospital only to return again at a later time, without having any opportunity to work on the "mental" side of their experience and only receiving treatment for the physical side of their experience.

Sue described feeling in a constant battle with different professionals. She's been to see so many people in so many different services and she had only rarely had a supportive relationship. She spoke about one example where there was a female psychologist she was working with that she got on really well with. However, she felt let down by this person who said she would always be there for her but ended up leaving the service, possibly due to exhaustion from work.

Sue's mum sounds like she's always been a very strong supporter of her, and a strong woman in her own right. Sue reflected on how her mother had difficulties around her own relationship with her body and food, but how her mother has learned to accept this over the years. Even when she felt she could not understand what Sue was going through, Sue's mum started researching eating disorders, listening to stories of others' experience of anorexia. She always stood up for Sue in relation to some of the awful unprofessional experiences she's had with services.

Overall Sue feels like the eating disorder has ruined her life. It has prevented her from having children, and from doing the things she would prefer to be doing. Although Sue is currently in a very supportive relationship with her partner she still feels very unwell, very physically weak and is undergoing more physical tests. Although recently her psychiatrist tried to discharge her from his service she is grateful that she has been able to re-refer herself after determining that there were no other organisations offering appropriate services in her area.

Sue continues to feel very low. She has been offered an appointment to meet with a psychologist from a different service, and despite all of her previously disappointing and frustrating interactions with services and professionals, she has decided to meet with them in the hope that she will be able to find someone who can see her for more than her difficulty with food.

Sue describes her daily struggle in terms of how she needs to feel empty to feel comfortable and satisfied, and how maddening it is to feel full. She gets exhausted very easily and needs to be supported by her partner quite a lot, but she still

has dreams of starting her own retail business in natural cosmetic products. Sue described herself as someone who has always understood the difference between right and wrong, and how important it is to do the right thing for others. I wonder if this worldview makes it even more disappointing that she feels like others haven't treated her like this, especially the majority of mental health professionals that she has worked with.

Sue spoke about understanding the wider context of how much pressure NHS services are under at the moment and wonders how this has affected the care that she has received. She has experienced first-hand the disinterest of some of her psychiatrists, and was told when she requested further psychotherapeutic input that there were no other options available to her. Sue has described times where she has experienced services being as abusive as some of her early life and work experiences. She worries that some professionals have been put in a position of power where they can prey on vulnerable people, and has experienced first-hand how dangerous this can be.

Sue would like to see more caring services, which allow professionals to develop collaborative and understanding relationships with their clients where, rather than asking people what it is that they *want* from services, professionals can sit down and work with patients side-by-side in figuring out together what might be worth trying.

Professionals have consistently told Sue that her difficulties “run deep”. However, they have always worked from the perspective that she needed to change her eating first, and Sue wonders if, for her, it was the depression that “came first”. Sue recognises that there will never be a “magic wand” to fix her, and that change to a large extent depends on the person themselves wanting to change and being in a position to work with the support that is offered. But she also talked about how for her the support has been limited, and at times harmful and abusive. She hopes for a better offer from services and intends to keep playing her part in relationship with them.

Appendix B3: Emma's Summary Story

Emma began talking about how she felt her experience of living with a long-term eating disorder was not typical, in that she has only recently received support for this over the last 18 months and has been able to maintain her ability to function at a low weight for a long period of time; ‘being good at appearing ok’ is, at least partially, why Emma believes she did not receive professional support before this recent experience. She described having been living with Anorexia for over 12 years, having first experienced related thoughts and feelings when she was about 11 years of age.

Emma first came into contact with specialist services in the summer of 2015, and with their support, and the work she has been putting in, she described currently feeling the best she has ever been. Emma reflected on how she felt the ‘conditions for recovery’ were right for her just now, in terms of having such a supportive partner, friends and professionals involved as well as a more a positive relationship with her sister. She wonders occasionally if she had received the quality of care and support she is benefiting from now would she have been able to recover earlier, but reflected that this was unlikely given how recently she felt able to acknowledge that she had a ‘problem’ in her relationship with food.

Emma described the process of getting to a place where she could acknowledge she needed and wanted some help. It sounds like this recognition had wavered over the years. There had been several times when she presented with physical health complaints that she felt others could have acted on, and two previous occasions where she had asked for support from services. The first of these was in her early 20's when her younger sister shared her concerns about Emma's weight and wellbeing in a way that challenged her ability to 'brush' these off. Also around this time her employer had also acknowledged that she was very underweight and formally asked her to get some help. Emma went to see her GP, received a diagnosis of Anorexia and started to see a dietician. This was helpful for a short period but when the dietician stopped weighing her, once the minimum target had been reached, she felt this meant she was 'ok enough' to disengage.

The second time was about five or six years ago when Emma had first moved to her current area. She had approached her GP but was told that her weight was not 'low enough' to warrant input from specialist services. At the time Emma felt like this must mean that she was ok and took the doctor at their word, but as time passed and she saw others she knew going through specialist services she started to realise that her experience and her weight was similar enough to theirs to justify her attending those services too. Her friends were also conveying their concerns about her, telling her that they didn't feel that she was ok, and she found the courage to approach her GP again but this time prepared with a completed referral form in hand. Emma reflected that this third attempt to seek support was perhaps driven by the recognition that if she wanted to change things she wasn't going to be able to do it on her own.

Emma talked positively about this recent experience of asking for help, where this new GP respected her request and got her referred to her local ED services, which she has found to be a brilliant support. She was first involved in the CBT group of a comparison trial between CBT and CAT. She felt this was a good choice for her and found this initial interaction with services was useful up until a point, but that after awhile her weight became quite stuck. As her relationship with food was being challenged her levels of distress and anxiety were increasing, she felt the need for more intensive help to get her to a place where she could gain weight more consistently and process some of the accompanying difficulties, like fears of contamination, that were arising for her.

Emma then went to day service for about 18 weeks and found this particularly helpful in challenging some of the more rigid rules and fears she had about food. She also found this a tough experience as she felt it was difficult to manage her emotions with this more intense and frequent contact. From this experience Emma began to make some connections between how her experience of an eating disorder was related to her early life experiences, and she started to see it as a 'double-edged sword' whereby it was protective in managing difficult feelings for her but life limiting in the way it did so. Emma described an almost impossible task of giving up these protective strategies that helped her feeling calmer in herself, while at the same time becoming more aware of some really difficult memories and feelings that were arising for her.

Emma has since gone on to participate in a more CAT informed therapy, which she is finding useful in seeing how these difficult feelings and states of anxiety all fit together. She expressed her concern that she might be quite a 'frustrating' client to work with because of how slow she feels her progress has been in that she is still in the weight restoration phase 18 months on. However, she also seems to recognise that although it might seem like she just has a little bit more weight to gain, this is incredibly difficult for her to do considering how controlled she still feels by weight.

This is very understandable considering how long she has been relying on her relationship with food and her body as a way of coping.

Emma described how she probably started displayed signs of having an eating disorder from about 11 years of age as she became concerned about her weight and her food intake even though she had never been overweight. She remembers feeling uncomfortable in her body and thinking that if she lost weight this would help her feel better in herself, and so she maintained her low weight during times where she should have ordinarily been gaining weight and growing. It got to the point where her mother took her to the doctor at age 14 or 15, but she doesn't remember anything significant changing after that. She wasn't diagnosed or told to try anything in particular, but she managed to gain a bit of weight herself, possibly in an attempt to appease her mother or the doctor. Nevertheless, she remained quite ill and underweight.

Things were very difficult for Emma at home in those early years. Her father was an alcoholic and a violent man, and her mother was quite fragile and found it very difficult to cope. Emma was very much the responsible one at home, who got things sorted out and looked after everyone else. Her parents split up in her teens, and while she saw this as a positive thing she was let down by how little it changed things for them. Things still weren't settling and actually become more difficult for a while. To have gone from living in such a volatile, uncertain place with her father to then have her hopes of a more consistent stable home environment dashed after their separation felt unbearably disappointing. Emma described making a connection between this period and how her relationship with her Mum has triggered her feeling more reliant on the eating disorder, reflecting on the time she had moved back home in her early 20's and how low and isolated she felt during this period.

Emma described how her relationship with food and her body had improved somewhat when she had left home and went off to college, but then how she started to struggle with not having a real sense of where she wanted to go in life. She finished her degree and was enjoying working in a school but knew she didn't want to stay in that role and felt no sense of direction. This left her feeling quite dependant on her eating disorder to provide a sense of achievement in 'doing something' and she felt she became quite addicted to losing weight in this context. When she decided to go back and do social work she found this sense of purpose for a while, which helped her maintain her weight and her ability to function for the job.

Emma reflected on how during the next period in her 20's while she was working as a social worker, she described a tension between feeling, on the one hand, unhappy in her body but thinking that there was nothing really wrong with her so there was no need to gain any weight, while on the other hand, feeling overweight and wanting to lose weight but knowing that this would stop her from being able to do the job she liked. Work had always been something that Emma felt she could do well, and so it was usually a positive focus for her, but it sounds like the real turning point came for Emma when she met her current partner. Until that point, her relationships had remained quite 'surface level', and so she recognised she had a choice to make between developing a more meaningful relationship and holding onto the eating disorder. On some level she saw the opportunity this choice presented, and found the courage to decide to try and take this relationship further.

Emma described how, for her, recovery looks a lot like her sister's relationship with food, where she can eat what she wants and doesn't have any strong desire to lose weight. She is active and walks lot but that is more about a lifestyle preference than an intention to manage her weight. She sees her sister's body shape and weight to be quite healthy, and above her own target BMI of 20. But she also spoke about how

although she feels very ‘hung up’ on weight gain at the moment, for her, recovery is a lot broader than this and involves developing a more rounded sense of herself, which is something she feels the eating disorder takes from you, especially over such a long period of time. Emma reflected that while she is keen to ensure her image of recovery is a realistic one, her evolving experience of recovery has shifted (and continues to shift), what she thought and hoped could be possible. She is relieved to find herself letting go of expectations that she thought she would be quite fearful about, like the intention of returning to her old running routines in the future. She reflected that this sense of relief will be important to remember going forward.

Emma spoke about how important the ED services’ targets and encouragement around weight gain have been for her. She reflected on how it made sense to her that they advocate for weight gain up to a minimum of a BMI of 20 with the recognition that any less than this is not going to allow for a more ‘normal’ relationship with food, but will involve a continuously restrictive or compensatory strategy. She acknowledged that while this is hard, and initially felt like an impossible goal, it feels very important to be aiming for something realistic. Emma struck me as being very determined in her goal to get to a place where her relationship with food is not controlling her life anymore. She would like to be in a position to start a family with her partner, and to ensure she feels able to be emotionally responsive to herself, and those around her. Emma has already seen some of the benefits of the hard work she is putting into understanding herself and the ways she has been managing things. She writes a blog as a way of reflecting and openly communicating her experiences with others, and she has noticed the quality of her relationships improving, particularly with her partner and her sister, which feels like an important step towards her image of recovery.

Emma talked about her mixed experience of seeking support from GPs over the years, where she has found their lack of understanding about eating disorders to reflect some of the more common narratives and stereotypes. These include inaccuracies such as how eating disorders only happen to young women, how they tend to be related to concerns about appearance and are linked with narcissistic tendencies. Emma feels these stereotypes can lead to professionals and the public being quite dismissive of eating disorders as something people chose to experience. She also reflected on how these perspectives were often circulated in her work environment when she was working in a CMHT, and about how on occasion she even found herself internalising these assumptions. The recognition that it was unreasonable to expect herself to be able to just think differently about her relationship with her body and food was unexpected and only very recently realised.

Emma’s own experience has led her to conclude that eating disorders are closely related to early life experiences, relationships and trauma rather than a desire to look a certain way. For Emma the tangible, conscious feelings were sometimes about not being thin enough and wanting to feel slimmer but the roots of those feelings went much deeper and were far more complex. From listening to her story it seems like Emma’s experience has been much more about personal worth, value, and direction; of managing deep rooted anxieties and difficult feelings associated with her early life experiences and of wanting to feel ‘good enough’ in a culture where personal success and achievement are deemed paramount. Nevertheless, Emma had reflected how these alternative ways of understanding eating disorders do not seem to be considered by the majority of mental health professionals that she has worked with.

Throughout the interview Emma reflected how she did not feel her experience was typical of others who have lived with a long-term diagnosis of anorexia. She

described how at times she had not seen herself as ‘thin enough’ to be ‘anorexic’ which translated as not being ‘good enough’ at the eating disorder. While this may have stopped her from overly identifying with the alluring ‘anorexic’ identity portrayed on instagram and pro-anorexia websites, it also perpetuated a sense of isolation during her most difficult periods. It is likely this distorted sense of failure undermined an impetus to change in Emma for a long period, however she now feels like she is in a very different (if imperfect) place with things, and that she has much to hope for going forward.

Appendix B4: Diane’s Summary Story

Diane began her story by reflecting on her early life experiences, specifically having had a very strict upbringing with no sense of an identity outside of what her father wanted her, and her brothers, to embody. At 18 Diane was diagnosed with lung cancer and had to have a large section of her lung resected. She recounted the memory of how she woke up from this surgery with her father’s hand in hers. He asked her to squeeze his hand if she could hear him, and although she could, she felt very powerful in resisting this request from him. For once she wanted to be the one in control and to have *him* worrying about *her*.

When Diane went back to University after this period, she had to restart her first year while her friends had progressed. She remembers how, when one of the popular guys had taken an interest in her, she felt confused and flattered by his attention, compelled to ensure that she remain ‘exactly as she was’ for him. She used the then popular grapefruit diet as a way to start restricting her intake and soon, as her weight began to drop, she forgot about the boy in question and instead became consumed by this way of life. She stopped going to classes, sleeping through the day to avoid eating and working by night. Her course tutors called her parents to convey their concerns, and they returned her to London, with memories of how angry her father was at her for ‘letting the side down’.

At 22, Diane felt like a complete failure. She was diagnosed with depression by her GP, and while no one acknowledged her relationship with diet and exercise as a problem in its own right, she continued restricting and over-exercising, pushing herself to her limits in every way. Diane got a job in the hotel industry and had soon worked her way up to a top sales executive position. In the process however, she had dropped to 4 and 1/2 stone and her manager asked her to take some time off. She didn’t think there was anything wrong, and her parents had not mentioned anything to her, but she remembers always feeling cold, and tired a lot of the time, and receiving unsympathetic responses from the GP about this; but still nobody had considered that she might be living with an ED up until this point.

She was sent to a general hospital to try and stabilise her health, however she managed to lose weight even in this environment, and was quickly referred on to an 8-bed specialist ED unit. She remembers thinking how underweight one of the other inpatients looked, but had not yet realised that she herself must be presenting in a similar, if not worse, way. She reflected on this inpatient stay with a humorous take on the horror; about how at 24 years of age she was considered too old to be a typical ‘anorexic’ and was diagnosed as having ‘a-anorexia’; about how they were all just ‘fed up’ with triple portions and no psychological support; and about how after just

eight weeks she had gained 2 stone and was discharged with two-weeks' worth of anti-depressants and sleeping tablets.

She remembers coming back to the family home that night and being permitted to skip dinner given how 'overwhelmed' she must have been finding the transition out of the hospital. She went up to her room and took all of the medication she had been prescribed with the intention of ending her life, but when they hadn't taken effect half an hour later, she snuck out of the house and walked down to the family GP. She was feeling quite woozy at this stage and at some point in her conversation with the doctor must have let slip her concern that she 'couldn't *even* kill herself'. The doctor took her immediately back to the ED unit and had her stomach pumped. It was then decided by the psychiatrist on the ward that as she was just 'attention seeking' she should be transferred to the general psychiatric ward rather than back onto the specialist unit.

Diane remembers feeling deeply depressed at this time, having been diagnosed with a condition that didn't appear to hold much hope of a positive prognosis. During her time at the specialist unit most of the women she had met were on their second or third stay, and there was a general sense that this was just the way it was with Anorexia. She spent about 8 months on the general psychiatric ward, receiving high doses of medication and little else until a clinical psychologist from the specialist unit asked if he could start to see her therapeutically. She became understandably very dependent on this psychologist, as the first person who had ever really wanted to know her, he started to give her some hope, and some space to tell her story.

Diane was discharged into her cousins' care this time, rather than her parents, and she found their hands off approach quite refreshing and containing. She went back to work in the hotel industry and continued a relationship with her psychologist when he moved out of area. Although she did not realise the inappropriateness of it at the time, she would often visit him, stay with his family and go out to dinner with him when he was back in London. This relationship ended badly, suddenly and unexpectedly. Diane very quickly disconnected from any consideration of this, moving on with her life with little thought of how this relationship had affected her until she got the opportunity to reflect on it in later therapy.

Diane went on to meet her husband in her 30's. She married him after unexpectedly falling pregnant with his child. She had been maintaining her weight at about 6 ½ stone but had not considered the likelihood of becoming pregnant, given how much her body had been through since she was 17. But she enjoyed being pregnant, becoming a mother three times over a 6-year period.

After her second child was born she chose to start a business from home. She had no therapeutic input at this time but managed to maintain her weight around 7 stone by being very careful about what she would allow herself to eat. She continued in this way until she and her husband divorced when her eldest was about 10 years of age. This was a difficult period as her ex handled his part of it very badly, and her eldest struggled to adapt to the separation, but a good friend supported her to get a good lawyer, and she managed to get through this by applying her usual combination of sheer dedication and commitment to the next phase.

It wasn't until her eldest son's Bar Mitzvah 3 years later that her weight began dropping again, and her brother shared his concern with her that she ought to consider getting some support. Her brother introduced her to his own therapist who she took to immediately, but when her weight dropped a second time after her younger son's Bar Mitzvah 13 months later, this therapist organised a bed for her in a different specialist unit. Diane entered this inpatient stay feeling like she wasn't a 'good enough

anorexic' and assumed that they would just put some weight on her before letting her go again. Despite assurances that this time would be different, Diane felt the need to 'act out' insofar as she refused to talk to the staff initially or let her family visit her. She was reluctant to engage in the intensive therapeutic programme or any of the psychologists on the ward because she knew her therapist was waiting for her the community. Initially she refused to 'play' along, but over time she settled in to the routines, and had a positive experience over the next 12 months.

Diane would have been in her late 30's around this time, and found herself again mostly surrounded by younger girls. She warmed to the clinical lead of the programme, a psychiatrist who slowly became a benevolent father figure to her. He, along with the head sister, created a safe environment that Diane described as providing a way to allow them to experience a kind of childhood they had never had. Having organised a nanny for her children, and a trusted business partner for the business, she described with affection how she developed relationships with the other inpatients over this period, about how they used to test and challenge their boundaries in way that replicated an adolescent phase of childhood. Diane reflected on how she had never been good at playing with others as a child but how this inpatient stay had a definite therapeutic effect on her.

Diane was discharged, and somehow managed to 'slip through the net' without reengaging with the hospital. Consequently, she ended up losing some of the weight she had gained and with the support of her psychologist returned to the ED unit for a 6-week rehabilitation period. Her close friends supported her with this by helping her send the children away on a Camp America type trip, and with their wellbeing attended to, she permitted herself to return to invest in herself again. She continued to work collaboratively with the psychiatrist, and after this second discharge began to see him first on a fortnightly, and then a monthly basis. She also had some useful practical input from the dietician on the ward that helped Diane reflect on the necessary steps towards 'normality' that she wanted to commit to.

Diane reflected on how the most influential experience she had in relation to managing her weight, was the work she did with her therapist in the community. This work focused on her sense of self, rather than about the ED in particular. Their work together allowed her to process the power her father's worldview had held over herself and her brother. She spoke about how her father's mantra 'don't laugh in the morning or you'll cry at night' had instilled a kind of dread in her that she couldn't enjoy anything for fear that it would all go horribly wrong. Therapy, in all of its varied relational stages, helped her get to a place where she began to 'quite like herself', and she found that she was able to eat more and worry about her self-doubt less.

Diane spoke about how her relationship with her daughter has helped her develop a helpful irreverence towards herself. She described her daughter as a positive person, 'a little powerhouse' whom she is very proud of, and reflected on how close she was to all of her children, of their importance to her. This closeness had taken some time to develop after Diane felt she wasn't able to be around for them as much as she would have liked when they were little. She became the main bread winner for the family very early on, and this combined with the time she spent as an inpatient, meant that she perceived some distance between them during their early years that she has made every effort to reduce over recent years.

Diane reflected on the on-going challenge that is trying to negotiate 'normality' since finishing her work with her therapist, and trying to move on with her life. She has replaced restrictive rules around food and exercise with a rule of

thumb about maintaining a strict routine about not missing any meals in a day. She notices that while she has some food preferences, she doesn't really taste or enjoy it and has to support herself to eat regularly. She also reflected on how her sense of normality has been influenced by her relationship with friends; giving the example of being encouraged to maintain some flexibility in her approach towards what is considered a working lunch and whether or not she should permit herself to go back to the gym.

Diane described how she no longer considers herself Anorexic anymore, about how she 'eats to live rather than lives to eat'. It has been described to her as an Achilles heel that might affect her during times of stress or anxiety, and she reflected on how she has developed a different way of managing this tendency now. She also reflected on the importance of hope in learning to live with and move beyond this diagnosis, and on how professionals have a responsibility to hold this for their clients. Diane has gone on to become a psychotherapist herself and works with people who have their own experience of living with an ED, and with professionals in this area. She conveyed her concern that the current trend of adopting CBT for this presentation does not seem to be the answer, and how the *person* can often get forgotten about in the collective discussions about EDs.

We also discussed the general sense of apathy that can surround this experience, and about how this can be related to individuals' resistance to change and concern that moving away from their ED can feel like moving back to the time where they needed to develop this way of managing to begin with. We also discussed this in terms of how professionals' need to provide categorisations can reinforce the sense of not feeling important or special enough, which may unwittingly enhance individuals' identification with the label of Anorexia as the only thing they can feel they are good at, and as a something they don't want professionals to take away. Diane wondered what her experience would have been like if she got better quality help earlier, and has made the move from a career in the corporate world as a way to try and be in a position to provide this to others.

She reflected on the on-going challenges in her relationship with her parents, and the support she receives from her older brother in particular around this. Diane also spoke about hoping for more from her own relationships in the future, about being open to romantic love, and wanting to find the opportunity for that in her life. She shared her view on the importance of 'Carpe Diem' seizing the day, being able to take joy and appreciation in the present, and believing that things, which are meant to be, will be. She has less of a need for certainty in her life, and believes in the worthy endeavour of attempting to understand the opportunities and limitations of living in a black and white world, the implications of social expectations, and investing in a way to help others reach a place that enables them to feel like they can fit into these somehow, perhaps without compromising themselves too much.

Appendix B5: Rachel's Summary Story

Rachael remembers being about 5 years old the first time that she weighed herself. She remembers that food was always an issue from a young age and believes this was due to tension in her family home. Rachael lived with her parents and her brother, who got all the attention. He was an outgoing, clever and funny. Rachael accepted that that was just the order of things - that he would be better liked than her.

Rachael has early memories of being sat in the dinner hall in school being forced to eat. She was kept behind a year in school and felt a lot of shame about this, feeling separate to her brother. This contributed to her earliest memory of feeling “not good enough” at about the age of 7. She always felt separate from the others, on the edge of things, and remembers how starting high school was another example of this when her mother chose not to buy her a school uniform, and kept her hair short and boy like. It was embarrassing when others mistook her for a boy.

Rachael did well in sports in school and it felt good to be good at something. She remembers throwing sandwiches away as this was an opportunity not to have to eat. At home she was shouted at and forced to eat during mealtimes, which increased her anxiety and contributed to a sense of defiance that she could avoid eating when the opportunity arose. Even when she went to great lengths to avoid eating at home her mother would force her to consume inedible food. Rachael believes her mum thought she was being a good parent in these decisions not that she was being intentionally cruel, but it was still an awful, shaming process to have been put through.

Rachael mentioned her mother and her granny as being importance figures in her early life. They were very critical people and always seemed to think the children were being naughty. Rachel remembers feeling very frightened as a child, but reflected on how her brother and her were really very good children. Rachael spoke about how one teacher in high school seemed to take a special, caring interest in her, making sure she had her dinner tickets. She felt resentful towards this person, and didn't like the feeling of being under surveillance by her. She remembers being quite cheeky to this teacher, and thinks that perhaps this was because she couldn't be like that to her mum.

Rachael also spoke about her relationship with her twin and how he would help her out in clearing her dinner plate, if it suited him. She spoke about how his friends used to be hers as she didn't have much confidence or opportunity to have her own. Although they were separated when her parents split up, Rachael spoke about reconnecting with her twin after her mother's death. She explained that they are very close now and that they talk about everything, except eating. She does not want him to challenge or police her on this. It is something that is hers alone that she will not share.

Around the age of 12 Rachael remembers feeling alarmed and embarrassed by family comments about her developing and her appearance. She remembers how her mother and granny were always preoccupied by dieting and how afraid she was of gaining weight. Rachael didn't want to be seen as attractive or sexual in any way, and she recognises this a drive to protect herself.

Her mum and dad were fighting a lot at home and her father had an affair so her mum told him to leave. She remembers this being very traumatic, as they got a divorce at a time where there was a lot of shame about this. She also remembers receiving distressing letters from a neighbour accusing her mother of being promiscuous, and feeling a real need to look after her mother in her father and brother's absence.

She took on more responsibility at home and although this felt scary she had no choice. She got a part time job after school at a hairdressers and remembers feeling frightened of the very loud raucous ladies who worked in the sausage factory and left with sausage-like rolls in their hair. While it felt satisfying to do a good job she remembers how it was really hard, and painful at times after developing dermatitis in

a reaction to the soap they used. But it was also another good opportunity to avoid food as she would go straight to the hairdressers after school.

Rachael spoke about feeling very isolated during this time, without her twin at home but the job kept her going. Each weekend she would get an hour and half bus journey over to see her brother and her father, and reflects now on how ridiculous that was considering her father had a car, but she didn't question it at the time.

When Rachael left school she got a job as a management trainee, which kept her separate again from her peers. Her mother had a lot of influence over her job choices at the time and she didn't feel like she had any choice in the matter. She worked hard and was offered a pay rise quite quickly into the role. It helped her feel good about herself to be good at something, and she was flattered when her future husband started showing some interest in her and they started dating.

But soon after this relationship started up she was devastated when her mother told her they were moving to [REDACTED] for a fresh start. She was offered a flat with work but felt she was too young to live on her own and her mother needed her contributions to afford a mortgage in the new house. Her partner didn't understand and was angry with her, he finally gave her an ultimatum and she moved in with him in [REDACTED]. She was told to pack her bags by her mother and felt very judged for going to live with him as an unmarried woman.

But it also felt like freedom. She started working in a laundry, and they were drinking a lot. Although she feels this should have been a happy time, it wasn't really. She went to work for [REDACTED] and felt different to everybody again as she had a bit of a "bad girl" image. She got pregnant soon after and got married as a consequence of her mother's suggestion to do so.

This period was a struggle; she was trying to settle down but felt very much on her own. [REDACTED] was going out a lot, spending their money and acting in very controlling ways. She felt that she didn't deserve any better, that's just the way it was. But in all of this she was determined that things were going to be very different for her baby than things had been for her. I wonder if her relationship with her body and with food changed during this period? how Rachael managed the drive to restrict and fear of gaining weight during her pregnancy?

Rachel's daughter was born premature which was a bit of a shock but when Rachael got through this she remembers being very happy. But she was also very overwhelmed at this time and believes this was the start of her mental health problems. She went a bit "loopy" and didn't know what she was doing half the time. She felt very protective of her daughter and a lot of love for her but this was difficult because it didn't always feel natural and she felt she had no one to turn to for support. She became a bit obsessed with doing research in the library about good parenting, and, as always, she worked very hard to make it work on her own as her husband was not around much at all.

When she became pregnant again, with her second daughter she was more relaxed as she knew what to expect. After her birth she started working nights in a care home, which worked out well from a childcare perspective but meant that Rachael was getting very little sleep and no time to herself. At 21 years of age this was the time when she was first asked by someone if she had an eating disorder, but Rachael dismissed this because anorexia was something that only happened to young teenage girls and couldn't possibly be something that she was going through.

At 25 Rachael eventually started a new job as a debt collector and remembers feeling frustrated that although she was now earning a fair amount they had nothing to show for it. She also reflected on how dangerous this job was but how little this

concerned her at the time. She felt so tired, she was very depressed and was getting thinner all the time. It was difficult to stop eating when she started so she began to make herself sick. She felt hopeless, like there was nothing for her and no time for enjoyable things. She felt like she was purging the anger from herself when she would vomit. This was usually triggered by her husband putting her down in some way, and it was her way of taking back some control.

Rachael also started taking laxatives around this time and was questioned by the pharmacist about this. I wonder what had made her start to manage things in this way? How did she know or come to believe that laxatives would help? She remembers starting to cry through shame and relief. She knew she wasn't in control of it anymore and she was so relieved that someone had noticed. When she went to her GP she found it difficult say anything about the eating, and was just prescribed tablets for low mood, which just made her feel different and separate again. I wonder what her worry was if she did tell the doctor about her eating and laxative use? What made he hold back? She carried on but began to display some "bizarre" behaviours again for example decorating the house in the middle of the night, and her husband got the doctor out. This made her feel like a massive failure, that this was the end, that there was no happiness for her just for them, her children.

Rachael had made sure they got everything they needed and wanted, and she had poured all her energy into them. They both had the confidence to play instruments and always went to the parties or the school trips. But Rachael didn't know how to live, to pursue anything for herself. She took an overdose and ended up in A&E. She remembers distinctly how the doctor just dropped her wrist when he learned she had overdosed as he felt this meant she was not worth bothering with. She felt blamed, and although she can look back at this time now and recognise that is could have been the start of HER time, to get better to look after herself - she just felt misunderstood.

She was sent to an inpatient service, which was "horrendous". She was so frightened and felt blamed even when others stole her stuff, she felt in the wrong by the way the nurses treated her. Even when she was discharged she remembers an occasion where her care co-ordinator insisted that she would come to pick her up for a review and then blamed Rachael for not turning up. She remembers the nurse commenting on "who's got the MH problem here?" in a threatening and coercive way, which Rachael took to mean the doctor would believe her over Rachael.

Rachael felt that she had no choice in her engagement with MH services at this time but that this was just something she had to do to get better. But she felt like she just kept hitting a brick wall and made another attempt on her life. This time the doctor sent her to the ED unit in [REDACTED] and for the first time she met others "like her". This gave her hope that maybe she could get help, and it was such a nice place compared to [REDACTED]. Nevertheless she observed how others on the ward would get a bit indignant about how the nurses treated them, there was no therapy but they were just shut away in a cupboard as if they weren't worth anymore and didn't deserve anything.

Rachael noticed herself feeling empathy and curiosity that others she met on the ward felt that way too but she always felt her concern landed on deaf ears. Even when other mirrored this empathy and compassion towards her, she felt she couldn't believe them, as they couldn't possibly being seeing the real her. She feels she was discharged too early as the funding ran out and she got very depressed and hopeless again. She tried to hang herself, and was sent to [REDACTED] again where she vividly remembers the trauma of doctors attempting to tube feed her against her will. By the time she got transferred to [REDACTED] she was determined not to let anything penetrate

her again. She didn't speak, didn't eat and was on 1:1 observations with a nurse because she was so determined to hurt herself.

Her daughter came to visit her here and she remembers her asking "mum are you ever going to eat again? Are you going to die?" This made Rachael more determined to fight, but it was so hard and she found staff at the hospital just so harsh. But she started seeing a psychologist around this time and they seemed to understand somewhat. There were also relaxation groups and a self-esteem group that she remembers learning a lot from. It was here that she realised that she was actually entitled to an opinion and that that was a basic human right. And she thinks that was the real start, the catalyst to her recovery.

But after 6 weeks she was discharged again - too early, as there were not enough places. Things were a lot harder with her husband this time at home because she was more opinionated, her children had left for University and she had no support except from the unsympathetic care co-ordinator she had been assigned. She went straight back to restricting because that was her identity and this was responded to by others commenting "that this was getting boring now". She started feeling hopeless again since the ECT she had received in hospital hasn't cured the ED she felt it was never going to get better. Her own sense of feeling better in mood after this treatment had been invalidated by the doctor who had deemed it ultimately a failure.

Rachael wanted to get better for her children but she didn't know how to. She slowly realised that the depression and ED went hand in hand but she didn't yet want to give the ED up. She sees the ED as lifesaving and life threatening at the same time. And described the level of fear associated with giving it up in terms of the terror of a child being told to let go of the side of the pool when you are learning to swim. She just wanted to disappear. She was sectioned and she was briefly sent to [REDACTED] again before being transferred into [REDACTED]. And this final inpatient stay was 8 months long. During which time her marriage broke down and she had nowhere to live upon discharge.

She negotiated with her ex-husband to buy a new flat that she could move into and was then told that she couldn't be seen as an outpatient in [REDACTED] because her new flat was not in the catchment area. She disengaged from services at this stage and became isolated in the flat; terrified to go back into hospital. She declined the offer of attending a new ED service in the area but was chased up by a new care co-ordinator. Rachael was impressed by the first contact she had with this service and felt that they really understood how difficult things were for her. It was hard to trust that they wouldn't leave her and it took her time to open up but when she did she found this really rewarding, she started to feel valued for the first time and accepted.

Rachael was blown away by the unconditional respect she received in this service and since she has started to recognise that compassion for yourself is the key it has all come together for her. She wants to reconnect with her daughters and has made the decision to try and move over to them, which has given her a goal to work towards. She feels her eating disorder doesn't have the same hold over her anymore. She has up and down days and is aware that she still works long hours, and eats because she has to rather than because she wants to, but she is feeling better physically and enjoying things. She understands the ED to be not an enemy but a coping strategy and a kind of fake friend. Her goal of moving to [REDACTED] has helped in her recovery but she is realistic about this and she knows that she will be ok even if it doesn't happen just yet.

For Rachael recovery is the hope that one day it won't matter to her anymore, but for now she is managing it now one day at a time. She feels like she is on the edge

a lot of the time but she is strong, and doesn't believe she will fall over it again. She is tired but she is grateful for what she has gone through. It has given her a wisdom, a strength and an understanding that she probably wouldn't have had otherwise. She feels very sorry for her mum and gran to have not had any awareness of the impact of their behaviours and she knows that even though she wants to be closer to her daughters, she has no evidence that she has anything to repair with them.

At the end of our time taking together Rachael reflected on a memory from when she was 17 and walking home on her own after a date. She noticed a truck pulling over and the driver leaning down, before she decided to run back the way she came. Years later she read about the way in which Peter Sutcliffe used to attack his victims but had initially dismissed the possibility that had been him as she thought he was based in a different part of the country. Since this was challenged however, Rachael has come to believe that this was more than likely a lucky escape from him. She feels lucky that there was someone watching over her or that she has such strong instincts inside of herself.

Appendix B6: Mark's Summary Story

Mark was 49 the first time his ED was acknowledged. He was 4 ½ stone and was consequently hospitalised. An orthopaedic consultant had initiated this referral after Mark had presented with a broken shoulder, and a diagnosis of osteoporosis was made. Mark believes his experience of eating difficulties first started around the age of 12 or 14 after his Gran, who he was very close with, passed away. His Gran had been the person to make the meals, ensure he got to school and who spoke out for him to keep him safe. She had been diagnosed with Cancer and Mark watched her fade away over two years, before passing away.

After his Gran passed away, everyone in the household had to make their own breakfasts, and Mark explained that he stopped eating breakfasts from then until he went into hospital in his late 40's. This was something about wanting to be like one of the grown-ups, being too busy to eat breakfast, but was also perhaps related to wanting to deny himself this meal. He had already started restricting the amount of food he would leave behind at meals, and it became more controlled after this. Since then, Mark has always tried to stay between 6 ½ and 7 stone and he spoke about how he would ask for help from his GP if his weight dropped below this. He was always told everything was ok, and that he just needed to eat more, as if it was that simple.

Mark believes that restricting his food intake is about proving he can do more than others on less. He is told that he's a hard worker, and he feels the need to stay busy. He also isn't someone that follows the crowds, and he didn't want to be big and Macho just because others told him to be. But he also thinks that for a long time, it was just that he didn't like eating, especially between the ages of 18 and his mid 40's. He feels that his GP reinforced this belief, and although some of his friends and ex partners expressed their concern that there was something more going on he found this difficult to believe when most people didn't seem to mention it, including his GP. It was also easier to believe he didn't have an eating disorder because Mark didn't know much about them at the time except what he would hear about in the papers, including famous cases like the child actress who had died from it, and how it mainly affected young women.

So by the time Mark was admitted to hospital his immune system was “packing up” and he was very unwell. He didn’t realise that this was a compulsory admission until he asked if he could try the process out as an outpatient. It felt strange to see only young women on the ward and he was worried about the ward not being a good fit for him initially, but the other residents soon made him feel welcome. They showed an interest in his interests and encouraged him to do his best at the weekly quiz night, even when he was the one always winning. They cheered him when he won the 10th week in a row and this really made him feel accepted, a feeling which is recounted is very different to what the current inpatient service seems to offer.

Staff told him that in order to leave he needed to put on a pound in a week, which sounded like an impossible task. And the more he got to know the others on the ward, he gradually realised that it was going to be a longer stay than they had told him. He ended up staying there for 7 months in total. It felt like a relief to Mark that he was given care in this way because he knew things were bad, and he doubted his ability to carry on like that. He was told that he would have been dead within 6 months if he had not been admitted at this time and this wasn’t a surprise to him.

Mark had had a very difficult on-going relationship with a neighbour over 5 years, which had triggered his decline before he was admitted. Mark’s dog had also passed away during this time, and he turned to vodka for comfort. He was still cooking for himself but eating less and less of it, and as his stress levels increased he was controlling and restricting his food intake more and more. Mark has never felt hungry since this period, which precipitated his referral. He dreams about feeling hungry sometimes but when he wakes this sensation goes away. Mark doesn’t feel like he has a relationship with food but he would love to have one day, he would love to be able to enjoy food

Mark still cooks for himself on a daily basis because this feels like what he is meant to be doing. He reflected that sometimes the act of cooking helps him trick himself into thinking that he has consumed food. He does not always have awareness about this happening in the moment, but he can reflect on it from a distance as a strategy he probably uses to convey the sense that he is doing better than he is. So at the moment he is just eating ready meals and Ensure, and he relies on his supportive relationship with a good friend who he met through the ED service and helps remind him when he should be eating or drinking. They keep in touch on a daily basis; where Mark has to snapchat all his planned meals to her as a way of promising he is going to eat it. And in a way that helps her give herself permission to eat, because she knows that Mark is trying too. Their daily messages serve as unspoken reminders that it’s time to eat or drink.

It was through this first admission that Mark met others with eating disorders, all women. Through the relationships he developed with these girls he learned more about the stereotypes that surround eating disorders. It frustrates Mark that professionals believe people who experience anorexia can’t support one another but will only create competition between one another. He believes his relationship with his friend is a direct contradiction to this, and that while some of the service users might feel panicked or competitive by some relationships it just depends on personality and ‘how well they are doing’. Mark feels like there is a lot of damage in the way that stereotypes are perpetuated inside and outside of the services, and that this is worse for the girls than it is for him.

Mark described the difficulty of explaining what it’s like to live with an ED and he tried to convey this through his art, by putting a shape and a picture to feelings that are there. Mark doesn’t believe it is possible to draw one image of what an ED is,

and struggled to do this when asked to during his first inpatient stay. Instead he came up with the image of the ED dog, which is one step removed from an image about the experience itself, and this image occurs in his art quite a bit. It consists of a dog chained to the wall with a lovely bowl of food just out of reach. It conveys an incredibly cruel, frustrating, and painful process.

Mark hadn't believed in his diagnosis until he looked into the eyes of the girls he met in that first inpatient admission and could see that they got it. "My god they're the same... they're feeling the same". It's very difficult diagnosis to describe, like describing the colour red to someone who has been blind since birth. There's no frame of reference. And it's infuriating at times when others don't get it – "it feels like your speaking Chinese", especially to his family. But seeing the girls do their best to overcome it and having his art as a way of expressing this, and the girls encouraging him with this, has helped Mark start to believe in himself and in the value of this process. He hopes that his work can stimulate conversation both without and outside of services, to start to display some of the unhelpful stereotypes and judgements that surround EDs. Mark shared another "paper" piece with me, and expressed his hope that his work can go back into services to help people understand how difficult it is to understand the experience of ED. He mentioned how this piece had already been used to stimulate conversation in a Saturday day service group.

It had been a relief to meet others who understood what it was like to live with an ED, it was a relief that others could see finally that there was something wrong. Mark was advised to change GPs during this time and remembers one of the last appointments he had with his GP who was very scathing of the option of therapy being useful for Mark. So Mark changed his GP and continued his sessions with his psychiatrist. It was a relief that someone was going to do something. He described how when you're an inpatient it's such a relief that you've just got to do it - to eat and deal with the resulting feelings. The girls call this main feeling guilt but Mark sees it more as a sense of foreboding – and feels that guilt is a negative word that reinforces some sense of blame and shame. For Mark that feeling of foreboding wouldn't happen in hospital because he had to eat in that context. All choice was removed. Which is how Mark feels it needs to be.

Mark recognised that he needed something to motivate him to get out of where he was and the girls were always encouraging him to do something with his Art so he started at University September 2013. He has a great relationship with the BA course director and tutor who did his interview and who is still very supportive of his work, and it feels good to have people around him now who care. But before he started the BA he had to be admitted again as he had been losing weight for 3 months. He knew he would need to go back into hospital but negotiated staying involved in his Fine Art course before agreeing to do so. One of the day centre staff had gone out of her way to organise him a flat in [REDACTED] that was very near to Uni and so he was able to ensure he started attending his course while as an inpatient. Although he felt that the psychiatrist at the unit at that time kept trying to trick him to give up the course, he played along with them in a way that meant he could maintain his weight. Staying in Uni was a good incentive to keep his weight at an agreed level, where later his friend had acknowledged that it was a positive thing for her to see him getting on with it and leaving the service every day.

Mark started his work with charcoal drawings, an unbeknown to him he was creating work with a surveillance theme. It expressed his feeling of being watched. The girls were helping him with his art, they didn't mind him drawing them. They had this idea that he should do a graphic novel with story lines around them which is the

piece that he is working on now. We watched his visual and audio piece on the iPad that conveyed what it feels like to be an inpatient. To me Mark's piece captured the chaos, the tensions and the conflicts of that experience. As he explained: "You're not mentally ill but you are. No one talks about food but it's all about the food." He also showed me another piece. A naïve, fairytale and happy ever after book that everyone wants access to, but is hidden from them. You can't see every page and in order to do so you have to violate it. Only when you violate it do you get the rest of the story, with the not-so-nice distorted images, thoughts and feelings that go along with it.

Mark believes a lot of the misguided descriptions and sensationalist stereotypical understandings of what EDs are like is guided by the press not wanting to understand, because a genuine understanding wouldn't sell. It's easy to blame women for wanting to lose weight to look good and it's prejudiced against young girls around a certain age, by conveying them as "silly girls". It's ultimately dismissing how difficult it is to be female - to have so many assumptions and expectations about what you should be doing, getting a job and settling down while men are freer to do what they want. He believes that more generally experience of ED might be about people who feel like they have to conform, or be pushed into a certain way of life. Mark thinks his religious background was a factor in his developing an ED. How he, as the vicar's son had to wait until the end of the buffet to eat at church events, which is probably related to the idea of control. Of wanting to take some back, especially after watching his Gran slowly died in front of him.

He feels others portray EDs as a choice when this is most definitely not the case. He would love to get rid of it but it's like a spider's web - the more you struggle the more it gets you. Mark explained that he is open about having an ED with others, and talk about how that had been a conscious decision. It was embarrassing at first, particularly because it's a concept traditionally associated with young women and also because he worried people would see him as not normal, as a bit strange. Having to admit that he was coming from a psychiatric hospital was hard, and he remembers getting dragged out of event one evening by a nurse who wanted to take him back to the ward. But now others are ok with it all, and while he feels he can be more honest with other, being so open can be another way of hiding. He asks close friends and professionals to listen for what he is not saying because he find the ED can easily trick him as well as those around him.

Mark spoke about not wanting to think too much about the future and trying to remain in the present because thoughts about the future can feel confusing and overwhelming; about the need to take it one meal at a time. He described how it's a bit like the Coyote from the roadrunner cartoon, how you can't look down or otherwise you will fall off the cliff. Mark's hope is that if he keeps doing it long enough, his appetite will come back slowly and naturally. His hope is that it just takes time. But he fears that it's been gone too long. He has observed that there seems to be a cut off point at about 26 where others decide if they're going to beat it or live with it and hide it. After so long you just get bored, frustrated and you can't keep trying forever. So it's best not too think about it too much. In this respect Mark feel that's he is also different because he is older and still trying, when most of the others have given up a long time ago, but he thinks that this is because he only relatively recently started to make sense of his experience in this was and is less worn down by the system.

Mark spoke about the importance of getting more knowledge about patient experience out there from the patient's perspective. About how difficult this is when professionals misinterpret people's experience. For example Mark spoke about how

some people speak about ED as if it is a separate voice in the head, but he feels this is unhelpful because everybody has a voice in their head and that it's not unique to ED. He believes that it's very easy to trick yourself whether you're a patient or a professional; whether you have an eating disorder or not. Everybody finds it hard to maintain a constant level of insight or awareness and we will all get side tracked by their thoughts and biases. Mark gave an example of how the bible says "be sure your sins will find a way" and he interpreted this to mean if you have a weakness or a vulnerability you can always justify what you've done. He made reference here to Anna of Mia and acknowledged them as sort of a friend, as a way of taking refuge that people don't always want to let go of it because they worry there is nothing to replace it with. Mark hopes that he has found something in his Art to replace his relationship with his ED, but he worries that his age will hold him back now because it has been around for so long for him.

He spoke about how his father had told him when he was admitted and diagnosed with anorexia in his late 40's that their family GP had queried this with him when Mark was only 18, shortly before they retired. The GP that replaced them never followed up on this and Mark feels a regret and a wondering about what might have been if he did. Mark also reflected that he may have had a good opportunity to get passed it after that first inpatient stay but worries that staff have become less understanding and supportive over time, making subsequent inpatient admissions less helpful. He explained how staff had to eat with patients during that first admission, that on a subsequent admissions they didn't because "they weren't the one's with the problems", and that now they seem to be able to decide if they wanted to eat with patients or not, or start a meal without finishing it, which ultimately feels very unsafe for patients.

Mark believes the standards or staff are sliding, and he wants more therapy for himself and others, as well as a consistent, containing supported eating environment, with clear rules and consequences. But he feels that lately patients are allowed to do what they want in terms of eating and that ultimately becomes unhelpful and uncontainable for fellow patients. It stops the inpatient setting from being a safe haven. Mark has previously found a benefit from having responsibility removed in inpatient settings as long as it has been done by a well-informed, supported and respectful care team. But he points out that this doesn't work when the staff don't have any training. This contrast has made me wonder about the importance of having trust in your care team and about how when this is eroded away, the therapeutic value of being looked after - and of having the choice of having to eat taken away - becomes worthless and at worst unhelpful because it becomes oppressive in its own right. Ultimately I got the sense that Mark feels that there is a need to create more discussion about this, and about how the way people who experience and manage eating disorders varies vastly from person to person. It is a complex process and one we have yet to learn a lot about.

Appendix B7: Lisa's Summary Story

Lisa described having had difficult relationship with food from a young age, and experience deep rooted negative feelings about her body. When she was very young, her older brother bullied her, putting her off idea of meat so much that she became a vegetarian from the age on 9. She started more intentionally restricting her diet in high school when she became more aware of body image, and she remembers

feeling fat during this period, although now when she looks back she recognises that she was terribly underweight. Being in a single parent family, and with a mother who was experiencing her own mental health difficulties made it easy to hide how little she was eating.

At 16 she met her eldest son's father, he was older, and it became a violent relationship. He would often put her down about how she looked and this kept her feeling conscious about her weight. She became pregnant at 17, which was incredibly difficult but she managed to have a more positive relationship with food during pregnancy because it was easier to justify this when she had her baby to take care of. But the pregnancy took an understandable toll on her body, and with her boyfriend's continued negative comments this made she feel like she was 'disgusting'. She found the courage to end this relationship but she was left with little confidence and a lot of body image concerns. She described not knowing how to eat "normally"; and how confusing this was and still is.

Lisa then went to work in the image conscious world of beauty, and even though she liked parts of the job, the environment did not help her confidence and her eating behaviours continued. She started taking slimming tablets and remained very body conscious. When she met the father of her youngest son in her early 20's he became aware of her difficult relationship with food. He had a different attitude towards food and socialised a lot around mealtimes, which was difficult because she found it difficult to eat with others, feeling judged and uncomfortable. This put a strain on their relationship as she understandably tried to avoid these social events.

She studied diet and fitness as part of her beauty training, and this made her very aware of food. From this experience, and from watching what her partner ate she became more 'lenient' in terms of what she allowed herself to have, but her partner still noticed the difficulties she was experiencing and mentioned these on a visit to her new GP. The doctor never followed this up at the time but it made her more aware of how her relationship with food might be influencing her son's as well. She continued to be more lenient on herself, and over time she got to a weight of 10 stone, which felt like a real achievement.

But then a neighbour commented on her having "put on weight and looking well", and this was a really negative experience for her, setting her straight back to restricting food. She felt "at", and angered that they thought they had the right to comment on her body like that. So this apparently "small thing", a throw away comment had a really powerful effect, one that she has never forgot. As she was planning another move she started to use that as a reason to lose some weight so that she could almost start "afresh" where others would expect this lower weight as her norm. Her target was to be thin, and although she didn't really weigh myself at the time, she knew from how clothes felt on her what she wanted to aim for.

Looking back now she realised what a powerful affect her partner had on her own judgements of herself and how she would feel anxious about wearing the right things around him. He was "the negative voice" at that time to her, and she didn't feel strong enough to question him. Given her early relationship with her brother and the physically abusive relationship with her ex she felt very scared, and "always fearful". Around this time Lisa had a miscarriage, and this triggered thoughts of self-blame about her body not being "healthy enough" to sustain the pregnancy. She started treating her body like a "temple" after this, exercising all the time.

Lisa was hurting so badly emotionally that her body became her sole focus. Because nobody else encouraged her to get any support, it made her feel like this loss wasn't important enough to be acknowledged by others. She became pregnant again

three months later and this changed her relationship with food again, where she started eating well with the baby in mind. But this was a really difficult period, because she felt like she had to “fight” to eat well, even when she didn’t want to, and she was plagued by worry because she had fairly regular bleeds throughout this pregnancy.

Lisa felt like she was in a haze during this pregnancy, and afterwards. It felt like everything was happening to someone else. She had a haemorrhage after the birth, and then 6 weeks afterwards they discovered that she had a retained placenta. It was a really serious complication that could have resulted in her death and this left her wondering “how could they have done this to me?!”. She felt like she hadn’t mattered to them. And it subsequently felt like her partner had only started looking after her because of her son’s birth, rather than because she was important in her own right.

Around this time Lisa’s Mum left out an article for her about post-natal depression. When she spoke to her Mum about this she suggested that she to go and see the doctor. She remember this as being the first time, at 28 years of age, that someone shared their concern for her. That was an important step for her as it initiated her going to the doctors and saying that she wanted some help. She received a diagnosis of bi-polar disorder and began a ‘trial and error’ period of medications. This was really difficult because some of them made her feel heavy and bloated, and caused her to put on weight. She carried on eating normally because she was breast-feeding. But things were really difficult in her relationship, and her self-esteem was at an all-time low.

So Lisa decided to go to slimming world to do something about this, and she went ‘hell for leather’; she started over-exercising as a way to manage her anger with her partner and over 9 months she lost 3 stone by staying focused on the scales. She got positive feedback from others which reinforced the weight loss, and she reflected that this was the first time she became obsessed by the scales rather than on body image alone. Slimming world helped her feel normal, that she wasn’t the only one struggling in her relationship with food. And she gained a lot of confidence from losing that weight, but looking back at this period she feel it triggered a ‘manic’ phase, which she now understands in the context of receiving a diagnosis of bi-polar disorder.

As a consequence of this period, and gaining confidence through her career, Lisa decided to break up with her partner. She felt ok about initiating this decision at first but once they moved out and she heard they had met someone else, this triggered a “breakdown”. Lisa’s mum and step dad moved in with her for support, and she was confined to her room. She was in so much pain, she felt suicidal, and her mum got in touch with the crisis team in mental health services. This felt like the lowest of the low, and her body image concerns came back with a vengeance. She started to feel like the breakup was about him “not wanting her” anymore rather than as a decision that she made because she deserved better.

Lisa spoke about this in relation to how her Dad had left when she was six, and about how this felt like the start of a pattern for her, a pattern of interpreting others’ leaving she as something to expect. She felt somehow like she was to blame in this pattern, which her partner had encouraged by trying to make her feel guilty for splitting up the family. So then Lisa’s relationship with food and exercise became something she could control independently of all the other painful things that was going on. It became “a powerful tool” to manage the uncontrollable patterns that were happening in her life. It distracted her from the pain, by consuming her whole focus.

At this point Lisa's eldest son had gone away to college, and she decided to sell her business. She also made a decision to sell the family home, and she rented a place near her son's school, which gave her the opportunity to withdraw for a while, with the belief that things would just "sort themselves out". Lisa had been working long hours as a manager at another salon, and started restricting her food intake again, but when she sold the house, she quit this job and things ended on bad terms with the owners. She locked herself away, feeling like the world was out to get her. And with this privacy, and the money she had from the sale of the house she began to overeat, motivated by the sense that she could do what she wanted behind closed doors without anyone judging her. It was like she was "rebellling" against herself, rebelling against her own rules of living and eating. She could do what she wanted now, as long as it was behind closed doors.

She got into the pattern of sleeping all day, eating food and feeling very low in herself. She felt out of control and was shocked by her weight gain over this period so she started taking laxatives to try and manage this, and she didn't stop even when she started passing out from the consequences of these. She didn't know what else to do. This period, which started about 5 years ago, was the start of the journey Lisa now finds herself on. She locked herself away and became obsessed with weighing herself again, and Lisa felt like she has been in this 'space' ever since.

Then she met with a friend, who had lost a lot of weight and was looking really well. Something clicked for her during this catch up. She decided that she needed to start looking after herself again so she stopped taking laxatives and went back to slimming world and lost over 5 stone in under a year. The group meetings became a social outlet, and this combined with eating better and regular runs made she feel good about things again. But she noticed that the closer she would get to her target weight the slower it was coming off, and this was so frustrating that she started taking laxatives again. And she started passing out again. This was when Lisa finally "admitted" to her GP that she was struggling with her weight and her relationship with food. She talked about her positive relationship with her GP and about how well they handled this, making her feel like she would be able to cope with it and ensuring that she got support from specialist services quickly to help.

Lisa described feeling embarrassed that she'd managed to get to this stage in life and had never admitted to anyone what she had been struggling with food. It had been this big secret that, throughout her engagement with mental health services, her counselling, and her mindfulness training, she'd somehow managed to keep hidden. She had spoken about her body image concerns and confidence but nobody had ever asked specifically about the food, and she always manage to talk around it. Lisa didn't believe this was intentional but rather came from not realising that her relationship with food was related to the mental health issues she was experiencing.

Lisa talked about her current experience with services, and about how hard and confusing it is at times. She has also found this a helpful process but she is really struggling currently with learning how to eat 'normally', and has returned to slimming world again to help her lose weight even though she are aware of how triggering this is for her. She talked about how this confusion had led her to start taking laxatives again, and how ambivalent she feels about telling her therapist this. She understands that part of the recovery process for her is becoming more accepting of herself but she does not know how to do this when she is not currently happy with her weight.

Thus, Lisa experienced a tension between wanting to lose weight but also feeling that this is not endorsed by the eating disorder service. She spoke about how her therapeutic experience has been focused on increasing compassion for herself, and

recognising that this confusion about food and diet is not her fault but an understandable consequence of how much the world has changed, and how easy it is to get food now without having to work as physically hard for it.

Lisa's current romantic relationship gives her a lot of confidence and support. She has had the courage to share her difficulties with her partner, her mum and a friend and seems to find this helpful, and more liberating. It is not just her secret anymore. But she is reluctant to share her experience with everyone because of the fear of judgement, and because she doesn't want to create any barriers or awkwardness between her and other people, which has already happened in her experience with the psychiatrist for example, when they realised she had been experiencing eating difficulties and stopped being able to make jokes about attending slimming world together.

Lisa's relationship with food, exercise and her body remains a constant, consuming and confusing struggle with other people's comments about looks being very triggering. But she also recognises that she is in a different place with this now, and that she is able to notice when this is happening, and react to it less, giving the example of recognising how judgmental some of the conversations that happen at slimming world are. She finds it useful to be guided by what she would want for her niece, who is her new "powerful tool", and an inspiration for Lisa to live in a way that is consistent with how she would want her niece to be treated. She hopes that she will move towards an easier relationship with food and body image and also recognises how much progress she has already made, having survived so many difficult experiences and developing the courage to share these with others.

Appendix B8: Rosie's Summary Story

Rosie spoke about being able to recognise, but not remembering that she used to enjoy food. She spoke about being told that she had difficulty feeding as a newborn and was always quite "faddy" and particular when it came to food and eating utensils. From the age of 4 her mother was very ill and she went to live with her aunty, where she just wouldn't eat unless it was a very particular type of food on a particular saucer.

Early memories of school are quite difficult as Rosie remembers being bullied. It was here that she started throwing away food because she felt uncomfortable with a growth spurt around the age of 9 and "didn't want to take up any more space". She found high school just as difficult, with even more viscous bullying. It was around the age of 12 when she started to develop depression; she was coming to terms with her sexuality and had started self-harming. It was also around this time that she believes the eating difficulties became the disorder.

Rosie's mum knew about her difficulties before anyone else did. She was caught hiding food at home. She remembers feeling terrified of doctors and how the school pastoral support would offer her money for food that would never get spent. She decided around this time that she wanted to become a vegetarian, for ethical reasons, but also because she had heard somewhere that this would help her lose weight. Weight loss was a big motivation at this stage but when her friends noticed her losing weight she would claim she was just slim because she was tall.

Rosie took an overdose at 14 and was forced to go to CAMHS. She felt this didn't work for her at all because they were just like the "domineering critical voice", which mirrored the one in her own head; the one she had had all her life from her

father. It was around this time she started lying about her food diaries, and she kept calm and silent when she felt her CAMHS worker was trying to get a rise out of her. She talked about not having a temper, and deciding to stop talking when it all felt like too much - she was getting it from all sides, her parents at home, CAMHS and school.

So she started drinking, and self-harming and around this time experienced the breakup of her first relationship, which started a downward spiral. She was put in a ward where she feels like she learned “new tricks” to manage her weight, and to fake her way into CAMHS every week “lying through my teeth”. Rosie was tube fed until the age of 16 and was then discharged. This was only point where she felt she was in a state of recovery, for about a month, but she is unsure if this was a superficial or a real motivation to eat a bit more food to avoid the Ensure supplements.

She kept to herself during this time and started self-harming again. She was admitted to the [REDACTED] and felt she “was not treated like a human being, just an illness”. Here Rosie was exposed to a lot of very ill people at quite a young and impressionable age. She “faked” her weight up to a BMI of 17 and was threatened with a section if she discharged herself at a BMI of 16. Rosie spoke about feeling like a specimen not a person and spoke about a time where she hid under a desk just to get them to leave her alone, to let her go.

Rosie detailed the mischief herself and the other residents would undertake, with a smile and a sense of humour. She described this as rebelling against the feeling of being oppressed and being treated like an object. She spoke about how this second admission was the worst admission (although it rivalled with her experience in [REDACTED]) because she did not make any friends. She was forced to buy new clothes as her weight rose, and this felt like someone taking her identity away, like they were trying to fit everyone in the same mould.

Rosie spoke about how the ED doesn't take over your whole identity but that it does become part of it. She spoke about how she doesn't believe in all of the “recovery stuff, in the magical fairy happy glowy health foody rubbish” she described how treatment is “crying bloating pain anger panic all the time” and how she had often questioned herself about whether she would suffer more if she recovered than if she stayed “like this”. She spoke about how instagram and ED hospitals paint this picture of recovery, and that instagram in particular made her nervous about the recovery process as it looked like those actively pursuing recovery would swing from idealising the process to wanting to die. At least she didn't feel that desperate.

It was also during this second admission that Rosie got her GCSE results which were not great, and talked about how this was a massive shock to her as she had always been academically strong and a “perfectionist”. She spoke about receiving these “over the phone” from her mother who was too far away from the hospital to visit. She then felt coerced by services into taking the B-Tec over A-levels with the argument that they would be less pressure. She started late in college, as she was only discharged from hospital in October, so she found it difficult to make friends and relied the support staff who were “second to none”.

Rosie spoke about the importance of academics to her and in particular about her interest in psychology, having always been the person her friends could turn to. She spoke about volunteering on LGBT forums and providing support to others. She also shared some of the ways she makes sense of her own experience by using mind maps or doodles, and about the tension between her logical brain, and her emotional brain. She shared her thoughts on how one of the effects of living with an ED long term is that she does know the logical side of it and tries to be guided more by that in University. And she spoke about how she felt she was not in recovery but in “limbo”.

Limbo was described as “feeding herself enough not to die but not enough to live”. She contrasted this against the need to stay active and her own feeling of luckiness that she is “very functional”. She reflected on how the effects of not being able to do anything can be quite scary and referred to a time in 2014 when she was critically ill leaving college. She was not eating or sleeping. Somehow she got really good results but she didn’t feel ready to leave yet.

Starting University was another difficult time as she was immediately bed ridden with the fresher’s flu as her immune system was “shot”. This period was made a lot worse when she was sexually assaulted by a male student on campus. Her grandmother passed away around the same time and she would phone her Mum every day crying, saying that she wanted to come home. She felt very “out of it around this time and doesn’t have many vivid memories but she does remember that although her mother didn’t seem to be listening to her over the phone, she came to visit and took one look at her before breaking down in tears.

Rosie was told by doctors during this time that she could die at any stage, and she felt the need to prove she was stronger than she looked and to make sure she did things she enjoyed just in case they were right. She wanted to show that she was a person “to be seen as something real” as opposed to just a name on a piece of paper, she wanted to prove them wrong, to show that then she could “do something extraordinary”. She did a fire spin with the Circus society in University and she is so proud of this achievement, and of herself for overcoming her fear and her physical weakness to be able to pull this off. The University asked her to leave after this. Between leaving University and attending her Grandmother’s funeral she described entering “starve binge” cycles as a way of coping.

She can’t remember much about this next period but does remember going out with friends for her 19th birthday and meeting one of her favourite musicians. She was “threatened” with going to the [REDACTED] again and with her parents fighting at home, and her mother being unwell again she went to stay with her Aunt again. They both tried really hard to make this work but her Aunt found it too raw, having recently lost her husband and having Rosie staying in the same room that her son had passed away in.

Rosie was then sectioned and sent to a specialist inpatient unit. Everything about this time was “just so wrong”, so “dehumanising” where she felt all of her “dignity was stripped away” and “her identity gone”. Rosie spoke about her ability to argue a point but that they didn’t believe her arguments simply because she was Anorexic. She wrote a structured and referenced essay to support her appeal at tribunal but was not discharged because her BMI was 0.2 below the threshold of 14 that they wanted her to reach. She spoke about “not being helped but drugged” in this institution. She ate “to get out of there”, but didn’t speak to them about anything. She started self-harming and felt humiliated when they came to search her room. She felt like she came out of hospital “more of a mess” and that it was infuriating with the psychiatrist apologised for sectioning her in the first place.

When she was discharged from hospital she abruptly went “into crisis”, which she believes was at least partially as a result from the withdrawal to Diazepam. She was devastated after this experience and couldn’t leave her room. She was sent to an acute therapy service, which she remembers as “such long days”. It was here that she also received diagnoses of generalised anxiety disorder, which helped Rosie make sense of some of the sensory sensitivities she experiences. This was validating, as before then Rosie had felt that if she had anything wrong with her it was always put down to the ED like she’d just been given that label now and that was it. Rosie strongly contests that she “is not an ED but that she is living with it”. This period in

acute therapy was more about addressing the anxiety as it was a general mental health service. However, it wasn't very effective and Rosie felt exhausted most of the time. She found "some of the patients, even some of the staff were invalidating" and expressed frustration that she wasn't able to "just eat".

Rosie's friend passed away from her ED in October 2015, and this was her first experience of someone dying. Her friend was only a month older than her. She felt so shocked and saddened by this as they planned to continue their friendship when Rosie came back to University. This was all "just taken away", and Rosie felt a sharp contrast between herself, as someone with "minimal impact" of the ED compared to her friend who had died from it. This was also the time of her Grandmother's anniversary, which initiated a "massive binge-purge cycle" and the onset of a "starve-binge cycle". Although her BMI was only in the low 15's it felt very high to her, and Rosie then attempted suicide again.

Rosie can't remember much of her 20th birthday, only that she was terrified. She didn't want to not be a teenager any more, even though she didn't feel like much of a teenager when she was one. She felt trapped in childhood, an unhappy childhood, and feels that she is still childlike now, even though she also identifies as quite gothic. As an example Rosie introduced me to Raffy (the gender fluid Giraffe), which was a birthday present she got from her mother at 17 and had gone everywhere with her since. She feels that now she is back in University again things are going better for her. She has much more supportive non-judgemental flatmates and is based in a smaller flat nearer campus which means she has less walking to do, and she feels safer. Rosie feels she has matured somewhat over the last year and is looking after herself better – joining societies and engaging with them more. She spoke about feeling like she is currently at a "weird crossroads" where she feels like she is "99% in Limbo", but that she also wants to work in psychiatry and do the Clinical Doctorate and she knows that she won't be able to do that with her current BMI.

Rosie recognises the irony in her way of surviving being so harmful, but also recognises that weight loss keeps her calm. ED to her is a "life taking" and "life altering" disorder, not a friend or a "buddy". She feels that she can be open about having a diagnosis of Anorexia and that people in Uni are ok with that. She recognises that the diagnosis becomes "entangled in her identity" and struggles to understand how that can be removed. She suggests the idea of a "dimmer switch" over and "on/off" switch. She doesn't feel very hopeful about finding this but feels that now is not the time to decide so she is "shelving it" for the time being, and she's trying to limbo around a BMI she has unwillingly agreed with services.

Rosie described how she would like services to support people with EDs rather than seek to provide "treatment". There is no "cure" or "pill" to fix this, but rather she explained "the person needs to want to change". She feels there is not enough understanding of this perspective in hospital staff, whom she found mostly to be "cold", "clinical" and "corrupt". She feels this misunderstanding maintains an "us and them" culture, where rigidity and powerlessness fosters a hopelessness in the system. Rosie reflected on her dismay that there is a lot of stigma and unfounded assumptions about EDs: that they are a choice; a response to fashion trends; or a desire to impress others. While she understands her development of an ED to be a combination of genetic and environmental factors she talked about how she believes we are "constantly growing and changing" and that she feels she has just about got her "foundations" back after her last inpatient stay, and that in some ways she is more grounded and vibrant than she was before everything she has been through.

Appendix C: Analysis

Appendix C1: An example of how data was summarised for each participant

| | Plot: main events as an interrelated sequence. | Narrative Tone: language that reveals attitude | Imagery: visually descriptive or figurative language | Characters: personal or moral qualities in order of appearance | Changes in tone/pace: indicating emotion/mood | Themes: recurring ideas or subjects Love and Power | Prop: object identified by participants as particularly meaningful |
|--------------|--|--|---|---|---|---|---|
| Angie | In a culture of 'impoverished' NHS resources, the medical profession is held in a respectful reverie, with no safeguard against the prioritising of 'profits over people'. A young woman on the verge of adulthood, who has felt unloveable and overlooked all her life, accidentally stumbles across a way to feel cared for, a way to impart some 'control' on her new found freedom | Punishing/ judged. Overall outrage; frustration; feeling offended and criticised; lonely; and helplessness but with a remnant of hope for a better future; for redemption through compassion, connection and care. | p. 2 "threaten to send me away to boarding school...I was very sporty as a kid for the right reasons my trophies and things she wouldn't put them on display they were always hidden away..." the lesser of the evils was not to have any contact rather than to be abused but then I didn't have any family" p. 3" it... this kind of snowball effect" "there was an element of unhealthiness creeping into it [competing/exercising] as well" p.4" my weight is if you will a by-product of the need to be in control" "my whole kind of existence was so controlled ..." more guilt creeping in if I broke my rules ""[the psychotherapist] never twigged about the eating ...the eating thing was still bubbling away under the surface | Self Mother Father 'noticer' ED Partner CruellaDV Nurse Therapist 1 Those who "know" and those who don't | p.40 I have ever met recoverers in inverted commas that then almost everyone can recover recovery is possible (overly positive voice) almost kind of over positive because then as much as you want to be inspired in one way can go and make you feel like a failure if you're not doing as well as they are doing in inverted commas p. 41 (exasperated | "for the greater good" "weighing the right number" – everything is 'abnormalised ' feeling misunderstood and overlooked by Dad, by partner by medics, by services, by society. | Poem; The [29] Commandments (Mass Exodus? 2. Verse 1) Thou shalt... |

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| | <p>and independence from her abusive mother. She enters into a dangerous relationship with herself, her body and her identity; becoming ever more vulnerable, and dependent on others in her search for love and connection. She is at the mercy of an authoritative and uncompassionate discourses that surround her experiences, which leaves her planning for survival in an attempt to hold on to some hope.</p> | | <p>“ p.33 “it’s a bit like we’ll patch up your broken leg and your bone’s fixed but actually whether you can walk is irrelevant” p.36 “I was kind of completely stuck” “it was one of those where you knew if you didn’t jump or you’re going to be pushed kind of scenario...””I was told when I asked for help with my body ‘you look a million dollars’ you look amazing when it wasn’t about how I looked it was about how I felt he could have put me on the cover of Vogue as the next model and it wouldn’t have done any good as it was about how I felt this body wasn’t mine ”p.37” I had got as far as knowing that I felt like an alien invasion and was struggling with body image but as I say it was just kind of lost really.” p.46/7 “very aware that it’s a paradox the more I need for control with my illness the more out-of-control I am and I kind of know that but somehow I can’t turn off that mental kind of need to <i>comfort starve</i> ... it’s weird it’s like you know you know you have this daemon it’s not like a sort of psychosis where it’s actually real you know it’s like sort of this Devils got a grip</p> | | <p>high pitched) I’ve seen like a GP who used to get me to like bend down and stand up again which I could do bearing in mind I had done sports and everything all my life yes I had anorexia but I could perfectly bend down and stand up again and she’d see me do it but used ask me to do it every week now I understand if you are really really poorly really really thin then you might struggle to do that but if she seen me do it one week p.43 it just makes you more obsessive (whispers) I’m going to use the stairs and not supposed to rather than do a bit of exercise</p> | | |
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| | | | <p>on you and you know that”p.48 I mean my community consultant has come out with this pearl went to me do you not think it would be a good idea if you just weighed a little bit more (scoffs) ... I dread going to see him because I just sit there and think what is the point of this am I just ticking your boxes of being what am I getting out of this absolutely nothing” ”all it means is that you are chasing your tail because all these thoughts and worries about the fact that you started gaining weight have all started kind of happening before your ever getting any help so even if you do get some help your kind of body and your head aren’t in sync because your head is trying to catch up with your body”p.50” [meics/staff/services] imposing these things that aren’t hitting the spot and their then blind to the fact that most of it isn’t hitting the spot and therefore nothing is changing but it does fascinate me that the powers that be are spending all this money and that there are so many revolving doors that somewhere along the line nobody is saying why is this”</p> | | <p>then it almost pushes you taking normality out of it makes you more obsessed. (faced paced frustration) that is frustrating it’s not that I expect them to fully get it it’s almost as if it’s not an illness.... P.47 you sort of can’t explain it because you know it’s mad but yet you can’t make it go away why would anybody not want to eat properly why would anybody want to feel tired and cold and hungry it doesn’t make any sense as I said you’re aware it doesn’t make sense (exasperated laugh)...</p> | | |
|--|--|--|---|--|---|--|--|

Appendix C2: Table organising features of narrative content for each participant, as proposed by Crossley (2000).

| | Life Chapters | Ideology | Significant Events | Significant People | Stresses and Problems | Life theme | Future script |
|-------|---|---|---|---|---|--|--|
| Angie | Childhood provided the foundation. Leaving Home. Early relationship disappointing. Feeling more noticed by a stranger. Attempts at becoming more independent. Falling in love. Feeling betrayed (first contact). Getting lost in the system. Living in the Spiral. Learning about self and hoping for more. | Does not identify with a religion or a sense of spirituality but a belief in fairness and consideration for others. Wanting to share her story for the benefit of others. | That time she felt noticed in school, which triggered the ED. Falling in love but being scared of this and not knowing how to trust it. Terrified by first contact with services. Traumatized in inpatient services. Not enough intensive support as an outpatient: doomed to failure | Self Mother Father 'noticer' ED Partner CruellaDV Nurse Therapist 1 Those who "know" and those who don't | Relationships independence autonomy externalised self-worth | Feeling overlooked and unimportant; father didn't fight for her, mother was hateful and abusive services don't care or get it right | Hoping to help others - to create a chance for them, get the balance right between treatment practice and aims. Hoping to feel more loved and valued in her own relationships. |
| Sue | Puberty Referral to hospital and then psychiatry. Discovering restriction and exercise. | Personal ideology around right and wrong needing to stand up for yourself doing the right thing for others | Fathers recent death. Being discharged from current psychiatry; abandoned again. The unwelcoming psychotherapist. | Dad; Older lady psychiatrist; Violent controlling boyfriend; | Feeling objectified and antagonised by others. Finding purpose and meaning beyond the ED. Feeling | Others as dismissing and abusive leaving her feeling unworthy and overlooked. But attention is a dangerous thing, especially from men. The ED ruined | Waiting to die but also wanting to want more. Dreams of running own business. |

| | | | | | | | |
|------|---|---|---|---|---|--|--|
| | Early romantic relationship controlling and violent. Working in the service industry. Anxiety. Working as a nanny. Hospitalisation. Being abused and let down by services. Eating to get out. Trying again and again to find professional support that would help. Menopause. | | The challenging psychologist. The caring psychologist; The disinterested psychiatrist; The abusive psychiatrist; The disinterested psychiatrist 2; The family therapist; sex ed from the clinical director; inpatient stay; years spent as a nanny, years spent as a waitress, early abusive relationship, that first referral to the hospital. | Abusive Chef; Another manager who took a “liking”; Ex boyfriend of 14 years; Hospital staff as a collective; Supportive Mum; Specialist doctor; Supportive partner; Male psychiatrist 1; Male psychiatrist 2: Dr. Fadele; Current male psychiatrist; Past psychotherapist who twisted things; Adored psychologist; challenging male psychologist; Future psychologist | safe and cared for. Trying to overcome low mood, low self-worth. | my life and the relationship with services has taken the rest of my hope away. | |
| Emma | Currently feeling the best she’s ever been. Difficulty accessing services for a long time. | Other’s needs as more important than own. Could not validate own distress but | Meeting current partner. Interaction with GP: deemed not low or good | local services GP 1 GP 2 Partner Therapist | Relationships Personal expectations Identity as a mental health | “I must be okay because no one really no one really told me I wasn’t” her distress did | Wants to start a family with her partner and feel more healthy in her body and |

| | | | | | | | |
|-------|--|---|---|---|---|--|---|
| | Childhood as abusive, neglecting and disappointing. Finding something to move towards; direction and purpose in her career. Starting the process of legitimising distress. | instead held self responsible for it. Feeling like a failure with no purpose, it was work that kept her going initially now it is relationships and the hope for a family. | enough to receive care. Filling in her own referral form. Committing to the trial, then day service, then therapy. Moving in with her mum. Given ultimatum by job. Asked to get help by her sister. The nutritionist stops weighing her at BMI of 16. Trying again to ask for support. Changing her mind about being involved in the follow-up process in the research. | The ED Sister Mum Dad The reflective self The 'typical anorexic' | practitioner; "knowing what services are like" Emotionally reconnecting Feeling less of a failure and more deserving of care | not feel legitimised until very recently | more responsive to her emotions to enable this. |
| Diane | From feeling powerful to being left behind. Moving home, feeling like a failure and becoming a success. First inpatient admission and suicide attempt. | Seize the day, make time in the present belief in what will be will be but also a sense of responsibility to others to her children and to her experience living with symptoms others | being diagnosed with and treated for cancer; waking up with father. 'having to' return to Uni. feeling wanted by someone. ED takes over everything. Parents return her home in disgrace. | Father boy at Uni GP Manager Psychiatrist 1 Mother Family GP Clinical Psychologist Husband Children Therapist | Wanting people to take an interest and being let down by those who did. Feeling the need to take it all on herself, on her own e.g. Bar Mitzvah's. Giving herself permission to take care of herself. | Having to 'do the right thing' by others and suppress her own needs in response. Learning this was her fathers value not her own but struggling all the same to feel 'not enough'; important/good/special. | Wants to be more social, and experience romantic love for the first time. Wants others to be able to get access to the support they deserve, and for professionals to take a more |

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| | <p>Second psychiatric admission and rape. Starting a family. Third time lucky inpatient experience. A decision to move on with life and commit to self in therapy. Committing career to the greater good and holding the importance of love and relationships in mind.</p> | <p>continue to experience.</p> <p>Believes in the worthy endeavour of attempting to understand the opportunities and limitations of living in a black and white world, the implications of social expectations, and investing in a way to help others reach a place that enables them to feel like they can fit into these somehow, perhaps without compromising themselves too much.</p> | <p>She redeems her self through achievement in work. Simultaneously displays need for care, which is finally acted upon in a misguided way. First inpatient stay. Suicide attempt. Living as a psychiatric patient. Finding a psychologist who cared. Being let down and assaulted by them. Cutting off from this. Finding and creating a family for herself. Marriage breaks down. Introduced to therapist. Second specialist inpatient admission: relieving the childhood she never had. Slipping through the net. Attending rehab and making a go of life</p> | <p>Psychiatrist 2 Ward sister Other patients Brother Friends</p> | | | <p>explicit role in this.</p> |
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|---------|---|--|--|---|---|--|---|
| | | | beyond the eating disorder. Change of career. | | | | |
| Rachael | <p>Oppressive childhood; living in the shadow of her brother.</p> <p>Becoming the adult at 12.</p> <p>Leaving school and doing well at her first job; meeting her husband to be</p> <p>Moving to Blackpool and falling out with her family.</p> <p>Falling pregnant and getting married.</p> <p>Providing for the family and burning out.</p> <p>First inpatient stay</p> <p>Second inpatient stay</p> <p>Third time lucky</p> <p>Discharged out of area once marriage broke down</p> | <p>Needing to be the good girl but never quite fitting in. Always feeling on the edge and striving to do the best she could for herself and her daughters regardless.</p> <p>Putting others needs before her own, but ever so slowly putting faith back in hope.</p> | <p>Possible abduction as an infant</p> <p>Being made to eat her dinner off the floor</p> <p>Being made anxious at the dinner table and creating the opportunity to avoid food in school</p> <p>Experiencing sexual assault</p> <p>Parents' divorce</p> <p>Separation from her brother</p> <p>Finding escapes in work</p> <p>Meeting ex husband</p> <p>Being told to leave home</p> <p>Becoming pregnant</p> <p>Receiving hospitalised 'care'</p> <p>Being informed she had the right to an opinion in her 30's</p> | <p>Brother</p> <p>Mum as unloving and punishing</p> <p>Gran the critic</p> <p>Absent Father</p> <p>Nosy teacher</p> <p>Ex Husband</p> <p>Children</p> <p>Pharmacist</p> <p>GP</p> <p>unsympathetic care co-ordinator</p> <p>unsympathetic ER doctor</p> <p>doctors who force fed</p> <p>peers who also experienced ED</p> <p>therapist vs. psychiatrist</p> <p>therapist in the community</p> <p>compassionate self</p> | <p>Being a girl</p> <p>Childhood neglect</p> <p>Navigating independence from a dependent family</p> <p>Surviving an abusive and toxic marital relationship</p> <p>Learning that she had a right to an opinion</p> <p>Maintaining hope in a hopeless and apathetic system</p> <p>Learning to trust again</p> | <p>Needing to be the good girl but everything, all the just rewards of this, being just out of reach</p> | <p>Wanting to reconnect with her daughters and experience recovery in the conventional sense.</p> |

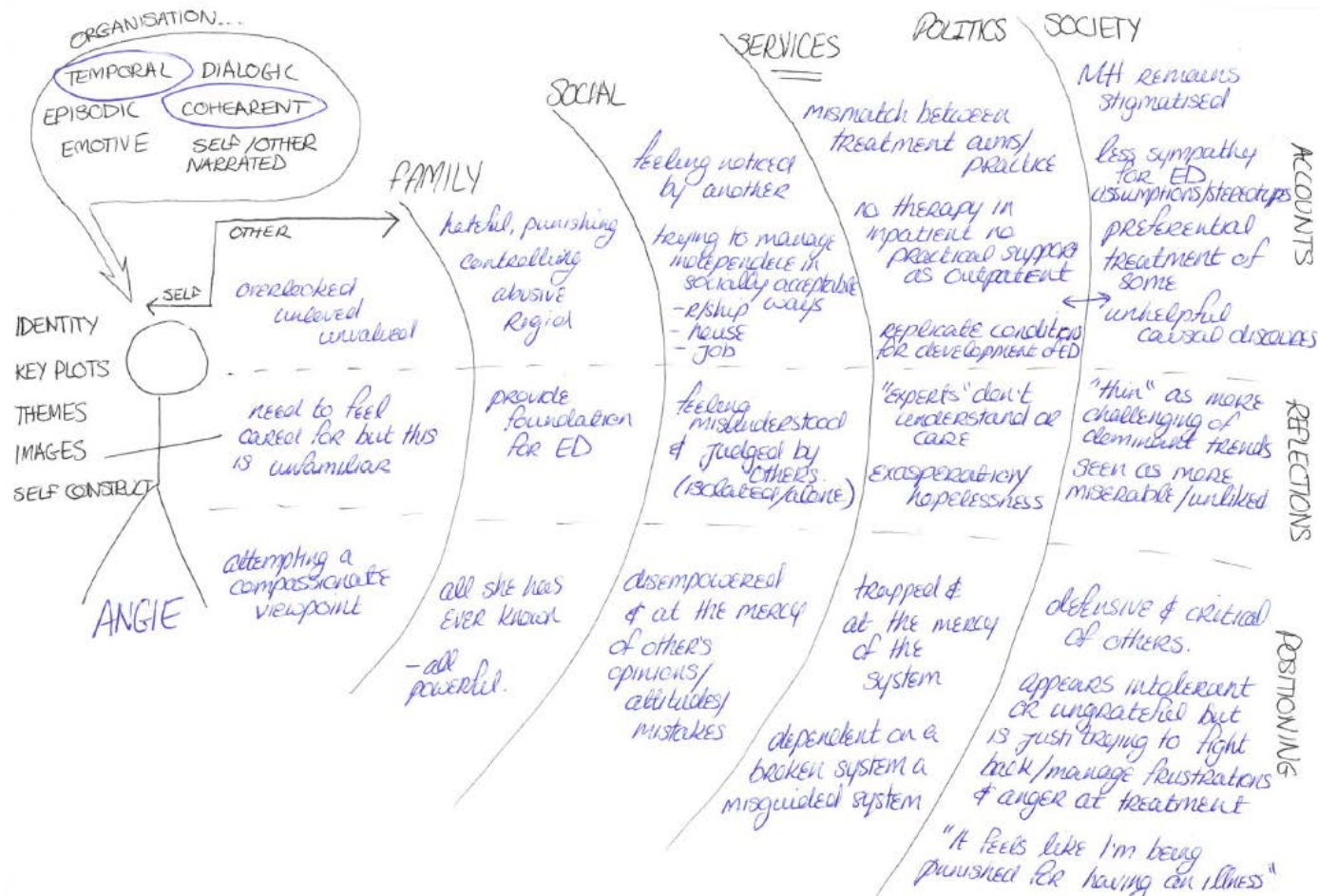
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|------|---|--|--|--|--|--|---|
| | Postcode lottery and a valued new service set up. Negotiating Recovery and holding hope. | | ECT Marriage breakdown Learning to trust again Finding a goal to work towards Maintaining consideration about and hope for recovery | | | | |
| Lisa | Early Life First Violent relationship Second Controlling Relationship Mental Health Crisis Family Support Selling up life Hiding away Emerging again | Needing to be stronger and having this feeling and sense of security tied up with romantic relationships. Lisa feels strongly about educating other on mental health and reducing judgement or stigma. | Being bullied by brother growing up Finding opportunities to avoid eating in school Falling in love and pregnant at 16 Coming to terms with and leaving violent relationship Finding a meaningful career Second relationship Miscarriage Third pregnancy Traumatic Birth Septicaemia Scare Meeting with new GP | Brother Mother First boyfriend First child Second Partner Second Child Neighbour Father Step-father Crises Team GP Psychiatrist Therapist Friend Current partner Favoured brother Sister in law Niece | Transitions; needing to feel loved and valued by others; feeling abandoned and blamed by others. | Finding “powerful tools “ to make your way through life. | Wants to help others in sharing her experience but still struggling to know the best way forward for herself. |

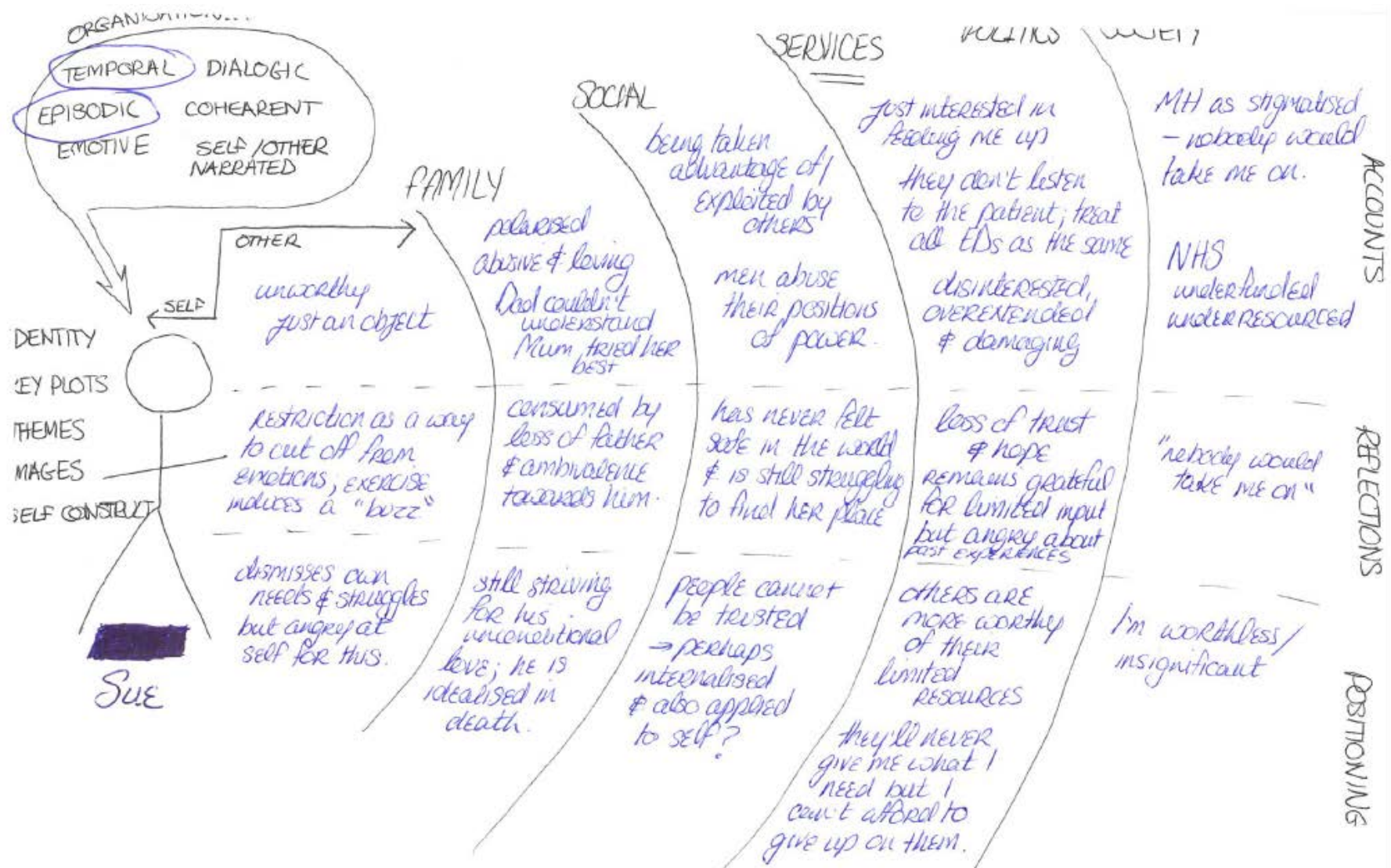
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|------|--|---|---|---------------------------------------|---|---------------------------------|--|
| | | | <p>Comment from well-meaning neighbour</p> <p>Career Focus</p> <p>Second relationship ends on her terms</p> <p>“Breakdown”</p> <p>Diagnosis of bi-polar</p> <p>Selling the business</p> <p>Selling the family home</p> <p>Moving into rental house and hiding away</p> <p>Slimming World</p> <p>Meeting with friend</p> <p>Acknowledged concerns with GP</p> <p>Weekly sessions with therapist</p> <p>Meeting new partner</p> <p>Contributing to mental health foundation resources</p> | | | | |
| Mark | Becoming an adult at 12; self-sufficiency backfired. | Needing to find his own way and resisting the expectations of | Death of grandmother. Repeated attempts at asking for help. | Orthopaedic Consultant Gran Dad | Relationship confrontations/ environmental stressors. | Doing more than others on less. | Wants to find a way to articulate personal experiences and |

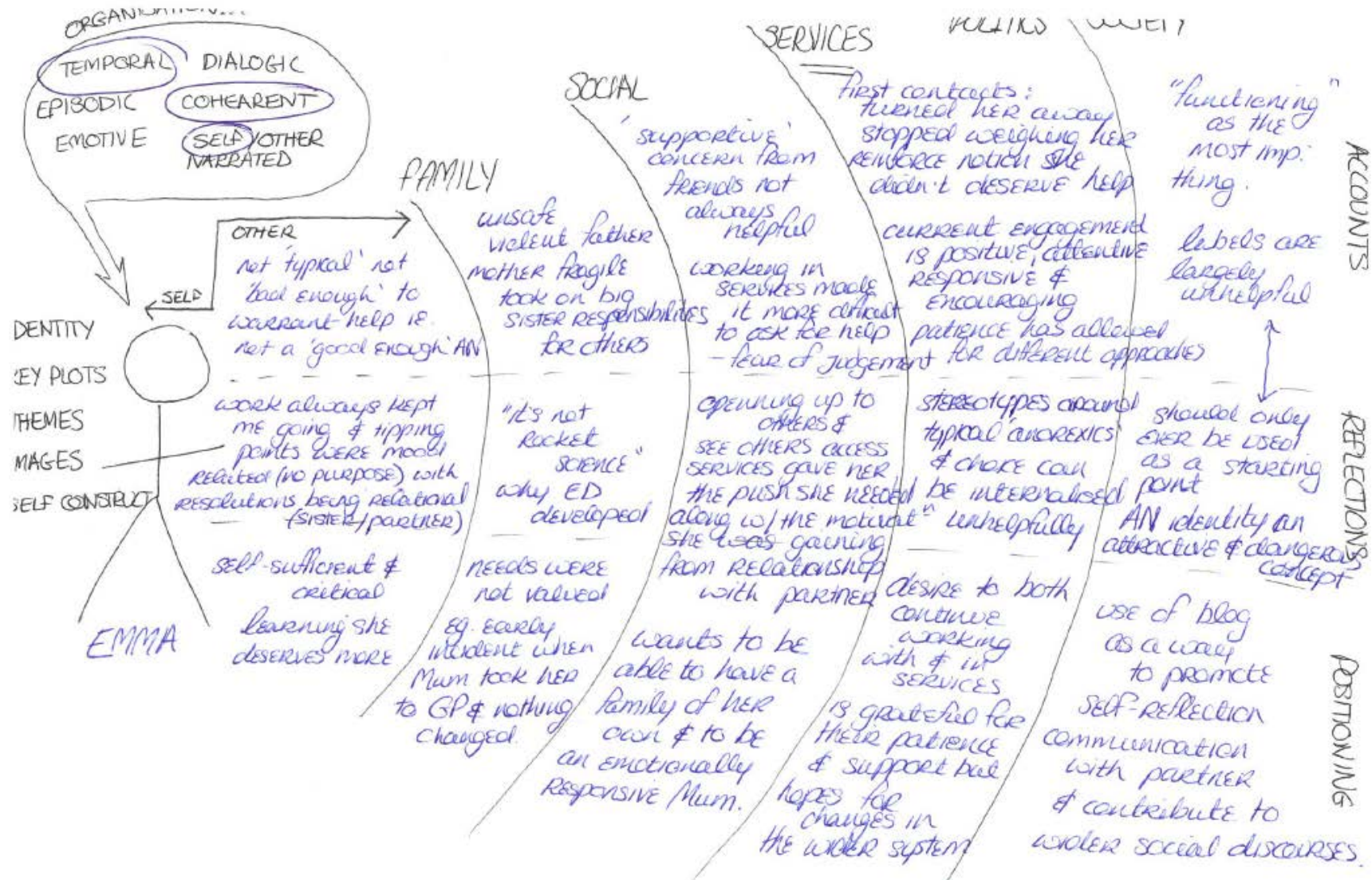
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|-------|--|---|--|--|---|--|---|
| | <p>A life of doing more on less. Being asked the right question. Initial inpatient stay. Starting the Course. Second inpatient stay. Progressing to Masters level.</p> | <p>his family upbringing. Feeling on the outside because of this but not wanting to be part of the crowd either. Wanting to do good for other, advocate for those with even less of a voice. Adopting the caring role for others and thriving on the value of friendship.</p> | <p>Broken should, orthopaedic consultation. Referral to specialist unit first time. Being celebrated on quiz night. Discharge after 7 months. Falling out with neighbours. Finding fine art course and being accepted. 2nd inpatient stay. Being interrupted by nurse at course event. 2nd discharge and day service support. Discovering diagnosis by family GP at 18 that was never followed up.</p> | <p>Friends/ 'the girls' Psychiatrist Course director The family GP</p> | <p>Not liking eating. Feeling different to family. Moving away from such an accepting place as the first inpatient experience. Moving away from a diagnosis that has created his social circle and provided the direction and purpose of his art.</p> | | <p>translate the pain and the panic of others to educate others and challenge stigmas.</p> |
| Rosie | <p>Early years School Relationship breakdown and suicide attempt CAMHS Inpatient 1</p> | <p>Struggles to find identity and purpose outside of self. Feels like she should be caring and supportive of others but this</p> | <p>Staying with aunt. bullied in school. Realising she was gay. First relationship Overdose and CAMHS referral.</p> | <p>Mother Aunt Friends Doctors CAMHS Ed therapist Father</p> | <p>Finding a sense of herself; seeking 'an identity' coming to terms with being gay at 15; coming to terms with having</p> | <p>Ambivalence, and tension between the emotional and the rationale brain. Seeking a way to feel comfortable in her own skin, didn't want to</p> | <p>Wants to work in mental health to ensure people get better services than she did. But recognises she cannot do it in her</p> |

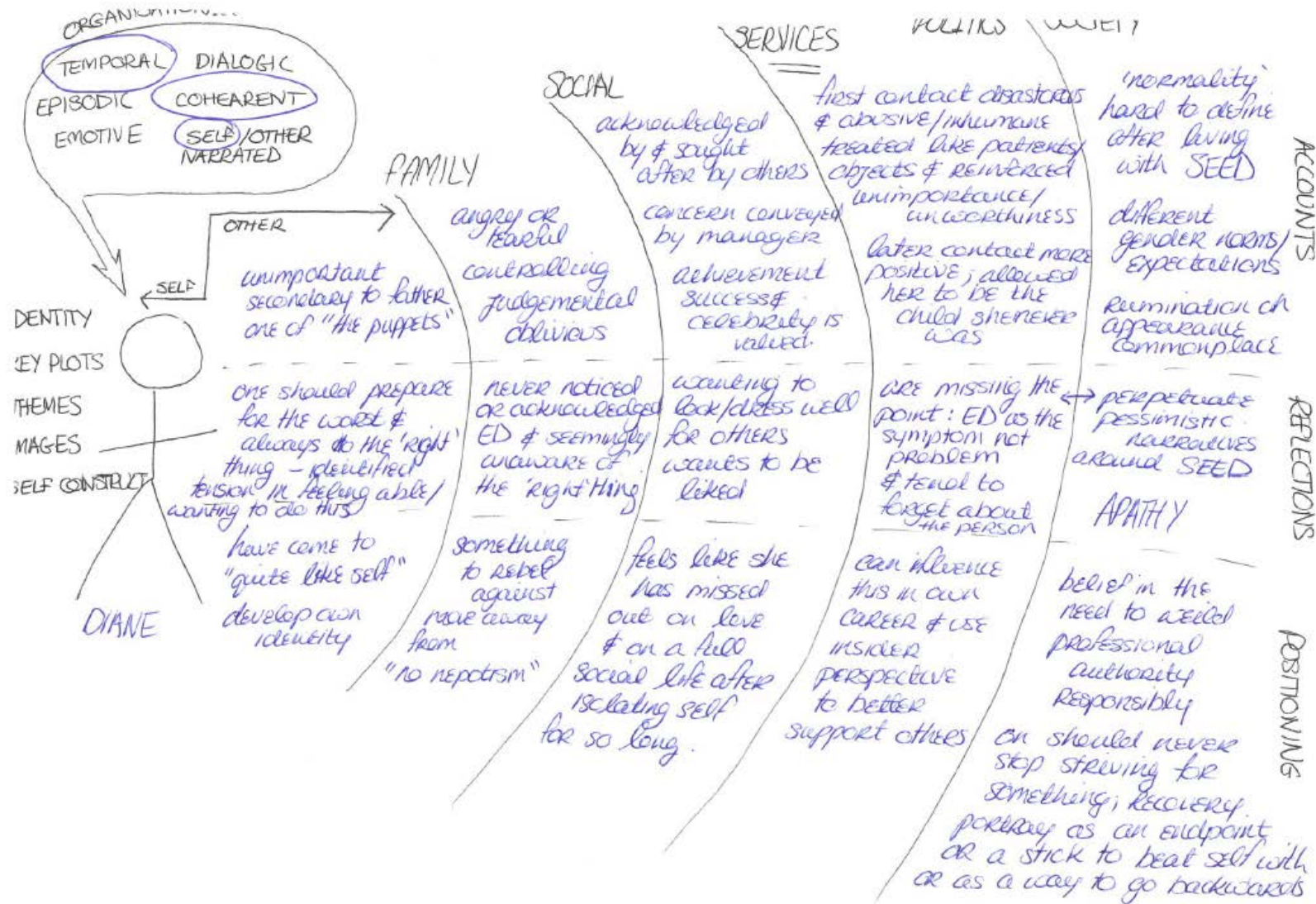
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|--|---|---|--|---|--|---|--|
| | Inpatient 2 College Uni First Time 18 month Section Uni second time | feels more like adherence to social expectation than a genuine desire to do so. Loves to rebel against social convention and is enjoying finding her own voice. | Inpatient experience as minor. Inpatient experience as an adolescent. GCSE results Uni first time sexual assault death of grandmother fire spin section death of friend Uni 2 nd attempt | Inpatient stay Cruel nurses The other patients School support staff Psychiatrist Uni friends The assault Grandmother Friend from service who passed away New Uni friends | several selves; navigating romantic relationships. | take up space be an object to others but also craved validation and connection. | present relationship with anorexia. Feeling very opposed to endorsing any sense of recovery. |
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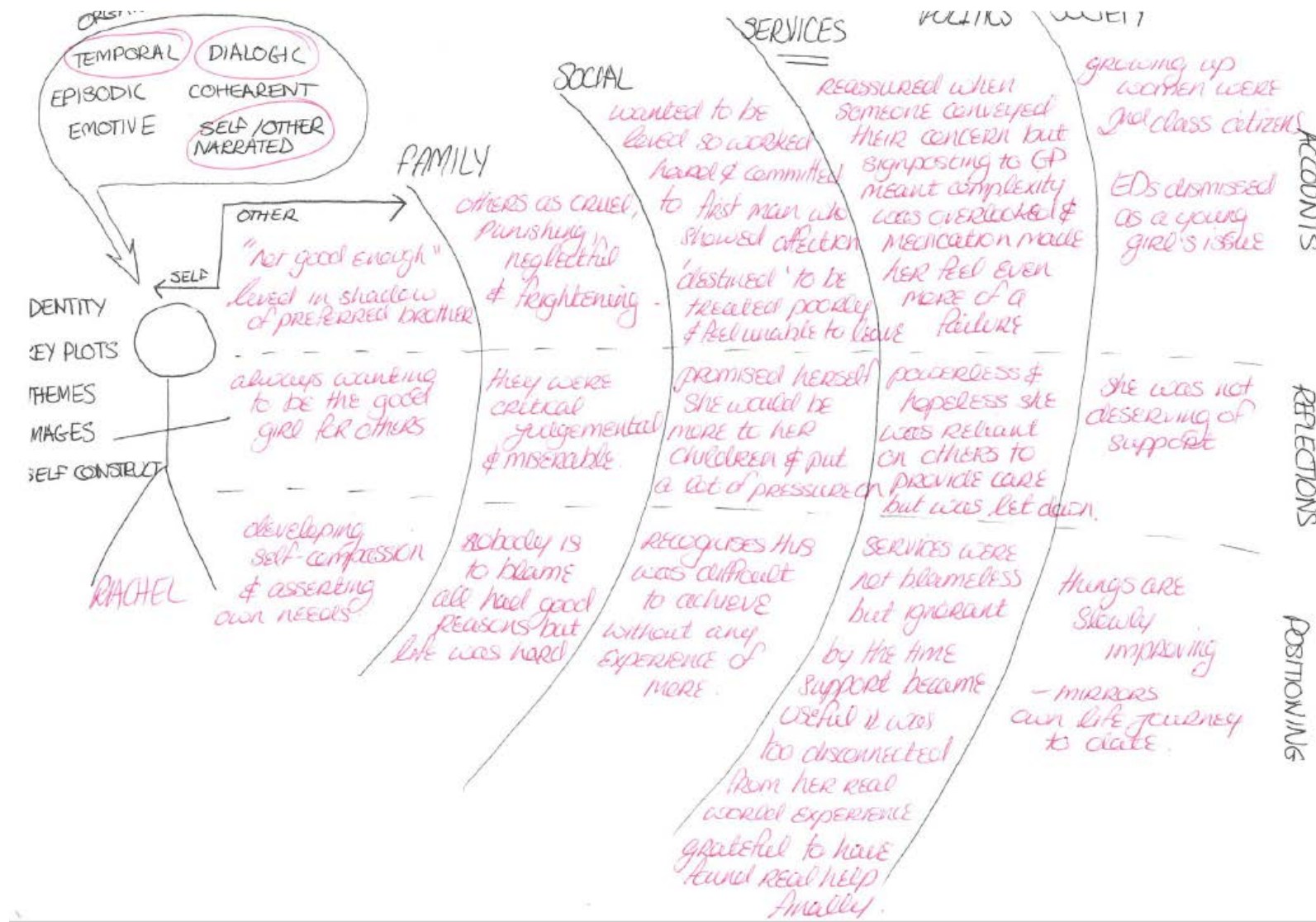
Appendix D: Narrative Maps

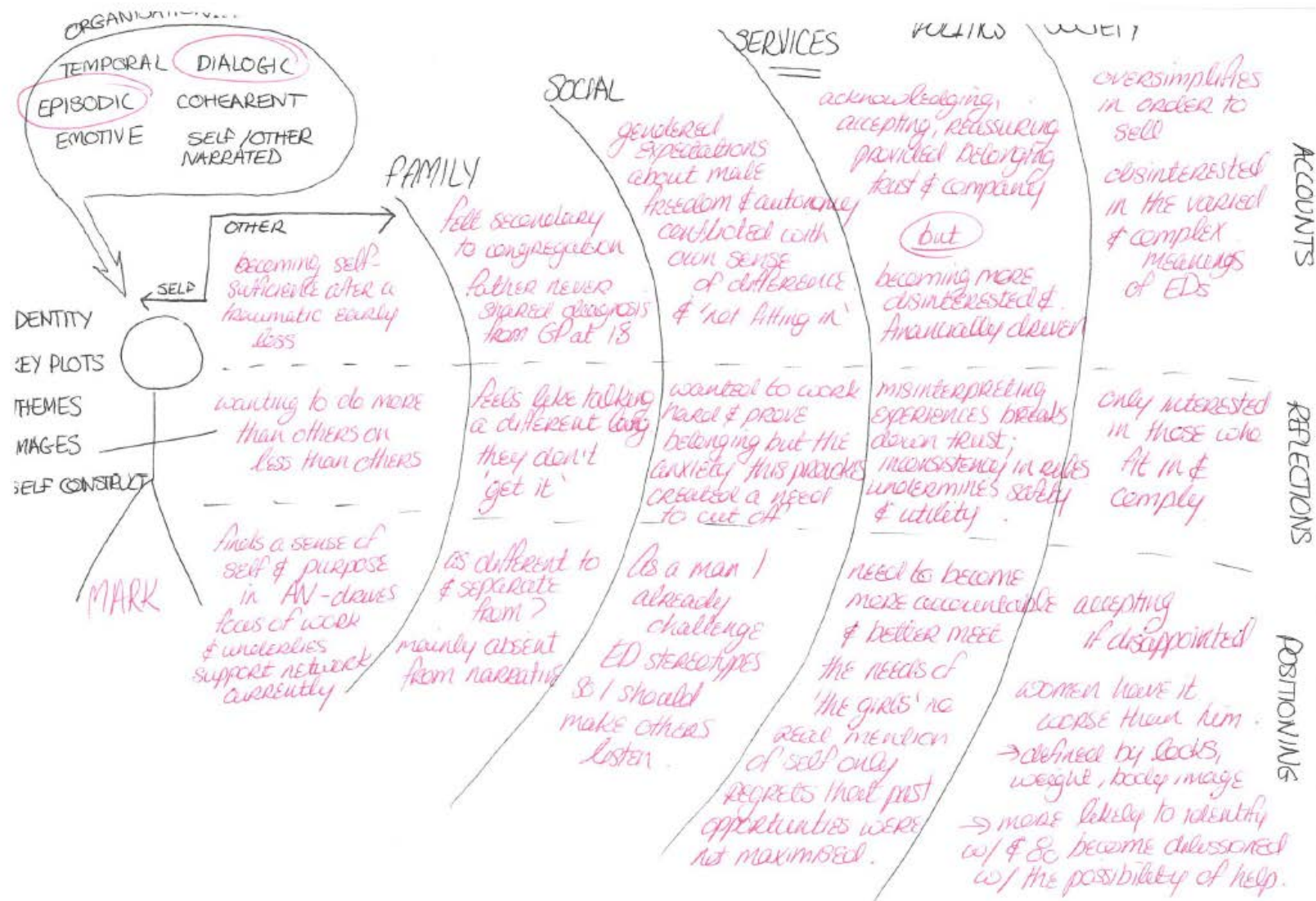




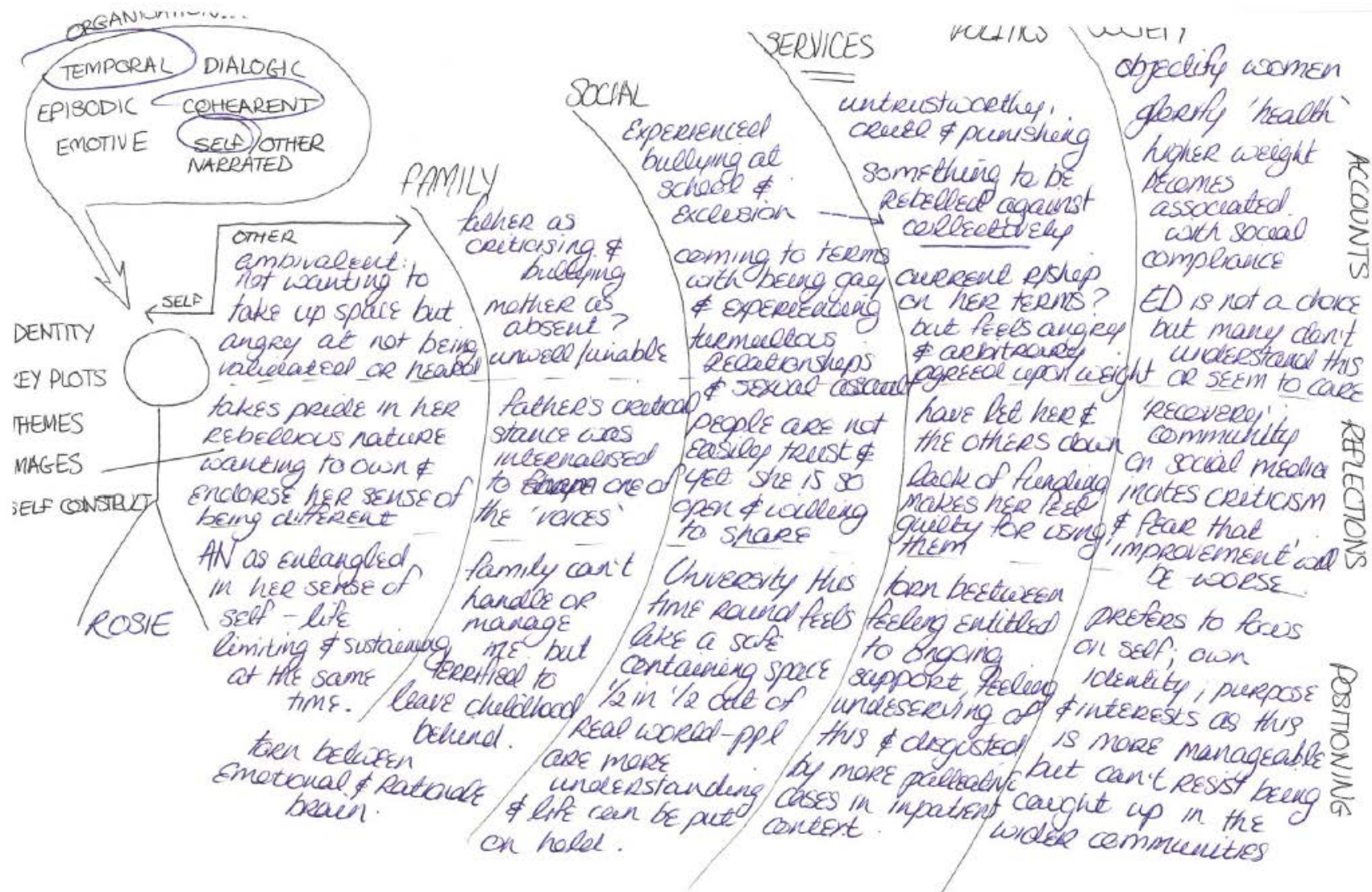












Appendix E: Guidelines for Target Journal

Qualitative Health Research

2015 Impact Factor: 1.403

2015 Ranking: 48/75 in Health Policy & Services

1. Article types

Each issue of QHR provides readers with a wealth of information — book reviews, commentaries on conceptual, theoretical, methodological and ethical issues pertaining to qualitative inquiry as well as articles covering research, theory and methods.

1.1 What types of articles will QHR accept?

QHR asks authors to make their own decision regarding the fit of their article to the journal. Do not send query letters regarding article fit.

- Read the Mission Statement on main QHR webpage.
- Search the QHR journal for articles that address your topic. Do we publish in your area of expertise?
- Ask these questions: Does it make a meaningful and strong contribution to qualitative health research literature? Is it original? Relevant? In depth? Insightful? Significant? Is it useful to reader and/or practitioner?
- Note the sections: General articles, critical reviews, articles addressing qualitative methods, commentaries on conceptual, theoretical, methodological, and ethical issues pertaining to qualitative inquiry.
- QHR accepts qualitative methods and qualitatively-driven mixed-methods, qualitative meta-analyses, and articles addressing all qualitative methods.
- QHR is a multi-disciplinary journal and accepts articles written from a variety of perspectives including: cross-cultural health, family medicine, health psychology, health social work, medical anthropology, medical sociology, nursing, pediatric health, physical education, public health, and rehabilitation.
- Articles in QHR provide an array of timely topics such as: experiencing illness, giving care, institutionalization, substance abuse, food, feeding and nutrition, living with disabilities, milestones and maturation, monitoring health, and children's perspectives on health and illness.

Look Out for These Regular Special Features

Pearls, Pith and Provocation: This section fosters debate about significant issues, enhances communication of methodological advances and encourages the discussion of provocative ideas.

Advancing Qualitative Methods: Qualitative inquiry that has used qualitative methods in an innovative way.

Evidence of Practice: Theoretical or empirical articles addressing research integration and the translation of qualitatively derived insights into clinical decision-making and health service policy planning.

4. Preparing your manuscript

4.1 Article Format (see previously published articles in QHR for style):

- Title page: Title should be succinct; list all authors and their affiliation; keywords. Please upload the title page separately from the main document.
- Blinding: Do not include any author identifying information in your manuscript, including author's own citations. Do not include acknowledgements until your article is accepted and unblinded.
- Abstract: Unstructured, 150 words. This should be the first page of the main manuscript, and it should be on its own page.
- Length: QHR does not have a word or page count limit. Manuscripts should be as tight as possible, preferably less than 30 pages including references. Longer manuscripts, if exceptional, will be considered.
- Methods: QHR readership is sophisticated; excessive details not required.
- Ethics: Include a statement of IRB approval and participant consent. Present demographics as a group, not listed as individuals. Do not link quotations to particular individuals unless essential (as in case studies) as this threatens anonymity.
- Results: Rich and descriptive; theoretical; linked to practice if possible.
- Discussion: Link your findings with research and theory in literature, including other geographical areas and quantitative research.
- References: APA format. Use pertinent references only. References should be on a separate page.

Additional Editor's Preferences:

- Please do not refer to your manuscript as a "paper;" you are submitting an "article."
- The word "data" is plural.

4.2 Word processing formats

Preferred formats for the text and tables of your manuscript are Word DOC or PDF. The text should be double-spaced throughout with standard 1 inch margins (APA formatting). Text should be standard font (i.e., Times New Roman) 12 point.

4.3 Artwork, figures and other graphics

- Figures: Should clarify text.
- Include figures, charts, and tables created in MS Word in the main text rather than at the end of the document.
- Figures, tables, and other files created outside of Word should be submitted separately. Indicate where table should be inserted within manuscript (i.e., INSERT TABLE 1 HERE).
- Photographs: Should have permission to reprint and faces should be concealed using mosaic patches – unless permission has been given by the individual to use their identity. This permission must be forwarded to QHR's Managing Editor.
 - TIFF, JPED, or common picture formats accepted. The preferred format for graphs and line art is EPS.
 - Resolution: Rasterized based files (i.e. with .tiff or .jpeg extension) require a resolution of at least 300 dpi (dots per inch). Line art should be supplied with a minimum resolution of 800 dpi.
 - Dimension: Check that the artworks supplied match or exceed the dimensions of the journal. Images cannot be scaled up after origination.
- Figures supplied in color will appear in color online regardless of whether or not these illustrations are reproduced in color in the printed version. For specifically requested color reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

4.4 Supplementary material

This journal is able to host additional materials online (e.g., datasets, podcasts, videos, images, etc.) alongside the full-text of the article. These will be subjected to peer-review alongside the article.

Supplementary files will be uploaded as supplied. They will not be checked for accuracy, copyedited, typeset or proofread. The responsibility for scientific accuracy and file functionality remains with the author(s). SAGE will only publish supplementary material subject to full copyright clearance. This means that if the content of the file is not original to the author, then the author will be responsible for clearing all permissions prior to publication. The author will be required to provide copies of permissions and details of the correct copyright acknowledgement.

4.5 Journal layout

In general, QHR adheres to the guidelines contained in the Publication Manual of the American Psychological Association [“APA”], 6th edition (ISBN 10:1-4338-0561-8, softcover; ISBN 10:1-4338-0559-6, hardcover; 10:1-4338-0562, spiral bound), with regard to manuscript preparation and formatting. These guidelines are referred to as the APA Publication Manual, or just APA. Additional help may be found online at <http://www.apa.org/>, or search the Internet for “APA format.”

4.6 Reference style

QHR adheres to the APA reference style. [Click here](#) to review the guidelines on APA to ensure your manuscript conforms to this reference style.

4.7 English language editing services

Articles must be professionally edited; this is the responsibility of the author. Authors seeking assistance with English language editing, translation, or figure and manuscript formatting to fit the journal’s specifications should consider using SAGE’s [Language Services](#).

4.8 Review Criteria

Before submitting the manuscript, authors should have their manuscript pre-reviewed using the following QHR criteria:

| |
|--|
| 1. Importance of submission: Does it make a meaningful and strong contribution to qualitative health research literature? Is it original? Relevant? In depth? Insightful? Significant? Is it useful to reader and/or practitioner? |
| 2. Theoretical orientation and evaluation: Is it theoretically clear and coherent? Is there logical progression throughout? |
| 3. Methodological assessment: Appropriate to question and/or aims? Approach logically articulated? Clarity in design and presentation? Data adequacy and appropriateness? Evidence of rigor? |
| 4. Ethical Concerns(Including IRB approval and consent): |
| 5. Data analysis and findings: Does the analysis of data reflect depth and coherence? In-depth descriptive and interpretive dimensions? Creative and insightful analysis? Linked with theory? Relevant to practice/discipline? |
| 6. Data analysis and findings: Does the analysis of data reflect depth and coherence? In-depth descriptive and interpretive dimensions? Creative and insightful analysis? Linked with theory? |
| 7. Discussion: Results linked to literature? Contribution of research clear? Relevant to practice/discipline? |
| 8. Manuscript style and format: Please evaluate writing style: Length (as short as possible), organization, clarity, grammar, appropriate citations, etc.); presentation of diagrams/illustrations? |



Section 3: Critical Appraisal

“What’s good enough?”

Ciara Joyce

Doctorate in Clinical Psychology

Division of Health Research, Lancaster University

Word Count: 3,957 (Including Abstract)

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Abstract

This critical appraisal captures some of the processes, personal reflections and challenges in exploring peoples' long-term lived experience of eating disorders (EDs) and specialist services. In keeping with the narrative methodologies employed throughout, this appraisal adopts a narrative approach to the exploration of this experience. Like the empirical paper, it is divided into six scenes across three acts that comprise an introduction to ED Services and deciding to do research in this area, the personal experiences that informed these decision, an overview of my experience conducting this research, and the final climax and resolution of the challenges I faced. The epilogue considers current reflections on what I have learned from researching this topic in this way.

Act One: An Introduction to Eating Disorder Services and Narrative Analysis

“It is the questions we can't answer that teach us the most. They teach us how to think... The harder the question the harder we hunt... the more we learn.”

(Rothfuss, 2011, p. 556/7)

Opening Scene: Adult placement allocation

During the second half of my first year on the clinical doctorate I was allocated a placement in an ED service. Having found the breadth of presentations on my child and adolescent placement daunting, I had requested a specialist placement in adult mental health. I decided I would start to feel more secure (Mason, 1993) and less “consciously incompetent” (Tri, 2017, para. 8) if I could “know” a specific “area” of mental health “comprehensively”. However, when I received my allocation I felt

my heart sink and reflected that this was due to my concern that I would find it difficult to relate to this clinical population, given how enjoyable I found food, and how I felt I would struggle to understand those who could seemingly deny themselves of its nourishment, and pleasure.

I look back at this reaction now and thankfully no longer feel shame about this uninformed, oversimplified and rather judgemental instinctive response but instead entertain a compassionate consideration about where this came from. I had a limited, stereotypical understanding of EDs having never knowingly met someone who experienced an ED. I was aware of negative media illustrations, and professional narratives about how working was similar to working with people with substance misuse and addiction issues, with a comparable level of distress and frustration for the individuals themselves, their families and the professionals around them.

Needless to say, as soon as I started working with this service, I realised that I could easily empathise and relate with service-users' experience, as well as with my colleagues and the therapeutic models of compassion-focused, narrative and cognitive analytical approaches. Consequently, my decision to undertake this research was influenced by a practical interest in deconstructing and broadening my professional understanding of EDs in light of an epistemological shift and turning point in my clinical practice, which was triggered by a personal awareness of the unhelpful, oversimplified and prejudicial dominant narratives that surround EDs, and the power these can hold over us.

The more I worked with this population, in this context, the more I began to appreciate the common humanity we all shared. This process further exposed some uncomfortable truths about myself as unintentionally still clasping onto the notion of there being a "them and us" (Richards, 2010). To paraphrase two of the participants

Rosie and Angie, it helped me make a shift between an idea I believed “logically” and one that I appreciated “emotionally”. Furthermore, I was heartened by the extent of hope the service held for individuals who had been living with long-term experiences of EDs, which opposed much of the professional literature (see Fassino & Abbate-Daga, 2013), and existed in spite of any substantial evidence-base of effective interventions in this population (Robinson, 2014).

As a consequence of the personal and professional development I was enjoying on this placement, my placement (and later thesis) supervisor and I decided that a narrative analysis (NA) of people’s experience living with long-term EDs could be beneficial in facilitating a richer understanding about the experience of this marginalised group with a methodology that privileged their voices to be heard over dominant narratives. NA was considered appropriate because of its alignment with social constructionist epistemology in which the importance of social context is considered (Weatherhead, 2011), and its ability to preserve the sequential features of participants accounts over the more fragmented but similarly detailed grounded theory approach (Riessman, 2008).

Moreover, the strength in narrative approaches’ non-reductive philosophy to interview practices, meant that participants were given the opportunity to focus on aspects of their experiences that felt important to them (Bauer, 1996) rather than these being prescribed by etic or researcher-orientated perspectives. Finally, I was also drawn to the potential for NA to encourage a socio-political dialogue of individuals’ experiences, and in doing so contribute to broader social changes (Riessman, 2008; Weatherhead, 2011) that I felt were required for this area of clinical research and practice, particularly given how my own professional interest had been inspired.

Scene Two: How did I get here?

As I had no previous experience using this method I followed an autobiographical interview protocol (Crossley, 2007) to generate narrative data on my own life experiences so that I could gain familiarity with the NA approach to interpretation. I gained experience of interpreting aspects such as narrative tone, descriptive imagery and personal ideology in relation to identity and self-construct (Crossley, 2007), and this created the opportunity to develop my own tools to help with this. For example, I created a narrative map to organise my thinking in relation to descriptive accounts, reflections and positioning in narrative content, across different levels of context (Murray, 2008; see Figure 1). In doing so I also gained an appreciation for some of the other reasons this research felt so important to me.

Having been born to parents who separated when I was at a young age, I grew up with very distinct parental ideals, and initially struggled to form a sense of identity independent of their seemingly polarised values. On the one hand my mother was a strong successful role model, emotionally and financially independent; she normalised the use of therapy to promote wellbeing and personal development. Where my mother was reliable and consistent, my father was spontaneous, outgoing and adventurous. As a long-term, reluctant user of mental health services, he had a tumultuous relationship with them, which created ambivalence for me. On the one hand I felt grateful for services, in that they were able to seemingly keep him safe when others could not. On the other hand, I saw the distress they caused him, and the oversimplified accounts of his experience they perpetuated that did not make much sense to either of us.

I grew up becoming more critical of the individualised, medicalised model of understanding mental health, but unfamiliar with any alternatives I avoided having to face the reality of their pull until I came to terms with my own experiences of

overwhelming anxiety and low mood during my final year of my undergraduate degree. Similarly to my father I felt I needed to engage with services without an alternative way of making sense of these experiences, but I did not find them overly helpful. However, I was incredibly fortunate to find myself surrounded by compassionate friends and family, who saw me through to the other side again. This experience left me with a new found appreciation of the importance of supporting others through difficult emotional places, and the role of social and environmental factors in determining mental health, which ultimately led me to consider pursuing a career in this area.

Figure 1 provides a depiction of the narrative map I plotted in relation to my own experiences, in the same way that I did for each of the participants in the research paper. From this a summary of some of the main narrative themes or subplots in my account can be seen to overlap with some of those that were conveyed in participants' narratives, perhaps making sense of how easy I found I was able to relate to working clinically in this area.

For example, feeling “good enough” was an understandable motivation having felt very responsible for others and myself from a young age (similar to Emma), overlooked (similar to Angie and Rachel), and associating self-worth with achievement (similar to Mark and Diane). Of more relevance perhaps is the latter two “columns”, which refer to the “service, political and societal levels”. These capture how I felt conflicted by my interpretation of societal values around achievement, success and wealth, and ambivalent about my choice to go into services when I knew how harmful they could be.

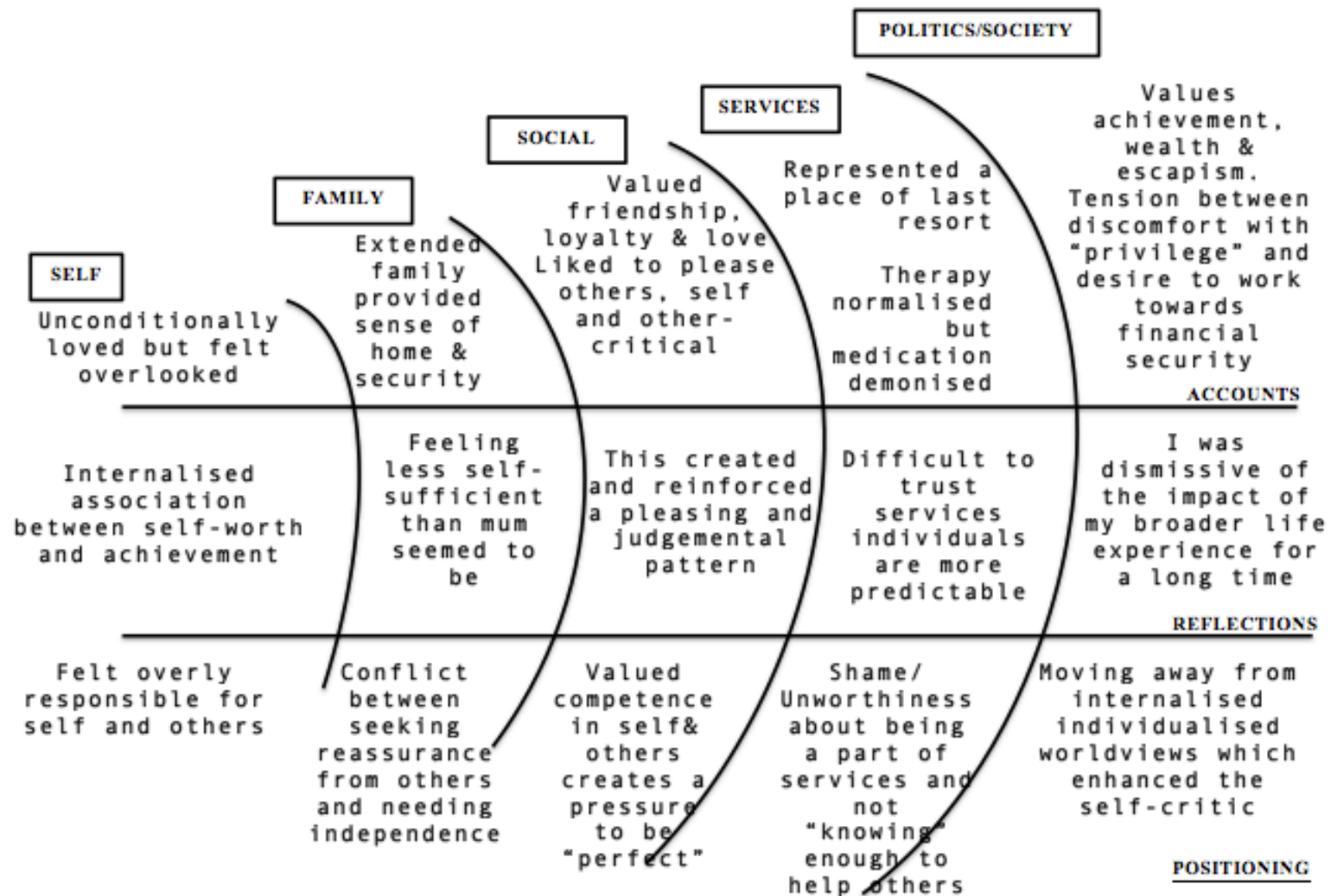


Figure 1. Narrative Map of Personal Experiences.

Thus, given my interest in the social change potential for this research, these were the levels at which I focused on presenting the data in the research paper. In facilitating the plotting of participants' stories across systemic levels, a narrative approach permitted an exploration of how each participant perceived specialist service provision and came to understand their experience of self, and identity in this context, and it gave me a chance to reflect on my own. I had come to this project with personal experience of a parent living with a long-term mental health condition, which at the time of this research had contributed to several inpatient admissions and a successful legal case contesting of the quality of care they received during the most recent of these. But I had also come with a desire to understand more about how I could integrate my personal experiences in a meaningful way with the profession I had sought to establish myself in.

I was looking forward to being able to challenge the notion of etic or researcher informed outcomes by facilitating a greater focus on emic or insider knowledges about EDs, and the role of services within this. But I was also daunted by the magnitude of the task, and with some personal and professional understanding of the negative impact of services on people's experience, I was fearful that my research would unearth pessimistic narratives and contribute to the sense of hopelessness that can sometimes surround this presentation of distress.

Thus, I started from a place of being interested in the topic and method but at a loss of where this might helpfully fit in to the literature or the profession or in other words what it might helpfully "solve". Looking back now I understand this uncertainty to be exactly "right" for the social constructive and critical epistemology of the approach I was taking, but alas I was still a recovering critical realist worried about not having a hypothesis.

Act Two: In Relationship with Research: Obstacles and Allies

Act 2, Scene 1: What I tell you you are

Having worked in ED services I was very conscious of the “not good enough” themes that were being perpetuated by the different service thresholds and commissioning structures nationally. I was reluctant to start advertising for a study that contributed to this narrative by *only* wanting to interview participants with *severe and enduring experiences* of eating disorders. In consultation with my supervisors it was felt this could be minimised by recruiting through services who could circulate the advertisement around service-users that were more likely to meet the inclusion criteria of a minimum of 10 years self-reported experience, and the exclusion criteria of having to be known to specialist service.

However, this did not result in enough interest initially. Previous qualitative research with individuals have reported a reluctance of participants with long-term experience with EDs to trust new professionals and researchers (Robinson, Kukucska, Guidetti, & Leavey, 2015), and one of the participants, Mark, sheds further light on why this might be the case, by sharing, with permission, a text from his friend who didn't want to participate:

INT. ART STUDIO – DAY (FOLLOW UP MEETING)
We sat across from one another and Mark passed me his
phone to read a text from his friend.

MARK
I think you can see from her reply there:

INTERVIEWER PICKS UP PHONE AND READS
For many especially as an inpatient the prospect of an
outsider (if you will) coming into their now safe
territory asking them personal questions about their
experiences is a daunting challenge – many won't open up
to a stranger about their story. They will probably
already have said no before they meet you. The fear is
around someone coming in stepping into their eating
disorder letting someone in is accepting the disorder..

I also suspected that recruitment was slow because I was dependent on clinicians informing potential participants, which was going to be subject to their 1) remembering to do so in a busy work environment and 2) ascertaining if they felt their clients were “well enough” to approach.

This challenge was happening during the period where I was undertaking my literature review and coming across structuralist and postmodern schools of thought for the first time. By exploring the role of language in the experience of anorexia nervosa I began to understand more about the oppressive nature of language and patriarchal service structure. I began to – again - emotionally rather than logically appreciate the truth behind statements like “the world is not a simple reflection of how it actually is, but is created and sustained by social processes, particularly language” (Forrester, 2010, p. 22).

This helped me make sense of why I had been so nervous about the way I spoke to people, and service-users in particular, about why I was constantly worried about how I answered questions about clinical theory and research and what I felt uncomfortable about getting “wrong” in these conversations with colleagues, peers and even friends. Having spent much of my formative academic years learning about a positivist interpretation of psychological theory and research, much of what I was feeling and assimilating was at odds with how I had come to understand how knowledge was constructed and deemed credible.

However instead of these realisations making me more nervous about how I approached things, I felt my knowledge and understanding about structural approaches and feminist perspectives gave me the confidence to better understand and articulate my intentions. I put through an amendment to expand recruitment to a special interest group, and I redrafted some of the recruitment material in line with

how participants I had already interviewed spoke about their experience, making changes like “long-term experience” instead of “severe and enduring experience”. A further six interested parties came forward after this second phase of recruitment, three of which took part in the study. Of the other three, two stopped responding to emails and one had to cancel the interview and was unable to reschedule within the timeframe the interviews needed to be completed by.

Of the two that had stopped responding I initially excluded one due to them not having experience of specialist services. However, when they explained that this was because it had not been available in their geographical area when they required it, I went back to the NHS ethics committee and advocated for their inclusion. I was surprised and disappointed that in my own attempt to extend beyond an objectivist stance and enabling people to self-define their experience in terms of length and type of eating difficulties, I had overlooked the possibility that this research would end up being so excluding. Unfortunately by the time the Ethics committee responded to and accepted my request, this person was no longer responding to my emails.

This highlighted for me how easy it is to overlook those who have already been overlooked. In the interplay between undertaking my literature review, and simultaneously recruiting, interviewing and listening to participants’ experiences, I was beginning to realise the full value of postmodern and discourse analytic approaches, which “retreat from the investigation of core questions” (Abraham & Hampson, 1996, p 226 in Crossley, 2007) and end up highlighting alternative considerations you could never have identified from within the dominant framework.

Act 2, Scene 2: How I went about this

For the research paper, my research question remained broad. Although I was interested in experiences of specialist service provision, I employed an unstructured approach to the qualitative interviews to facilitate the generation of biographical narratives (Howitt, 2010). I did this so as not to put a boundary on the type of story I wanted to hear, and there were strengths and limitations to this approach. A strength was that participants might have found it prescriptive or deterring to limit the content of their interviews to their experience of services, particularly given how many were still availing of their support. I also wanted to maximise on the value of the narrative approach in situating an individual in their wider social and cultural contexts.

Nevertheless, while narrative approaches can be particularly powerful and emotive, the potential for this was made clear to interested participants, and I wanted to give them as much or as little time as they felt comfortable with to express their experiences. Summary stories were made available within two weeks of the initial interview date and participants were offered to review these in person, via email or over the phone. This created the opportunity to provide containing feedback about the interview experience, and an acknowledgement of the value and importance of participating, which Emma in particular reported to find helpful:

INT. OFFICE (FOLLOW UP CONVERSATION BY TELEPHONE)

EMMA

Yeah no I think there is something very validating about having that written down on paper from someone feeling that they get that so I think that it's really important research that you doing it's really nice that someone is wanting to actually hear from people. I think a lot of people hugely appreciate that it's really quite powerful.

However, this also resulted in hours of rich data per participant, to which I later had to apply a more content specific narrative analysis in to order explore participants' interactions with services, and elicit the consequent impact of these on the development of their self-constructs.

Thus, while I found this approach reassuring as it allowed me to verify my understanding and interpretation of the participants' personal narratives and better facilitated the two-way "dance" of appropriation in narrative interpretation (Murray, 2008, p. 121) in allowing me to feel more confident that I understood participants' perspectives, and motivations for sharing different aspects of their stories. This process heightened both the challenges, and the value of employing a narrative approach, which "can appreciate the linguistic and discursive structuring of 'self' and 'experience'" (Crossley, 2007, p.226) while also maintaining a sense of the personal and "real" nature of individual subjectivity.

Act Three: Climax and Resolution

Scene Four: Breaking Point; how can I demonstrate what I've heard?

Personal narratives play a fundamental role in the development of our identities as Mair (1989, p. 2) explains:

Stories are the womb of personhood. Stories make and break us. Stories sustain us in times of trouble and encourage us towards ends we would not otherwise envision. The more we shrink and harden our ways of telling, the more starved and constipated we become. (in Crossley, 2007)

This sentiment inspired me to search beyond the limited and circular narratives about eating disorders, but also made me nervous in highlighting my responsibility in the

co-creation of these narratives (Riessman, 1993; 2008), and of reflecting these back to the participants in an honest and considerate way. I feared that I would face harrowing and potentially hopeless accounts of individuals' experiences, and I felt the pressure of sharing these more broadly in a respectful and useful way.

Initially I felt like I was trespassing on participants' inner lives, with nothing immediately tangible to offer in return. I struggled to maintain my "researcher" focus at times, and felt tempted to slip into a more "therapeutic" role, to reflect back a sense of determination, resilience or hope I was hearing in the narratives. However, I was cautious to maintain appropriate boundaries throughout, and sought the support of supervisors when this felt particularly challenging. Underneath my research and clinician roles, however, I am human, and I had to respond with the compassion each situation warranted. Consequently, I found the interviewing, and transcribing process emotionally demanding.

Some of the participants I interviewed were visibly distressed and others composed. Some were exploring notions of "recovery" (Rachel) and others were in a place of "limbo" where "you eat too much to die but not enough to stay alive"(Rosie). All stories however, were characterised by some sense of loss, abuse and trauma, of feeling undervalued and overlooked. And all stories were thus difficult to bear witness to. At times I felt intensely sad, angry, and powerless while on other occasions I was elated by the determination, courage and strength that was demonstrated. As has been previously noted by qualitative researchers in this area (Robinson et al., 2015), it felt difficult to step out of participants' lives after building up a trusting relationship.

This process was difficult to work through, but it felt so important to the analytic process in helping me identify with the emotions these experiences promoted in the participants themselves, and in those around them. At one point, after finishing

the transcribing, I found myself going through what felt like a period of apathy or disconnection. I found little motivation towards the project and little anxiety about it. I “coasted” for a couple of weeks just absorbing and avoiding, processing and pausing. Thankfully, I had a good personal and professional support network to reassure me this was an understandable response, and I was able to allow myself to take the pressure off and embrace this part of process.

When I came through this phase I found myself more engaged with the research than ever. I felt a new sense of purpose and direction in capturing the multiple truths that the narratives possessed in a way that conveyed the most powerful accounts I felt had been shared with me. Similarly to previous authors of other DClinPsy theses, which have used narrative methods (e.g. Hewitt, 2014), I realised that when there is no singular truth to be discovered, one can really value personal subjectivity, and construct a meaningful illustration of diverse experiences with the guidance of a common aim – to help professionals access and hear such experiences.

Closing Scene: Hopes For the Future

I hope that that my literature review and research paper will help expand professional understanding of the experience of eating disorders, and help maintain a critical view of the role that the language, structures and environments we adopt play in the development and maintenance of distress. I hope that it can one day contribute to an argument for the need to radically rethink the way we organise, fund and employ services in the name of those most vulnerable and in need of our compassion. I hope that this has been a “good enough” illustration of such need, and the urgency of these requests.

From a personal perspective working with people, as research participants, in a more collaborative way than I had ever previously done was inspiring, and has

instilled in me a commitment to continue working in this way. The narrative approach allowed me to constructively embrace my critical nature, and interact with participants' accounts creatively and compassionately. By vindicating the subjective nature of this approach to myself, I feel more hopeful about the role of clinical psychology and research in promoting social justice by improving understanding about, and the ability to advocate for, respectful and equitable care in services.

Epilogue

I feel very grateful to be officially beginning my qualified career with such a clear understanding and commitment to the reason I entered the profession. The people who agreed to participate in this research have helped me clarify concerns I had about working in healthcare by sharing their candid and courageous responses to this system. In critically exploring the role of language in the construction and experience of anorexia, I have begun to identify and articulate its limitations, finding hope in the “hopeless” by navigating a new way of understanding about what drives such unhelpful narratives, and charting a different epistemological direction for myself as a professional and a person.

In doing all of this I unexpectedly found a way to hone clinical skills in what appeared to be a very academic endeavour. The process of learning about the historical, philosophical and political underpinnings of the systems and services I inhabit helped me understand the value and method of deconstruction as a tool for understanding and growth. Attending to personal narratives with such a focus and energy has woken within me a newfound respect for the power of story to reflect how our sense of selves develop in the context of our social and emotional worlds, and how this understanding can create space within these to promote change.

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Section 4: Ethics Section

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Table of Contents

| | |
|---|----|
| IRAS Application Form | 4 |
| Letter of Approval from NHS REC | 41 |
| Letter of Approval from HRA..... | 45 |
| IRAS Amendment Form | 48 |
| Letter of Approval for Amendment from NHS REC | 54 |
| Email Confirmation of Amendment Approval from HRA | 56 |
| Research Protocol..... | 57 |
| Introduction | 57 |
| Diagnostic Categories, Prevalence and Outcomes | 57 |
| Debates in Service Provision..... | 59 |
| Aims of the current research | 60 |
| Principal Research Question | 61 |
| Secondary Questions: | 61 |
| Method..... | 62 |
| Participants | 62 |
| Design..... | 62 |
| Procedure..... | 63 |
| Storing participant information | 65 |
| Proposed Analysis | 65 |
| Practical Issues | 66 |
| Ethical Considerations..... | 66 |

| | |
|---|-----|
| ETHICS SECTION | 4-3 |
| Plans for Dissemination..... | 67 |
| Proposed Timetable of Key Milestones | 67 |
| Appendices | 68 |
| Appendix A: Recruitment Email to Services | 68 |
| Appendix B: Recruitment Leaflet | 69 |
| Appendix C: Participant Information Sheet | 70 |
| Appendix D: Consent Form | 73 |
| Appendix E: Debriefing Sheet | 74 |
| References | 75 |

IRAS Application Form

IRAS Form

Reference: 16/nw/0543

IRAS Version 5.3.1

Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please complete the questions in order. If you change the response to a question, please select 'Save' and review all the questions as your change may have affected subsequent questions.

Please enter a short title for this project (maximum 70 characters) Lived experience of severe and enduring eating disorder

1. Is your project research?

☒ Yes ☐ No

2. Select one category from the list below:

- Clinical trial of an investigational medicinal product
- Clinical investigation or other study of a medical device
- Combined trial of an investigational medicinal product and an investigational medical device
- Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice
- Basic science study involving procedures with human participants
- Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology
- ☒ Study involving qualitative methods only
- Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)
- Study limited to working with data (specific project only)
- Research tissue bank ☐ Research database

If your work does not fit any of these categories, select the option below: ☐

Other study

2a. Please answer the following question(s):

- a) Does the study involve the use of any ionising radiation? ☐ Yes ☒ No
- b) Will you be taking new human tissue samples (or other human biological samples)? ☐ Yes ☒ No
- c) Will you be using existing human tissue samples (or other human biological samples)? ☐ Yes ☒ No

3. In which countries of the UK will the research sites be located? *(Tick all that apply)*☒ England☐ Scotland

- Wales
- Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:☒ England

- Scotland
- Wales
- Northern Ireland
- This study does not involve the NHS

4. Which applications do you require?

IMPORTANT: If your project is taking place in the NHS and is led from England select 'IRAS Form'. If your project is led from Northern Ireland, Scotland or Wales select 'NHS/HSC Research and Development Offices' and/or relevant Research Ethics Committee applications, as appropriate.

☒ IRAS Form

- Confidentiality Advisory Group (CAG)
- National Offender Management Service (NOMS) (Prisons & Probation)

For NHS/HSC R&D Offices in Northern Ireland, Scotland and Wales the CI must create NHS/HSC Site Specific Information forms, for each site, in addition to the study wide forms, and transfer them to the PIs or local collaborators.

For participating NHS organisations in England different arrangements apply for the provision of site specific information. Refer to IRAS Help for more information.

Most research projects require review by a REC within the UK Health Departments' Research Ethics Service. Is your study exempt from REC review?☐ Yes ☒ No**5. Will any research sites in this study be NHS organisations?**☒ Yes ☐ No**5a. Are all the research costs and infrastructure costs (funding for the support and facilities needed to carry out research e.g. NHS Support costs) for this study provided by a NIHR Biomedical Research Centre, NIHR Biomedical Research Unit, NIHR Collaboration for Leadership in Health Research and Care (CLAHRC), NIHR Patient Safety Translational Research Centre or a Diagnostic Evidence Co-operative in all study sites?**

Please see information button for further details.

☐ Yes ☒ No

Please see information button for further details.

5b. Do you wish to make an application for the study to be considered for NIHR Clinical Research Network (CRN) Support and inclusion in the NIHR Clinical Research Network Portfolio?

Please see information button for further details.

☐ Yes ☒ No

The NIHR Clinical Research Network provides researchers with the practical support they need to make clinical studies happen in the NHS e.g. by providing access to the people and facilities needed to carry out research "on the ground".

If you select yes to this question, you must complete a NIHR Clinical Research Network (CRN) Portfolio Application Form (PAF) immediately after completing this project filter question and before submitting other applications. Failing to complete the PAF ahead of other applications e.g. HRA Approval, may mean that you will be unable to access NIHR CRN Support for your study.

6. Do you plan to include any participants who are children?

☐ Yes ☒ No

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

☐ Yes ☒ No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the Confidentiality Advisory Group to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?

☐ Yes ☒ No

9. Is the study or any part of it being undertaken as an educational project?

☒ Yes ☐ No

Please describe briefly the involvement of the student(s):

The applicant is a doctoral student on the DClinPsy Programme at Lancaster University. This project will form part of the chief investigators' thesis dissertation.

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

☒ Yes ☐ No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?

☐ Yes ☒ No

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?

☐ Yes ☒ No

Integrated Research Application System

Application Form for Research involving qualitative methods only

IRAS Form (project information)

Please refer to the E-Submission and Checklist tabs for instructions on submitting this application.

The Chief Investigator should complete this form. Guidance on the questions is available wherever you see this symbol displayed. We recommend reading the guidance first. The complete guidance and a glossary are available by selecting [Help](#).

Please define any terms or acronyms that might not be familiar to lay reviewers of the application.

Short title and version number: (maximum 70 characters - this will be inserted as header on all forms) Lived experience of severe and enduring eating disorder

Please complete these details after you have booked the REC application for review.

REC Name:

North West/Lancaster

REC Reference Number:

16/nw/0543

Submission date:

29/06/2016

PART A: Core study information

1. ADMINISTRATIVE DETAILS

A1. Full title of the research:

Lived experience of severe and enduring eating disorder: A narrative analysis

A2-1. Educational projects

Name and contact details of student(s):

Student 1

Title Forename/Initials Surname

Miss Ciara Joyce

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Give details of the educational course or degree for which this research is being undertaken:

Name and level of course/ degree:

Doctorate in Clinical Psychology

Name of educational establishment:

Lancaster University

Name and contact details of academic supervisor(s):

Academic supervisor 1

Title Forename/Initials Surname

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Telephone 01254593535

Fax

Please state which academic supervisor(s) has responsibility for which student(s):
Please click "Save now" before completing this table. This will ensure that all of the student and academic supervisor details are shown correctly.

Student(s)

Academic supervisor(s)

Student 1 Miss Ciara Joyce

☒ Dr Pete Greasley

A copy of a current CV for the student and the academic supervisor (maximum 2 pages of A4) must be submitted with the application.

A2-2. Who will act as Chief Investigator for this study?

☒ Student

- Academic supervisor
- Other

A3-1. Chief Investigator:

Title Forename/Initials Surname

Miss Ciara Joyce

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* Personal Telephone/Mobile 07975564960

Fax

** This information is optional. It will not be placed in the public domain or disclosed to any other third party without prior consent.*

A copy of a current CV (maximum 2 pages of A4) for the Chief Investigator must be submitted with the application.

A4. Who is the contact on behalf of the sponsor for all correspondence relating to applications for this project?

This contact will receive copies of all correspondence from REC and HRA/R&D reviewers that is sent to the CI.

Title Forename/Initials Surname

Dr Diane Hopkins

Address Research Services

Room B14, Furness College

Lancaster University, Lancaster

Post Code LA1 4YW

E-mail ethics@lancaster.ac.uk

Telephone 01524592838

Fax

A5-1. Research reference numbers. *Please give any relevant references for your study:*

Applicant's/organisation's own reference number, e.g. R & D (if available):

Sponsor's/protocol number:

Protocol Version:

Protocol Date:

Funder's reference number:

Additional reference number(s):

| Ref.Number | Description | Reference Number |
|-----------------|-------------|------------------|
| IRAS Project ID | | 210390 |

Registration of research studies is encouraged wherever possible. You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you have registered your study please give details in the "Additional reference number(s)" section.

A5-2. Is this application linked to a previous study or another current application?

☐ Yes ☒ No

Please give brief details and reference numbers.

2. OVERVIEW OF THE RESEARCH

To provide all the information required by review bodies and research information systems, we ask a number of specific questions. This section invites you to give an overview using language comprehensible to lay reviewers and members of the public. Please read the guidance notes for advice on this section.

A6-1. Summary of the study. *Please provide a brief summary of the research (maximum 300 words) using language easily understood by lay reviewers and members of the public. Where the research is reviewed by a REC within the UK Health Departments' Research Ethics Service, this summary will be published on the Health Research Authority (HRA) website following the ethical review. Please refer to the question specific guidance for this question.*

This qualitative research is being completed as a doctoral thesis in clinical psychology and aims to explore the way in which individuals with experience of severe and enduring eating disorders (SEED) have come to understand their experiences, with a focus on how personal, interpersonal, social and broader political factors contribute to such understanding.

People who experience SEED are reported to have a low recovery rates, with there being few efficacious approaches to intervention evidenced within this population. Qualitative research has sought to investigate service users' experiences of eating disorder services and recovery. The current literature recommends that treatment move beyond targeting core areas of risk associated with eating disorders such as with weight restoration, and start developing ways of managing the personal and social costs of long-term presentations. This research will contribute to this literature by facilitating a greater understanding of the lived experience of people with SEED who are accessing services, in order to clarify what narrative components may characterise this.

The study will recruit between 6 and 10 participants who are over 18 years of age, who self-report severe and enduring experience of eating difficulties and are currently accessing eating disorder services across the NHS sites in the North West of England. A narrative approach to analysis will be used. This will involve gathering and analysing participant's life stories and experiences. After providing informed consent, participants will take part in individual interviews. The study is expected to take 10 months from recruitment to completion and will be disseminated accordingly.

A6-2. Summary of main issues. Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them.

Not all studies raise significant issues. Some studies may have straightforward ethical or other issues that can be identified and managed routinely. Others may present significant issues requiring further consideration by a REC, HRA, or other review body (as appropriate to the issue). Studies that present a minimal risk to participants may raise complex organisational or legal issues. You should try to consider all the types of issues that the different reviewers may need to consider.

Purpose and design

This research proposal has been developed in collaboration with a practicing clinical psychologist working in the area of Eating Disorders, and a supervisor with previous experience of narrative analysis. Narrative analysis has only recently been applied to researching this population in one study that is known to the principal investigator. While this study has focused on the recovery process in an Australian context the present research intends to focus on the experience of current service users in the North West of England. While one purpose of the research is to be educational, it is hoped that we will be able to learn from the stories and the voices of service users to better inform service development, delivery and clinical practice as well as future research.

Recruitment

Recruitment will take place through three NHS Eating Disorder services simultaneously. Potential participants will be provided with paper copies of recruitment leaflet that gives a brief outline of the research and details how their decision to participate or withdraw from participation in the project will not affect their service provision in any way. Interested parties can indicate their interest anonymously online by following the link to the online information sheet and consent form provided on the initial information sheet. Alternatively, they can request that the chief investigator give them a call to arrange to go through the full information sheet, any questions and complete the consent form over the phone, by post or in person.

Inclusion / exclusion

Inclusion criteria will involve individuals who are 1) over 18 years of age, 2) currently accessing specialist eating disorder services and 3) consider their experience of eating difficulties to have lasted for 10 years or more with a severe impact on their quality of life. Participants will only be excluded if there is any question regarding capacity to consent raised by the individual, the chief researcher or any of the professionals involved in their care.

Consent

Informed consent will be obtained from all participants. An information sheet clarifying the purpose and nature of the research, what the research involves, its benefits (or lack of benefits), risks and burdens and alternatives to taking part will be provided. As will time to ask any further questions before undertaking the interviews. Participants will be informed they can withdraw from the study up to two weeks after their interview. The chief investigator has attended capacity assessment training and understands the ethical principles underpinning informed consent.

Risks, burdens and benefits

Sharing personal stories and experience can be an exposing, and uncomfortable experience.

Participants will only be

sharing what they chose to discuss in the interviews as with a narrative approach it is not intended that we ask any specific questions but rather allow for the person to tell the story of their experience at a pace that suits them. Additionally, participants will be assured that any involvement in the project will not impact their package of care in any way.

Confidentiality

Caldicott Principles will be adhered to throughout the project.

Conflict of Interest

One of the supervisors of the project is clinical lead for [REDACTED] Eating Disorder network and potential participants will be aware of their involvement in the project. We have remained mindful of the impact this may have on recruitment and confidentiality, and have ensured that their role in the project will be made transparent, and they will not review the transcripts of any participants known to them or involved in their service.

Additionally, the chief investigator has previously worked in the [REDACTED] but has no current obligations to them.

3. PURPOSE AND DESIGN OF THE RESEARCH

A7. Select the appropriate methodology description for this research. Please tick all that apply:

- Case series/ case note review
- Case control
- Cohort observation
- Controlled trial without randomisation
- Cross-sectional study
- Database analysis
- Epidemiology
- Feasibility/ pilot study
- Laboratory study
- Metanalysis
- ☒ Qualitative research
- Questionnaire, interview or observation study
- Randomised controlled trial
- Other (please specify)

A10. What is the principal research question/objective? Please put this in language comprehensible to a lay person.

What do personal narratives tell us about individuals' experience of severe and enduring eating difficulties in the context of receiving specialist service input?

A11. What are the secondary research questions/objectives if applicable? Please put this in language comprehensible to a lay person.

What do personal narratives tell us about people's sense of support, and hope, in the context of living with a severe and enduring eating difficulties?

What do peoples' narratives tell us about their understanding of personal agency, and their constructions of power and control?

What do personal narratives tell us about how individuals with long-term experience of eating difficulties perceive service provision?

A12. What is the scientific justification for the research? Please put this in language comprehensible to a lay person.

Eating disorders (EDs) are associated with significant psychosocial and physical health consequences (Jenkins, Hoste, Meyer, & Blissett, 2011) and generate a lot of interest in the general public and the scientific community alike (Fairburn & Harrison, 2003). Described as "serious and often fatal illnesses that cause severe disturbances to a person's eating behaviours" by the National Institute of Mental Health (NIMH, 2016), EDs are characterised by intense preoccupation with food, body weight and shape. Furthermore, a concept of severe and enduring eating disorder (SEED) has been introduced in the literature to capture the group of individuals for whom their experience of eating difficulties comprises chronic, compromising conditions of at least 10 years in duration (Robinson, 2009).

Due to changes in the diagnostic and classification criteria over time (Treasure, Claudino, & Zucker, 2010), the relative rarity of EDs in the general public (Smink, van Hoeken, & Hoek, 2012), and the apparent reluctance for individuals who experience an ED to seek professional help (Hoek & van Hoeken, 2003), the incidence of EDs may be underestimated in the general population (Smink et al., 2012). Current lifetime prevalence estimates predict that 5% of the general population will experience an ED at some point in their lives (Treasure et al., 2010) and some 20% of those might go

on to develop more severe and enduring presentations (Arkell & Robinson, 2008). However, the demand on ED services have been increasing over time (Hoek & van Hoeken, 2003). Whether this is due to an increase in prevalence or detection rates remains to be determined (Smink et al., 2012).

People who experience EDs have an elevated mortality risk compared to people who are in receipt of other mental health diagnoses, and this risk is most elevated in people with a diagnosis of AN (Smink et al., 2012). Physical health problems associated with low weight and inadequate nutrition are prolific in individuals with SEED, and SEED-AN has the highest death rate associated with any psychiatric disorder (Arcelus, Mitchell, Wales, & Nielsen, 2011). Moreover, individuals who could be considered within the SEED group participate in different treatments and psychotherapies with minimal improvement in terms of service defined outcomes such as weight restoration and measures of quality of life (Robinson, 2014). In this way, they are found to have particularly low recovery rates, with there being few efficacious approaches to intervention evidenced within this population (Hay, Touyz, & Sud, 2012). However, research has recently looked to establish a qualitative understanding of the lived experience of, and recovery from, SEEDs (Robinson, Kukucska, Guidetti, & Leavey, 2015), and Dawson, Rhodes and Touyz (2014) found that full recovery from SEED-AN is possible where hope, support, motivation and self-efficacy can be nurtured.

Debates in Service Provision

Severe, enduring and chronic experiences of EDs are the topic of much debate in the literature and provide a significant challenge to the individuals affected, their carers and professionals alike (Robinson, 2009; Robinson et al., 2015; Strober, 2004). Although seemingly at the centre of such debates, the voices of the service users in question are not well documented, with few papers referring to the wishes of people they have worked with. On the one hand, those papers that do illustrate cases are often characterised by how the professionals supersede the client or patient's requests for compromise, and forcibly treat the physical symptoms at the expense of attending to the psychological consequences and the therapeutic relationship (Guarda et al., 2007; Strober, 2004). For example individuals might ask their professional networks to work in ways that would support the maintenance of an emotionally acceptable weight rather than a medically prescribed one (Case M in Strober, 2004). On the other hand, some individuals with experience of involuntary treatment for EDs have subsequently shared their support of professionals who initially employ coercion to encourage people into treatment, and advocate that psychological work cannot begin until the body has been restored to its optimum weight (Australian Prescriber, 1998; Guarda et al., 2007; Watson, Bowers, & Andersen, 2000).

Amongst the contradictions that permeate discourse around EDs and SEED in particular, there is general consensus of the value of professional support for people experiencing long term eating difficulties (Robinson et al., 2015) with service users reporting a sense of abandonment when they withdraw (Case S in Strober 2004). Although discussion around "treatment resistance" and "medical futility" in SEEDs continues in the psychiatric literature, recent papers have cited the need for critical challenges to such pessimistic conversations (Fassino & Abbate-Daga, 2013; Geppert, 2015) and have made recommendations that treatment protocols move beyond targeting core areas of physical health risk associated with eating disorders, and focus on developing ways of managing the personal and social costs of chronic EDs presentations (Hay et al., 2012) in line with recovery models (Dawson et al, 2014). In the light of such conversations, it would seem prudent to listen to current service users' experiences, and get a sense of what they might hope for in the future.

Aims of the current research

The aim of this research is to further our understanding of what it is like to experience severe and enduring eating difficulties in the context of receiving services. This will contribute to the literature by specifically gaining insight into how individuals in receipt of services have come to understand their experiences, with a focus on how personal, interpersonal, social and broader political factors contribute to such understanding.

A13. Please summarise your design and methodology. *It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.*

Design

As the purpose of the research is to facilitate a greater understanding of the lived experience of people with SEED this research will utilise a qualitative methodology, specifically a narrative approach. The interviews will be conducted in line with a narrative analytic approach. In this respect, they will be asked a narrative inducing, open-ended question to start the interview process. Prompts will be only used to encourage of participants to tell the story of their experiences in a way that feels comfortable to them. Analysis will involve an observation on how and why participants chose to tell the story of their experiences in the way they do, while remaining mindful of the role of the interviewer in this process.

Participants

Participants will have a reported history of long-term, severe and enduring eating difficulties. They will be known to services and may be inpatient or community based. Inclusion criteria will involve individuals who are 1) over 18 years of age, 2) currently accessing specialist eating disorder services and 3) consider their experience of eating difficulties to have lasted for 10 years or more with a severe impact on their quality of life. Participants will be excluded if there is any question regarding capacity to consent raised by the individual, the primary researcher or any of the professionals involved in their care.

Procedure

Participants through three specialist eating disorder services simultaneously, including [REDACTED]

[REDACTED] Participants will be invited to read through a recruitment leaflet provided for them by the service and access an information sheet, sign a consent form online or in hard copy, by post or in person, depending on their preference. Participants will be invited to attend an interview at a location of their choosing. Lancaster University lone-working policies will be adhered to, where for each interview a check in time will be confirmed and a supervisor will be given access to sealed envelope containing the location of every interview. If I do not get in contact by the appointed time to confirm the interview has been concluded and that all is well, the supervisor will be able to access the location of the interview to be able to make direct enquiries about my whereabouts and wellbeing. If required they will be able to pass this information on to the authorities.

A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?

☒ Design of the research

- Management of the research
- Undertaking the research
- Analysis of results
- Dissemination of findings ☐ None of the above

Give details of involvement, or if none please justify the absence of involvement.

Recruitment leaflets will encourage service users to share ideas about the research project and process without their having to agree to participation.

Participants will be offered a summary of their story post interview with the opportunity to correct any errors or make and changes. This process is line with the narrative methodology and principles that state the product of research to be a collaboration between the participant and the researcher.

The chief investigator will offer to keep the participants informed of any publications or dissemination events so that they can make a decision to be kept informed or to more directly contribute to this process.

4. RISKS AND ETHICAL ISSUES

RESEARCH PARTICIPANTS

A15. What is the sample group or cohort to be studied in this research?

Select all that apply:

- Blood
- Cancer
- Cardiovascular
- Congenital Disorders
- Dementias and Neurodegenerative Diseases
- Diabetes
- Ear
- Eye
- Generic Health Relevance
- Infection
- Inflammatory and Immune System
- Injuries and Accidents
- ☒ Mental Health
- Metabolic and Endocrine
- Musculoskeletal
- Neurological
- Oral and Gastrointestinal
- Paediatrics
- Renal and Urogenital
- Reproductive Health and Childbirth
- Respiratory
- Skin
- Stroke

Gender: Male and female participants

Lower age limit: 18 Years

Upper age limit: 110 Years

A17-1. Please list the principal inclusion criteria (list the most important, max 5000 characters).

- 1) Participants who are be over 18 years of age
- 2) Participants who are currently accessing specialist eating disorder services
- 3) Participants who consider their experience of eating difficulties to have lasted for 10 years or more with a severe impact on their quality of life

A17-2. Please list the principal exclusion criteria (list the most important, max 5000 characters).

Participants will be excluded if there is any question regarding capacity to consent raised by the individual, the chief investigator or any of the professionals involved in their care.

A18. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol. These include seeking consent, interviews, non-clinical observations and use of questionnaires.

Please complete the columns for each intervention/procedure as follows:

1. Total number of interventions/procedures to be received by each participant as part of the research protocol.
2. If this intervention/procedure would be routinely given to participants as part of their care outside the research how many of the total would be routine?
3. Average time taken per intervention/procedure (minutes, hours or days)
4. Details of who will conduct the intervention/procedure, and where it will take place.

| Intervention or procedure | 1 | 2 | 3 | 4 |
|---------------------------------|---|---|-------------------|---|
| Informed Consent | 1 | 0 | 10 minutes | Prior to beginning the interview, the chief investigator will confirm the participant has read and signed the consent form, ensuring that any additional questions or concerns have been addressed. |
| Open ended interview | 1 | 0 | 30-120 minutes | Individual interviews will be conducted at a pace led by the participant. |
| Follow up discussion | 1 | 0 | 15-30 minutes | Each participant will be offered a summary narrative. They will be given the option of this by post, on the phone or in person. They will be encouraged to provide feedback on their summary. |

A21. How long do you expect each participant to be in the study in total?

It is expected that data collection for each participant will not last longer than 1 month, however this will depend on the availability of participants in terms of when interviews and follow up discussions can be arranged. After the initial interview is transcribed a summary narrative will be written to discuss with the participant, either in person, by post or over the phone.

A22. What are the potential risks and burdens for research participants and how will you minimise them?

For all studies, describe any potential adverse effects, pain, discomfort, distress, intrusion, inconvenience or changes to lifestyle. Only describe risks or burdens that could occur as a result of participation in the research. Say what steps would be taken to minimise risks and burdens as far as possible.

Sharing personal stories and experience can be an exposing, and uncomfortable experience. This will be acknowledged with participants, who will be encouraged to share only what they are comfortable with. Additionally, participants who are recruited through services may feel a burden or pressure to participate, or if they do participate to give only positive experience of the support they have received. In order to manage this potential participants will not need to inform their service of their participation in the research unless they would like to. Additionally, participants will be assured that any involvement in the project will not impact their package of care in any way. Participants will be assured that if they chose to withdraw from the project it will not impact their package of care in any way. Participants will also be assured that the normal standards of confidentiality upheld during a therapeutic session will apply to the interview process. Participants will be encouraged to let their support workers or case managers be aware of their participation in the research if they feel this would enable them to feel more supported around the process. Participants will also be provided with additional resources around independent supportive services.

Should the chief investigator become concerned that the participant might be a risk to themselves or others through the information that they share, this will be risk assessed during the interview process and discussed with the research supervisors. Participants will be made aware of the limits of confidentiality with regard to identifying such risk and the typical safeguarding processes that will follow, which might include sharing such concerns with their care-coordinator or GP and encouraging them to attend A&E.

A23. Will interviews/ questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study? ☒ Yes ☐ No

If Yes, please give details of procedures in place to deal with these issues:

This study may be sensitive in nature for participants. The chief investigator has experience working clinically in an Eating Disorder service, amongst others, and has experience in managing potential distress. Prior to participating in the study, participants will be informed that any disclosure including risk to self or others will be disclosed to the relevant parties (clinical team, GP, research team).

A24. What is the potential for benefit to research participants?

Participants may find contributing to research that hopes to facilitate a deeper understanding of the experience of SEEDs a rewarding process. Additionally, for some individuals sharing their experiences with an attentive and non-judgemental other can be a validating, containing and cathartic experience.

A26. What are the potential risks for the researchers themselves? (if any)

The researcher involved in data collection will be meeting services users not ordinarily known to them at locations that may also be new to them. To this extent lone worker policies will be adhered to. The researcher will have access to a mobile telephone during the interviews and will inform a colleague of their whereabouts at all times, checking in before and after a scheduled interview is due to take place. Lancaster University lone-working policies will be adhered to, where for each interview a check in time will be confirmed and a supervisor will be given access to sealed envelope containing the location of every interview. If I do not get in contact by the appointed time to confirm the interview has been concluded and that all is well, the supervisor will be able to access the location of the interview to be able to make direct enquiries about my whereabouts and wellbeing. If required they will be able to pass this information on to the authorities.

It is also likely that due to the nature of the subject area the chief investigator may find the content of interviews quite emotional and distressing. This will be attended to by way of typical self-care strategies including peer support, personal reflection, and speaking with supervisors during the course of the data collection and analysis.

RECRUITMENT AND INFORMED CONSENT

In this section we ask you to describe the recruitment procedures for the study. Please give separate details for different study groups where appropriate.

A27-1. How will potential participants, records or samples be identified? Who will carry this out and what resources will be used? *For example, identification may involve a disease register, computerised search of GP records, or review of medical records. Indicate whether this will be done by the direct healthcare team or by researchers acting under arrangements with the responsible care organisation(s).*

Recruitment will take place through three NHS Eating Disorder services simultaneously, and potential participants will self-select. They will be provided with paper copies of recruitment leaflet that gives a brief outline of the research and details how their decision to participate or withdraw from participation in the project will not affect their service provision in any way. Interested parties can indicate their interest anonymously online by following the link to the online information sheet and consent form provided on the initial information sheet. Alternatively, they can request that the chief investigator give them a call to arrange to go through the full information sheet, any questions and complete the consent form over the phone, by post or in person.

A27-2. Will the identification of potential participants involve reviewing or screening the identifiable personal information of patients, service users or any other person?

☐ Yes ☒ No

Please give details below:

A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?

☐ Yes ☒ No

A29. How and by whom will potential participants first be approached?

Potential participants will be provided with paper copies of recruitment leaflet that gives a brief outline of the research and details how their decision to participate or withdraw from participation in the project will not affect their service provision in any way. Interested parties can indicate their interest anonymously online by following the link to the online information sheet and consent form provided on the initial information sheet. Alternatively, they can request that the principal investigator give them a call to arrange to go through the full information sheet, any questions and complete the consent form over the phone, by post or in person.

A30-1. Will you obtain informed consent from or on behalf of research participants?

☒ Yes ☐ No

If you will be obtaining consent from adult participants, please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, videos, or interactive material). Arrangements for adults unable to consent for themselves should be described separately in Part B Section 6, and for children in Part B Section 7.

If you plan to seek informed consent from vulnerable groups, say how you will ensure that consent is voluntary and fully informed.

If you are not obtaining consent, please explain why not.

Please enclose a copy of the information sheet(s) and consent form(s).

A30-2. Will you record informed consent (or advice from consultees) in writing?

☒ Yes ☐ No

A31. How long will you allow potential participants to decide whether or not to take part?

As soon as approval has been granted invitation emails and recruitment leaflets will be sent to distribute in services. I will stop recruiting as soon as the maximum number of interested participants has been reached (10). I will continue to recruit should the number of participants who are will to undertake interviews, and have their data used in the project, falls below the minimum number (6). Participants will be informed they can withdraw from the study up to two weeks after their interview.

A33-1. What arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs? (e.g. translation, use of interpreters)

As Eating Disorder services in the North West of England are English speaking, this is not anticipated. However if interested participants did require the use of an interpreter this would be facilitated considering the importance of socio-political culture and context to narrative analytic approaches. Nevertheless, the use of interpreters would be limited to a maximum of two, given that the focus of the research question does not involve specific issues of cultural integration.

Should participants have special communication needs beyond the use of an interpreter adaptations will be made to ensure informed consent has been attained and the method of their contribution to interview will be adapted accordingly to suit their needs i.e. with the use of drawings or pictures or audio recordings.

A35. What steps would you take if a participant, who has given informed consent, loses capacity to consent during the study? *Tick one option only.*

- ☒ The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team may be retained.
- ☐ The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.
- The participant would continue to be included in the study.
 - Not applicable – informed consent will not be sought from any participants in this research.
 - Not applicable – it is not practicable for the research team to monitor capacity and continued capacity will be assumed.

Further details:

CONFIDENTIALITY

In this section. Personal data means any data relating to a participant who could potentially be identified. It includes pseudonymised data capable of being linked to a participant through a unique code number.

Storage and use of personal data during the study

A36. Will you be undertaking any of the following activities at any stage (including in the identification of potential participants)? (Tick as appropriate)

- Access to medical records by those outside the direct healthcare team
- Access to social care records by those outside the direct social care team
- ☒ Electronic transfer by magnetic or optical media, email or computer networks
- Sharing of personal data with other organisations
- Export of personal data outside the EEA
- Use of personal addresses, postcodes, faxes, emails or telephone numbers
- Publication of direct quotations from respondents
- Publication of data that might allow identification of individuals
- Use of audio/visual recording devices
- Storage of personal data on any of the following:
 - Manual files (includes paper or film)
 - NHS computers
 - Social Care Service computers
 - ☐ Home or other personal computers
 - University computers
 - ☐ Private company computers ☒
 - Laptop computers

Further details:

With regard to electronic transfer - information regarding the data analysis will be passed between the chief investigator, transcriber and the supervisors. However, at this stage data will be anonymous and no personally identifiable information will be shared, and files will also be encrypted where possible.

With regard to the use of personal addresses, emails and phone numbers - each participant will be asked to provide their preferred contact details. This information will be stored separately to research data.

With regard to publication of direct quotes - this will be made known to participants on the participant information sheet and will be discussed prior to consent. All efforts will be made to anonymise quotes unless participants do not want to be anonymised.

Participants will be given to choice about remaining anonymous and where this is indicated as a preference all efforts to anonymise data in the analysis and dissemination will be made. However there is a possibility that participants do not want to remain anonymous, and this will be there choice.

With regard to use of audio or visual recording devices - all interviews will be audio recorded using a dictaphone and pictures may be taken of images or objects that participants want to include in the data. It will not be possible to encrypt these portable recording devices so files will be uploaded to a password protected account at the earliest convenience. The files will be saved as password protected digital files on the chief investigator's laptop and/or password protected university account as soon as possible after the interview has taken place, at which point they will be deleted from the devices.

A37. Please describe the physical security arrangements for storage of personal data during the study?

Electronic copies of the recordings, transcripts and reports will be stored on a password protected personal PC for the duration of the data collection and analysis. Data will be stored longer term on the Lancaster University server. Demographic information including, age, gender, religion, accommodation status and occupational/educational experience will be collected and stored electronically where possible on a secure password protected platform (Box,

housed by Lancaster University). These documents will be kept separately to audio recordings, transcripts and photographs. Any paper copies of consent forms or demographic information will be kept in a locked filing cupboard and destroyed after being transferred to the secure electronic storage system.

Any data on portable devices, such as dictaphones or memory sticks will be encrypted where possible, and where this is not possible any identifiable data including hard copies of notes, or recordings of participants' voices will be kept securely until transferred to a password protected computer located on Lancaster University Campus. This transfer will take place as soon as possible, after which time any insecure recordings will be deleted and hard copies of notes shredded. In line with the Data Protection Act, the NHS code of confidentiality and University guidelines, electronically stored documents will be kept securely on a password-protected system (Box, housed by Lancaster University) for 10 years from the point of collection, after which they are destroyed.

A38. How will you ensure the confidentiality of personal data? *Please provide a general statement of the policy and procedures for ensuring confidentiality, e.g. anonymisation or pseudonymisation of data.*

The participant will be given confidentiality assurances in line with ethical guidelines and NHS Trust protocol. The chief investigator will be the only person to have general access to these documents as they will be secured stored in the University system. However in the case of an emergency where they are not available, the password to this secure system will be made available to a designated member of the supervisory/research team in case they need to follow up on contacting participants for any unforeseen reason (i.e to inform them of a cancellation, or to enquire about the chief investigators whereabouts if unknown).

Therefore it is likely that only the chief investigator will have access to data containing participant's personal information like consent forms, demographic and contact information. Audio transcriptions will be stored separately to this information so as to remain anonymous. Where participants would like to remain anonymous, pseudonyms will be used during the transcribing and analysis of the data, and these will also be used for the write up. Supervisors may have access to transcriptions and audio recordings, where they are not known to the participant. A third party transcriber will have access to audio recordings only. These will be securely transferred to them using encrypted files, and they will be destroyed by the third party once transcription is completed.

A40. Who will have access to participants' personal data during the study? *Where access is by individuals outside the direct care team, please justify and say whether consent will be sought.*

The chief investigator will have access to data containing participant's personal information like consent forms, demographic and contact information. Supervisors will only have access to this in case of emergencies as described earlier.

Storage and use of data after the end of the study

A41. Where will the data generated by the study be analysed and by whom?

Analysis will take place in the chief investigators home or on University premises. The analysis will mainly be undertaken by the chief investigator, however to ensure trustworthiness and rigour supervisors will also be involved in reviewing transcripts and providing perspectives on interpretation.

A42. Who will have control of and act as the custodian for the data generated by the study?

Title Forename/Initials Surname

Miss Ciara Joyce

Post Trainee Clinical Psychologist

Qualifications BSc Psychology; MSc Psychological Science; DClinPsy pending completion of this research. Work Address Furness College,
Lancaster Univeristy

Lancaster

Post Code LA1 4YW

Work Email c.joyce@lancaster.ac.uk

Work Telephone 01524592970

A43. How long will personal data be stored or accessed after the study has ended?

- Less than 3 months
- 3 – 6 months
- 6 – 12 months
- 12 months – 3 years
- ☒ Over 3 years

If longer than 12 months, please justify:

In line with the Data Protection Act, the NHS code of confidentiality and University guidelines, electronically stored documents will be kept securely on a password-protected system for 10 years from the point of collection, after which they are destroyed.

A44. For how long will you store research data generated by the study?

Years: 10

Months: 0

A45. Please give details of the long term arrangements for storage of research data after the study has ended. Say where data will be stored, who will have access and the arrangements to ensure security.

Documents will be kept securely on a password-protected system called Box, house by Lancaster University. Administration Staff from the Doctorate of Clinical Psychology will make the arrangements to ensure security and grant access under the freedom of information act if required.

INCENTIVES AND PAYMENTS

A46. Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?

☐ Yes ☒ No

A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or incentives, for taking part in this research?

☐ Yes ☒ No

A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?

☐ Yes ☒ No

NOTIFICATION OF OTHER PROFESSIONALS

A49-1. Will you inform the participants' General Practitioners (and/or any other health or care professional responsible for their care) that they are taking part in the study?

☐ Yes ☒ No

If Yes, please enclose a copy of the information sheet/letter for the GP/health professional with a version number and date.

PUBLICATION AND DISSEMINATION

A50. Will the research be registered on a public database?

☐ Yes ☒ No

Please give details, or justify if not registering the research.

Registration of research studies is encouraged wherever possible. You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you are aware of a suitable register or other method of publication, please give details. If not, you may indicate that no suitable register exists. Please ensure that you have entered registry reference number(s) in question A5-1.

A51. How do you intend to report and disseminate the results of the study? *Tick as appropriate:*

- Peer reviewed scientific journals
- Internal report
- Conference presentation
- ☐ Publication on website
- ☒ Other publication
 - Submission to regulatory authorities
 - Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators
 - No plans to report or disseminate the results
 - Other (please specify)

A52. If you will be using identifiable personal data, how will you ensure that anonymity will be maintained when publishing the results?

All information used in any such publications and reports, including direct quotations, will be anonymised, where this has been indicated as a preference, and all efforts will be made to remove any personally identifying information.

A53. Will you inform participants of the results?

☒ Yes ☐ No

Please give details of how you will inform participants or justify if not doing so.

I will provide a brief summary report of the findings initially once the report has been complete and submitted. I will subsequently inform them of any resulting publications or dissemination events if they are interested.

5. Scientific and Statistical Review

A54. How has the scientific quality of the research been assessed? *Tick as appropriate:*

- Independent external review
- Review within a company
- Review within a multi-centre research group
- Review within the Chief Investigator's institution or host organisation
- Review within the research team
- Review by educational supervisor

☐ Other

Justify and describe the review process and outcome. If the review has been undertaken but not seen by the researcher, give details of the body which has undertaken the review:

The proposal of the study was presented at a peer review panel at Lancaster University, and was modified as the result of advice received at this stage. The final research protocol was sent to the research team, including the educational supervisor and the ethics office at the University for review.

For all studies except non-doctoral student research, please enclose a copy of any available scientific critique reports, together with any related correspondence.

For non-doctoral student research, please enclose a copy of the assessment from your educational supervisor/ institution.

A59. What is the sample size for the research? *How many participants/samples/data records do you plan to study in total? If there is more than one group, please give further details below.*

| | |
|---|----|
| Total UK sample size: | 10 |
| Total international sample size (including UK): | 10 |
| Total in European Economic Area: | 10 |

Further details:

A sample size of approximately 6-10 will be sought for.

A60. How was the sample size decided upon? *If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation.*

We hope to identify a minimum of six and a maximum of ten participants that satisfy the inclusion and exclusion criteria, with the aim of ascertaining a feasible balance between providing in depth analysis across a range of different perspectives and experiences. This is in keeping with numbers of participants typically recruited within narrative approaches (Dawson et al., 2014; Wilson, Weatherhead, & Davies, 2015) and is considered a sufficient number to provide data for narrative analysis.

A62. Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives.

A narrative approach assumes that events become meaningful because of their placement in an individuals narrative, and that while stories do not represent a mirror of reality, they compose a creatively authored, constructed account complete with personal assumptions and interpretations (Kohler Riessman, 1993). By focusing on participants'

contributions as narratives, research can reach beyond a description of an individuals' past actions and experiences to explore their understanding of those events, and gain insight into how they have been interpreted to unravel the meaning attached to them. Unlike other qualitative methodologies, such as grounded theory, narrative analysis is particularly useful for investigating a process over time and seeks to portray a holistic depiction of phenomena rather than a fragmented account (Dawson, Rhodes, & Touyz, 2014). For this reason this approach is considered a useful approach to further our understanding of what it is like to experience long-term, severe and enduring eating difficulties in the context of receiving services.

Individual interviews will be conducted following an initial open-ended question, an example of which may be: "I am interested in hearing about your experience of living with an eating disorder over such a long period of time. I would like to know about your experiences from childhood to where you are now. In your story please include any events or relationships that you think are important. Please start wherever you like, take as much time as you need and share only what you feel comfortable sharing. " Follow transcription the narrative will be summarised and be offered to the participant for review to enhance reliability. All stories will be collated and themes across and within the data will be developed.

6. MANAGEMENT OF THE RESEARCH

A63. Other key investigators/collaborators. *Please include all grant co-applicants, protocol co-authors and other key members of the Chief Investigator's team, including non-doctoral student researchers.*

| | |
|----------------|---|
| | Title Forename/Initials Surname |
| | Dr Pete Greasley |
| Post | Research Supervisor and Teaching Fellow |
| Qualifications | PhD |
| Employer | Lancaster Univeristy |

Lancaster

Telephone 01524593535

Fax

Mobile p.greasley@lancaster.ac.uk

Work Email

Title Forename/Initials Surname

Dr Ste Weatherhead

| | |
|------|--|
| Post | Research Supervisor and Clinical Tutor |
|------|--|

| | |
|----------------|----------|
| Qualifications | DClinPsy |
|----------------|----------|

Employer Lancashire Care NHS Foundation Trust

Work Address Furness College

Lancaster University

Lancaster

Post Code LA1 4YW

Telephone 01524592754

Fax

Mobile s.weatherhead@lancaster.ac.uk

Work Email

Title Forename/Initials Surname

| | | |
|------|---------------|--|
| Post | Clinical Lead | |
|------|---------------|--|

| | |
|----------------|----------|
| Qualifications | DClinPsy |
|----------------|----------|

Employer [REDACTED]

| | |
|--------------|-------------|
| Work Address | |
| | |
| | |
| Post Code | |
| Telephone | 01772647004 |
| Fax | |
| Mobile | |
| Work Email | |

A64. Details of research sponsor(s)

Lead Sponsor

Status: NHS or HSC care organisation

Contact person

Name of organisation Lancaster University
Given name Diane
Family name Hopkins
Address Research Services, Room B14, Furness College, Lancaster University
Town/city Lancaster
Post code LA1 4YW
Country UNITED KINGDOM
Telephone 01524592838
Fax 01524843087
E-mail ethics@lancaster.ac.uk

Is the sponsor based outside the UK?Yes ☒ No

Under the Research Governance Framework for Health and Social Care, a sponsor outside the UK must appoint a legal representative established in the UK. Please consult the guidance notes.

A65. Has external funding for the research been secured?

- Funding secured from one or more funders
- External funding application to one or more funders in progress ☒

No application for external funding will be made

What type of research project is this?

- Standalone project
- Project that is part of a programme grant
- Project that is part of a Centre grant
- Project that is part of a fellowship/ personal award/ research training award ☒ Other

Other –

please

state:

Thesis

A66. Has responsibility for any specific research activities or procedures been delegated to a subcontractor (other than a co-sponsor listed in A64-1) ? Please give details of subcontractors if

applicable. ☐ Yes ☒ No

A67. Has this or a similar application been previously rejected by a Research Ethics Committee in the UK or another country?

☐ Yes ☒ No

Please provide a copy of the unfavourable opinion letter(s). You should explain in your answer to question A6-2 how the reasons for the unfavourable opinion have been addressed in this application.

A68-1. Give details of the lead NHS R&D contact for this research:

Title Forename/Initials Surname

[REDACTED]

Organisation

[REDACTED]

Address

Lantern Centre

Vicarage Lane, Fulwood

Preston

Post Code

PR2 8DW

Work Email



Telephone

01772773498

Fax

Mobile

Details can be obtained from the NHS R&D Forum website: <http://www.rdforum.nhs.uk>

A69-1. How long do you expect the study to last in the UK?

Planned start date: 12/07/2016 Planned end date: 12/05/2017 Total duration:

Years: 0 Months: 10 Days:

A71-1. Is this study?

☐ Single centre

☒ Multicentre

A71-2. Where will the research take place? (Tick as appropriate)

☒ England

- Scotland
- Wales
- Northern Ireland
- Other countries in European Economic Area

Total UK sites in study 3

Does this trial involve countries outside the EU?

☐ Yes

☒ No

A72. Which organisations in the UK will host the research? Please indicate the type of organisation by ticking the box and give approximate numbers if known:

☒ NHS organisations in England 3

- NHS organisations in Wales
- NHS organisations in Scotland
- HSC organisations in Northern Ireland
- GP practices in England
- GP practices in Wales
- GP practices in Scotland
- GP practices in Northern Ireland

☐ Joint health and social care agencies (eg

community mental health teams)

- Local authorities
- Phase 1 trial units
- Prison establishments
- Probation areas

☐ Independent (private or voluntary sector)

organisations

- Educational establishments
- Independent research units
- Other (give details)

A73-1. Will potential participants be identified through any organisations other than the research sites listed above?

☐ Yes ☒ No

A74. What arrangements are in place for monitoring and auditing the conduct of the research?

The chief investigator will be working closely with their supervisors to ensure close monitoring of the conduct of the research. Additionally, research sites and participants will be provided with the contact details of supervisors should they wish to raise any concerns.

A76. Insurance/ indemnity to meet potential legal liabilities

Note: in this question to NHS indemnity schemes include equivalent schemes provided by Health and Social Care (HSC) in Northern Ireland

A76-1. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) for harm to participants arising from the management of the research? Please tick box(es) as applicable.

Note: Where a NHS organisation has agreed to act as sponsor or co-sponsor, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For all other sponsors, please describe the arrangements and provide evidence.

- ☐ NHS indemnity scheme will apply (NHS sponsors only)
- ☒ Other insurance or indemnity arrangements will apply (give details below)

Lancaster University legal liability cover will apply

Please enclose a copy of relevant documents.

A76-2. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of the sponsor(s) or employer(s) for harm to participants arising from the design of the research? Please tick box(es) as applicable.

Note: Where researchers with substantive NHS employment contracts have designed the research, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For other protocol authors (e.g. company employees, university members), please describe the arrangements and provide evidence.

- ☐ NHS indemnity scheme will apply (protocol authors with NHS contracts only) ☒ Other insurance or indemnity arrangements will apply (give details below)

Lancaster University legal liability cover will apply

Please enclose a copy of relevant documents.

A76-3. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of investigators/collaborators arising from harm to participants in the conduct of the research?

Note: Where the participants are NHS patients, indemnity is provided through the NHS schemes or through professional indemnity. Indicate if this applies to the whole study (there is no need to provide documentary evidence). Where non-NHS sites are to be included in the research, including private practices, please describe the arrangements which will be made at these sites and provide evidence.

- ☒ NHS indemnity scheme or professional indemnity will apply (participants recruited at NHS sites only)
- ☐ Research includes non-NHS sites (give details of insurance/ indemnity arrangements for these sites below)

Please enclose a copy of relevant documents.

A78. Could the research lead to the development of a new product/process or the generation of intellectual property?

☒ Yes ☐ No ☐ Not sure

Please enter details of the host organisations (Local Authority, NHS or other) in the UK that will be responsible for the research sites. For NHS sites, the host organisation is the Trust or Health Board. Where the research site is a primary care site, e.g. GP practice, please insert the host organisation (PCT or Health Board) in the Institution row and insert the research site (e.g. GP practice) in the Department row.

| | | | |
|-------------------------|---|-------------------|-------------------------|
| Investigator identifier | Research site | Investigator Name | |
| IN1 | <input checked="" type="radio"/> NHS site | Forename | |
| | <input type="radio"/> Non-NHS site | Middle name | Ciara |
| | | Family name | |
| | | Email | Joyce |
| | | Qualification | c.joyce@lancaster.ac.uk |
| | Country: | (MD...) | BSc, MSc, DClinPsy |
| | England | | pending |
| | | Country | UNITED KINGDOM |
| | Organisation name | | |
| | Address | | |
| | | | |
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| Post Code | | | |
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|-----|---|---------------|-------------------------------|
| IN2 | <input checked="" type="radio"/> NHS site | Forename | |
| | <input type="radio"/> Non-NHS site | Middle name | Ciara |
| | | Family name | |
| | | Email | Joyce |
| | Country: | Qualification | c.joyce@lancaster.ac.uk |
| | England | (MD...) | BSc, MSc, DClinPsy pending |
| | | Country | UNITED KINGDOM |
| | Organisation name | | |
| | Address | | |
| | | | |
| IN3 | <input checked="" type="radio"/> NHS site | Forename | |
| | <input type="radio"/> Non-NHS site | Middle name | Ciara |
| | | Family name | Joyce |
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|-------------------|---------------|-------------------------------|
| Country: | Email | c.joyce@lancaster.ac.uk |
| England | Qualification | BSc, MSc, DClinPsy pending |
| | (MD...) | UNITED KINGDOM |
| Organisation name | Country | |
| Address | | |
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D1. Declaration by Chief Investigator

1. The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.
2. I undertake to abide by the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research.
3. If the research is approved I undertake to adhere to the study protocol, the terms of the full application as approved and any conditions set out by review bodies in giving approval.
4. I undertake to notify review bodies of substantial amendments to the protocol or the terms of the approved application, and to seek a favourable opinion from the main REC before implementing the amendment.
5. I undertake to submit annual progress reports setting out the progress of the research, as required by review bodies.
6. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to security and confidentiality of patient or other personal data, including the need to register when necessary with the appropriate Data Protection Officer. I understand that I am not permitted to disclose identifiable data to third parties unless the disclosure has the consent of the data subject or, in the case of patient data in England and Wales, the disclosure is covered by the terms of an approval under Section 251 of the NHS Act 2006.
7. I understand that research records/data may be subject to inspection by review bodies for audit purposes if required.
8. I understand that any personal data in this application will be held by review bodies and their operational managers and that this will be managed according to the principles established in the Data Protection Act 1998.
9. I understand that the information contained in this application, any supporting documentation and all correspondence with review bodies or their operational managers relating to the application:
 - Will be held by the REC (where applicable) until at least 3 years after the end of the study; and by NHS R&D offices (where the research requires NHS management permission) in accordance with the NHS Code of Practice on Records Management.
 - May be disclosed to the operational managers of review bodies, or the appointing authority for the REC (where applicable), in order to check that the application has been processed correctly or to investigate any complaint.
 - May be seen by auditors appointed to undertake accreditation of RECs (where applicable).
 - Will be subject to the provisions of the Freedom of Information Acts and may be disclosed in response to requests made under the Acts except where statutory exemptions apply.
 - May be sent by email to REC members.
10. I understand that information relating to this research, including the contact details on this application, may be held on national research information systems, and that this will be managed according to the principles established in the Data Protection Act 1998.
11. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named below. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

Contact point for publication *(Not applicable for R&D Forms)*

NRES would like to include a contact point with the published summary of the study for those wishing to seek further information. We would be grateful if you would indicate one of the contact points below

- ☒ Chief Investigator
- Sponsor
 - Study co-ordinator
 - Student
 - Other – please give details ☐ None

Access to application for training purposes *(Not applicable for R&D*

Forms) Optional – please tick as appropriate:

☒ I would be content for members of other RECs to have access to the information in the application in confidence for training purposes. All personal identifiers and references to sponsors, funders and research units would be removed.

This section was signed electronically by Miss Ciara Joyce on 28/06/2016 13:05.

Job Title/Post: Trainee Clinical Psychologist

Organisation: Lancaster University

Email: c.joyce@lancaster.ac.uk

D2. Declaration by the sponsor's representative

If there is more than one sponsor, this declaration should be signed on behalf of the co-sponsors by a representative of the lead sponsor named at A64-1.

I confirm that:

1. This research proposal has been discussed with the Chief Investigator and agreement in principle to sponsor the research is in place.
2. An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.
3. Any necessary indemnity or insurance arrangements, as described in question A76, will be in place before this research starts. Insurance or indemnity policies will be renewed for the duration of the study where necessary.
4. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.
5. Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.
6. The duties of sponsors set out in the Research Governance Framework for Health and Social Care will be undertaken in relation to this research.

Please note: The declarations below do not form part of the application for approval above. They will not be considered by the Research Ethics Committee.

7. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named in this application. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.
8. Specifically, for submissions to the Research Ethics Committees (RECs) I declare that any and all clinical trials approved by the HRA since 30th September 2013 (as defined on IRAS categories as clinical trials of medicines, devices, combination of medicines and devices or other clinical trials) have been registered on a publically accessible register in compliance with the HRA registration requirements for the UK, or that any deferral granted by the HRA still applies.

This section was signed electronically by An authorised approver at ethics@lancaster.ac.uk on 28/06/2016 16:33.

Job Title/Post: Head of Research Services
Organisation: Lancaster University
Email: y.fox@lancaster.ac.uk

D3. Declaration for student projects by academic supervisor(s)

1. I have read and approved both the research proposal and this application. I am satisfied that the scientific content of the research is satisfactory for an educational qualification at this level.
2. I undertake to fulfil the responsibilities of the supervisor for this study as set out in the Research Governance Framework for Health and Social Care.
3. I take responsibility for ensuring that this study is conducted in accordance with the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research, in conjunction with clinical supervisors as appropriate.
4. I take responsibility for ensuring that the applicant is up to date and complies with the requirements of the law and relevant guidelines relating to security and confidentiality of patient and other personal data, in conjunction with clinical supervisors as appropriate.

Academic supervisor 1

Signature:

Print Name: Pete Greasley

Post: Research Tutor/Teaching Fellow

Organisation: Lancaster University

Date: 27/06/2016 (dd/mm/yyyy)

Letter of Approval from NHS REC**North West - Lancaster Research Ethics Committee**

Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

Telephone: 020 71048008

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

01 August 2016

Miss Ciara Joyce
Furness College
Lancaster University
Lancaster
LA1 4YT

Dear Miss Joyce

| | |
|-------------------------|--|
| Study title: | Lived experience of severe and enduring eating disorder: A narrative analysis |
| REC reference: | 16/NW/0543 |
| IRAS project ID: | 210390 |

Thank you for responding to the Committee's request for further information on the above research and submitting revised documentation.

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

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Mrs Carol Ebenezer, nrescommittee.northwest-lancaster@nhs.net.

Confirmation of ethical opinion

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

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

You should notify the REC once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Revised documents should be submitted to the REC electronically from IRAS. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which you can make available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

NHS sites

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

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

| Document | Version | Date |
|---|----------------------|--------------|
| Confirmation of any other Regulatory Approvals (e.g. NIGB) and all correspondence [Confirmation from peer review process] | peer review feedback | |
| Covering letter on headed paper [Cover Letter] | | 28 June 2016 |
| Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance Letter] | | 28 June 2016 |
| Interview schedules or topic guides for participants [Interview Outline] | 1 | 30 June 2016 |
| IRAS Application Form [IRAS_Form_30062016] | | 30 June 2016 |
| IRAS Application Form XML file [IRAS_Form_29062016] | | 29 June 2016 |
| IRAS Application Form XML file [IRAS_Form_30062016] | | 30 June 2016 |
| Letter from sponsor [Sponsorship letter] | | 27 June 2016 |
| Letters of invitation to participant [Recruitment Leaflet] | 1 | 28 June 2016 |
| Other [Lancaster University Insurance Certificate] | | 28 June 2016 |
| Other [Lancaster University Research Data Policy] | v2 | 20 July 2016 |
| Other [Letter of response to the Committee's provisional opinion] | | |
| Participant consent form [Revised Consent Form] | v2.0 | 20 July 2016 |
| Participant information sheet (PIS) [Revised Participant Information Sheet] | v2.0 | 20 July 2016 |
| Research protocol or project proposal [Research Protocol] | 1 | 23 June 2016 |
| Summary CV for Chief Investigator (CI) [Summary CV Ciara Joyce] | | 23 June 2016 |
| Summary CV for supervisor (student research) [Supervisor CV] | | |

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments

- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

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

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/qualityassurance/>

HRA Training

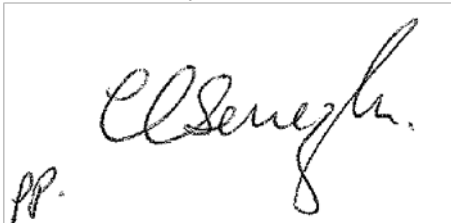
We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

| |
|-------------------|
| 16/NW/0543 |
|-------------------|

| |
|---|
| Please quote this number on all correspondence |
|---|

With the Committee's best wishes for the success of this project.

Yours sincerely

A handwritten signature in black ink, appearing to read 'L Booth', is written over a horizontal line.

Dr Lisa Booth Chair

Email: nrescommittee.northwest-lancaster@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to:

[Redacted]
[Redacted]

Letter of Approval from HRA



Health Research Authority

Miss Ciara Joyce
Furness College
Lancaster University
Lancaster
LA1 4YT

Email: hra.approval@nhs.net

21 September 2016

Dear Miss Joyce

| | |
|-------------------------|--|
| Study title: | Lived experience of severe and enduring eating disorder: A narrative analysis |
| IRAS project ID: | 210390 |
| REC reference: | 16/NW/0543 |
| Sponsor | Lancaster University |

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details

Page 1 of 8

and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

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.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the [HRA website](http://www.hra.nhs.uk), and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the [HRA website](http://www.hra.nhs.uk).

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at <http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/>.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

User Feedback

ETHICS SECTION

4-47

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please email the HRA at hra.approval@nhs.net. Additionally, one of our staff would be happy to call and discuss your experience of HRA Approval.

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

Your IRAS project ID is **210390**. Please quote this on all correspondence.

Yours sincerely

Alison Thorpe
Senior Assessor

Email: hra.approval@nhs.net

Copy to: *Dr Diane Hopkins, Sponsor Contact, Lancaster University*

[REDACTED]

IRAS Amendment Form

Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please complete the questions in order. If you change the response to a question, please select 'Save' and review all the questions as your change may have affected subsequent questions.

Please enter a short title for this project (maximum 70 characters) Lived experience of severe and enduring eating disorder

1. Is your project research?

☒ Yes ☐ No

2. Select one category from the list below:

- Clinical trial of an investigational medicinal product
- Clinical investigation or other study of a medical device
- Combined trial of an investigational medicinal product and an investigational medical device
- Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice
- Basic science study involving procedures with human participants
- Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology

☒ Study involving qualitative methods only

- Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)
- Study limited to working with data (specific project only)
- Research tissue bank ☐ Research database

If your work does not fit any of these categories, select the option below: ☐ Other study

2a. Please answer the following question(s):

- a) Does the study involve the use of any ionising radiation? ☐ Yes ☒ No
- b) Will you be taking new human tissue samples (or other human biological samples)? ☐ Yes ☒ No
- c) Will you be using existing human tissue samples (or other human biological samples)? ☐ Yes ☒ No

3. In which countries of the UK will the research sites be located? *(Tick all that apply)*

- ☒ England
☐ Scotland

- Wales
- Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

☒ England

- Scotland
- Wales
- Northern Ireland
- This study does not involve the NHS

4. Which applications do you require?

IMPORTANT: If your project is taking place in the NHS and is led from England select 'IRAS Form'. If your project is led from Northern Ireland, Scotland or Wales select 'NHS/HSC Research and Development Offices' and/or relevant Research Ethics Committee applications, as appropriate.

☒ IRAS Form

- Confidentiality Advisory Group (CAG)
- National Offender Management Service (NOMS) (Prisons & Probation)

For NHS/HSC R&D Offices in Northern Ireland, Scotland and Wales the CI must create NHS/HSC Site Specific Information forms, for each site, in addition to the study wide forms, and transfer them to the PIs or local collaborators.

For participating NHS organisations in England different arrangements apply for the provision of site specific information. Refer to IRAS Help for more information.

Most research projects require review by a REC within the UK Health Departments' Research Ethics Service. Is your study exempt from REC review?

☐ Yes ☒ No

5. Will any research sites in this study be NHS organisations?

☒ Yes ☐ No

5a. Are all the research costs and infrastructure costs (funding for the support and facilities needed to carry out research e.g. NHS Support costs) for this study provided by a NIHR Biomedical Research Centre, NIHR Biomedical Research Unit, NIHR Collaboration for Leadership in Health Research and Care (CLAHRC), NIHR Patient Safety Translational Research Centre or a Diagnostic Evidence Co-operative in all study sites?

Please see information button for further details.

☐ Yes ☒ No

Please see information button for further details.

5b. Do you wish to make an application for the study to be considered for NIHR Clinical Research Network (CRN) Support and inclusion in the NIHR Clinical Research Network Portfolio?

Please see information button for further details.

☐ Yes ☒ No

The NIHR Clinical Research Network provides researchers with the practical support they need to make clinical studies happen in the NHS e.g. by providing access to the people and facilities needed to carry out research "on the ground".

If you select yes to this question, you must complete a NIHR Clinical Research Network (CRN) Portfolio Application Form (PAF) immediately after completing this project filter question and before submitting other applications. Failing to complete the PAF ahead of other applications e.g. HRA Approval, may mean that you will be unable to access NIHR CRN Support for your study.

6. Do you plan to include any participants who are children?

☐ Yes ☒ No

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

☐ Yes ☒ No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the Confidentiality Advisory Group to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?

☐ Yes ☒ No

9. Is the study or any part of it being undertaken as an educational project?

☒ Yes ☐ No

Please describe briefly the involvement of the student(s):

The applicant is a doctoral student on the DClinPsy Programme at Lancaster University. This project will form part of the chief investigators' thesis dissertation.

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

☒ Yes ☐ No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?

☐ Yes ☒ No

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?

☐ Yes ☒ No

NOTICE OF SUBSTANTIAL AMENDMENT

Please use this form to notify the main REC of substantial amendments to all research other than clinical trials of investigational medicinal products (CTIMPs).

The form should be completed by the Chief Investigator using language comprehensible to a lay person.

Details of Chief Investigator:

Title Forename/Initials Surname
Miss Ciara Joyce
Work Address Furness College
Lancaster University
Lancaster
PostCode LA1 4YW
Email c.joyce@lancaster.ac.uk
Telephone 07975564960
Fax

For guidance on this section of the form refer to the guidance

Full title of study: Lived experience of severe and enduring eating disorder: A narrative analysis
Lead sponsor: Lancaster University
Name of REC: North West/Lancaster
REC reference number: 16/nw/0543

Additional reference number(s):

| Ref.Number | Description | Reference Number |
|-----------------|-------------|------------------|
| IRAS Project ID | | 210390 |

Name of lead R&D office: [REDACTED]
Date study commenced: 28.09.16
Protocol reference (if applicable), current version and date: 2.25.11.16
Amendment number and date: 1.24.11.16

Type of amendment

(a) Amendment to information previously given in IRAS

☐ Yes ☒ No

If yes, please refer to relevant sections of IRAS in the "summary of changes" below.

(b) Amendment to the protocol

☒ Yes ☐ No

If yes, please submit either the revised protocol with a new version number and date, highlighting changes in bold, or a document listing the changes and giving both the previous and revised text.

I am requesting a change to the recruitment process whereby I can circulate information about the study to interested stakeholders in a Division of Clinical Psychology special interest group that has been formed to create a briefing paper about understanding Eating Disorders. I have permission from members of this group to do so but I obviously will not circulate any information in this way without approval from the REC.

(c) Amendment to the information sheet(s) and consent form(s) for participants, or to any other supporting documentation for the study ☐ Yes ☒ No

If yes, please submit all revised documents with new version numbers and dates, highlighting new text in bold.

Is this a modified version of an amendment previously notified and not approved?

☐ Yes ☒ No

Summary of changes

Briefly summarise the main changes proposed in this amendment. Explain the purpose of the changes and their significance for the study.

If this is a modified amendment, please explain how the modifications address the concerns raised previously by the ethics committee.

If the amendment significantly alters the research design or methodology, or could otherwise affect the scientific value of the study, supporting scientific information should be given (or enclosed separately). Indicate whether or not additional scientific critique has been obtained.

I have currently recruited 5 out of the 8-10 participants I am hoping to recruit. I have recruited through two of the three NHS sites, one of which have not been able to support the project as they have a very small team and are in high demand. I have tried to support recruitment through these sites as best I can but interest seems to have slowed down and I would like to explore alternative options now if possible. I only need another 2 or 3 participants in total but ideally I would need to have them recruited this side of Christmas due to the research thesis deadline being in May next year.

Therefore, I am requesting a change to the recruitment process whereby I can circulate information about the study to interested stakeholders in a Division of Clinical Psychology special interest group that has been formed to create a briefing paper about understanding Eating Disorders. In doing this I hope that I may be able to increase awareness about the project and consequently the number of interested participants. Due to the nature of the experiences I am exploring it may be more likely that service users who have already voiced their willingness to share aspects of their experiences in this forum would be willing to participate in this research. This would also allow for the participants to have experience of more than two specific service sites.

The same safety protocols and procedures will be adhered to, and the only main difference this will make is in terms of creating the potential that future participants may not be currently engaged with services. Consequently I will offer people the options of 1) including people from their support networks at interviews if they would find this helpful, and 2) for me to contact their service provider to enquire as to whether clinical support after the interview would be available if required. I will also still have the option of discussing any perceived concerns about risk to self or others with my academic and field supervisor if necessary. Please see the attached amended protocol with any associated changes highlighted on pages 10 and 14. I look forward to hearing back from you.

Any other relevant information

Applicants may indicate any specific issues relating to the amendment, on which the opinion of a reviewing body is sought.
In summary this amendment request regards the expanding the recruitment protocol beyond NHS services by circulating information about the study around a relevant special interest group, with permission.

List of enclosed documents

| <i>Document</i> | <i>Version</i> | <i>Date</i> |
|------------------------|----------------|-------------|
| Research Protocol SEED | 2 | 25/11/2016 |

Declaration by Chief Investigator

1. *I confirm that the information in this form is accurate to the best of my knowledge and I take full responsibility for it.*
2. *I consider that it would be reasonable for the proposed amendment to be implemented.*

This section was signed electronically by Miss Ciara Joyce on 29/11/2016 13:05.

Job Title/Post: Chief Investigator
Organisation: Lancaster Univeristy
Email: c.joyce@lancaster.ac.uk

Declaration by the sponsor's representative

I confirm the sponsor's support for this substantial amendment.

This section was signed electronically by An authorised approver at ethics@lancaster.ac.uk on 02/12/2016 18:25.

Job Title/Post: Research Support and Systems Manager
Organisation: Lancaster University
Email: b.gordon@lancaster.ac.uk

Letter of Approval for Amendment from NHS REC**Health Research Authority****North West - Lancaster Research Ethics Committee**

Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

Tel: 020 71048008

Please note: This is the favourable opinion of the REC only and does not allow the amendment to be implemented at NHS sites in England until the outcome of the HRA assessment has been confirmed.

05 December 2016

Miss Ciara Joyce
Furness College
Lancaster University
Lancaster
LA1 4YT

Dear Miss Joyce

| | |
|--------------------------|--|
| Study title: | Lived experience of severe and enduring eating disorder: A narrative analysis |
| REC reference: | 16/NW/0543 |
| Amendment number: | 1 |
| Amendment date: | 24 November 2016 |
| IRAS project ID: | 210390 |

Change to recruitment procedures

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

The members had no ethical issues with this amendment.

Approved documents

The documents reviewed and approved at the meeting were:

| <i>Document</i> | <i>Version</i> | <i>Date</i> |
|---|----------------|------------------|
| Notice of Substantial Amendment (non-CTIMP) | 1 | 24 November 2016 |
| Research protocol or project proposal | 2 | 25 November 2016 |

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our Research Ethics Committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

| | |
|--------------------|---|
| 16/NW/0543: | Please quote this number on all correspondence |
|--------------------|---|

Yours sincerely



Dr Lisa Booth Chair

E-mail: nrescommittee.northwest-lancaster@nhs.net

Enclosures: *List of names and professions of members who took part in the review*

Copy to: [REDACTED]
 Dr Diane Hopkins
 North West - Lancaster Research Ethics Committee

Attendance at Sub-Committee of the REC meeting on 02 December 2016

Email Confirmation of Amendment Approval from HRA

From: THORPE, alison (HEALTH RESEARCH AUTHORITY) [alison.thorpe1@nhs.net]

Sent: 30 December 2016 15:25

To: Joyce, Ciara; Ethics (RSO) Enquiries

Cc: research@lancashirecare.nhs.uk

Subject: IRAS 210390 Confirmation of Amendment Assessment

Dear Ms Joyce,

Further to the below, I am pleased to confirm that HRA Approval has been issued for the referenced amendment, following assessment against the HRA criteria and standards.

The sponsor should now work collaboratively with participating NHS organisations in England to implement the amendment as per the below categorisation information. This email may be provided by the sponsor to participating organisations in England to evidence that the amendment has HRA Approval.

Please contact hra.amendments@nhs.net for any queries relating to the assessment of this amendment.

Yours sincerely,

Alison Thorpe | Senior Assessor

Health Research Authority

Nottingham HRA Centre, The Old Chapel,

Royal Standard Court, Nottingham NG1 6FS

E: alison.thorpe1@nhs.net | T: 020 7104 8064

| www.hra.nhs.uk

Research Protocol

n.b. highlighted text refers to where this protocol was updated in line with the accepted amendment.

Introduction

Eating disorders (EDs) are associated with significant psychosocial and physical health consequences (Jenkins, Hoste, Meyer, & Blissett, 2011) and generate a lot of interest in the general public and the scientific community alike (Fairburn & Harrison, 2003). Described as “serious and often fatal illnesses that cause severe disturbances to a person’s eating behaviours” by the National Institute of Mental Health (NIMH, 2016), EDs are characterised by intense preoccupation with food, body weight and shape. Historically EDs were considered to be a “nervous disease” located in the individual, resulting from a “perversion of the will” (p. 182, Striegel-Moore & Bulik, 2007) and psychological research around EDs focused on quantitative measurement of body image satisfaction within individuals (Malson, Riley, & Markula, 2009). More recently, however researchers are drawing attention to how distress that manifests in body concerns is socially constructed within socio-political and cultural contexts (Brooks, 2009; Riley, Rodham, & Gavin, 2009; Wiggins, 2009). Correspondingly, standardised causes of EDs remain elusive within the interplay of complex social, psychological and biological processes.

Diagnostic Categories, Prevalence and Outcomes

EDs are classified as “behavioural syndromes associated with physiological disturbances and physical factors” by the World Health Organisation’s diagnostic criteria for research (p. 135, WHO, 1993). They are considered to comprise two main diagnostic categories: anorexia nervosa (AN), bulimia nervosa (BN) with the third category of eating-disorder-not-otherwise-specified (EDNOS) being renamed other-specified-feeding-or-eating-disorder (OSFED), and the recent addition of binge-eating disorder (BED) in the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association (APA), 2013). Furthermore, a concept of severe and enduring eating disorder (SEED) has been introduced in the literature to capture the group of individuals for whom their experience of eating difficulties comprises chronic, compromising conditions of at least 10 years in

duration (Robinson, 2009). SEED can refer to different subgroups such as SEED-AN or SEED-BN in line with the diagnostic categories described above.

Conceptually there is overlap between AN and BN where body dissatisfaction and restrained eating behaviours are typically ‘symptoms’ of both ‘conditions’ (Kaye, Klump, Frank, & Strober, 2000), however EDs are often conceptualised as existing on a continuum of control with AN being understood as the manifestation of over-control and abstinence where BN represents a lack of control and even greed (Burns, 2004). In this way, constructions of EDs can inadvertently convey AN in a more ‘positive’ light as an achievement, which can leave people with experience of BN feeling less worthy, like “the failures” in comparison (Burns, 2004, p.276). Such comparisons are arguably reinforced in the broader literature, which appears to prioritise research and discussion around SEED-AN (Fassino & Abbate-Daga, 2013; Geppert, 2015; Marzola, Abbate-Daga, Gramaglia, Amianto, & Fassino, 2015; Robinson et al., 2015) despite the fact that, in practice, diagnoses are not always so clear cut. Binge eating is found to be a common consequence of extreme dieting, and many women who identify as anorexic also report practising binge eating behaviours (Gleaves, Lowe, Snow, Green, & Murphy-Eberenz, 2000). Similarly, theorists have argued for a “transdiagnostic” approach to understanding EDs, where eating too much or too little are seen as conceptually inseparable ways of managing emotional distress (Fox & Power, 2009).

Due to changes in the diagnostic and classification criteria over time (Treasure, Claudino, & Zucker, 2010), the relative rarity of EDs in the general public (Smink, van Hoeken, & Hoek, 2012), and the apparent reluctance for individuals who experience an ED to seek professional help (Hoek & van Hoeken, 2003), the incidence of EDs may be underestimated in the general population (Smink et al., 2012). Current lifetime prevalence estimates predict that 5% of the general population will experience an ED at some point in their lives (Treasure et al., 2010) and some 20% of those might go on to develop more severe and enduring presentations (Arkell & Robinson, 2008). However, the demand on ED services have been increasing over time (Hoek & van Hoeken, 2003). Whether this is due to an increase in prevalence or detection rates remains to be determined (Smink et al., 2012).

People who experience EDs have an elevated mortality risk compared to people who are in receipt of other mental health diagnoses, and this risk is most elevated in people with a diagnosis of

AN (Smink et al., 2012). Physical health problems associated with low weight and inadequate nutrition are prolific in individuals with SEED, and SEED-AN has the highest death rate associated with any psychiatric disorder (Arcelus, Mitchell, Wales, & Nielsen, 2011). Moreover, individuals who could be considered within the SEED group participate in different treatments and psychotherapies with minimal improvement in terms of service defined outcomes such as weight restoration and measures of quality of life (Robinson, 2014). In this way, they are found to have particularly low recovery rates, with there being few efficacious approaches to intervention evidenced within this population (Hay, Touyz, & Sud, 2012). However, research has recently looked to establish a qualitative understanding of the lived experience of, and recovery from, SEEDs (Robinson, Kukucska, Guidetti, & Leavey, 2015), and Dawson, Rhodes and Touyz (2014) found that full recovery from SEED-AN is possible where hope, support, motivation and self-efficacy can be nurtured.

Debates in Service Provision

Severe, enduring and chronic experiences of EDs are the topic of much debate in the literature and provide a significant challenge to the individuals affected, their carers and professionals alike (Robinson, 2009; Robinson et al., 2015; Strober, 2004). Case law, media coverage, and professional blogs around the topic of SEEDs discuss the tensions that exist in working with individuals who appear to have capacity to make life threatening decisions, and who may ultimately die of a “seemingly preventable mental health illness” (Lopez, Yager, & Feinstein, 2009; Ravin, 2009; Rosielle, 2009; Sokol, 2012). These conversations quickly turn into debates about whether or not primary treatment protocols should involve weight restoration with or without the affected individual’s consent (Australian Prescriber, 1998; Draper, 2000; Kendall & Hugman, 2016; Rosielle, 2009), and whether or not palliative care should be considered appropriate for people with SEED who make informed decisions not to participate in the recovery goals set by services (Lopez et al., 2009; Russon & Alison, 1998; Williams, Pieri, & Sims, 1998).

Although seemingly at the centre of such debates, the voices of the service users in question are not well documented, with few papers referring to the wishes of people they have worked with. On the

one hand, those papers that do illustrate cases are often characterised by how the professionals supersede the client or patient's requests for compromise, and forcibly treat the physical symptoms at the expense of attending to the psychological consequences and the therapeutic relationship (Guarda et al., 2007; Strober, 2004). For example individuals might ask their professional networks to work in ways that would support the maintenance of an emotionally acceptable weight rather than a medically prescribed one (Case M in Strober, 2004). On the other hand, some individuals with experience of involuntary treatment for EDs have subsequently shared their support of professionals who initially employ coercion to encourage people into treatment, and advocate that psychological work cannot begin until the body has been restored to its optimum weight (Australian Prescriber, 1998; Guarda et al., 2007; Watson, Bowers, & Andersen, 2000).

Amongst the contradictions that permeate discourse around EDs and SEED in particular, there is general consensus of the value of professional support for people experiencing long term eating difficulties (Robinson et al., 2015) with service users reporting a sense of abandonment when they withdraw (Case S in Strober 2004). Although discussion around "treatment resistance" and "medical futility" in SEEDs continues in the psychiatric literature, recent papers have cited the need for critical challenges to such pessimistic conversations (Fassino & Abbate-Daga, 2013; Geppert, 2015) and have made recommendations that treatment protocols move beyond targeting core areas of physical health risk associated with eating disorders, and focus on developing ways of managing the personal and social costs of chronic EDs presentations (Hay et al., 2012) in line with recovery models (Dawson et al, 2014). In the light of such conversations, it would seem prudent to listen to current service users' experiences, and get a sense of what they might hope for in the future.

Aims of the current research

The aim of this research is to further our understanding of what it is like to experience severe and enduring eating difficulties in the context of receiving services. A narrative approach assumes that events become meaningful because of their placement in an individual's narrative, and that while stories do not represent a mirror of reality, they compose a creatively authored, constructed account complete with personal assumptions and interpretations (Kohler Riessman, 1993). By focusing on participants' contributions as narratives, research can reach beyond a description of an individuals'

past actions and experiences to explore their understanding of those events, and gain insight into how they have been interpreted to unravel the meaning attached to them.

Unlike other qualitative methodologies, such as grounded theory, narrative analysis is particularly useful for investigating a process over time and seeks to portray a holistic depiction of phenomena rather than a fragmented account (Dawson, Rhodes, & Touyz, 2014). The language people use can provide a lens through which one can attempt to understand the influences of political, social and gender informed contexts on experience. It is not an analytic approach interested in unearthing objective truths but rather claims the truth within all experience and seeks to provide that which is neither “self-evident” nor “open to proof” (Personal Narratives Group, 1989, p.261).

Thus, the present research will explore the way in which individuals with lived experience of SEED have come to understand their experiences, by clarifying specifically what narrative components may characterise this. This research intends to aid the public and healthcare professionals in hearing the individual truths of people who experience long term eating difficulties by valuing and understanding the subjective nature of their personal experience, in terms of how it is grounded within a particular time, place and perspective (Personal Narratives Group, 1989) so that we can acknowledge their experiences, and learn from them.

Principal Research Question

What do personal narratives tell us about individuals’ experience of severe and enduring eating difficulties in the context of receiving specialist service input?

Secondary Questions:

- What do personal narratives tell us about people’s sense of support, and hope, in the context of living with a severe and enduring eating difficulties?
- What do peoples’ narratives tell us about their understanding of personal agency, and their constructions of power and control?
- What do personal narratives tell us about how individuals with long-term experience of eating difficulties perceive service provision?

Participants

Participants will have a reported history of long-term, severe and enduring eating difficulties. They will be known to services and may be inpatient or community based. In line with Robinson's (2009) description of SEED, participants will have long-standing, stable experience of eating difficulties, which have been present for a minimum of 10 years. This threshold is in keeping with research that has found rates of recovery to be significantly slower for individuals who have experienced eating difficulties for 10 years or more, compared to those who self-report experience of between 4-10 years (Steinhausen, 2000). Inclusion criteria will involve individuals who are 1) over 18 years of age, 2) currently accessing specialist eating disorder services or, if not recruited through these services, participants must have been previously known to healthcare services for reasons relating to their eating difficulties and 3) consider their experience of eating difficulties to have lasted for 10 years or more with a severe impact on their quality of life. Participants will be excluded if there is any question regarding capacity to consent raised by the individual, the primary researcher or any of the professionals involved in their care.

Design

As the purpose of the research is to facilitate a greater understanding of the lived experience of people with SEED this research will utilise a qualitative methodology, specifically a narrative approach. The interviews will be conducted in line with a narrative analytic approach (Bauer, 1996). Individual interviews will be conducted following an initial open-ended question, an example of which may be: *"I am interested in hearing about your experience of living with an eating disorder. I would like to know about your experiences from childhood to where you are now. In your story please include any events or relationships that you think are important. Please start wherever you like, take as much time as you need and share only what you feel comfortable sharing."* Prompts will be only used to encourage of participants to tell the story of their experiences in a way that feels comfortable to them. Following transcription the narrative will be summarised and will be offered to the participant for review to enhance reliability. All stories will be collated and themes across and within the data will be developed.

Analysis will involve an observation on how and why participants chose to tell the story of their experiences in the way they do, while remaining mindful of the role of the interviewer in this process. We hope to identify a minimum of six and a maximum of ten participants that satisfy the inclusion and exclusion criteria, with the aim of ascertaining a feasible balance between providing in depth analysis across a range of different perspectives and experiences. This is in keeping with numbers of participants typically recruited within narrative approaches (Dawson et al., 2014; Wilson, Weatherhead, & Davies, 2015).

Procedure

We intend to recruit participants through specialist eating disorder services across [REDACTED] [REDACTED] and circulate information about the study to interested stakeholders in the Division of Clinical Psychology special interest group that has been formed to create a briefing paper about understanding Eating Disorders. Participants who meet the inclusion criteria will be informed of the opportunity to be involved in the study by the services they are accessing (see Appendix A for an example of a recruitment email to services). Participant's will be invited to read through a recruitment leaflet provided for them by the service (see Appendix B) and access an information sheet (Appendix C), sign a consent form (Appendix D) online or in hard copy, by post or in person, depending on their preference. Participants will be invited to attend an interview at a location of their choosing.

Lancaster University lone-working policies will be adhered to, where for each interview a check in time will be confirmed and a supervisor will be given access to sealed envelope containing the location of every interview. If I do not get in contact by the appointed time to confirm the interview has been concluded and that all is well, the supervisor will be able to access the location of the interview to be able to make direct enquiries about my whereabouts and wellbeing. If required they will be able to pass this information on to the authorities. Interviews will be audio recorded and transcribed by a third party, while preserving confidentiality. I will develop summaries of research interviews and participants will have the option of this being fed back to them in a written or verbal format. Narrative analysis (NA) will be applied to the data.

The online consent form will be housed on Qualtrics, an online survey platform, which secures information safely in line with data protection protocols. This process will not require interested parties to disclose any personal information in the public domain. Upon following the link to the online information sheet they will be invited to email me (at my university email account) and ask any questions about the study or request a phone call from them. If they don't have any questions about the study, and would still like to participate, they can continue on to privately complete the consent form, and some demographic information including age, identified gender, ethnicity, religious or spiritual beliefs, length of experience with eating difficulties, any diagnosis they are aware of and comfortable to share, and current weight if known. They will also be asked to include their email or telephone number for further correspondence to arrange interview time and location, at which time I will also invite them to bring with them any significant images or objects that they feel represent their story or their relationship with their diagnosis. With their consent I will take pictures of these objects as a way of capturing and presenting data.

Information sheets will detail the flexible time commitment involved and outline how potentially emotive participating in narrative interviews can be. Participants will be encouraged to share only what they feel comfortable with and will be provided with the opportunity to debrief with the researcher involved or the services they are involved with. Participants will also be encouraged to inform their therapists or case-workers of their involvement in the research if they feel that doing so would help them feel further supported around the process. They will also be given a debriefing sheet (see Appendix E) with access to information about third party agencies that can provide support such as the Samaritans and the Beat charity (<https://www.b-eat.co.uk/>).

Face to face interviews will take place at a location that can ensure privacy and feels safe for both the researcher and participant. Lone worker policies will be adhered to. Where possible, interviews will take place at a neutral place that the participant does not directly associate with their service provision. This may not always be feasible or preferable for the participant so interviews may also take place at NHS service sites. Interviews will be audio recorded and transcribed by a third party, while preserving confidentiality. There will also be the opportunity to feed back interview summaries to participants if they are interested.

Storing participant information

The participant will be given confidentiality assurances in line with ethical guidelines and NHS Trust protocol. Demographic information including, age, gender, religion, accommodation status and occupational/educational experience will be collected and stored electronically where possible on a secure password protected platform (Box, housed by Lancaster University). These documents will be kept separately to audio recordings, transcripts and photographs. Any paper copies of consent forms or demographic information will be kept in a locked filing cupboard and destroyed after being transferred to the secure electronic storage system. I will be the only person to have general access to these documents as they will be secured stored in the University system. However in the case of an emergency where I am not available, the password to this secure system will be made available to a designated member of the supervisory/research team in case they need to follow up on contacting participants for any unforeseen reason (i.e to inform them of a cancellation, or to enquire about my whereabouts if unknown).

Proposed Analysis

Narrative analysis will be applied to the data. Narrative analysis provides methods for examining and relating meaning across the ideational (content-specific), interpersonal (relational) and textual (structural) qualities implicit within the stories people tell about their lives (Halliday, 1973 in Kohler Riessman, 1993). By using a narrative approach participants will be enabled to share their stories, at a pace that feels comfortable to them, in a way that can facilitate a consideration of how they viewed and understood their experiences (Josselson, 2011). Unlike some other research methods, narrative analysis preserves accounts shared by participants within their context, rather than fragmenting them (Riessman, 2008). Moreover, narrative analysis allows for the exploration of the cultural and social context surrounding participants' stories, with the aim of understanding these better (Patton, 2002). In order to increase the trustworthiness, reflexivity and rigour in the analytical process supervisors will be invited to listen to interviews, provide feedback and remain involved in the analytic process.

Considering this project's dependency on a specialist population for recruitment, numbers of interested participants that satisfy inclusion criteria may be low. Nevertheless, having worked in the area, and having a field supervisor based in the [REDACTED] the initial projections for service user participation are optimistic, especially as we will be recruiting through three separate Trusts. As of March 2016 there were a total of 538 active referrals across the 4 localities of [REDACTED] [REDACTED] While prevalence estimates for those who specifically experience long term, severe and enduring eating disordered behaviours are difficult to come by, research estimates that some 20% of people experiencing and eating disorder might go on to develop more severe and enduring presentations (Arkell & Robinson, 2008). By crudely applying this statistic to the numbers of active referrals in the network, there could be some 107 service users that would satisfy inclusion criteria. This calculation does not take into account the possibility that this ratio is higher in clinical populations.

Nevertheless, as a back up plan we will consider recruiting through social media via Professional Twitted accounts. A short advertisement of the research will include a link to the information and consent form so that interested participants can follow the process detailed above. If participants are not recruited through services we will add an additional inclusion criteria around having been known to services and we will offer to contact those services with permission, to enquire as to whether further support may be made available to them after the interview process if required. Also if participants are not recruited through services, the locations for interview will be restricted to privately bookable rooms in public buildings or NHS sites and participants will be invited to bring a family member or friend with them for support if they would find that more comfortable. The same considerations and procedures around risk will apply and lone working policy adhered to.

Ethical Considerations

As the field supervisor is clinical lead [REDACTED] we will need to be mindful of the impact this has on recruitment and confidentiality. This can be overcome with careful planning and adherence to ethical protocols and procedures. For example [REDACTED] role in the project

will be made transparent, and she will not review the transcripts of any participants known to her or involved in her service.

Narrative approaches can be particularly powerful and we endeavor to consider this carefully for the participants that volunteer to take part in the study. For example participants will be introduced to the research and informed of how they may find it difficult to share their stories and to remember distressing details from their experience. Participants will be given as much or as little time as they would like to express their stories and will be permitted as many breaks as they would like during the interview process. They will be given access to information and further supports after the interview process. Furthermore, I will develop and provide a summary of participant's narratives within two weeks of the initial interview date with the intention of being able to provide containing feedback of the interview experience and an acknowledgement of their participation.

Plans for Dissemination

The results will be written up and summarised in an academic assignment and may also be submitted for publication in an academic/professional journal; they may be written up as a book or book chapter, and/or presented at conferences or workshops.

Proposed Timetable of Key Milestones

| Date | Planned Action |
|---------------------------|--|
| June/July 2016 | Ethics Submitted |
| August/Sept 2016 | Recruitment & Lit Review |
| Sept/Oct 2016 | Data Collection and Transcription |
| Nov/Dec 2016 | Analysis |
| Jan 2017 | First draft lit review submitted |
| Feb 2017 | First draft research paper submitted |
| March 2017 | First draft critical appraisal submitted |
| April 2017 | Second drafts submitted |
| May 12 th 2017 | Submit |

Appendices

Appendix A: Recruitment Email to Services

Subject: Lived experience of severe and enduring eating disorder

Dear colleagues,

I am a trainee clinical psychologist conducting a narrative analysis of people's experiencing of living with long term eating difficulties for my thesis dissertation. I would like to ask for your help in recruiting participants if you are willing, and feel it would be appropriate. I am hoping to recruit up to 10 participants across 3 services, with self-reported severe and enduring experience of an eating disorder.

Specifically, this would involve recruiting people over 18 years of age who are accessing your services and report a history of eating difficulties for at least the previous 10 years. It may also involve being available to discuss any safeguarding concerns that may arise out of the interviews and providing a space for participants to debrief if they would prefer not to do this with myself.

Bearing all of this in mind I would be grateful if you would consider supporting this research and circulating an initial information leaflet (see attached **[see Appendix B]**) around the individuals in your service who may fit this criteria. A more detailed information sheet and consent form is available at **[live link inserted here]**.

Please email me if you have any questions about this process or queries about the research. I appreciate your time and consideration.

Best wishes,

Ciara Joyce

Trainee Clinical Psychologist

Lancaster University

Appendix B: Recruitment Leaflet

Lived experience of severe and enduring eating disorder; A narrative analysis.



I am a trainee clinical psychologist and I am looking for people with long-term experience of an eating disorder to participate in some interviews that I am undertaking as part of my thesis. The purpose of this research will be to capture and explore the stories of people whose experiences of eating difficulties have been enduring, with severe consequences on their lives. I hope that by sharing such stories, professionals and the public alike will be able to better understand and support them.

We are asking people who have lived with an eating disorder or difficulty for 10 years or more to volunteer their time and share their story. If you think you would be interested please contact me on **[insert research phone number here]** or at c.joyce@lancaster.ac.uk. Alternatively, if you would like to just find out some more information about the research, you can find a more detailed information sheet available at **[insert link here]**.

I very much appreciate your time and consideration. I recognise that this may not be an easy task to ask of anyone, and I understand if you have no desire to participate. However, if you do have any ideas or suggestions about elements that you feel this research should consider please feel free to contact me without expecting any pressure to participate. I am interested in hearing more about people's experience in general, as well as more formally in interview contexts.

Appendix C: Participant Information Sheet

(20.7.16/V2.0)

Lived experience of severe and enduring eating disorder; a narrative analysis.

My name is Ciara Joyce and I am conducting this research as a trainee clinical psychologist on the Doctorate in Clinical Psychology at Lancaster University.

What is the study about?

As part of my training I worked in an Eating Disorder Service for 6 months during which time I found listening to people's stories an interesting and useful experience. The purpose of this study is to support those for whom their experiences of eating difficulties have been enduring with severe consequences on their lives, to share their stories beyond the service context. In doing so I hope that we, as professionals and people alike, can learn from these and better understand the nature and impact of living with long-term eating difficulties.

Why have I been approached?

I am asking people who have lived with an eating disorder for 10 years or more to volunteer their time and share their experience. I hope to arrange interviews with up to ten people. If more than ten people volunteer they may not be chosen to take part.

Do I have to take part?

No. It's completely up to you to decide whether or not you take part. Whether you take part, or not, will have no effect on the services you receive.

What will I be asked to do if I take part?

If you decide you would like to take part, I will meet with you and ask you to share your story. This will take place at a location of your choosing, which might be your home, or in a private room at a public building like a community centre or an NHS building. Travel expenses can be covered up to a maximum amount.

Interviews will likely take between 30 and 90 minutes, depending on how much information participants chose to share. More time can be made available if required. Interviews will be recorded so that they can be later transcribed and analysed. Participants may also choose to bring images or objects with them that represent important aspects of their experience living with an eating disorder. With permission, any images or objects will be photographed and stored anonymously with the interview transcripts.

Will my data be identifiable?

Participants will be able to choose if they would like their contributions to be identifiable. Should you chose to participate you do not need to inform your clinical team that you are doing so. Although one of the research team is also the clinical lead for the [REDACTED] Eating Disorder network, they will not be involved in reviewing the interviews from any participant who is known to them. This study is being recruited for in a way that should hopefully prevent participants from having to disclose their participation if they do not want to. If you feel this has not been the case please inform a member of the research team (contact information is included below).

This project assures anonymity within normal limits. Unless there is concern raised through the information participants share that they, or someone else, is at risk of harm, personally identifying information will be protected. If I am concerned that someone is at risk of harm, I will have to speak to a member of their clinical team and my research team about this.

Unless participants would prefer to use their own name in the research, it will be omitted from transcripts. They may choose a pseudonym or one can be provided for them. Any information collected for research purposes may be used later in reports or publications. Nonetheless, all the information used in any such publications and reports, including direct quotations, will be anonymised where this is preferable.

What will happen to the information I provide?

Recordings of the interviews will be recorded, transcribed and anonymised where this is preferable. The data collected for this study will be stored securely for up to 10 years, after which they will be permanently deleted. All your personal data, including your consent form, will be confidential and will be kept separately from your interview responses.

Are there any risks?

Sharing your story can be an emotional and exposing experience. For some people this level of emotion or vulnerability can be distressing, and it might feel too difficult to take part in, or continue with. I will try to take interviews at a pace that feels comfortable. I won't be asking many specific questions but will encourage participants to share as much or as little of their story as they like. Should the interview feel too distressing or intense at any stage participants can ask to stop or take a break. There will also be opportunity to debrief after the interview with either myself, or a member of participant's clinical team. If participants experience any distress following the interview process I will ask them to let me or their clinical team know, or to access an independent source of support, such as the Samaritans on 08457 90 90 90 or MIND on 0300 123 3393.

Are there any benefits to taking part?

Although participants may find taking part in this research interesting, there are no direct benefits in taking part. Taking part will not influence the level of care or support participants receive in any way, and I cannot provide financial compensation for their time. However, contributions will be taken seriously and treated with respect and consideration. Ultimately the purpose of the study will be to use the information provided to aid the development of services in a way that feels meaningful to those who use them.

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

Withdrawing from the study will not affect participants' care or medical rights in any way. Participants can withdraw from the study up to two weeks after the interview has taken place, without giving a reason. If they decide to withdraw from the study during this time none of the information shared will be used in the research.

What will happen to the results of the research study?

The results will be written up and summarised in an academic assignment. They may also be submitted for publication in an academic or professional journal, be written up as a book or book chapter, and/or presented at conferences or workshops. The aim is to share participant's stories as widely as possible so that others can learn from them. I also intend to provide feedback on the research findings to participants if they would like this.

Who has reviewed the project?

This study has been reviewed by academic supervisors from Lancaster University and the Faculty of Health and Medicine Research Support Office. [REDACTED]

Where can I obtain further information about the study if I need it?

If you have any questions about the study please contact me at c.joyce@lancaster.ac.uk or on [insert research phone number here].

Alternatively, you can contact the supervisors of this project:

Pete Greasley, Research Supervisor and Teaching Fellow, Lancaster University
Tel: (01524) 593535 Email: p.greasley@lancaster.ac.uk

Ste Weatherhead Research Supervisor and Clinical Tutor, Lancaster University
Tel: (01524) 592754 Email: s.weatherhead@lancaster.ac.uk

[REDACTED] Research Supervisor and Clinical Lead [REDACTED]
Tel: (01772) 647004 Email: [REDACTED]

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to a member of the research team, you can contact:

Bill Sellwood
Chair in Clinical Psychology
Tel: (01524) 593998
Email : b.sellwood@lancaster.ac.uk
Division of Health Research, Lancaster University, Lancaster, LA1 4YG

If you wish to speak to someone independent, outside of the Clinical Psychology Doctorate Programme, you may also contact:

Professor Roger Pickup Tel: (01524) 593746
Associate Dean for Research
Email: r.pickup@lancaster.ac.uk
Faculty of Health and Medicine
(Division of Biomedical and Life Sciences)
Lancaster University
Lancaster
LA1 4YG

Thank you for taking the time to read this information sheet. **To register your interest in participating in this research** you can continue on to provide your contact information (if you are reading this online) or contact me directly at c.joyce@lancaster.ac.uk or on [insert research phone number here], if you have not already done so.

Appendix D: Consent Form**Consent Form**

We are inviting you to participate in a research project that will explore people's experiences of living with enduring eating difficulties that have had severe consequences on their lives. Before you consent to participating in the study we ask that you read the participant information sheet (20.7.16/V2.0) and mark each box below with your initials if you agree. If you have any questions or queries before signing the consent form please speak to the principal investigator, Ciara Joyce.

Please initial each statement

- | | |
|--|--------------------------|
| 1. I confirm that I have read the information sheet and fully understand what is expected of me within this study | <input type="checkbox"/> |
| 2. I confirm that I have had the opportunity to ask any questions and to have them answered. | <input type="checkbox"/> |
| 3. I understand that my interview will be audio recorded and then made into an anonymised written transcript. | <input type="checkbox"/> |
| 4. I understand that audio recordings will be kept until the research project has been examined. | <input type="checkbox"/> |
| 5. I understand that my participation is voluntary and that I am free to withdraw at any time, during and up to two weeks after the interview has taken place. | <input type="checkbox"/> |
| 6. I understand that once my data have been anonymised and incorporated into themes it might not be possible for it to be withdrawn. | <input type="checkbox"/> |
| 7. I understand that the information from my interview will be pooled with other participants' responses, anonymised where this is preferable, and may be published. | <input type="checkbox"/> |
| 8. I consent to information and quotations from my interview being used in publications, reports, conferences and training events. | <input type="checkbox"/> |
| 9. I understand that any information I give will remain confidential unless it is thought that there is a risk of harm to myself or others, in which case the principal investigator will need to share this information with my clinical team and/or her research team. | <input type="checkbox"/> |
| 10. I consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has finished. | <input type="checkbox"/> |
| 11. I consent to take part in the above study. | <input type="checkbox"/> |

Name of Participant _____ Signature _____ Date _____

Name of Researcher _____ Signature _____ Date _____

Appendix E: Debriefing Sheet



Thank you for taking part in this research project and for sharing your experience. Your participation will improve others' understanding of what it is like to live with enduring eating difficulties and receive service input. I will endeavour to do your experience justice and to anonymously share it with professionals, and members of the public, with the aim of improving the development of appropriate supports.

If this experience has raised any concerns for you there are a number of ways to receive additional support around managing this. Firstly, your clinical team can be made aware of your participation if you would like to reflect on it with them. Secondly, there are independent support agencies that you could contact including the Samaritans on 08457 90 90 90 or MIND on 0300 123 3393. Specific support around eating difficulties can be found at <https://www.b-eat.co.uk/>.

If you are unhappy about how the interview process has gone and would like to make a complaint to someone other than the researcher you met with you can contact any of the research supervisors, or an independent member of the research team. These contact details are included below.

Finally if you would like to receive a short summary of the information you have shared during the interview please let me know and I will ensure that you receive this within two weeks of your interview date.

Once again thank you for your time, and your participation.

All the best,

Ciara Joyce

Tel: [research number]

Email: c.joyce@lancaster.ac.uk

Additional Contacts:

Pete Greasley, Research Supervisor and Teaching Fellow, Lancaster University

Tel: (01524) 593535 Email: p.greasley@lancaster.ac.uk

Ste Weatherhead Research Supervisor and Clinical Tutor, Lancaster University

Tel: (01524) 592754 Email: s.weatherhead@lancaster.ac.uk

[REDACTED] Research Supervisor and Clinical Lead, [REDACTED]

Bill Sellwood, Chair in Clinical Psychology, Lancaster University

Tel: (01524) 593998 Email : b.sellwood@lancaster.ac.uk

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