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A Mixed Methods Exploration of Eating Disorder Self Help Groups in Relation to Social Value and Recovery

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Author's declaration

I declare that the work in this dissertation was carried out in accordance with the requirements of the University's Regulations and Code of Practice for Research Degree Programmes and that it has not been submitted for any other academic award. Except where indicated by specific reference in the text, the work is the candidate's own work. Work done in collaboration with, or with the assistance of, others, is indicated as such. Any views expressed in the dissertation are those of the author.

Signed: Susan Dixon

Date: Friday 11th July 2025

Acknowledgements

> 'There is nothing so elastic as the human mind. The more we are obliged to do, the more we are able to accomplish.'
>
> (Tyron Edwards)

The above quote sums up my PhD journey to a tee for I have grown and learnt much, surprising myself with the skills and knowledge that I have acquired.

This journey has not been an easy one with many challenges which I have had to navigate. However, I have had a broad network of people around me who I want to thank.

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As the African proverb states: 'It takes a village to raise a child' or in this case a PhD student!

Abstract

There has been a steady rise in the numbers of individuals with an eating disorder (ED) in the UK with estimated numbers ranging from 725,000 to 3.4 million in England. This has led to a demand on specialist services resulting in long waits for treatment and delays in accessing appropriate support in a timely fashion. Moreover, research has found a correlation between longer waits for treatment and relapse. It is within this context that the thesis addressed the following overarching research question: 'Who or what contributes to an individual's recovery from an ED'. This was set within the context of ED self help groups (SHGs). To explore this, five studies were conducted using a mixed methods approach.

The first two studies involved researching participants' experiences of attending an ED SHG and what matters in recovery for them. Study one involved semi structured interviews (n=9). The results were analysed using Interpretative Phenomenological Analysis (IPA). Three superordinate themes emerged (The journey leading to attendance at an ED SHG; The proximity of relationships; and Recovery as a dynamic experience and process) supported by eight subordinate themes (I looked it up and found the group; Fears and hopes; I've never been in a place like this before; Uplifting being in the group: like I jumped out of a plane; Self-exploration as a way/means to discover; Helpful and unhelpful aspects of relationships with others; Recovery reflections; ED Voice as saboteur; and Moments of Freedom). The findings highlighted that the ED SHG provided a unique support with recovery, that it helped some attendees engage with treatment and offered support post treatment. In addition, it showed that the attendees' recovery involved phases, and that the ED voice saboteur partially explained the ebb and flow of the attendees' recovery.

Study two was an online prevalence survey (n=106). The study found that 49% of participants attended the next group on finding out about it whilst 51% delayed their entry between one week to more than a year. A Principal Component Analysis identified seven factors related to recovery and four factors related to the experience of attending ED SHGs. A forward conditional binary logistic regression was used to see if any of the eleven factors were predictors of wellbeing (the WEMWBS instrument was used). It found that one of the factors, 'personal difficulties inside the group' (the internal personal frustration in not feeling able to use group in the hoped-for way) was potentially a six-fold high risk factor to wellbeing and that another factor 'impact on self' (experiencing the benefit of recovery on own life and seeing a reason to recover) was a potential protective factor.

Study three complemented study two, identifying why individuals with an ED had not attended an ED SHG. This was an online survey (n= 31). The key findings noted that the reasons for non-attendance was uncertainty about ED SHGs (such as not having heard about them), followed by being worried about matters such as being the biggest one there or not being sick enough). Almost 50% of the participants would consider attending an ED SHG if they had sufficient information about the group. In comparison with participants in study two, they rated statements around recovery more positively.

Study four focussed on the experiences of facilitators, and like study one used IPA and semi structured interviews (n=8). Three superordinate themes (Motivations for becoming a facilitator; The positive and challenging aspects of being a facilitator; and The importance of facilitator knowledge and skills). This was supported by nine subordinate themes (Lived experience: knowing and understanding the impact on self or family; Giving back: providing a nurturing role; Helping others: An enriching and rewarding experience; When things resonate: how it makes me feel; Making a commitment: balancing and juggling demands; Training and group process: Knowing what to do and when; Boundaries: creating a safe and/or confidential space; Being a container of distress; and The importance of self-care). The findings revealed the value of the lived experience that each facilitator brought which influenced how they carried out their role. Most recognised the importance of self-care (e.g., protecting personal time). Additionally, some used emotional distancing to manage issues arising in the group that resonated for them due to their lived experience.

Study five was an exploratory evaluative Social Return on Investment (SROI) project using an online survey (n=13) of stakeholders of an existing ED SHG. The results showed the positive value and impact that the group afforded the stakeholders on wellbeing and recovery. A SROI calculator, using the concept of a Wellbeing-Year (known as a WELLBY) as the valuation tool, was used to calculate the economic value impact of the group. The SROI ratio showed that for every £1 invested in the group there was between £9 and £14 of value.

Key implications arising from the five studies: i) the value of the lived experience of facilitators; ii) the importance of facilitators being offered training and supervision to enable them to carry out their role safely and competently; iii) the raising of the visibility of ED SHGs; and iv) a consideration of the place of ED SHGs within NHS support packages.

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List of Abbreviations

Abbreviation	Full name
AA	Alcoholics' Anonymous
ACT	Acceptance and Commitment Therapy
AN	Anorexia Nervosa
BED	Binge Eating Disorder
BLR	Binary Logistic Regression
BMI	Body Mass Index
BN	Bulimia Nervosa
CA	Content Analysis
CBT	Cognitive Behaviour Therapy
CI	Confidence Interval
df	Degrees of Freedom
EBE	Experts by Experience
ED	Eating Disorder
ED SHG	Eating Disorders Self Help Group
ED SHN	Eating Disorders Self help Network
EDE	Eating Disorder Examination Questionnaire
EDRQ	Eating Disorders Recovery Questionnaire
EEI	Eating Expectancy Inventory
ESG	Electronic Support Group
GSH	Guided Self Help
IBD	Inflammatory Bowel Disease
IHME	Institute for Health Metrics and Evaluation
IPA	Interpretative Phenomenological Analysis
JCPMH	The Joint Commissioning Panel for Mental Health
KMO	Kaiser-Meyer-Olkin Measure of Sampling Adequacy
MET	Motivational Enhancement Therapy
MH	Mental Health
MHG	Mental Health Group
MM	Mixed Methods
MMR	Mixed Methods Research
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
OA	Overeaters' Anonymous
OSFED	Other Specified Feeding or Eating Disorder
OSG	Online Support Groups
PCA	Principal Components Analysis
PSH	Pure Self Help
PwC	PricewaterhouseCoopers

Abbreviation	Full name
QALYs	Quality of Life Years
QoL	Quality of Life
QUAL	Qualitative
QUAN	Quantitative
RSD	Recovery Self Disclosure
RTA	Reflexive Thematic Analysis
sd	Standard Deviation
SH	Self Help
SHF	Self Help Friendliness
SHG	Self Help Group
SPSS	Statistical Package for the Social Sciences
SROI	Social Return on Investment
TA	Thematic Analysis
UFED	Unspecified Feeding or Eating Disorder
WEMWBS	Warwick Edinburgh Mental Wellbeing Scale (add copyright info)

Chapter 1: About the author

Thirty years ago, I began as a volunteer facilitator of an eating disorders (ED) self help group (SHG), concurrent with my career as a practising clinician (psychotherapist/counsellor). These two roles informed not only my professional portfolio, but also the ED lived experience which has largely influenced the writing of this thesis. I started to reflect on the value of ED SHGs and how they can assist those seeking support for recovery for their ED through reflective notes I kept after each session. These reflections subsequently sparked a curiosity in me to interrogate several *lines of enquiry*, such as leadership of ED SHGs and the use of the term sufferer.

The thesis also considers the importance of context regarding the high number of individuals with an ED, the long wait to receive appropriate help, and the numbers of individuals who are deemed ineligible for specialist input. Members of my group contributed ideas which I collated and sent through my work organisation, Goldsmiths, University of London to the mayor's London Assembly Health Committee. This was in response to a call for written evidence. The final report echoed many of the experiences individuals in the group had or were experiencing such as long waits for treatment, GPs not always being proactive in referring them, and the negative impact long waits had on their mental health (The London Assembly, 2024). In my response to the London Assembly, I highlighted the potential for the NHS to link with voluntary groups to draw on the knowledge and experience of people with lived experience and how they offer a space for people waiting for treatment.

It is of note, no reference was made about ED SHGs, further adding to the relevance and importance of this thesis.

My beliefs about ED SHGs

I am of the belief that ED SHGs or any peer-led group relies on its members being in an advanced stage of recovery and being able to lead the group. People with this lived experience who are involved in the running or leadership of the group are important: whether as someone who has had an ED or someone who has had a close relationship with EDs through a friend or partner for example. This is how I operate the group that I lead. Over time former members of the group who felt they were at a healthier stage of recovery have acted as either co-workers or co facilitators. This has been important for the group to see others at different stages of recovery get 'better' or start to move on with their lives. I was mentored at the start of my involvement by the previous group contact, a very skilled group psychotherapist who had co-facilitated the group for at least thirty years before she retired. We were able to co facilitate the group together for several years before her retirement.

The use of the term sufferer

I have opted not to use the term sufferer which has been in parlance in some literature. The definition of sufferer on the website of The Mental Health Foundation (n.d) is useful and captures the essence of who might use it, namely ‘‘agencies and organisations’ that are seeking to draw attention to the poor quality of life (QoL)for people experiencing mental health problems’. That premise aligns with two reports which were commissioned by BEAT (National ED charity), one by Pro Bono (2012) and one by PricewaterhouseCoopers (PwC) (2015). Both examined the cost of ED and used the term sufferer. They were written to highlight and convey to those within and outside the field of EDs the economic and human cost (suffering) of EDs on society and on the person with the ED. Similarly BEAT (n.d) uses the term sufferer when providing statistics for journalists on their website.

Historically the term sufferer was in common language in the 1990s as evidenced by scholastic literature where the term was used in part of the title of self help books (see Palmer, 1988; Schmidt & Treasure, 2007; Treasure, 1997). It was also used by other clinicians either within chapters inside the book such as Buckroyd (1989) or on the back cover blurb such as Cooper (1995). It is important to recognise that the landscape at the time was different. However, there seemed to be a shift in the mid-2000s where other clinicians used phrases naming the disorder, e.g., ‘people with Bulimia Nervosa’ (Cooper, 2009) or ‘people with Binge Eating Disorder’ (Fairburn, 2013, p. 41).

Moreover, as a volunteer I too have used the phrase sufferer perhaps as a shorthand when advertising the SHG that I co-facilitate, which has made me think about what message has been conveyed over the past two decades. It was formerly a categorisation on the BEAT Helpfinder database as part of a dropdown menu. None of the attendees had commented on the fact the group was called the Central London SHG for sufferers.

However, I am now of the view that the term sufferer when discussing self help, I would argue projects an identity on the individual with the ED as someone who is to be pitied or someone who is potentially powerless. In the context of this study, I view self help as empowering, using the term sufferer would almost negate that position. Yet, I recognise that this is a personal position and for others the term sufferer conveys the nature of their distress and experience. Therefore, in this thesis I have adopted the phrase ‘individual (s) with an ED’ unless the term sufferer has been used by an author that I am quoting or paraphrasing.

Chapter 2: Introduction

> *Eating Disorders Self Help Groups can support the recovery journey of an individual with an Eating Disorder and provide an adjunct to professional support.*

The narrative focus for this thesis is the place of ED SHGs and how they can support recovery. The following overarching research question is addressed:

Who or what contributes to an individual's recovery from an ED?

The paper is presented through the different lenses of individuals who have attended ED SHGs and their lived experiences of their ED and recovery. This is further complemented by the lived experiences of the people who run such groups, namely the facilitators. A series of five interrelated studies, using a mixed methods (MM) approach relay their individual experiences.

This chapter presents a justification for the place of the thesis within the context of the population of interest; namely those with an ED set against the rising numbers of individuals with an ED. It addresses the diagnostic criteria for EDs, recovery and what ED SHGs are. Finally, it will then briefly outline each of the remaining chapters.

2.1 Justification of the research

The most recent statistics show that the number of individuals affected by an ED in England and the UK range from 725,000 to 3.4 million depending on which source one reads. All figures are estimates and speculative, as not every person with an ED will come forward for treatment. For example:

- Virgo et al. (2021) has a range of between 1.3 million and 2.1 million people with an ED in England and the UK
- The national ED charity BEAT have suggested a figure of 1.5 million (The London Assembly, 2024)
- Another ED charity First Steps ED estimate between 1.25 and 3.4 million people in the UK
- National Institute for Health and Care Excellence (NICE) have a more conservative figure of 725,000 for people in the UK.
- Globally, 'the disease burden of EDs was 2.14 million females and 1.26 million males' (IHME, 2024, p. 1).

The high numbers being diagnosed with an ED has led to longer waits for specialist treatment; in some cases, more than six months (BEAT n.d). It has been reported that EDs have a high death rate with Anorexia Nervosa (AN) having the highest death rate of all psychiatric illnesses with people dying because of suicide and/or physical complications (Beat; Joint Commissioning Panel for Mental Health, 2013). Individuals with EDs have a 5.5 times higher mortality rate when compared to others with mental disorders (Pro Bono, 2012). Evidence points to there being a correlation between a longer waiting time and relapse, insomuch as the longer a person had to wait for treatment the higher the risk of a relapse (PwC, 2015).

Furthermore, the issue of the wait for treatment has been discussed in several reports. A London focussed report put forward twelve recommendations, one of which related to how to support those put on a waiting list, suggesting that they should be 'provided with clear information and resources; and additional interim support is commissioned for those on waiting lists who are at higher risk' (The London Assembly, 2024, p. 10). The same report does allude to the voluntary sector possibly working alongside NHS support, citing one medical professional who stated that: 'involving third sector organisations is fantastic and there is massive resource there and massive skills and intelligence there' (p. 61).

More recently, an All-Party Parliamentary Group on Eating Disorders, commissioned a report to 'highlight the urgent need for a national strategy to address the growing eating disorder crisis in the UK' (The Hearts Minds and Genes Coalition, 2025, p. 5). This report noted issues such as the shortages of specialist eating disorders units, patients being discharged at dangerously low BMIs and the postcode lottery for treatment.

Together the rise in numbers of individuals with an ED and the need for treatment has a cost. One such cost is an economic cost to society of treating and managing EDs which could be as high as 1.26 billion pounds per year (Pro Bono, 2012). Another lies with the cost to health where it has been suggested that *'3.3 million healthy life years worldwide are lost because of eating disorders'* (van Hoeken & Hoek, 2020, p. 521).

It is within this background that this thesis has been placed, as it provides insight into what other support is available, what ED SHGs can offer to support recovery and potentially the prevention of a relapse. This is an under researched area. Thus, the five studies which form the thesis provide a rich and unique picture of what ED SHGs afford its attendees. In addition, the paper contributes new knowledge, adding to the current research about what matters in recovery.

Furthermore, the thesis informs the following areas:

- Their potential economic and social value
- Their impact on the wellbeing of attendees
- An evolving definition of what matters in recovery through the voices of the research participants
- The clinical implications which can both support and inform future healthcare policies.

2.2 Key definitions

Eating Disorders

The diagnostic ED criteria used by medical professionals is often drawn from the Diagnostic and Statistical Manual of Mental Disorders (DSM-5-TR) (American Psychiatric Association, 2022). See Table 2.1 for an overview of the main EDs referred to in the thesis.

There are many overlaps across EDs in terms of behaviours and social impact such as social isolation and secretive behaviour. Moreover, consideration has been given to viewing EDs transdiagnostically and is about a recognition that 'eating disorder psychopathology is maintained by a largely common set of mechanisms' (Fairburn et al., 2003, p. 64). This belief about the commonalities and heterogeneity across EDs diagnostic criteria and behaviours can inform the treatments offered such as CBT-E. (Fairburn et al., 2003) and has been the feature of many research studies (Fairburn et al., 2015; McFarlane et al., 2008; Solmi et al., 2024; Wade et al., 2006). Notably, Shafran & Egan (2025, p. 1433) raised the question of how best to evaluate transdiagnostic treatments, recommending that such an approach 'should not be at the expense of a full understanding of the impact of disorder-specific approaches on comorbidity'. Similarly, the research of Levinson et al. (2023, p. 146) which examined evidence-based assessments for transdiagnostic ED symptoms argued for a need of 'timely and accurate assessments' as a way to support 'early recognition' and the reduction in ED death rates. Another dimension to research in this area is the examination of 'meaning in life' as a way to better understand EDs (see Schutzeichel et al., 2024).

As ED SHGs are often groups that are open to anyone who wants to attend irrespective of their ED diagnosis (formal or if they think they might have an ED), this is the approach taken within this thesis.

Table 2.1: ED Diagnostic Criteria

ED Type	Key features and characteristics (adults)	May lead to
Anorexia nervosa Two sub types: -Restrictive type -Binge eating/ purging type	-BMI less than 18.5 -Over evaluation of body weight -Self starvation -Fear of becoming fat -Bingeing and/or purging (vomiting and laxative abuse) -Excessive exercising to keep weight low	-Cessation of periods -Lanugo -Bone loss -Dry and cold skin -Depression -Muscle wastage
Bulimia nervosa	-Eating pattern which involves cycle of bingeing (consumption of large volumes of food at one sitting and purging cycle -Intermittent dieting and fasting -Sense of loss of control -Overconcern about body weight -Laxative and diuretic abuse	-Chronic throat problems -Enlarged salivary glands giving a 'chipmunk' appearance -Tooth problems due to acid from vomiting -Dizziness and heart problems
Binge eating disorder	-Bingeing large quantities of food in short discrete time period -Feeling of a loss of control -Eating despite feeling full or not hungry	-Low mood including depression -Eating in secret -Feelings of self-disgust

Adapted from the APA website

ED Recovery

Historically, there appears to have been an ongoing debate about the lack of consensus as regards what constitutes ED recovery clinically (Noordenbos, 2011; Noordenbos & Seubring, 2006; Rance et al., 2010). This has led to ED proponents calling for commonly agreed recovery criteria and that such criteria are research- informed (Bardone-Cone et al., 2018). This has been further echoed in a review by Bryson et al. (2024, p. 400) who called for a core body of knowledge about new treatments and a 'standardisation of outcome measures', while being cognisant that ED research is not well funded relative to other MH areas.

Furthermore, there have been calls for a broader set of criteria that may step beyond complete cessation of symptoms and remission, encompassing wider elements around quality of life (QoL). For example, a systematic review by de Vos et al. (2017, p. 7) explored perspectives from those who have experienced recovery. They noted that out of the criteria for ED recovery, 'psychological well-being (PWB) was mentioned more highly than the remission of ED pathology'. They concluded that the following might be an appropriate way to define ED recovery: 'the ability to adapt and to self-manage in the face of social, physical and emotional challenges with an overall tendency towards growth in psychological well-being and adequate symptom remission ' (de Vos et al. (2017, p. 11).

Likewise, Kenny & Lewis (2023) have suggested a new way of viewing recovery through a person-centred framework that they envision as going beyond the standard notions of recovery but encompasses an individual's wider life beyond their ED. Recovery is thus not fixed, but a 'constellation of changes' (p. 3). Their subsequent 'toolkit' with a 'recovery star' at the heart of it is completed

collaboratively between the patient and their clinician, capturing 'their broader life context' (p. 8).

Despite the lack of consensus when viewing recovery what seems clear is that the broader criteria consider the subjective experience of patients.

Furthermore, Noordenbos & Seubring (2006) generated a set of 52 criteria for recovery as part of their research and found that former patients and ED therapists agreed on what they felt was important for recovery (see Table 2.2 which shows the highest ranked criteria and levels of agreement between therapist and patients).

Table 2.2: Ranking of most important criteria for recovery (extract)

Criteria for recovery	Patients	Therapist
Does not take laxatives	100%	98%
Is able to express her emotions (verbal)	98%	94%
Does not feel fat	97%	64%
Self esteem is no longer dependent on weight	97%	92%
Does not punish herself after a meal	97%	86%
Has a realistic image of herself	97%	88%
Eats three meals a day	95%	96%
Has no binges	95%	76%
Does not vomit after dinner	95%	100%
Does not use diuretics	95%	90%
Is not obsessed by food and weight	95%	64%
Is able to express her emotions (nonverbal)	95%	76%
Is able to handle negative emotions	95%	90%
Is not isolated	95%	92%

Adapted from Noordenbos & Seubring (2006, p. 49)

What seems evident is that the highest-ranking criteria included a combination of ED behaviours, body image, and emotional constructs. The levels of agreement between patient and therapist could bode well for treatment insomuch as both may want to work towards the same outcomes. It is to be noted that the patients who participated in the research had AN or BN which has limitations as other ED types such as BED may have yielded different results.

Moreover, questionnaires such as the Eating Disorders Recovery Questionnaire (EDRQ) and The Eating Disorder Examination Questionnaire (EDE-Q 6.0), a self-report questionnaire addresses four areas: restraint, eating concern, shape concern and weight concern) (developed by Fairburn & Beglin, 2008) may have a place in identifying criteria for recovery. For example Bachner-Melman et al. (2018), (2021) in their call for a need for standardisation, suggest that the EDRQ, due to its reliability and validity offers a useful tool for recovery that patients, carers and clinicians agree on. Similarly, the research of Fitzsimmons-Craft et al. (2013) drew on another tool, the Eating Expectancy Inventory (EEI) (Hohlstein et al., 1998) which focuses on eating expectancy. Their research examined eating expectancy at various stages of the recovery process. They initially hypothesised that 'if an individual is psychologically recovered from an eating disorder, this will have some effect on her eating expectancies.' (Fitzsimmons-Craft et al., 2013, p. 1042). What

emerged was that those who were in partial recovery still presented as someone with an active ED in terms of their eating expectancies and those who were fully recovered (in terms of psychological and behavioural aspects of their ED) expected to find eating to be pleasurable.

By contrast, the exploratory research of De Young et al. (2020, p. 1231) led to recommendations being put forward regarding using different lengths of duration of recovery for differing ED types:

> '1) incorporate a duration criterion of 6 months for BN symptom composites and AN symptom composites; and (2) incorporate a duration criterion of 18 months if using the individual features of low weight, binge eating, or purging'

This they felt would help clinicians being able to accurately predict the likelihood of remission and recovery.

Self Help Groups (SHGs)

There has been a proliferation of SHGs to support individuals with a range of mental health (MH) concerns. The growth in SHGs has been linked to the 'civil rights movement' in the US in the 1960s (Dickerson, 1998). A decade later in the 1970s SHGs were perceived as a social movement with an interest in the value they afforded attendees of SHGs and professionals (Borkman, 1976; Katz & Bender, 1976). Consumerism was a market force in the 1970s and beyond, which impacted on a shift in healthcare policy provision which focussed more on a consumer-led environment with policy-makers providing healthcare that did not require the professionals' input (Sandaunet, 2008). For such a shift to work there needed to be clearly delineated roles for both consumers and the professional, otherwise there was a risk of the consumers' voices not being heard or real change not taking place (Wolfe, 1971). This resonated in the research carried out by Bolzan et al., (2001, p. 325-6) in Australia who purported that the mental health user's experience of being part of a support group created a positive description of who they were within the group and as a way of adopting their own identity not that of the 'professionals and policymakers', moving from 'mental health consumer to social citizen'.

Markowitz (2015) posited that there were several thousand Mental Health Groups (MHGs) in the US, UK, and Australia (p. 199). However, this assertion is not supported with statistical data. Some groups may be formed by the persons with the condition and their caregivers themselves (see Cohen et al., 2012). Professionals may form guided MHGs (see Laitinen et al., 2006). Furthermore, there is no single definition for the term SHG. Bolzan et al. (2001) suggest that SHGs are a subset of the term Support Group. Linked with this notion is the terminology associated with SHGs and subsequent terms that are in common parlance in the literature include peer support group (Davidson et al., 2006) and mutual help group (Kelly & Yeterian, 2011); and SHG (Newton, 2000). Newton (2000) posits that the people who attend the groups are best placed to define their group. However in the 1970s, Borkman (1976, p. 445) offered this definition: 'a human service oriented voluntary

association made up of persons who share a common problem and who band together to resolve the problem through their mutual efforts'.

Others such as Bond et al. (2019, p. 640) have further elaborated on Borkman's (1976) definition, adding features such as 'non -judgmental and the sharing of information and inhabiting the space'. The key essence is that both definitions propose a description of the constitution of the group, the operational aspects, and the purpose of the group.

Borkman (1976, p. 446) purports that 'experiential knowledge' is an essential constituent of a SHG which differentiates it from a professionally formed/led group. There is a different dynamic that ensues. Building on this idea Yalom & Leszcz (2005) suggest that there is a type of unique 'expertise' which exists within an MHG; the implication being that the group (i.e., the members) has its own expertise that it can draw on and subsequently rely less on the professionals for that expertise. Group members can thus hold a dual role; one of having the condition and one of being an expert (Yalom & Leszcz, 2005). The duality of role can help to give them credibility due to their lived experience (Bolzan et al., 2001; Davidson et al., 2006) and are experts by experience (Longden et al., 2018). This notion of experts by experience, sometimes shortened to EBE, implies a co-production of knowledge and has grown in many areas of mental health education such as in the field of mental health nursing (Happell, Warner, et al., 2021; Horgan et al., 2018) where lived experience is a valued part of the curricula. Happell et al. (2021, p. 8) showed how valuable an EBE component was in mental health student nurses' curricula. This exposure to being taught by recovered service users, 'counterbalance their experiences of seeing service users who are often unwell'. Furthermore 'EBE do not only teach recovery they demonstrate recovery' (Happell et al., 2021, p. 9)

Formats for SHGs

SHGs can be face to face where the members meet physically in a space or online. The online space can be in the form of, for example Online Support Groups commonly termed OSGs (Eichhorn, 2008), or Electronic Support Groups (ESGs) (Winzelberg, 1997) a term which is less commonly used in the literature, and online forums (Kendal et al., 2017). SHGs, whether as face-to-face SHGs or as an OSG or online forum offer value alongside professional support. For example Barak et al. (2008) suggest that OSGs have much value and when used alongside therapy, provides a useful adjunct to therapy. However, they are clear that they should not be perceived as a replacement for professional help.

Furthermore, they can offer support with recovery, and in some cases they are the only support that is available to people with a mental health condition (Bolzan et al., 2001; Kelly & Yeterian, 2011). Moreover, what seems apparent is that recovery is not a solo enterprise, and that people need others to support them (Shepherd, Boardman & Slade, 2008); whether through only a SHG or OSG or with the support of a professional in tandem.

Face to Face groups

Face to face SHGs can afford its members therapeutic dimensions such as the building of self-confidence, self-worth and self-esteem (Markowitz, 2015; Naslund et al., 2016). Research conducted by Laitinen et al., in 2006, explored how a group of Finnish women who had depression were able to learn about who they were, and what was important for their own self-development. The results indicated some form of personal change, thus empowering them. In a similar way, attendees can feel energised through the process of sharing feelings, practical ideas and mutual support (Seebohm et al., 2013). Moreover, face to face SHGs can have a positive impact on the social qualities of life and can act as a way of helping to prevent a relapse and referral to professionals (Salzer et al., 1999). Continued attendance at SHGs can be associated with an attendee feeling that the SHG was beneficial for them (Markowitz, 2015). However, the converse was found in the same study whereby being in the presence of others with an ED due to impact of other attendees' behaviour was deemed as unhelpful or undesirable (Markowitz, 2015).

The Online Space

Although there are potential overlaps in concerns around face to face and online spaces, people have expressed specific concerns about OSGs. One such concern is the manner in which members share information about themselves; when other attendees' responses to this are critical and inappropriate, this can then disrupt the dynamics of the group (Barak et al., 2008; Bartlett & Coulson, 2011). Breuer & Barker (2015) identified, when writing about OSGs, a concern about the potential struggles that members may have in forming a rapport with others, and their anxiety about what might be said by themselves or others causing some form of harm or distress.

Nevertheless, they offer several advantages. For example, they may help those who may be carrying stigma about their MH condition, enabling members a degree of anonymity, as members do not have to reveal themselves (Barak et al., 2008; Eichhorn, 2008; Finfgeld, 2000; Kendal et al., 2017, 2017; Lawlor & Kirakowski, 2014). Furthermore, 'reluctant or shy members can also use the safety of 'lurking' (reading messages without responding) until they feel comfortable with the group norms' (Winzelberg, 1997, p. 396). Research by Bartlett & Coulson (2011) showed that attendance at OSGs by patients had a positive empowerment impact for some on their relationships with healthcare professionals. For example, it enhanced the dialogue between the patient and healthcare professional, as patients felt able to verbalise what they had learnt in the group. Furthermore, a study by Breuer & Barker (2015) of an OSG for depression identified views such as participants supporting others and being a recipient of support, and finding comfort knowing that the group was there to draw on, should they need it even if they did not attend. Additionally, the group enabled others to have a call for action to affect change.

Similarly, online forums offer benefits to its members. Research by Kendal et al. (2017) and Winzelberg (1997) found that they provide access and support all the time (synchronous and asynchronous), which for some users is important, as well as offering a

global dimension as people can technically participate from anywhere in the world. Likewise, research by Kendal et al. (2017), which focused on a forum for young people with an ED, identified positive aspects, such as mentorship, where experienced members supported newer and younger members. They were able to offer reassurance and advice, and an ethos of encouraging members to engage in professional help. This mentorship is not unique to the online space and is something that could be replicated in a face-to-face setting.

However, the safeguarding of members to protect them from harm or misinformation is an important consideration and an area of apprehension (Finfgeld, 2000; Kendal et al., 2017; Winzelberg, 1997). This is not unique to online forums but has been raised within the context of peer-led groups with professionals' uneasiness of groups that are run without their input, potentially perpetuating the ED rather than promoting recovery (see Salzer et al., 2001; Timulak et al., 2013).

How SHGs are facilitated or led

In the same way that there are different formats of SHG, there are also several models of how SHGs are facilitated or led. This has led to a debate around who should get involved in an SHG and the legitimacy of their participation (Borkman, 1976). One format has the professional forming the group and leading the group (Karlsson et al., 2002), the second has a partnership type approach where the professional with members of the SHG co leading the group (Kofahl et al., 2014), and the third is solely a peer-led model (Yoak & Chesler, 1985).

Yalom, suggests that there is space for both peer-led groups and professionally led groups (Yalom & Leszcz, 2005), which would then create a space for professionals and people with an ED to consider a hybrid approach where both can work harmoniously together, as seen in a movement in Germany called Self Help Friendliness (Kofahl et al., 2014). This is where SHGs work in partnership with professionals in an embedded way, so that SHGs are part of the support package for patients. However, there are limitations insomuch as it has been suggested that Self Help Friendliness might only be beneficial with certain types of SHGs, in terms of the type of ideology the mental health professionals have towards mental illness in terms of how they are trained (Emerick, 1990).

Moreover, some professionals have been taught that they should keep a professional distance away from the patient (Constantino & Nelson 2009). Therefore, such training could impede professionals engaging positively with SHGs. Additionally, informing professionals about SHGs is not sufficient for engagement (Constantino & Nelson 2009). A two-way education process therefore is key on the part of both parties if any effective partnership is to be built on trust and mutual respect (Kofahl et al., 2014; Stewart et al., 1995).

The subsequent narrative review (chapter three) develops this definition further to focus on what is known in existing literature about ED SHGs and how they support recovery.

2.3 Thesis orientation

This thesis has been organised into eight further chapters as indicated in Table 2.3.

Table 2.3: Overview of thesis chapters

Chapter Title	Overview of content	Chapter Number
Narrative Review	The review explores what is known from existing research about attendees' experiences of ED SHGs in relation to supporting recovery. It interrogates eight studies, identifying themes that transcend the studies.	3
Methodology	Three methods are used (Interpretative Phenomenological Analysis (IPA), online prevalence surveys and Social Return on Investment (SROI)) to address four supplementary research questions. The methods and studies are mapped against these questions: I. What role do ED SHGs play in supporting an individual's recovery? ii. How do individuals use and experience ED SHGs as part of their recovery? iii. What constitutes recovery from an ED? iv. What economic and social value do ED SHGs offer? The Mixed Methods (MM) approach offers different perspectives on how ED SHGs can support recovery.	4
Study 1	This first study is the foundation of the Mixed Methods Research (MMR). It is an IPA study of nine individuals' experience of attending an ED SHG. It involves reflecting on their own ED lived experiences, how they found the group and why they chose to attend, ending with their reflections on recovery and relapse (in some cases).	5
Study 2	This larger quantitative online prevalence study builds on the previous one. Its design draws on direct quotes from study 1 to inform the content of the online survey regarding their experiences of attending an ED SHG. Additionally, it provides data on the types of support they use, their wellbeing as well as understanding what matters in recovery to them, drawing on quantitative and qualitative data.	6
Study 3	This quantitative online prevalence study complements study 2 as it focuses on those who have not attended an ED SHG and their reasons why, as well as the type of support they do access. It directly compares their views of recovery with those who have attended an ED SHG (study 2), drawing on t tests analyses and qualitative responses. Furthermore, data are gathered on whether they would attend an ED SHG.	7
Study 4	This IPA study is about eight facilitators' experiences of their respective ED SHGs. It examines why they chose to carry out the role, their ED lived experiences and how they manage any resonances as a result. It further explores the operational aspects of the role, how they are supported in terms of supervision and training, how they manage the personal demands on their time, and how they look after themselves (self-care).	8
Study 5	This is a Social Return on Investment (SROI) evaluative study of an existing ED SHG. It draws on quantitative and qualitative data to examine the value that ED SHGs offer its attendees (the main stakeholders), with a view to ascertain the social and economic value and impact. The impact is measured through quantifying the amount of change on recovery and their wellbeing (using The Warwick Edinburgh Mental Wellbeing Scale short version (SWEMWBS).	9
Discussion and Conclusion	This chapter revisits the main research aim and questions. It summarises the overall findings and discusses the key findings in the context of existing research. It then outlines the thesis' limitations and strengths and implications, including potential avenues for future research. It concludes with some final reflections.	10

Chapter 3: Narrative Review

3.1 Introduction

The previous chapter defined what SHGs are, their structure and how they are led. This narrative view expands on this further through its focus on ED SHGs and how they support recovery. As there is a sparsity of research with a greater focus on ED SHGs, after careful consideration a narrative review was opted for. In contrast to a systematic review, there are no set requirements for narrative reviews; this allowed for an exploratory and thematic approach to examine and present the scholastic canon of literature (Ferrari, 2015; Nundy et al., 2022).

The research question that guided the narrative review was:

'Do self-help groups support recovery for participants with an eating disorder'

3.2 The process

A scoping review framework was utilised in the absence of a defined framework for narrative reviews drawing on the work of Arksey & O'Malley (2005) who have developed a five-stage methodological framework to support the process of carrying out and writing up of scoping reviews (as outlined in Table 3.1).

Table 3.1: Methodological Framework

Stage	Guidance
1. Identifying the research question	-This will inform what literature is sought. -Clarity about parameters and terms is important at this stage.
2. Identifying relevant studies	-Search strategy e.g., electronic databases, reference lists, network -Search terms
3. Study selection	-Filtering out studies through application of inclusion and exclusion criteria
4. Charting the data	-How the information gained is going to be presented -Include author(s), year of publication, study location, intervention type, duration of the intervention, study populations, aims of the study, methodology, outcome measures and important results
5. Collating, summarizing and reporting the results	-How the data are presented will depend on the quantity of data gathered -Narrative review - Potential bias by research needs to be acknowledged

[Taken from Arksey & O'Malley (2005, p. 22 to 28)]

Levac et al. (2010) subsequently expanded this framework, making further recommendations to each stage; this is written from a position of adding to the debate surrounding scoping reviews. Of relevance to the author of this narrative review is a commentary by Levac et al. (2010) of stages three and five of Table 3.1. Levac et al. (2010, p. 4) describe stage three as an 'iterative process' for how the literature is searched for. Additionally, they describe the behaviour of the reviewers in terms of them meeting at key

points in the process as something which adds a layer of rigour. This expand expands on stage five describing it as three 'distinct steps':

1. 'Analysis …… qualitative thematic analysis
2. Reporting the results and producing the outcome that refers to the overall purpose or research question
3. Consider the meaning of the findings as they relate to the overall study purpose; discuss implications for future research, practice and policy'.

Methods

Five bibliographic databases (Pub Med, Scopus, Psych articles, Cinahl plus and Cochrane Library) were interrogated using the search terms described in Table 3.2.

Table 3.2: Bibliographic Search Terms

Theme	Bibliographic Search Terms	Rationale
Eating Disorder	anorexi*, bulimi*, eating disorder	The terms anorexia and bulimia are the most frequently cited eating disorder type in journals.
Self Help Group	self help group, mutual help group, peer support group, mental health group	All these terms have been used to describe self help groups.
Recovery	eating disorder recovery, mental health	The term recovery on its own would have yielded too many results. To ensure specificity, the whole phrase 'eating disorder recovery' was used. Mental health was included as eating disorders are mental health conditions.

The search

The search took place over an eighteen-month period commencing in 2020. Journal alerts to the thesis author's email account (up to September 2024) were set up to capture any newer articles that may have been written after that period. The results of the amalgamation of the three search themes yielded 270 results in total as captured in Table 3.3.

Table 3.3: Results of bibliographic database search

Bibliographic databases	Number of results combining all the search terms
Pub med	21
Scopus	8
Psych articles	1
Cinahl plus	0
Cochrane library	239

At that point it was unclear how many duplications were part of that number. The inclusion and exclusion criteria are given in Table 3.4.

Table 3.4: Inclusion and Exclusion criteria for narrative review

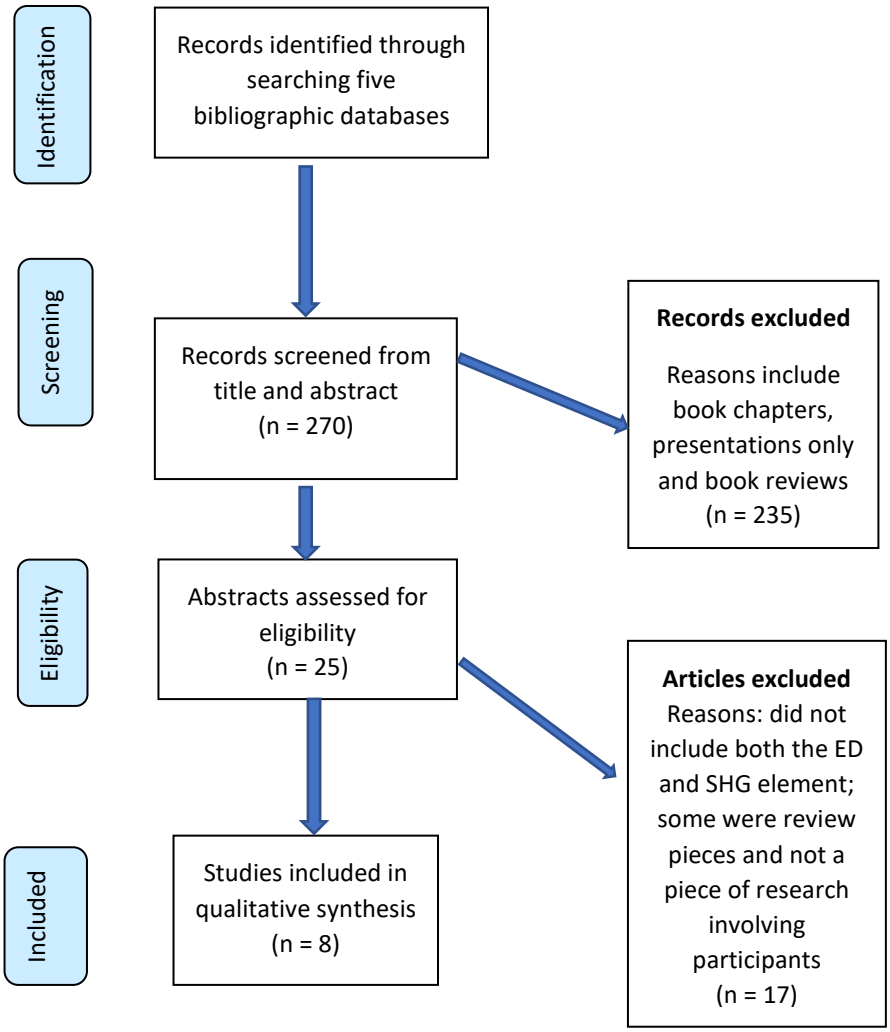
Inclusion Criteria	Exclusion Criteria
Full journal articles up to March 2024	Abstracts
Peer reviewed articles	Papers not in English
Articles written in English	Discussion papers
Papers focussed on eating disorders.	Conference papers
Mental health support; recovery; and self help groups.	Conference presentations
Qualitative and quantitative papers.	

The 270 articles were refined further leading to five articles from the search process. A further three articles were picked up through scrutinising the bibliographies of the five articles as illustrated in the PRISMA Diagram in Figure 3.1 (overleaf), thus leaving eight articles to form the review. The selection was disparate in the structural type of the groups but due to the limited studies available it was decided that it would be prudent to include all of them as each offered some data as to how attendees experienced ED SHGs in relation to recovery.

Eight studies emerged which included six qualitative studies, three of which were located within an Overeaters Anonymous (OA) setting but with different research foci and different years. Two were comparative quantitative studies (see Table 3.5). The papers spanned a breadth of countries and continents with one being translated from German to English (Stommel & Meijman, 2011). Appendix 3.1 provides a checklist assessment of the quality of the qualitative papers using the COnsolidated criteria for REporting Qualitative research (COREQ) Checklist (Tong et al., 2007).

Figure 3.1: PRISMA Flow Diagram

Research Question: Do self help groups support recovery for participants with an eating disorder?



Adapted from The PRISMA Group (Moher et al., 2009)

Table 3.5: Broad Summary of Research Papers

Qualitative Papers					
Author	**population**	**Participant size**	**recruitment**	**data gathering**	**Research location**
Wasson & Jackson (2004)	women with BN aged 20 to 59	26	Participants purposively selected for focus group	focus group and individual interviews	USA (North America)
Waller et al. (2020)	mainly female adults self-reported as having an ED (type not specified)	16	From ED service known to one of authors	Online Questionnaire	Australia (Oceania)
Stommel & Meijman (2011)	mainly female range of EDs including AN and BED	not specified	no formal recruitment process	analysis of 21 threads of online transcripts	Germany (Europe)
Russell-Mayhew et al. (2010)	mainly female (19), 1 male. 95% White/Caucasian, average age 53.6 years Type of ED not given.	20	self-selected	semi focused interview Focus groups	Canada (North America)
Ronel & Libman (2003)	80 female and 8 men aged 15 to 63 years from different backgrounds. Type of ED not given.	88	snowball method	Open-ended interviews	Israel (Asia)
McNamara & Parsons (2016)	mainly female (95%) 56% over 25 years+ BED (32%), BN (28%) and AN (20%), AN/BN (20%)	75	no formal recruitment processes	transcripts of 18 online support group sessions	UK (Europe)
Quantitative Papers					
Rathner et al. (1993)	women with BN. College educated mean age 27.3 years range 19.7 to 46 years	19 (11 attended group)	Advert in local press followed up by thorough screening	Semi structured interview testing at 6 & 15 months	Germany (Europe)
Peterson et al. (2009)	participants with BED diagnosis, mainly white and female (227 female and 32 male), average age 47.1	259	recruited through adverts and referrals	Several Questionnaires data collected at three points (end of treatment, 6 month and 12 month follow up)	USA (North America)

Research questions

The articulation of the research questions differed across the papers (see Table 3.6).

Table 3.6: Research Paper types and Research Question

Author(s)	Research question cited by authors	Focus	Summary of key findings	Strengths and limitations
QUALITATIVE PAPERS				
Ronel & Libman (2003)	'Eating Disorders and recovery: Lessons from Overeaters' Anonymous'	The transformation of overeaters and lessons learnt from OA with respect to their recovery with a focus on worldview transformation.	-Members made shifts in their worldview across the four domains because of their attendance at OA. Post OA is defined as post recovery **1) Self**: poor sense of self and worth linked to appearance before; impacted on relationships. OA helped change this to create a balance; self-worth improved 'awareness of powerlessness'. **2) Universal order/God:** negative view of God seen as 'distant and threatening'. Pre-OA and not spiritual. Post OA notion of 'Higher power in lives' so spirituality part of everyday functioning. **3) Relations with others:** Pre-OA sense of 'superficial' relationships with others; feelings of low worth meant that relationships also based on wanting to please others; feeling part of a group inside OA and witnessing others being open and being able to replicate this outside of group into own relationships; positive shift in self-esteem. 4) **The problem:** Pre-OA many come having tried lots of different ways of managing problem such as dieting, surgery, and therapy; leading to negative feelings such as 'despair' and 'guilt'; OA see problem as a disease ('physical, mental, and spiritual'), an addiction. In OA taught to take personal control of the addiction- might involve abstaining from certain foods.	-Granted approval by OA service in Israel. No mention of any other ethical approval. - No reference to authors' reflexivity or own bias - Gender imbalance of participants but at least they have some male participants -Research is about looking back which researchers point out. So not clear how the participants are currently experiencing recovery. -Limited generalisability due to all participants coming from one setting +Researchers identified possible bias- that sample are 'non-representative sampling of members' +Broad sample (88) in terms of age (16-63) and gender (80 women and 8 men) +shared prelim findings with participation; adds to robustness of the research +cultural dimension as set within Israel
Wasson & Jackson (2004)	'Analysis of the Role of Overeaters Anonymous in Women's	How OA supports the recovery of women suffering from Bulimia Nervosa.	Attendance at OA meeting and use of food plan two most critical recovery skills. F**ive OA skills** identified 1) **Participating in and attending meetings**: Regular participation in OA meetings crucial for participants and a key factor for their recovery; offered both emotional and practical support; group	-Small sample size (26) -Participants purposely selected for focus groups and interview which could lead to potential bias

	Recovery from Bulimia Nervosa'		was social system for participants. 2) **Sponsor support:** relationship sponsor-sponsee was perceived as hierarchical; evolving role as it developed; sponsor role to guide sponsee through 12 step program. 3) **Processing issues through journalling and writing**: participants captured feelings, thoughts and actions; led to better understanding of patterns and responses and behaviours; helped with self-reflection. 4) **Spirituality**: engagement in daily prayer and meditation; belief in Higher Power; some newcomers sceptical initially; OA helped with spiritual hunger (linked to compulsive eating and purging). 5) **Adherence to Food plan**: food plans (structured eating) were either rigidly followed or some employed more flexibility	-Participants self-reporting so there may be positive bias +Use a focus group +coding checked by two experts which shows rigour to data coding
Russell-Mayhew, von Ranson & Masson (2010)	'How Does Overeaters' Anonymous Help Its Members? '	Why people 'entered' the OA group and their perceptions of how OA operates.	Three main themes: **1) Problem:** reaching 'end of the line', 'abnormal relationship with food', compulsive eating; **2) Structure:** explicit (support, journalling, writing and, attending meetings), implicit tool was important framework ('purposively modelling what others' did'- learning from others, honest feedback, feeling that belong); **3) Attribution**- spiritual and emotional aspects of recovery 'Moving from a focus on the physical to an awakening of spirituality'	-Self-selected members presented for research. -mainly women (19 and 1 man) -No data could be collected on type of ED due to nature of OA (members are anonymous and data like this is not collected). +Ethical approval gained from OA local regional type body. +Participants gave informed consent. +Had multiple coders which helped with triangulation of data.
Stommel & Meijman (2011)	'Social accessibility of an online support group on EDs'	-Social accessibility with a focus on newcomers' experiences. -how newcomers joining OSG presented themselves	Focus on new here forum. **Three areas of analysis**: **1)Hesitant newcomer:** insecurity of the newcomers in joining. Ritualised behaviour before fully joining. Newcomer expresses insecurity, implying they are cautious. Described as 'lurking'. **2) Self-presentation with diagnosis as legitimization:** acceptance of becoming a legitimized member is made through self-disclosure of some form of ED diagnosis, acting as a form a self-introduction. Some members shift from not being fully registered to being registered revealing some more details about self. **3)Lack of diagnosis as legitimization problem**: If someone believes they do not meet criteria for legitimization do not join the forum; implication that not having a diagnosis can be	-The members were not told that their conversations were being analysed. This raises ethical issues and the lack of informed consent. -They were only told if the researchers planned to include part of their conversations in their paper. -/+The admin allowed this to happen; the researchers stated that the admin 'put in 'layers of protection for participants' -Lack of diversity and lack of demographics (set in Germany)

			problematic and raises issue of whether forum is accessible. BED seems to be a problematic ED to have in terms of legitimization.	-small narrow sample of data so can't be generalised +use of conversational analysis as chosen methodology suited to type of data collected +researchers had given some thought to ethics of using info from the forum
McNamara & Parsons (2016)	''Everyone here wants everyone else to get better': The role of social identity in eating disorder recovery'	How shared identity helps individuals with an ED manage their condition and promote recovery.	**ED functions as a social identity** Four themes emerged out of the data: **1. getting the right support for recovery':** creates a dichotomy whereby the persons with the ED view themselves as different but at the same time they want to belong to the very group that they see as different; dichotomy can lead to a feeling of a *'sense of alienation';* person with the ED can feel misunderstood by those who show concern, as concern by loved ones is rebuffed. **2. Shared identity fosters positive support'**: characterised by a focus on 'recovered-oriented identity'; develops because group members can talk about the feelings and emotions surrounding the ED rather than the behaviours associated with the ED; group participation brought emotional relief and a lessening of isolation. **3. Recovery is not a return to normal':** important that the person with the ED believes that recovery is something that is doable and attainable; some attendees believing that it is doable is unimaginable**;** recovery is seen as something that one learns to live with by some attendees. **4. 'Recovery means reaching out to others':** constitutes two core aspects-that of disclosure and the powerful sway of the group in encouraging members to elicit professional help new group members telling the group for the first time about their ED and then being lauded for doing so by existing members; the online group support can create a shift away from illness identity in some cases.	-Participants mainly female -Small sample sizes attended groups +but did have 75 individuals -No demographic data on participants +Robust data analysis process +Adds to research base around social identity and ED recovery +Positioning of recovery identities
Waller et al. (2020)	'What is the experience of	Experiences of adults recovering	Three themes	-Sample size was small -lack of diversity as mainly female

	adults recovering from an eating disorder in a professionally-led monthly support group?'	from an ED in a professionally-led support group. The paper also explicitly focuses on looking at the influence of the facilitator.	1) '**sharing the pain and the promise'**: a collective illness identity; being with others who understand; being able to share and listening to experiences of others helped with own self-reflection; lessened isolation (social connection), group was a safe space that also offered hope and motivation. 2) '**cautions and concerns'** (p. 222): some finding it hard to speak in front of large group; body comparisons and some found that 'triggering', frustration re behaviour of some in group e.g., talking and who takes up too much time and what people talk about- being off message (group dynamics; wanting some form of psychoeducation re recovery. 3) '**facilitators have influence'** (p. 223): skills in managing conversations (assertive compassion); friendliness; keeping group safe and members appreciated the 'warmth' shown by facilitator and trusted that they would keep the group safe.	-focused only on one group Results not generalisable due to lack of diversity + potential researcher bias acknowledged and mitigated for +captured lived experience and included some of participants' words to illustrate themes + important practical consideration as regards the role of facilitator and the need for right training
QUANTITATIVE PAPERS				
Peterson et al. (2009).	'The efficacy of SHG treatment and therapist-led group treatment for BED'	Comparative study of which of three treatments for Binge Eating Disorder (BED).	Three treatments: Therapist-led group, therapist- assisted, and self help 1. **Binge eating frequency:** therapist-led group had greatest reduction objective binge eating days and episodes when compared to self help and wait list 2**. Attrition:** Therapist-led group had fewest dropouts at the end of treatment 3. **Abstinence rates:** Post treatment therapist-led group had participants with the highest rates of abstinence from objective binge eating episodes. It was the same at the six month follow up, therapist-assisted scored the highest. **Implications:** therapist-led group was the most efficacious overall, structured self help has a role as did better than the wait-list treatment.	-Participants were not diverse they were mainly Caucasian female (white educated) -small sample size so not generalisable -SHG was heavily structured so not necessarily reflective of how typical non-professionally led SHGs might function No control group during the follow up phase +Study among the first study looking at the delivery of therapy assisted and self help intervention to patients with BED in a group format. +Robust methodology +Thorough screening of participants. +Checked inter-reliability. +Had control group which was their wait list- they raised ethics of leaving

Rathner et al. (1993)	'The impact of a guided SHG on bulimic women (attenders and non-attenders)'	A study of guided support for women with BN.	Benefits for those who attended GSH over period of 15 months. Non-attenders at self help group were used a control group **Improvements included:** reduction/abstinence bingeing and purging, improvement in mood (e.g., depression), positive change re drive for thinness **Differential changes**: Attenders showed lower pursuit for thinness, less depressed and improvements with their relationships (security) versus non-attenders who showed a decline. **At follow-up**: 12/14 in both attenders and non-attenders showed at least 50% reduction in bingeing Key finding: significant reduction in patients with BN- search for thinness and adverse effect of meals (authors not defined what this means but was part of an existing instrument but most likely purging, exercise etc.)- scores **For example, scores for adverse effects of meals: -** **Initial assessment scores** (mean, SD) Attender 11.78 (6.94), non-attender 15.40 (6.19) **6 months follow up** (mean, SD) Attender 6.56 (6.35), non-attender 11.00 (8.22) **15 months follow up** (mean, SD) Attender 6.44 (5.36), non-attender 10.60 (6.23)	-Small sample size (self-selected) that was used for compassion of figures -limitation as to the results due to lack of agree outcome criteria for BN -Lack of specificity as regards what abstinence means -sample- some were receiving outpatient treatment, -Some opted to attend the group so may be biased in responses -Some aspects involved attendees self-reporting such as frequency of bingeing and improvements + used robust instruments +longitudinal study as did follow up at 15 months +inclusion of non-attenders to act as a comparative group +used instruments

The Waller et al. (2020) paper was the only one which clearly articulated the research question. This may be linked to the fact that it is the most recent of the papers and/or may have been that journal's requirements. Terms such as aims (see Rathner et al., 1993; Stommel & Meijman, 2011; Wasson & Jackson, 2004); objective (see Peterson et al., 2009); and exploration (see McNamara & Parsons, 2016) were used in five of the papers to describe the nature of what they were going to research. The research question was inferred through the title of the last two remaining papers (see Ronel & Libman, 2003; Russell-Mayhew et al., 2010). The variability might be explained by the fact that the papers were from a diverse range of countries (see Table 3.5) and a range of journals. Despite the variability all achieved what they espoused to do.

ED SHG provision and ED coverage

Table 3.7 shows the diversity of ED SHG provision. Structurally there are two main modes of delivery either in person (assuming the OA groups are delivered like this) or online. Individuals with a range of EDs attend the groups. In addition, some groups have professional input, with some using guided resources. Attendees either choose to attend or are invited to join.

Table 3.7: ED SHG provision and coverage of EDs across the studies

Author	**Eating Disorder**	**Type of group**
Ronel & Libman (2003)	Overeating, brief reference to AN and BN in passing	OA structured face-to-face group
Russell-Mayhew et al. (2010)	Compulsive overeating	OA structured face-to-face group
McNamara & Parsons (2016)	BED (32%) BN (28%) AN (20%). Combination AN/BN (20%)	Weekly facilitated online group
Wasson & Jackson (2004)	BN	OA structured face-to-face group
Stommel & Meijman (2011)	Range of EDs but mainly some form of bingeing disorder e.g., BED, BN and Compulsive Overeating though AN was briefly referenced	OSG described as an SHG by the authors
Peterson et al. (2009)	BED	Three types of Self Help treatments (therapist-led, therapist-assisted, or Self Help) supported by psychoeducation
Rathner et al. (1993)	BN	Guided SHG
Waller et al. (2020)	Not specified by author. Self-reported ED	Guided SHG (professionally led) monthly

The people who manage or support recovery

Four terms with respect to how people managed or supported the group and/ or promoted recovery appeared in six of the studies. These terms were: facilitator; moderator; the OA sponsor and professional who provided psychoeducation. Table 3.8 presents a summary of this and their key function.

Table 3.8: Overview of the people who manage or support recovery

Author (s)	Term	Function
McNamara & Parsons (2016) Waller et al. (2020)	Facilitator	Ensuring 'psychological safety' Ensuring safety with 'assertive compassion' through guided self help
Stommel & Meijman (2011)	Moderator	Enforcing rules and regulations and correcting postings.
Wasson & Jackson (2004)	Sponsor	Guiding and mentoring sponsee.
Rathner et al., (1993) Peterson et al., (2009)	Professional providing psycho education	Delivering guided self help Delivering specialised structured self help treatment and psychoeducation

3.3 Discussion

The aim of this review was to examine how and if SHGs support recovery for participants with an ED. This section will present the findings of the review, implications, limitations, and the conclusion.

3.3.1 Findings

Five themes emerged from the overall analysis of the papers. They were:

- The structure of ED SHGs
- Reasons for joining an ED SHG and how newcomers join
- Recovery as a social process
- The people who manage or support recovery
- The entry of the researchers

The structure of ED SHGs

Based on the results one can infer what constitutes an ED SHG over and above supporting recovery. Namely, that there is a group of individuals coming together for support either by someone who has had an ED or a professional. This can take place online or in person. This type of intervention (peer-managed or professionally-led) are linked in part with the purported aims or ideology of the group.

Additionally, the group mainly support those who present with some form of overeating behaviour. This ED population demographic may have been skewed by the fact that three of the papers were situated in OA which is linked to an addiction model ideology.

Moreover, there is no consensus as regards the frequency of when individuals come together, and some groups are asynchronous (such as the online forum), and some are synchronous (e.g. OSG and OA groups).

Reasons for joining an ED SHG and how newcomers join

Russell-Mayhew et al. (2010) found that the reasons for attending the group were due to a sense of reaching the 'end of the line' (p. 35) insomuch as the people with the ED had exhausted all other avenues and were willing to try anything, sometimes out of a sense of desperation, wanting some way to manage their 'abnormal relationship with food' (p. 36) The remaining papers involved professionals instigating the group by both contacting potential attendees and having some involvement in the leadership of the respective groups (Waller et al., 2020).

Two papers presented an analysis of how newcomers join ED SHGs: one in an online space and the other in a face-to-face situation. Of the two, Stommel & Meijman (2011) provided a more detailed analysis of that experience. Their findings focused on the introduction of new members with a legitimised diagnosis, through age, the ED and the length of diagnosis. Commonality was outlined through discussions between non diagnosis, shared experiences of ED creating bonds between new and existing members.

By contrast, Wasson & Jackson (2004, p. 340) found that the way newcomers joined an OA group was by the newcomer, implicitly and explicitly signing up to participate and to learn the rules such as: to 'admit powerlessness over food and eating' and have a desire to overcome compulsive eating. This acceptance of rules is elaborated on in the research of Russell-Mayhew et al. (2010, p. 40) which described new members of an OA group needing to accept the addiction label that their ED is a 'disease'.

Recovery as a social process

Recovery as a social process was linked to the sense of self identity for the individual with an ED. For some who attended the ED SHG there was the holding of negative views about self (Ronel & Libman 2003) and there were feelings of 'otherness' and 'alienation' (McNamara & Parsons, 2016, p. 10). Through the process of attending the ED SHG there were shifts in worldview in terms of considering who or what contributed to a sense of self from a spiritual dimension (Ronel & Libman, 2003; Wasson & Jackson, 2004). For some this led to positive changes in how the individual with the ED related to others inside and outside the group, allowing for the forming of deeper relationships (Ronel & Libman, 2003; Wasson & Jackson, 2004).

Furthermore, the ED SHG created a space to lessen social isolation (Rathner et al., 1993; Waller et al., 2020) through sharing and disclosing feelings and thoughts (McNamara & Parsons, 2016; Waller et al., 2020; Wasson & Jackson, 2004), due to the recovery oriented identity nature of the group (McNamara & Parsons, 2016). Moreover, the group was a space to 'share pain and promise', forming a collective illness identity (Waller et al., 2020, p. 22).

There was an understanding that 'recovery is not a return to normal' (McNamara & Parsons, 2016, p. 10). Recovery was perceived as attainable (McNamara & Parsons, 2016; Ronel & Libman, 2003), and through the listening of other people's stories there was a sense of hope and motivation (Waller et al., 2020). These implicit social processing tools can be aligned with explicit tools such as eating plans, and interaction with the sponsor as outlined by Russell-Mayhew et al. (2010) and Wasson & Jackson (2004).

The people who manage or support recovery

An overarching theme that was apparent was how the people who support recovery keep members safe. This is through the management of conversations and enforcement of rules; whether online (Stommel & Meijman, 2011) or face to face (McNamara & Parsons, 2016; Waller et al., 2020). The sponsor role (Wasson & Jackson, 2004) and that of the professional who provides psychoeducation (Rathner et al, 1993; and Peterson et al., 2009) share commonalities in terms of offering bespoke input according to the context; with the sponsor being the expert in the OA 12-step program and the professionals in the structured guided self help contexts. Furthermore, for each role *holder* there may be a degree of subjectivity linked to their group's purpose (OA group), how they were self-trained (moderator) or their training (professionally-led group).

The entry of the researchers

Access to participants was gained in three broad ways: covertly, overtly and in a controlled manner (as indicated in Table 3.9).

Table 3.9: How researchers accessed participants

Type of access	Paper
Overt entry for the researchers involved them seeking consent or permission and subsequently explaining the purpose of the study before commencing any research.	Rathner et al. (1993) Peterson et al. (2009) Waller et al. (2020) McNamara & Parsons (2016)
Covert entry can be viewed as an entry where the participants who are being written about have not been approached to give consent at the point of data collection.	Stommel & Meijmann (2011)
Controlled entry required some degree of careful negotiation and patience, involving a mixture of covert and overt access to participants.	Russell-Mayhew et al. (2010) Wasson & Jackson (2004) Ronel & Libman (2003)

The nature of the entry appeared linked to the type of ED SHG and how ethical approval was gained. As referenced in Table 3.9, overt entry featured in three of the four studies which were led by professionals, and which were face to face. This was linked with transparent ethical procedures being put into place, ensuring participants were cognisant with the research study they were engaging in. Similarly, the researchers whose studies were in an OA group gained ethical approval from the organisation who *controlled* access to potential research participants.

In the online space ethical approval was granted from the owners of the sites. However, individual participant consent seemed implicit rather than explicit. For example, in the case of the OSG (Stommel & Meijman, 2011) researchers analysed transcripts and then sought the permission of the owners of each post they utilised. It is ambiguous as to whether the researchers ensured consent from everyone or deleted transcripts if someone objected or did not respond. Similarly, McNamara & Parsons (2016) sought the agreement to record sessions at the start of the session. It is to be noted that they had sent out information about the study to everyone who had registered on the site. However, what was not clearly stated was if members of the OSG were able to refuse consent, how the researchers responded and what point this happened.

3.4 Implications

The findings of the current study have several implications which will be explored.

Who attends ED SHGs

The first implication pertains to who attends ED SHGs. The findings seem to suggest that ED SHGs are more likely to be frequented by people with a diagnosis of some form of bingeing disorder like BN, BED or compulsive overeating (see Table 3.7). This would merit further research to ascertain if individuals with AN (irrespective of sub type) and other EDs, diagnosed or undiagnosed, do attend ED SHGs or not. This could lead to potential research studies exploring the lived experiences of those who have attended such groups. Conversely, research about individuals with an ED who have chosen not to attend an ED SHG can be conducted to better understanding the motivations behind their chosen actions. This would provide a fuller and richer picture of how ED SHGs support recovery and help to ascertain if ED SHGs are inclusive of all ED types and ethnicities (most participants in the review studies were white females).

Safety and recovery messages

The second implication concerns safety regarding what messages about recovery are promoted within the ED SHGs. Firstly, the OSG in the research of Stommel & Meijman (2011) revealed that conversations promoting unsafe ED behaviours between members of the online forum seemed to have bypassed the moderator whose role was to monitor and correct postings. The concern pertaining to the potential harm that OSGs in terms of how communities of practice that use them is documented in many studies (e.g,. Breuer & Barker, 2015; Brotsky & Giles, 2007; Lawlor & Kirakowski, 2014; Roberts Strife & Rickard, 2011). Secondly, the OA group has an ideology which promotes the ED as a ‘disease’ and a need for abstention from food. No reference was made to vetting procedures other than a requirement to agree to a ‘willingness to overcome compulsive overeating’ (Russell-Mayhew et al., 2010, p. 37). The abstention from certain foods which is part of the OA twelve step program (Wasson & Jackson, 2004) may not be appropriate for people with all types of EDs such as AN, whereby such actions reinforce maladapted thinking around food thus fuelling the very behaviours that people with AN need to address.

Leadership of ED SHGs

A further implication relates to the leadership of ED SHGs. Further consideration therefore needs to be given to the support that those who lead groups receive in their role whether as a facilitator, moderator, or sponsor, which may support the safety of the group members. Within the review studies, safety seemed linked to the articulated aims or ideology conveyed to anyone joining the group and how the groups were led. Moreover, those who have responsibility for leading such groups who have not been trained in facilitating groups may benefit from external structured training and ongoing support. Perhaps there may be a role for a government agency such as the NHS or a charity to support group leaders through the provision of initial and ongoing support to create safety for both volunteers and attendees of ED SHGs. Those experienced in facilitating ED SHGs are also well-placed to develop a manual or guidance for new facilitators and offer ongoing peer support.

3.5 Strengths and Limitations

The review has raised several limitations. For example, one is that the term self help elicited a plethora of responses and trying to analyse ED SHGs proved problematic, as some studies may have been missed as they referred to SHGs but they did not have the term group in the title. Future reviews would need to take this into consideration. Nevertheless, the papers that were used for this review captured a range of types of provision and the essence of what each type provided.

Another potential limitation is the fact that at least one of the studies was carried out in another language. For example, Stommel & Meijman (2011) explicitly mentioned they had translated their work from German to English, which meant that some of the semantics of the language may have been lost in the analysis of the qualitative data. Less so for the research of Rathner et al (1993) which was quantitative. It could be posited that translation adds an additional person in the research analysis process.

A further limitation is the fact that three of the papers were from the same type of ED SHG, namely OA. In addition, the researchers' access to participants appeared to have been carefully *orchestrated* by the OA administration which may have skewed the findings.

Furthermore, the research spanned six countries and four continents across the eight papers (see Table 3.5), adding an international dimension to the findings. This could be construed as a strength. This is notwithstanding the possible differences in cultural norms and the impact these norms may have had. These differences may have influenced how the data were analysed, as both researchers and participants will have experienced the ED SHG and recovery through their own lenses.

Additionally, this breadth of geographical locations offers scope for further exploration about the nature of the health services provision in each country and whether there was public health service provision for ED, or if there was a private health system in place and how accessible each was. This may provide insights into why some of the

participants attended ED SHGs as it might have been the only type of support available to them. Moreover, such a breadth of coverage may mean that the results can be potentially viewed as generalisable with the caveat that there was a lack of diversity in terms of demographics, namely sex and ethnicity. The majority group were described as white and female.

3.6 Suggestions for future research

There seems to be a research data gap that is evident from this review. Perhaps it would be useful to gather further evaluative and outcomes data which focussed about the impact of ED SHGs on supporting ED recovery at different stages. This may help to inform funders and support those facilitating such groups in securing funding. Additionally, it may thus aid the development of more groups.

To further evidence the research gaps as regards ED SHGs, a formal scoping review is something that is worthy of merit. A scoping review can help to identify research priorities and avoid potential duplication by checking if any identical studies have been undertaken, especially if such a review is registered on the Open Science Framework[1] (Khalil et al., 2025). A quality assessment checklist on individual papers (which was carried out Appendix 3.1) can be used to give a level of confidence in terms of the quality of papers.

However, it has been suggested that both narrative reviews and scoping reviews can lack sufficient depth due to the flexible nature of the methodology which is perceived as not as rigorous as systematic reviews. The employment of a suitable team with the requisite expertise to carry out the scoping review (Alexander et al., 2024) is one way of addressing this. Additionally, as both are shaped by the researcher it can be subject to bias, which can be mitigated for through ongoing researcher reflexivity (Mak & Thomas, 2022) and a bias assessment (Sucharew, 2019).

3.7 Recommendations

- Involve individuals with a lived experience in leading ED SHGs as they offer much value and ensure that training is offered to them to ensure the safe management of groups.
- Foster partnership working relationships between those with a lived experience and professionals to develop co led groups that offer support for recovery.

[1] The Open Science Framework offers has a protocol offering guidance and a template. https://osf.io/ym65x/overview

3.8 Conclusion

This review has shown that there is a paucity of research around ED SHGs. However, the papers that were reviewed did offer some insight through understanding experiences of people with an ED who have attended a form of ED SHG to support their recovery. The review revealed how individuals with an ED attend a wide variety of ED SHGs in terms of structure and delivery. It identified that what might constitute an ED SHG is broad. ED SHGs within this context included: an online forum; online group; structured face to face groups; groups focussed on psychoeducation set up and/or run by professionals. Each type of group had their own identity and way of functioning. Furthermore, the lived experience of the people who *led* the group was an important feature of most of the ED SHGs in terms of how group members were kept safe, who they were as individuals in terms of their own experience and how the group was organised.

In summary, to build further on the research base, it would be helpful to have studies about individuals with lived experience who supported their peers with recovery such as the OA sponsor and the moderator. This was lacking in the reviewed papers. Additionally, more in-depth studies about the reasons why individuals do or do not attend ED SHGs is needed such as qualitative studies to gain a deeper understanding of attendees' lived experiences.

Chapter 4: Methodology

This chapter has been organised into three sections. It commences with a description of the three methods that have formed the basis of how the data were gathered for the five studies that form this thesis:

- Qualitative: Interpretative Phenomenological Analysis (IPA) used for two studies
- Quantitative: Online prevalence survey used for two studies
- Social Return on Investment (SROI) used for one study.

The adoption of these three different methods meant that each has required different styles in how the studies were compiled.

This will be followed by a section about how the different methods are situated within the mixed methods approach and how the research questions and aims are addressed. Finally, there is a section about ethics.

4.1 Methods

4.1.1 Qualitative: Interpretative Phenomenological Analysis (IPA)

IPA is drawn from 'phenomenology, hermeneutics and idiography' (Smith, 2011, p. 9). Phenomenology is concerned with experience of a phenomenon being researched in its context through the lens of the person experiencing it (Smith, Flowers & Larkin, 2009). The hermeneutic aspect relates to the researcher having to both interpret and connect with that experience (Smith, 2011). Idiography 'is concerned with the particular' (Smith et al., 2009, p. 9) whilst remaining true to the person who is sharing their experience (Eatough & Smith, 2017). IPA is focussed on the lived experience of people and the meaning that they attach to their world or a phenomenon (Eatough & Smith, 2017; Smith et al., 2009). It is concerned with the subjective reflections on an event or experience (in the case of this thesis, attendance at an ED SHG) and creates an opportunity for the participants to give voice to their experiences (Willig, 2013). This creates a richness of data as these experiences emerge. It is not about predicting but letting the description of a phenomena unfold and making sense of the phenomena that have been described by the participants which Smith (2011, p. 9) sees as a process involving a 'double hermeneutic'. This can be likened to double sense making where 'the researcher is trying to make sense of the participant trying to make sense of what is happening to them' (Smith 2011, p. 9).

Epistemological position

The epistemological framework for the studies was based on two positions within phenomenology: that of Husserl and Heidegger (Smith et al., 2009). A critical realist stance also contributes to this framework, founded by Bhaskar (Roberts, 2014). Such a position, which sees knowledge as being socially constructed, lends itself to a qualitative approach such as IPA. For Husserl, phenomenology is about a detailed examination of human experience (Smith et al., 2009). An important part of this examination is épochè which is a

bracketing off researcher's own biases and pre-conceptions (Wertz, 2005). In contrast Heidegger draws on the idea of intersubjectivity where phenomenology is concerned about how an individual relates to and interacts with the world; a meeting of two - of the individual and that of the world (Smith et al., 2009).

A critical realist perspective is concerned with the subjective experience of the participants and their versions of their truths. Roberts (2014, p. 2) suggests that critical realists purport that the 'world is 'layered' into different domains of reality' and it is the job of the researcher to examine these domains at the same time recognizing that the truths may not always be accurate. This also requires a researcher to engage in reflexivity, which is an important part of the process to help the researcher to recognise the impact of their own subjectivity on the whole process of the research (Kasket, 2015). McLeod (2001, p. 45) echoes similar sentiments in that he describes qualitative research as a 'hermeneutic enterprise where interpretation occurs' and where the researcher's own background and experience in the world will have a bearing on how the data are interpreted, synonymous with the idea of épochè.

Process of analysis

The IPA method, as defined by Smith et al. (2009, p. 79), was used as a framework for analysing the data for studies one and four. This framework was built on a series of six steps with one of the key premises being that one moves 'from the particular to the shared' and 'from the descriptive to the interpretative'. Taking this into account the six steps were followed as detailed below:

Step 1: Reading and re-reading

This phase of the analysis was a key initial stage and was an important one. Smith et al. (2009, p. 82) use words such as *'*immersion', 'entering', 'active' and Inhabiting'. Each recording was listened to whilst reading the transcript three times; this was to allow immersion within the data, enabling that which was not apparent to the forefront and bringing it alive (Nizza et al., 2021). At the same time, by just listening, this allowed the researcher to enter the world of the participant again undisturbed. Further, it enabled reflections to be noted on any emotional or bodily responses to the data which occurred on listening.

Step two: Initial noting

The researcher found themselves initially doing what Smith et al. (2009) had identified i.e., being *'descriptive'* (p. 83). The process of supervision and participating in a peer supervision group helped the researcher move beyond the descriptive to a more reflective and analytical position. A template (Table 3.10) devised by Smith et al. (2009) was used to capture the responses. Appendix 4.1 annotated transcript extract (study one). By being interpretative the researcher was able to draw on their professional background as a psychotherapist/counsellor and their experience of facilitating an ED SHG.

Table 4.1: Template for analysing the data (Smith et al, 2009)

Emergent themes	**Transcript (Participant's words)**	**Exploratory comments**

Step Three: Development of emergent themes

This is the stage that is identified as involving the hermeneutic circle (Smith et al., 2009, p. 91). This is where the identification of themes emerging out of the data commenced. This process involved less of the participant and more of the researcher whose interpretation is forming themes.

Step Four: Searching for connections across emergent themes

The essence of this stage was about finding the patterns between the emergent themes and grouping them together case by case to start forming superordinate themes (Smith et al., 2009, p. 96).

Step Five: Moving to the next case

Step four was repeated for each case. Smith et al., (2009) reiterate the need for the researcher to treat each case as a new case and to avoid allowing the findings for the previous case to shape the findings for the next case. This requires the researcher to '*bracket off*' what they have learnt from the first case (Smith et al., 2009, p. 100).

Step 6: Looking for patterns across cases

This step was concerned with looking for patterns and connections across the cases and the themes that have emerged from the analysis of the data for each participant. It was also about how the themes might complement each other or be at odds with one another (Nizza et al., 2021; Smith et al., 2009).

This four-stage iterative process was repeated for each subsequent participant until no more new themes were emerging. At each stage, the themes for each participant were captured on an overview grid by using master excel spreadsheets to cross reference across each participant. The final themes table was built through a robust process of reviewing coverage across each of the participants as example of which is included in Appendix 4.2.

Consideration of other qualitative approaches

Two other qualitative approaches were considered: grounded theory (GT) and reflexive thematic analysis (RTA).

Grounded theory

GT has its roots in sociology having initially been created by Glaser & Strauss who were based in that discipline (McLeod, 2001; Willig, 2008). They handle the data by grouping them into categories by coding them. The coding process will start with the identification of *descriptive labels* moving through to *analytic* categories (Willig, 2008, p. 36). The data is constantly being refined. Willig (2008, p. 38) describes this as a process of 'to and fro' in the quest to find links between categories. The research question is broad and can change over the period of the data immersion (McLeod, 2001; Willig, 2008). The immersion in the data is key in GT; it is a solo enterprise at that stage which means that 'theoretical saturation' occurs (McLeod, 2001, p. 3). The data are constantly being gathered and *refined* (Charmaz & Belgrave, 2019). There are main categories and 'structure of subsidiary categories' defined with quotes (Charmaz & Belgrave, 2019, p. 5). Whilst there are similarities with IPA such as the creation of main themes and sub themes, immersion in the data and looking for connections the researcher chose IPA, because IPA is concerned with the phenomenon and lived experience of the people being interviewed.

Reflexive Thematic Analysis (RTA)

Thematic Analysis (TA) has its root in phenomenology (Willig, 2013). There are different forms of TA including RTA which was the type considered. It is seen as flexible as it is not linked to any specific theoretical framework like some qualitative approaches such as IPA (Braun & Clarke, 2013; Spiers & Riley, 2019). Furthermore, it is perceived as enabling a wide range of research designs and questions, thus enabling a variety of approaches to data gathering (Braun et al., 2016). Proponents such as Braun and Clarke have developed and refined processes for how to carry TA out (Braun et al., 2016; Braun & Clarke, 2021). TA data analysis involves six stages:

- familiarisation
- coding
- generating themes
- reviewing and developing themes
- refining, defining and naming themes
- writing up.

(Braun & Clarke, 2013, 2021; Clarke & Braun, 2017).

Moreover, TA allows for 'inductive (data-driven) and deductive (theory-driven) orientations of coding, capturing semantic (explicit or overt) and latent (implicit, underlying; not necessarily unconscious) meanings' (Braun & Clarke, 2021, p. 39). The six stages are similar in some respects to the IPA approach to data analysis. However, what sets

IPA apart from TA is the idiographic nature of immersion in the data and the focus on the participant's experience of the phenomena (Spiers & Riley, 2019) which was what the researcher wanted. By contrast, the development of themes in TA is drawn from the coding of the whole dataset at the outset, whereas IPA considers all the participants after having considered each participant's experience on their own, thus generating individual themes (Spiers & Riley, 2019).

4.1.2 Quantitative Approach

The overall aim of studies two and three were to investigate difference and effect sizes. A series of questions were developed for study two which were derived from the participants' words from study one. Additionally, a robust instrument, Warwick-Edinburgh Mental Well-Being Scale (WEMWBS) (Tennant et al., 2007) which measures subjective wellbeing formed part of the survey. Likewise, a series of questions for study three were generated drawing on some of the existing questions from study two to enable a test for inference between the two sets of respondents with respect to the participants' experiences of recovery. These questions were generated into two separate online prevalence surveys using Qualtrics Software (Qualtrics, Provo, UT). An analytic tool, IBM SPSS Statistics, version 27 was then used to analyse the two datasets from the two prevalence surveys.

Consideration was given to how many participants would be the optimum number for the two studies. This was being mindful that there are no available data to draw on about the two populations, namely those who had attended an ED SHG and those who had not, to inform this. A calculation tool, G* power version 3.1.9.7 (Faul et al., 2007), was used to generate a power analysis to estimate the sample size for each study with a priori power analysis (Faul et al., 2007). The statistical power analysis was simulated multiple times changing various variables, with an effect size of 0.5 (medium) and statistical significance level of 0.05 respectively as illustrated by Table 4.2. The effect size and error figures were based on the work of Jacob Cohen (Cohen, 1962; J. Cohen, 1992, 2013).

Drawing on the figures from Table 4.2 it was decided that an allocation ratio of 3 and a participant size of 76 for study two (individuals who had attended an ED SHG) and 26 for study three (individuals who had not attended an ED SHG) would be appropriate for the two studies. Study two subsequently recruited 106 participants (30 participants did not complete all questions) and study three recruited 31 (two participants did not complete all questions).

Table 4.2: Statistical Power Analyses

Input parameters		Output parameters	
Cohen's effect size	0.5	Df	100
Error	0.05	Sample size 1	26
Power	**0.7**	Sample size 2	76
Allocation ratio	3	Total sample size	102
Cohen's effect size	0.5	Df	132
Error	0.05	Sample size 1	34
Power	**0.8**	Sample size 2	100
Allocation ratio	3	Total sample size	134
Cohen's effect size	0.5	Df	184
Error	0.05	Sample size 1	47
Power	**0.9**	Sample size 2	139
Allocation ratio	3	Total sample size	186
Cohen's effect size	0.5	Df	118
Error	0.05	Sample size 1	24
Power	0.7	Sample size 2	96
Allocation ratio	**4**	Total sample size	120

a. *Assuming one tailed test.*
b. *Means: Difference between two independent means (two groups)*

4.1.3 Social Return on Investment (SROI)

The notion of SROI has been purported to have its roots in the 1990s from an US organisation called the Roberts Enterprise Development Fund (Arvidson et al., 2013; Banke-Thomas et al., 2015). The term SROI appears to have been derived from the Return on Investment field linked with 'measur[ing] a company's success' (Lingane & Olson, 2004, p. 118). It has also been associated with 'social accounting' (Bellucci et al., 2019, p. 49).

There appears to be a range of definitions describing what SROI is and what It represents. For example, Arvidson et al. (2014, p. 277) perceives SROI as a type of 'cost benefit analysis (CBA) developed to reflect the value of intangible/social benefits in a way that CBA has sometimes failed to do'. Building further on the social aspect of SROI, Courtney (2018, p. 541) describes the social value aspect as 'thinking about how scarce resources are allocated and used'.

Furthermore, in the UK, the cabinet office has published online guidance which has both defined what an SROI is and its methodology, describing it as: 'a framework for measuring and accounting for... broader concept of value; it seeks to reduce inequality and environmental degradation and improve wellbeing by incorporating social, environmental and economic costs and benefits' (Nicholls et al. 2012, p. 8).

This has led to SROI projects usually adhering to a set of principles. A previous version involved seven principles (Nicholls et al. 2012); these have been updated and an eighth pertaining to responsiveness has been added by Social Value International (n.d) on their website:

1. Involve stakeholders
2. Understand what changes
3. Value the things that matter
4. Only include what is material
5. Do not overclaim
6. Be transparent
7. Verify the result
8. **Be responsive**

It would appear that SROI was borne out of a need to support third sector organisations (which are 'neither public sector or private sector [which] includes voluntary and community organisations...including SHGs (National Audit Office, 2011, [no pagination])) with assessing and evaluating outcomes and value. Thus enabling a common framework for the assessment of social value' (Courtney, 2018, p. 544) and in the analysis of the 'social and financial benefits' of a project (Lingane & Olson, 2004, p. 119).

In addition, it has the capacity to act as an accountability tool (Banke-Thomas et al., 2015). Bellucci et al. (2019, p. 47) describes it as 'a participatory framework'; thus, noting the importance of stakeholder involvement (National Audit Office, 2011). This a key feature evident in all SROIs (e.g., see Leck et al., 2016; Mook et al., 2015). This is in keeping with the Public Services (Social Act) which became effective in 2013 cited on the gov.uk website. Though the Act is aimed at commissioners of services, it has relevance as it aligns with the importance of ensuring value for stakeholders and their involvement as part of the procurement process. Furthermore, having a tool like a SROI which attributes a monetary value can give credibility to third sector organisations; aiding this sector in gaining funding from government and other sources (Arvidson et al., 2013).

Concerns, however, have been raised about the potential limitations of a SROI approach. One such criticism is that the process involves 'subjective value judgments regarding measures outcomes' (Lingane & Olson, 2004, p. 127). Similarly, Arvidson et al. (2013) has questioned quantifying volunteering in terms of the availability of suitable metrics to draw on. Millar & Hall (2013) noted the acquisition of suitable proxies as a barrier for some of the social enterprise groups that they interviewed as part of their research into SROI and performance measurement. They noted too that some expressed concern around having the capability to carry out a SROI themselves and having the financial resources to do so.

Nevertheless, the SROI was chosen as the most appropriate approach to measure the value of an ED SHG through a social and economic lens. The ED SHG in question was a voluntary group, the planned process of data collection was designed to involve stakeholder engagement, and due consideration was given to how to measure outcome using a robust instrument. Additionally, the subsequent evaluation of the ED SHG acknowledged limitations, ensured transparency, and did not overclaim (see chapter nine). Moreover the SROI enabled the researcher to reflect on the impact of the group on its stakeholders (Millar & Hall, 2013).

4.2 Mixed methods

Introduction

Together, the three methods previously described contributed to a Mixed Methods (MM) approach- the approach that was chosen for this thesis. The rationale for this succeeds a discussion about what MM is and how it is situated within different research paradigms.

Maxwell (2016) asserts that the historical accounts of MM have not been conveyed accurately, citing for example the fact that there are studies that technically could be described as MM but have not been addressed as so, sometimes due to political reasons. He presents a comprehensive overview of how MM has appeared across several disciplines e.g., geology, medicine, and epidemiology over an extended period citing examples from as early as 1609, mid 1800s to the 21st century. Furthermore Maxwell (2016, p. 13) believes that the earlier studies which, for example did not include references to typologies or 'paradigm' conflicts are important to be considered when examining MM to ensure that 'insights' are not missed as there is a danger of a narrow thinking.

The 1960s heralded a time when the mixing of qualitative and quantitative methods was accepted and subsequently became more used by researchers a range of disciplines, leading to an increase in the number of Mixed Methods Research (MMR) studies being published (Doyle et al., 2009; Leech & Onwuegbuzie, 2009). However, several years earlier Bryman (2006) carried out a Contents Analysis (CA) of over 200 social science literature papers and reported a struggle to find enough studies using MM.

MM creates opportunities for researchers to design studies which generate a breadth of data richer information about 'human phenomena' which by its very nature can require this (Sandelowski, 2000, p. 246). There is a suggestion that over time MMR is being seen as its own 'distinctive research approach' (Bryman, 2006, p. 97).

Defining Mixed Methods

Scholars and researchers have cogitated with the idea as to what constitutes MM for some time. For example Greene et al. (1989, p. 256) suggested a definition that specified that MM includes qualitative and quantitative methods 'where neither type of method is inherently linked to any particular inquiry paradigm'. Moreover, this definition did not lead to a consensus in the use of the term MM (Tashakkori & Creswell, 2007), thus resulting in the

term not being used congruently (Bryman, 2006; Creswell & Tashakkori, 2007; Doyle et al., 2009). Bryman (2006) suggests that other terms such as multi methods and multi strategy research are in existence in the literature too, which further adds to the definition debate. Teddlie & Tashakkori (2006, p. 14) build on this idea of incongruence by purporting that 'newer conceptualizations of MM' concur that any MMR must involve 'integration across stages' to be recognised as MM. This implies that the definition is much more than a study only having a mixture of qualitative and quantitative methods but that the researcher must articulate how and where the integration occurs (Fetters et al., 2013).

Tashakkori & Creswell (2007, p. 3), created a definition which encompasses, what they describe as an 'inclusive' range of perspectives from existing and their own research whilst still recognising that there is still more work needed on reaching a satisfactory definition and addresses the previous point regarding integration:

> 'MM ..[is] research in which an investigator collects and analyzes data, integrates the findings, and draws inferences using both qualitative and quantitative approaches or methods in a single study or a program of inquiry'

What is absent is explicit reference to paradigms which is an area alluded to by Greene et al. (1989) and subsequently Sandelowski (2000, p. 245-6) who articulate this as:

> 'MM studies are not mixtures of paradigms of inquiry per se, but rather paradigms are reflected in what techniques researchers choose to combine, and how and why they desire to combine them'

The idea of paradigms is an important strand, not without its contentions, that contributes to the picture of what defines MM and is debated further.

Nevertheless, what these definitions reveal is a multiplicity of layers which have merited elucidation by other authors in the field. The quest for a definition seems to have led to the identification of typologies (Bryman, 2006), frameworks (Greene et al., 1989) and guidelines (Teddlie & Tashakkori, 2006), which is explored in more detail in the subsequent subsection to ascertain what they are and what purpose they serve or can serve.

Mixed Methods Typologies, Frameworks and Guidelines

The term typology within the context of this discussion is being used to mean 'the study of types or a system of dividing things into types' (Cambridge Dictionary). Three significant analyses of research papers that contributed to the idea of MM typologies (also guidelines and frameworks) emerged between the period 1989 to 2006. They will each be considered in turn drawing out salient points to best understand some of the debates about MM typologies.

Firstly, Greene et al (1989, p. 259), who having carried out a detailed examination of the literature base leading onto a review of a mixture of 57 empirical studies (spanning 1980-

1988), created a MMR conceptual framework which identified five purposes of MM evaluations:

- triangulation ('corroboration' of findings)
- complementarity ('clarification of the results from one method with the results from the other method'),
- development (first method outcomes informing subsequent method)
- initiation (viewing the phenomena through different lenses) and
- expansion (using the suitable method for the research question) with seven design characteristics.

The seven design characteristics titles they used are emboldened (Greene et al., 1989, p. 262-263) and an explanation of each follow:

- **Methods** are linked to a consideration of how similar or different the studies will be or are.
- The number of **phenomena** that are being assessed as part of the research.
- The degree to which **paradigms** the studies are linked to
- **Status** relates to the which of qualitative and quantitative data collection approaches has precedence
- **Implementation: independence** concerns how qualitative and quantitative are integrated or whether they sit separately in the study
- **Implementation: timing** links to the length of each study and when each study is implemented
- **Study** poses the question as to how many studies are involved.

Furthermore, several core recommendations emerged from their evaluation in terms of the conditions that might be suitable for the use of MM. The first recommendation identified that MM is acceptable but is problematic for research studies which serve the purpose of development or expansion intent. The second intimated that MM is suitable for design for initiation intent, which have been created to 'maximise the possibility of unlikely findings' , Greene et al (1989, p. 267) and the third acknowledged that MM is not suited for the purposes of triangulation and for mitigating biases. Greene et al (1989) critiqued their own findings, noting that they had 'side stepped' the issue of paradigms, they acceded that 20% of the papers did not specify why they had opted for a MM approach.

By contrast, Teddlie & Tashakkori (2006), carried out a comprehensive analysis of different types of MM designs, which led to the development of their own typology which they termed The Methods-Strand Matrix' (reproduced in Table 4.3). It was informed from existing ideas such as and their own work which they developed over several years. They describe it as being formed of 'families of research designs' (Teddlie & Tashakkori, 2006. p. 5). They created the Methods-Strand Matrix to be an interactive decision tool to support researchers at the design stage using their own Matrix or other existing typologies (Teddlie & Tashakkori, 2006, p. 16-17):

- How many **methodological approaches** will be used (MM or just one method of data collection is used in the study)
- The number of **strands** or phases the study would entail. Strand in this context means 'a phase of a study that includes three stages- conceptualization..., experiential... and inferential'
- The kind of **Implementation** i.e., how the data will be collected, 'sequentially or concurrently'
- When the **stage of integration** occurs e.g., at the 'experiential stage', at all points in the study or a mixture.

The Methods-Strand Matrix elaborates on elements of the design characteristics of Greene et al., 1989).

Table 4.3: The Methods-Strands Matrix: A Typology of Research Designs Featuring Mixed Methods

Design Type	Monostrand Designs	Multistrand Designs
Monomethod designs	Cell One Monomethod Monostrand Designs: (1) Traditional QUAN design (2) Traditional QUAL Design	Cell Two Monomethod Multistrand Designs: (1) Concurrent Monomethod a. QUAN+QUAN b. QUAL+QUAL (2) Sequential Monomethod a. QUAN➡QUAN b. QUAL➡QUAL
Mixed Methods Design	Cell Three Quasi-Mixed Mono-Strand Designs: Monostrand Conversion Design	Cell Four A) Mixed Methods Multistrand Designs: (1) Concurrent Mixed Designs (2) Sequential Mixed Designs (3) Conversion Mixed Designs (4) Fully Integrated Designs B) Quasi-Mixed Multi-Strand Designs: Designs Mixed at the Experiential Stage Only, including the Concurrent Quasi-Mixed Design

Taken from Teddlie & Tashakkori (2006, p. 15)

Teddlie & Tashakkori (2006, p.25) supplemented their Matrix with a 'seven step process' to guide the researcher at the outset of their research design, involving the researcher in:

1. Giving due consideration as to what type of method will best address their research question
2. availing themselves of a variety of designs
3. choosing the MMR design that suits their study
4. being conversant with the criteria of each typology
5. listing the criteria and choosing the appropriate one that matches their research study
6. applying the criteria
7. designing their own MM approach if one does not exist.

Comparatively, Bryman (2006, p. 98) conducted an evaluation of over 200 papers, in which he also drew on the analysis method that Greene et al. (1989) had used in their own work, suggesting that a more 'formalized approach' to typology development appears to be occurring in the MM academic community in North America, and that there has been a rapid rise in the 'typologies of integration'. Bryman (2006) believes that typologies have their place and can support researchers. He reflected on the fact that there is an overemphasis on approaches rather than what MM is achieving; the beauty of the MM approach and the fact that MMR can generate a plethora of data that provides unplanned outcomes. As part of his findings, Bryman (2006) collated a series of 'instructive' questions across the literature, an interpretation of which is summarised in Table 4.4. The framing of the questions provides a framework for the MM researcher and is in line with the previous typologies which have been discussed.

Table 4.4: Five 'instructive' Questions

	Instructive Questions
1	How and when are the qualitative and quantitative data collected?
2	Which method has seniority?
3	What purpose does the integration of the two data collection methods serve?
4	When does the integration happen?
5	What research methods and data collection have been utilised?

To conclude, the three papers which have been examined emphasise in different guises a need for a researcher to reflect upon whether the research they are doing is MM and to question the *what and how* of why they are carrying out MMR, paying attention to how qualitative and quantitative methods are integrated. Subsequent researchers concur with this, such as Leech & Onwuegbuzie (2009) who developed their own typology, based on a notional design system, identifying where other aspects of typologies might fit such as

the one proposed by Teddlie & Tashakkori (2006), whilst recognising that researchers may need to create their own.

The instructive questions of Bryman (2006) and the seven-step process of Teddlie & Tashakkori (2006) provide the structure that some researchers may benefit from before embarking on MMR at the design stage. Moreover, typologies offer a framework of support for researchers in providing clarity for external audiences, allowing that audience to comprehend the approach taken as well as the rationale for pertinent issues. This aids credibility, offering a sense of rigour and robustness to the research (Bryman, 2006) and thus perhaps quells the critics and the concerns of those who are either unfamiliar with MMR or who have fixed viewpoints due to their paradigmatic belief structure. Paradigms will be examined further in the following section.

Research Paradigms

A paradigm can be defined as 'basic belief systems, based on ontological, epistemological, axiological and methodological assumptions' (Guba & Lincoln, 1994, p. 107). The term was derived by Kuhn in 1970. In its simplest form, they can be construed as relating to worldviews. Epistemology concerns knowledge, how that knowledge is acquired and understood by the knower and relates to the notion of 'what counts as knowledge' (Krauss, 2015, p. 759). Ontology concerns how reality is conceived (Sandelowski, 2000; Schraw & Olafson, 2008). Axiology pertains to values (Fraser, 2014; Guba & Lincoln, 1994) and methods to the ways in which the data are handled from design stage through to the evaluation stage; namely procedural ways of managing the research data (Doyle et al., 2009; Smith et al., 2009; Sommer Harrits, 2011).

There are two key paradigmatic positions which are prominent in the literature; positivism and interpretivism (sometimes called constructivism in the literature). Both paradigms are often presented as diametrically opposed, lying on a continuum (Doyle et al., 2009; Onwuegbuzie & Leech, 2005). Knowledge within such a positivist paradigm is independent of the knower or the collector of the data and is gathered scientifically through the collecting of quantitative data, generally with larger sample sizes, so that bias does not impact on the research process (Doyle et al., 2009; Fraser, 2014; Guba & Lincoln, 1994; Krauss, 2015). Knowledge within a interpretivist paradigm involves qualitative data methods where the researcher is concerned with understanding the subjective experiences of the participants (Doyle et al., 2009) where 'reality is locally constructed and co-constructed' (Leech et al., 2010, p. 17). Table 4.5 (overleaf) provides an abridged comparative overview of some of the perceived differences of the two paradigms as interpreted by Fraser (2014, p. 53).

Table 4.5: Overview of Paradigmatic differences

Positivist paradigm	**Interpretivist paradigm**
Tends to produce quantitative data	Tends to produce qualitative data
Uses large samples	Uses small samples
Concerned with hypothesis testing	Concerned with generating theories
Data is highly specific and precise	Data is rich and subjective
The location is artificial	The location is natural
Reliability is high	Reliability is low
Validity is low	Validity is high
Generalises from sample to population	Generalises from one setting to another

Alternative paradigmatic positions have been described such as one purported by Rossman & Wilson (1985) which has three paradigms: purists, situationalists, and pragmatists situated on a continuum. Purists, occupy one end are perceived as those who have a strongly held belief that quantitative and qualitative methods cannot be mixed in the same study due to their differing ontology and epistemology paradigms (Greene et al., 1989; Onwuegbuzie & Leech, 2005; Rossman & Wilson, 1985). Situationalists posit that there is a place for quantitative and qualitative paradigms but neither has precedence over the other, whilst maintaining their 'mono methods' belief'(Onwuegbuzie & Leech, 2005, p. 376). There is more scope in their worldview insomuch as the research question should be the determinant of the method that is employed (Onwuegbuzie & Leech, 2005). Pragmatists believe in the idea of integrating quantitative and qualitative methods at different stages of the research process (Johnson & Onwuegbuzie, 2004; Onwuegbuzie & Leech, 2005), implying that they can co-exist in the same project with the research question being the determinant of the choice of methodology (Bacchus et al., 2018; Onwuegbuzie & Leech, 2005).

Another alternative paradigm is critical realism, a 'philosophical paradigm' which is linked to axiological assumptions as the values that each of those involved in the research are an instrumental part of the research (Krauss, 2015). Within this paradigm qualitative and quantitative data collection methods are acceptable within the same study to research the phenomena (Krauss, 2015).

Summary

Drawing on the ideas of Howe's, 1988 *Incompatibility Thesis*, Onwuegbuzie & Leech (2005, 376) have suggested that there is an ongoing debate which has led to a 'quantitative versus qualitative contest' which has impacted negatively on some students engaged in research, implying that they have been left with an ideology that this mixing cannot and should never occur. The implication is that such an ideology is a misconception, and that 'the epistemology does not dictate which specific data collection and data analytical methods should be used by researchers' (Johnson & Onwuegbuzie, 2004). However, Krauss (2015, p. 759) believe that the debate is more 'philosophical, not methodological'.

Furthermore, Onwuegbuzie & Leech (2005) postulate that purists have an over propensity to look for the differences between quantitative and qualitative research methods and would be better placed looking at which aspects of their philosophical stances concur. Sommer Harrits (2011, p. 151) argues for a 'paradigm-sensitive typology of MMR' and that the debates regarding paradigm differences is to be expected due to the fact that MMR will involve different paradigms and rationales for how the research was carried out. Guba & Lincoln (1994, p. 116) echo a similar perspective in that they believe that there should be a coming together of the different paradigms so that the differences can be explored rather than proponents of each paradigm arguing their own stances.

Moreover, the debate has led to the recognitions of the limitations of MMR which have been raised in the literature. Sommer Harrits (2011) suggests that MM does not overtly address the issue of paradigms, and this is what needs addressing when defining MM not just the how you do it.

Sandelowski (2000, p. 247) however, asserts that MMR is not about mixing paradigms but that they are an aspect of the research, otherwise this would require the interchangeability of worldviews by the researcher. Furthermore, she believes that a researcher cannot hold two different worldviews at the same time for example 'the positivist and the critical theorist may not really be studying the same phenomenon, because to see a phenomenon in a certain way is to change that phenomenon', namely they would be viewing that phenomena through their own lenses holding their own biases.

There is a suggestion that MM could be seen as a third research paradigm (Bryman, 2006; Johnson & Onwuegbuzie, 2004) or a research paradigm in its own right (Bryman, 2006), positioning MM in the middle of the paradigm continuum. This affords a potential way forward to advance the MMR debate. The idea of the pragmatic researcher suggested by Rossman & Wilson (1985), offers 'a middle position philosophically and methodologically', according to (Bryman, 2006) and a way of commencing the conversations required to address concerns about the perceived lack of structure and lack of frameworks for assessing the quality of research that the more well-known paradigms have.

Moreover, it will aid researchers at the design stage in terms of choosing methods and how those methods are integrated (Onwuegbuzie & Leech, 2005; Teddlie & Tashakkori, 2006). This may then lead to a position where researchers who engage in MMR will put the research question first and not be impeded by potential research paradigm 'biases' that they might hold (Johnson & Onwuegbuzie, 2004, p. 23)

Integration in Mixed Methods Research

> 'Mixed methods research questions provide the specific reasons why the researcher intends to integrate during the study. When researchers have a reason to integrate, it is more likely that integration will occur' (Plano Clark, 2019, p. 108)

Bryman (2006) believed that integrating qualitative and quantitative methods was gaining credence and popularity, notwithstanding earlier writers who raised concerns. For example Maxwell (2016) highlighted the fact that earlier studies which demonstrated integration had no need for typologies whilst later studies did so, such as Teddlie & Tashakkori (2006) which was signposted in their critique. Maxwell (2016) appears to imply that typologies are not necessary, and it was an oversight of writers such as Teddlie & Tashakkori (2006) and their contemporaries not to have acknowledged this. By contrast, Greene et al. (1989) found in their research evaluation of 57 papers which purported to be MM that 44% had no integration and 16% did not report on the integration while 41% had integration at different stages. This led to them suggesting that more research was needed into how the mixing of the data was employed.

Similarly, research by Bryman (2007) which involved the interviewing of twenty UK researchers to ascertain their views on integrating qualitative and quantitative methods identified a number of important barriers to integration. These barriers included areas such as the lack of expertise of the researchers in integration and who the researchers were writing for in terms of audience and where the work might be published. Additionally, the barrier of methodology (e.g., ontology and epistemology) seemed to be addressed by the researchers by identifying themselves as pragmatic researchers, with some of the researchers not fully able to articulate what the term meant.

MM integration involves the combining of qualitative and quantitative methods (Bryman, 2007; Fetters et al., 2013; Plano Clark, 2019). The specificity of what will be integrated is paramount and that the 'quantitative and qualitative components of the mixed methods study have something to say to each other about the topic(s) being examined' (Plano Clark, 2019, p. 109). Leech & Onwuegbuzie (2009, p. 273) identified five types of MM designs whilst developing their typology: 'Sequential studies, parallel/simultaneous studies, equivalent status designs, dominant-less dominant designs, and designs with multilevel use of approaches. Each will therefore require different types of integration. MMR creates a space for researchers to utilise a broad range of approaches drawn from different methodologies to address their research question allowing for the potential of 'new insights' emerging (Bryman, 2007; Plano Clark, 2019).

4.3 Methodological design

Having examined what MMR involves, particularly the notion of typologies, this section expounds the rationale for the chosen type of MM approach. The starting point was the thesis title and the associated research questions:

'Eating Disorders Self Help Groups can support the recovery journey of an individual with an Eating Disorder and provide an adjunct to professional support.'

To answer the overall thesis title the following overarching research question was formulated:

'Who or what contributes to an individual's recovery from an ED?'

This was supported by four supplementary questions:

I. What role do ED SHGs play in supporting an individual's recovery?
II. How do individuals use and experience ED SHGs as part of their recovery?
III. What constitutes recovery from an ED?
IV. What economic and social value do ED SHGs offer?

The rationale for the design choices

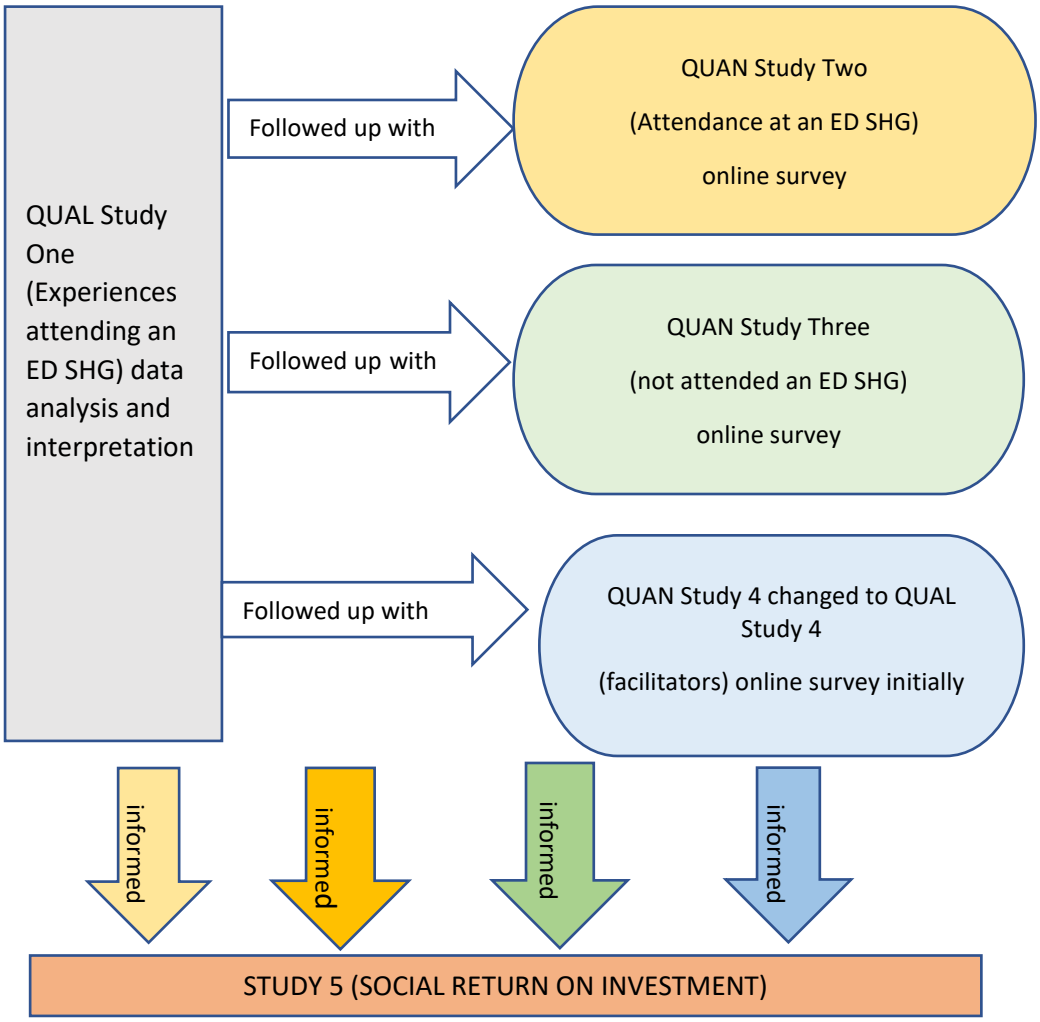
The design process and the relationship between answering the research questions in the most appropriate way to best investigate the phenomena i.e., the ED SHG was an important consideration as reiterated in the body of literature concerning MMR (see Bryman, 2006; Greene et al., 1989; Krauss, 2015; Teddlie & Tashakkori, 2006). The resultant outcome was a series of studies outlined in Table 4.6 which summarises the relationship between the research questions, the data collection approach. with the aligned research question and the points of integration. It has been suggested that researchers might need to create their own methodological design if one does not exist (Leech & Onwuegbuzie, 2009; Teddlie & Tashakkori, 2006). This thesis has therefore potentially adopted a *unique* design in that there appears not to have been research studies which have included SROI as part of its overall design.

Table 4.6: Research questions, study titles and sequence of execution

Study	Study Title	Research question (s)	Main Approach	Sequence of collection
One	Experiences of ED SHGs in Relation to Recovery: A Qualitative Study	i, ii and iii	QUAL	First
Two	ED SHGs and what matters in recovery	i, ii and iii	QUAN	Second
Three	What matters in recovery: Adults with an ED who have never attended a SHG	i, and ii	QUAN	Third (commenced midway during Study Two data collection)
Four	What matters in recovery: Facilitators' perspectives of ED SHG	Overarching research question	Started as QUAN moved to QUAL	Third (QUAN commenced midway during Study Two data collection). Fourth QUAL commenced end of Study Three
Five	SROI Study: Evaluating the impact of the Central London SHG for Adults	iv	QUAN and QUAL (outcomes-based measurement tool)	Fifth

An exploratory sequential design was employed and deemed the most suitable MMR approach as it involved the acquisition of data from a qualitative study to inform data in future quantitative studies (Onwuegbuzie & Leech, 2005), as exemplified in Figure 4.1. A synonymous way of describing such an approach is 'integration through building' where the results of an initial qualitative study informs constructs of a subsequent quantitative study (Fetters et al., 2013, p. 2140). Overall the implementation of this approach for the thesis was 'interactive' using several methods to research the 'phenomena' (Greene et al., 1989, p. 267).

Figure 4.1: Diagram of The Research Exploratory Sequential Design



The first study, QUAL study one, involved the gathering of QUAL data using IPA, the aim being to find out about the lived experiences of people with an ED who had or were attending an ED SHG. There was a deliberate reason to start with the QUAL study as it was

instrumental that the lived experienced represented the key *spine* of the thesis from the outset. Direct words, phrases, and experiences of the participants from study one formed two of the key constructs of the quantitative online prevalence survey for study two. This was the first explicit point of integration. This integration acted as a way of examining if the QUAL findings from study one was replicated across a larger population, or the findings were unique to that group of participants. The two threads that were drawn on from QUAL study one were: experiences of being a member in an ED SHG the group and relationship with recovery.

The WEMWBS instrument formed part of studies two and five to collect data about the wellbeing of the survey participants, adding a further point of integration.

The overall aim of QUAN study three was to discover the reasons why some people with an ED do not attend ED SHGs. One construct from study two (relationship with recovery) was added to the survey for QUAN study three in addition to descriptive questions. This was an additional point of integration between the QUAL study one and QUAN study two. Thus, QUAN study three afforded an opportunity to have viewpoints and comparative data on relationship with recovery from three *types* of participants: the lived experience from QUAL study one, the larger survey group of QUAN study two and the non-attendees/ engagers of an ED SHG of QUAN study three. Additionally, the scorings that emerged from the analysis of study two related to the relationship with recovery were used to score the findings from study three.

The survey that was developed for QUAN study four, was aimed at facilitators and arose out of the analysis from studies one and two. This was to acquire further data on the structure of other ED SHGs and find out more about the people who run the groups as this was an important theme that emerged from study one. Moreover, facilitators represent one of the stakeholders for the SROI. This recruited slowly (n= 5, after eight months) so a decision was made to change this study to a QUAL study using semi structured interviews of a small group of facilitators (seven). The aim was to discover more about them as individuals, their motivations for facilitating their groups and how they manage the group processes.

The purpose of study five was to determine the value that ED SHGs offer through a social and economic value lens. An existing SHG (facilitated by the author) was used. The views and experiences of stakeholders is an important principle of an SROI study. Across the four studies stakeholders have included people who have attended an ED SHG, people who have not, and facilitators.

4.4 Ethics and safeguarding

Before any data were collected, full ethical approval was sought and approved by the University of Hertfordshire's ethics committee who allocated following protocol numbers for each of the five studies (see Table 4.7). See Appendix 4.34 for the ethics approval notifications. Informed consent was gained from all participants which required them to acknowledge that they had read the participant information. The potential distress of participants was considered through a risk assessment, and they were signposted to a debrief sheet post the completion of the interview or survey.

Table 4.7: Ethical Approval Numbers

No:	Study Title	Protocol Number	Date granted
1	Experiences of Eating Disorder Self Help Groups in relation to recovery	LMS/PGR/UH/03244	06/03/2018
2	Eating Disorders Self Help Groups and what matters in recovery	LMR/PGR/UH/04306 LMR/PGR/UH/04306 (1) extension	17/11/2020 02/02/2022
3	What matters in recovery: Adults with an Eating Disorder who have never attended a Self Help Group	LMS/PGR/UH/04873	01/04/2022
4	What matters in recovery: Facilitators' perspectives of Eating Disorders Self Help Groups	LMS/PGR/UH/05154	10/02/2022
5	Evaluating the impact of the Central London Eating Disorders Self Help Group for Adults and what matters in recovery	LMS/PGR/UH/05633	03/05/2024

Furthermore, safeguarding risks around the duality of role that the researcher occupied with respect to interviewing participants known to them for study one (chapter five) was explicitly considered. Table 4.8 outlines the potential risks and the measures that were adopted.

Confidentiality and GDPR was considered at all stages of the design process. No email addresses or IP addresses were collected. Additionally, confidentiality was conveyed to participants prior to them deciding to start the research through the participant information sheet which detailed what data would be collected and the length of time they would be retained. There are supporting appendices for each study which contains ethics paperwork.

Table 4.8: Safeguarding risks (lived experience)

Potential Risk	Measures adopted
-Bias: The researcher's lens shaping the analysis of the data and the direction of questions during interview. **-Power imbalance:** Shared relationship may have led to participants feeling compulsion to disclose more and not being able to challenge any interpretations. **-Over identification**: Shared assumptions being made on both parts due to relationship which may have led to over heightened emotional responses. Impact on objective responses by researcher. **-Role confusion:** the researcher's lived experience may have blurred boundaries between the duality of their role; that of researcher and the ED SHG group facilitator which participants attended/were attending.	-Risk assessment carried out prior to the research. (Appendix 4.4) -Debrief and information sheet signposting to support services post interview (Appendix 4.6). -Use of reflexive diary post each interview and throughout the analysis stage which created space to reflect on emotional responses, counter transference and any safeguarding concerns. -Regular meeting with supervisors both of whom are qualified clinical psychologists. -Transparency with co facilitators who agreed to researcher inviting group members to participate (without breaking confidentiality as to who eventually participated).

Study One

Study one involved interviews, and due to the nature of the topic matter the issue of confidentiality was of paramount importance from the outset. Careful thought was given as to how any data that were collected would be stored throughout the interview process. All data pertaining to the participants were stored securely in a locked filing cabinet in the researcher's office and electronically in a password protected environment on the researcher's password protected laptop. All interviews were recorded, and each one was transcribed verbatim by a professional transcription service. This service signed a confidentiality agreement (Appendix 4.3). No identifiable details of the participants were shared, and the data were sent in an encrypted manner. All transcripts were checked for accuracy by the researcher. The interview recordings, once transcribed, were deleted. All participants were allocated a pseudonym and any documentation with their real names was kept separate from the pseudonym, thus protecting their anonymity. This information was carefully documented in the participant information sheet (Appendix 4.5).

In addition, the participant information sheet detailed how the data would be collected, stored, and how long it would be kept. Participants who had met the entry criteria for the study were sent the participant information sheet and were asked to read through it carefully. Once they were happy, they were asked to sign and return a consent form. It was only at that point they were formally invited to start the first part of the recruitment process. It was important that throughout the process the right to withdraw was signposted to them. This started prior to the interview process. Participants were asked to re-confirm consent on the day of the interview to add another layer of robustness.

As the participants were going to be asked about aspects of their mental health and stories from their past, a debriefing sheet (Appendix 4.6) was designed which signposted participants to sources of support. At the outset of the interview process participants were told they could stop at any time or withdraw. Time was built into the interview schedule for a debrief session to allow participants space to express any distress, ask any questions and for the researcher to go through the debrief sheet (as evidenced in the supporting appendices for each study). No participants displayed any distress during or post the interview.

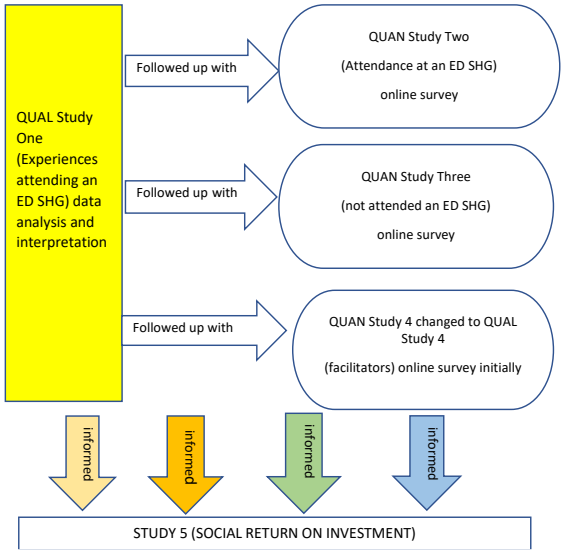
Appendix 4 contains the documentation that was used for each of the five ethics applications (which includes the participant info, consent forms, details of any questionnaires, questions, risk assessments and debrief sheets).

Chapter 5: Experiences of Eating Disorder Self Help Groups in Relation to Recovery (Study 1)

5.1 Overview of the study

The focus of this qualitative study was to research the experiences of nine people with an ED who had attended a face-to-face ED SHG, exploring their feelings about, and experiences of their respective ED SHG and its role in supporting their recovery. It represents the start of the exploratory sequential design highlighted in yellow in Figure 4.1. To the author's knowledge, such an exploration does not appear to be reflected in current literature (see chapter three). This study thus creates an opportunity to contribute to new knowledge and extend on what already exists.

Figure 4.1: Diagram of The Research Exploratory Sequential Design



5.2 Literature Review

The narrative review's limited findings highlighted the sparsity of research as to what was known about ED SHGs (chapter three). The review offered insights into understanding who attends ED SHGs and how they support recovery. It found that there was variability in the structure: online forum; online group; structured face to face groups; and groups focussed on psychoeducation set up and/or run by professionals. Each type of group functioned independently and had different types of leadership. Due to this paucity of research around ED SHG, there will be a focus on MHGs as aspects of their ethos aligns with ED SHGs to further understand how they support individuals. This builds on the definitions of SHGs which was discussed in chapter two.

The Value of Mental Health Self Help Groups

It is necessary here to reclarify exactly what is meant by the term MH SHG as there appears to be no degree of consensus as to what they should be called. Similarly, the review (chapter 3) noted the same lack of clarity as regards what ED SHGs are. Once this has been clarified the value of such groups for its attendees will be discussed. The common terms that appear in the literature are: peer support group (Davidson et al., 2006); mutual help group (Kelly & Yeterian, 2011); SHG (Newton, 2000) and support group (Bolzan et al., 2001). Sometimes the terms are used interchangeably for example Repper & Carter (2011) use the term mutual support group. Borkman (1976, p. 445) offered this definition of an MHG: 'a human service oriented voluntary association made up of persons who share a common problem and who band together to resolve the problem through their mutual efforts.'

Borkman's description has much merit and currency despite it being written over four decades ago, as it comprises all three labels of mental health groups (MHGs) above and provides a useful umbrella description. Drawing on Borkman's (1976) original description, Bond et al. (2019, p. 640) describe SHGs as follows: 'people with shared issues coming together informally, providing mutually supportive non-judgemental environments and sharing information'.

The key essence of both definitions is support and self help (SH). In addition, both offer a description of the constitution of the group; how the group operates, and the purpose of the group. Having defined what is meant by an MHG the next discussion will progress by examining some aspects of the value such groups afford their members.

MHGs offer a space for people with mental health conditions to come together. How such groups are formed varies. For example, some groups may be formed by the persons with the condition and their caregivers themselves (see Cohen et al., 2012). Professionals may form guided MHGs (see Laitinen et al., 2006). Irrespective of how an MHG is formed, self-learning is 'the core wisdom of self help' (Laitinen et al., p. 308) and it is through this mutually coming together, when defining what MHGs are, that self-learning can occur. Members can be curious together, not only to learn from others but learn about parts of themselves which they may never have considered. This offers an important therapeutic dimension.

Similarly, Newton (2000, p. 1) citing the work of Longden et al. (2018), Caplan (1974) identifies the fact that MHGs can offer attendees 'social feedback regarding their behaviour'. For example, in a group for Finnish women with depression learned about who they were and what was important for their own self-development. This resulted in some form of personal change, thus empowering them (Laitinen et al., 2006), providing a space for building self-confidence and esteem (Naslund, Aschbrenner, Marsch, & Bartels, 2016). Furthermore, this is a type of learning that members might not be able to receive elsewhere and can be viewed as a special type of support.

This was noted in a study that Longden et al. (2018) carried out involving the Hearing Voices Network. Members of that group felt heard and understood by others in the same situation as themselves which they felt they could not receive elsewhere. Additionally, they stated that the support inside the group also helped them cope with everyday living outside of the group. Building on this idea Salzer et al. (1999) identified a similar strand when they appraised SHGs where they noted that groups like this can have a positive impact on the social aspects of life and can act as a way of helping to prevent a relapse and referral to professionals. In a review carried out by Seebohm et al. (2013), it found that members who attended self help type groups felt energised through the process of sharing feelings, practical ideas and mutual support. The sharing within the group can create a space where members are 'amongst equals' (Bolzan et al., 2001, p. 322) and they share common experiences (Naslund et al., 2016; Yalom & Leszcz, 2005). Moreover, hope was another important feature that emerged from literature according to Yalom & Leszcz (2005) and that through this process the sense of hope pervades the group, and it is this which makes such groups even more valuable.

Another important function that MHGs offer is support with recovery and can be helpful alongside existing professional support (Bolzan et al., 2001; Kelly & Yeterian, 2011) and in some cases they are the only support that is available to people with a mental health condition (Kelly & Yeterian, 2011). What seems apparent is that recovery is not a solo enterprise and that people need others to support them (Shepherd, Boardman & Slade, 2008). One is left wondering how much power the person who has recovered has, in encouraging members that they too can recover and whether it is this which adds even more value to the MHG.

This section has touched on the value that MHGs can offer; it appears that the mutuality and reciprocity of the support can give strength to many MHGs.

5.3 Methodology

This section is about the design of the study and includes information about how the study was created.

Research Design

This research took a qualitative approach with IPA being identified as the most appropriate methodology, as much of the data were related to reflections on a personal lived experience. See chapter four for a more detailed description of IPA.

The researcher occupied in part an insider's perspective as they interviewed some members of the ED SHG that they co facilitated. Mindful of this they thus maintained a reflective diary to capture reflections and feelings that arose during the collection and analysis of data (Appendix 5.1: researcher diary extracts). To further address the issue of potential bias the research was assessed against the 'eight big tent' criteria for assessing the quality of qualitative research devised by Tracy (2010, p. 840) (see Table 5.1). Of note the

third criteria, sincerity, addresses bias the most explicitly, but the eight criteria demonstrate the high quality of the research at the outset of this study.

Table 5.1: Quality Assessment

Criteria for quality (end goal)	Description of the criteria	Evidence for meeting the criteria
1-Worthy topic	The topic of the research is: - Relevant - Timely - Significant - Interesting	-Very few studies in the field related to research question (picked up in narrative review). - Timely as there is a rise in the number of EDs and more people may need to make use of ED SHGs. -Liaised with co-workers of ED SHGs about the relevance of study and a clinical psychologist who is experienced in EDs. -Both supervisors have worked in the field of EDs. -Researcher works in the field as a facilitator of an ED SHG and as a psychotherapist/counsellor. -Researcher carried out an IPA research study involving four former attendees who became co-workers and/or facilitators who endorsed the subject matter. - Aim is to build on this study to hear real lived experiences of people with an ED participating in such groups and to hear stories of recovery using IPA
2-Rich rigour	The study uses sufficient, abundant, appropriate and complex: - Theoretical constructs - Data and time in the field - Samples - Contexts - Data collection and analysis processes	-Gathered data from nine in-depth interviews from across four different ED SHGs to endorse findings. -Demographic data about all participants is provided including age, nature of ED, engagement with health professionals, age of onset (when provided) -Data were collected over four months through one-to-one semi structured interviews which were transcribed and analysed.
3-Sincerity	The study is characterized by: - Self-reflexivity about researchers' values and biases - Transparency about methods and challenges	- The researcher's personal and epistemological position is clearly articulated early on into the research, regarding methodology, and concerning the participants' experiences of attending their ED SHG and their views about recovery. -This inclusion enables the reader to gain a fuller picture of the researcher and reflect on the researcher in relation to the position and values they occupy and the impact on the double hermeneutic of how the participants' accounts are understood by the researcher. -As is good practice with IPA a reflective diary was kept and there were ongoing discussions with the researcher's supervision team. There was an opportunity for a peer supervision session. This helped the researcher to continue to reflect on how their own experiences as a therapist and as a group facilitator may be having on the interpretation of the data and the development of the emergent themes.
4- Credibility	The research is marked by: - Thick description, concrete detail, explication of tacit knowledge - Triangulation or crystallisation	-The findings section, using direct quotes from the participants, supports the themes developed by the researcher. In some cases, the titles of the themes are the participants' exact words or variations of them. Furthermore, this demonstrates that the researchers' analysis is grounded in the participants' experiences.

	- Member reflections	-The second supervisor was involved in ensuring the credibility of the analysis of the interviews by reviewing the development and creation of the themes and the ongoing refinement of the first four interviews. This supported the researcher in staying true to the data that emerged from the interviews i.e., the participants' words rather than being over analytical and losing the essence of the participants' words.
5-Resonance	The researcher influences, affects, or moves readers or a variety of audiences through: - Aesthetic, evocative representation - Naturalistic generalisations - Transferable findings	-The researcher carefully selected quotes from the nine interviews that they hoped would move and connect with readers who may have never attended an ED SHG such as the first experience of attending a group, the journey leading up to attending a group and the fears associated about who would be there, recovery relapses, hopes and dreams. -It has the potential to reach out to professionals inside and outside the field of ED to help them learn more about the value that attendees attach to groups, and what recovery means to people with EDs. -The researcher has been at pains to accurately capture the participants' words and to represent them accurately.
6-Significant contribution	The research provides a significant contribution: - Conceptually/theoretically - Practically - Morally - Methodologically - Heuristically	-The findings of this research contribute to a field where there is a shortage of research into the area of unstructured face to face ED SHGs in relation to recovery. -There is a place for this research to contribute to government policy into ED SHGs being seen as a pathway for support pre and post specialist treatment. -The research has a place to contribute to the body of literature about what constitutes recovery and what is an ED SHG and how it can support people with an ED.
7-Ethics	The research considers: - Procedural ethics (such as human subjects) - Situational and culturally specific ethics - Relational ethics - Exiting ethics (leaving the scene and sharing the research)	- Ethical approval was granted by the University's ethics committee following a successful application. A protocol number was attached to the research. - Potential distress was considered at the development stage of the research and a debrief sheet was provided for all participants post interview. The researcher is a practising psychotherapist/counsellor so is well versed in identifying distress and addressing it as and when it arises. -A reflective diary was kept. Regular supervisory meetings and communications were a key feature of the interview and analysis stages of the research. -Any ethical issues which arose were addressed immediately through the appropriate channels.
8-Meaningful coherence	The study: - Achieves what it purports to be about - Uses methods and procedures that fit its stated goals - Meaningfully interconnects literature, research questions, findings, and interpretations with each other	-The Methods chapter of the thesis outlines why IPA, the chosen methodology was the most appropriate method to use in addressing the research question for this study. -The Discussion section articulates how Findings address the research question. -The Findings section represents the culmination of ideas from across the nine interviews which enabled the researchers to create the superordinate and subordinate themes. Furthermore, the researcher sought to present the uniqueness of each interview staying true to each participant's experience whilst identifying where the data across the nine participants diverge.

5.4 The Participants

Inclusion criteria

The key criteria for inclusion were that all potential participants needed to be over the age of 18, have or have had an ED and have attended or are attending some form of face-to-face ED SHG. A screening questionnaire was created to capture data relating to potential participants' age, ED history, treatment, and attendance at an ED SHG (Appendix 5.2: Pre interview questionnaire). This approach ensured that only eligible participants were invited to join the study.

Recruitment

An advert outlining the nature of the study including eligibility criteria was created. This advert was used to recruit potential participants through a variety of channels including members of the ED SHG facilitated by the researcher, with direct email to facilitators of other local ED SHGs who advertised their services on the national charity BEAT's Self Help Finder database; social media; and colleagues. This yielded fifteen expressions of interest. As a result of email and telephone conversations six were deemed not to be suitable for this study. This was because whilst all had an ED, four had not attended an ED SHG and two did not meet the minimum age requirement (they had been told about my study via word of mouth).

The Sample

Nine suitable participants were recruited (some were attendees of the group that the author of the thesis facilitates). Eight were female and one was male. They had a range of EDs with the main one being AN. Two self-diagnosed their ED based on what they had read or what they had been told by others. They ranged in age from 24 to 43 years of age with the majority being in their 20s (five) with one in their 40s and the rest being in their 30s. All bar one was actively attending an ED SHG at the time of their interview. Identifiable features were disguised using pseudonym names chosen by the participants. All participants attended face to face ED SHGs.

Ethics

Before any data were collected full ethical approval was sought and approved by the University of Hertfordshire's Health and Human Sciences Ethics Committee with the protocol number: LMS/PGR/UH/05633 (full details chapter four).

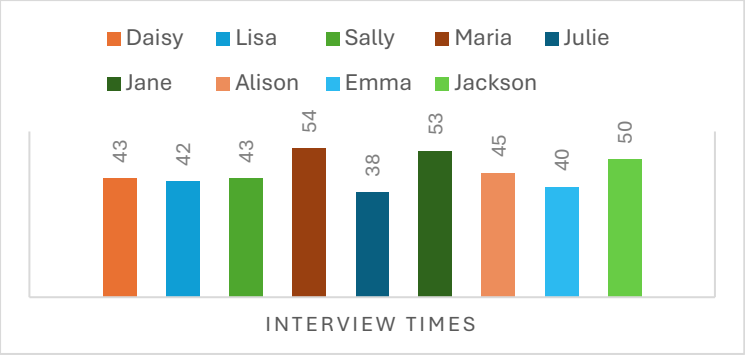
Table 5.2: Participant demographic information

Pseudonym	age	Sex	ED symptoms/diagnoses and previous treatments
Daisy	26	F	- Diagnosed with ED which started in teens. -Had dietetic and psychotherapeutic input.
Jane	24	F	- Self-diagnosed ED which started in teens. -Had psychotherapeutic input
Sally	37	F	-No official ED diagnosis. -Eating issues started in teens.
Alison	37	F	-Diagnosed with ED. -Had psychotherapeutic input.
Maria	27	F	- Diagnosed with ED which started in teens and BN - Had dietetic and psychotherapeutic input
Jackson	43	M	-Self-diagnosed ED which started in late teens. -GP support.
Emily	25	F	-Diagnosed with ED which started in 20s. -Had psychotherapeutic and dietetic input.
Julie	25	F	-Diagnosed with ED which started in teens. -Had psychotherapeutic and dietetic input.
Lisa	32	F	-Diagnosed with ED which started in 20s. -Had psychotherapeutic and dietetic input.

Interview schedule

The interview range time was 38 minutes to 54 minutes (mean=45 minutes and SD =5.7 (see Figure 5.1)). Participants were given the choice of how the interview would be carried out, i.e., whether they wanted an interview that was face-to-face, over the telephone, or over Skype. A semi structured interview approach was identified as the most appropriate approach for IPA studies due to their flexibility (Smith et al., 2009). This allowed space for the participants to go off in a direction that the researcher may not have considered, resulting possibly in much fuller data, enabling participants to be in charge and be the expert (Eatough & Smith, 2017). See chapter four for fuller details of the IPA methodology.

Figure 5.1: Interview times



The questions broadly explored recovery and the participants' experiences leading up to the group and their experiences inside their ED SHG (see Figure 5.2, overleaf). The questions went through many iterations which involved input from the supervisors. They

were also derived based on the researcher's two decades of experience as a facilitator of an ED SHG and as a psychotherapist/counsellor with experience of working with clients presenting with an ED history.

A draft of the questions was sent to one of the co-facilitators of the ED SHG, who had a lived experience of an ED and who was known to the author. They endorsed the questions and raised an interesting point around the use of the word challenges (question 5) suggesting that the term was also thought of in relation to relapses and setbacks. This was very apt as this emerged from the data. The nine questions were intended to be used as a framework to ask the same questions to the participants with any question prompts intended to allow the interview to follow the direction that the participants wanted to pursue. Across the interviews having a variety of strategies to engage the participants was key. For some, the pre-interview questionnaire was used as a segue into the conversation about their ED history which then led more easily to the first question.

Figure 5.2: Interview Questions

I am interested in finding out two key things: your personal experiences/views of recovery and your experiences of attending an Eating Disorders Self Help Support Group.

1. What has your relationship with recovery from an eating disorder been like for you?
   Prompt: What would recovery look/feel like for you / How will you know if you have recovered?
2. What motivations did you have when you started attending the group?
   Prompt: what were your hopes and expectations?
3. How does the group help you in your everyday life?
   Prompt: Your eating, your emotions, your relationships
4. From your own experience, what do you find helpful within the group
   Prompt: The topics, the style of the group, the facilitator(s), others in the group
5. What have you found challenging within the group?
   Prompt: The topics, the style of the group, the facilitator, others in the group
6. How have you experienced others within the group?
   Prompt: Listening to their experiences, their responses to what you might say? Your responses to what they might say to you
7. Having been in the group, what does recovery now mean to you?
   Prompt: Has it changed over time e.g. from when you first started attending?
8. How do you think those around you view your recovery and what it might look like?
   Prompts: professional help, friend, family etc
9. What do you make of their view(s)? For example,
   a) is it the same/different to your own? b) Is it helpful or unhelpful for you in your recovery?

Analysis

IPA was used as outlined in the methodology chapter four. Appendix 5.3 includes an example of how the stages of analysis was employed for one of the participants named 'Jane'. Appendix 5.4 contains a draft version of the initial thoughts around superordinate and subordinate themes.

As the sample size was over six an overview grid was created to check coverage of the final themes for the whole cohort as recommended by Smith et al. (2009). (Appendix 5.5: Coverage of themes for whole cohort).

Bias

There was a concern that researcher bias might influence the analysis of the data as five of the participants were known to her. This was considered at the onset of the study's design. It was thought that those five participants' responses would be completely different to what the other four participants not known to the researcher would say. However, the results showed that there were many areas of concurrence.

5.5 Results

This section presents the outcomes of the analysis of the data. As a result of the analysis three superordinate and eight subordinate themes emerged and these are captured in Table 5.3. Each theme is described and then illustrated with verbatim quotes and a commentary.

Table 5.3: Superordinate and subordinate themes

Superordinate themes	Subordinate themes
The journey leading to attendance at an ED SHG	-I looked it up and found the group -Fears and hopes: I've never been in a place like this before -Uplifting being in the group: like I jumped out of a plane
The proximity of relationships	-Self-exploration as a way/means to discover -Helpful and unhelpful aspects of relationships with others
Recovery as a dynamic experience and process	-Recovery reflections -ED voice as saboteur -Moments of Freedom

5.5.1 The journey leading to attendance at an ED SHG

This superordinate theme was involved with underlying and aetiological factors that led participants to the ED SHG.

I looked it up and found the group

Each of the participants had their own unique yet overlapping ED aetiology that ultimately led them onto the path towards an ED SHG group. An overwhelming emotive aspect within the ED experience was often prevalent, for example, Jane recalled her ED starting when she had left university and started purging:

> I first started making myself sick my first year out of university… and then it got a lot worse in quite a short period of time…. It became more frequent and became more of a sort of panicky, a more intense feeling…. Like something I was less able to ignore...I couldn't live with the mental processes every day and so I had to go and sort it out. (Jane)

Phrases such as 'panicky', 'more intense feeling' highlighted this emotive aspect and for Jane her rapid decline 'in quite a short period' impacted her to the point where she 'couldn't live with' the daily onslaught of her associated thoughts. Exploring this further, Lisa 'used' food as a way of dealing with 'emotions and stuff'. A rapid decline was evocatively portrayed when Lisa stated that she 'spiralled out of control, and the descent was so sudden for she did not 'realise' it. Lisa went on to highlight how 'obsessive' and 'controlling' behaviours helped her reduce the impact of her emotions:

> I kind of became obsessive about like how many calories I would have per day. My exercise would go up… Well, I just knew that when I was controlling my food, my emotions were kind of they weren't as bad, like it was a way to kind of block them out. (Lisa)

Lisa demonstrated a sense of self-awareness regarding why she was 'controlling' her food; she had found a way to quell the feelings she could not handle.

Jackson recalled leaving school and entering the world of work as a sixteen-year-old and being in a very difficult environment:

> I didn't cope with leaving school and I struggled. It was a very difficult couple of years beginning with the apprenticeship… having my own money for the first time in my life, I think the very first thing I turned to is food very early on as well…. My confidence was destroyed… I was probably being bullied. (Jackson)

The extremity of the impact on his 'confidence' can be sensed through the term 'destroyed', there was also an element of uncertainty in his acknowledgment of others' behaviour when he said, 'I was probably being bullied'. There was a dichotomy in his understanding of his position in the world, and uncertainty in understanding his newly attained financial independence in relation to others:

> I was well-paid as an apprenticeship. I was rather extravagant for a 16, 17-year-old. And along with that I came into my eating. … I wasn't particularly well-educated as most people… so it was bad choices. It was every version you could think. I never purged. (Jackson)

Thus, whilst he was 'extravagant', he believed he 'wasn't particularly well-educated as most people' consequently making 'bad choices'. It seemed that the transition into adulthood was challenging for him, not just emotionally, but also financially. Such an emphatic, out of context, statement at the end suggested it was important for him to let the researcher know that he 'never purged'; perhaps unconsciously highlighting that he could make good choices too.

The rapid descent into the ED prior to searching for help continues with Maria's explanation about how her ED initially started as a physiological response 'my throat was just closing' and 'I just couldn't eat' to a difficult psychological situation relating to her family, which then crescendoed:

> It was pretty quick. I mean I was having a lot of family problems, and I think that I felt like physically my throat was just closing. And I just couldn't eat for like a week. And then it started to build up into not eating at all for months and then years.
>
> I didn't feel hungry at all. And so, I basically stopped eating for a week. And then it started building up into not being hungry at all for many more weeks, and then. and then… it just became like this obsession to just be more slim. (Maria)

It is as if Maria's body went into shut down – almost like a hunger protest where she 'didn't feel hungry at all'. It seemed the hunger did not return and instead she developed 'this obsession to just be more slim'. Given the initial stressors, one wonders what happened to the associated feeling as the hunger shutdown continued. The hunger shutdown seemed to act as a buffer to protect not only Maria from her feelings but also to protect her family from the reality of what was happening to Maria.

> My family was going through a lot. So, they didn't really have… I would say time to just figure out what was going on. And I was going to school and doing my things and they were doing theirs. So, I wasn't really taken care of for that time, I would say. (Maria)

Maria, on one hand, seemed to be excusing her family for not engaging in her distress ('my family was going through a lot'). In contrast she described feeling neglected ('I wasn't really taken care of') and left to be self-sufficient, so she carried on with her normal routine of 'going to school'. One can posit that it was perhaps a way to instil some sense of normality in her life and, thus, keep the difficult feelings at bay.

Jane's search for an ED SHG was due to her treatment ending and her feeling that she needed more support:

> And I just looked it up and found the group. But the interesting thing was when I finished therapy, I wasn't...I went for review. I wasn't in very good place and she just said, 'I'm so sorry but there's nothing else we can do for you.' I said, 'Well, is there any group in London, any sort of group therapy?' And she said no. They don't exist. And then I just... So, I didn't even look for a really long time and my boyfriend prompted me just to have a look just see, and it came up straightaway. (Jane)

The starkness in awareness of how to help Jane and where to access this was clear when she recalled that she was told support groups 'don't exist'. That advice meant that Jane did not 'even look for a really long time'. Clearly her struggle was evident to those around her when her 'boyfriend prompted me'. Prior to this, she had wanted help, had asked for it, it was not on offer nor was there advice on where else to seek it, so she seemed resigned to there being no group support available to her. Yet it was only after a 'really long time' that, perhaps, her desperation enabled her to seek it out.

Lisa sought out the group's details, not through google but via the database of the charity BEAT. She did not attend straightway and needed the active encouragement of others:

> It's kind of like we're talking with my HR manager that's like I was really struggling, and I needed to do something and previously I've looked on the BEAT website about support groups, but I've never done anything, but it got to the stage where I needed to do something.
>
> Like to kind of trying to help myself… so, yeah, I kind of saw the—saw the group was there and then with the encouragement of like friends, I attended the group in February. (Lisa)

Jackson's description of his drivers to attend had a sense of urgency and need ('I'm freaking out'), as with others, he was encouraged by his partner to attend a group:

> …despite understanding how well I could lose weight and having a couple more stone to lose, I just spotted the old me was creeping back. And I said to my wife I'm freaking out. I said, 'I've done so well. Why would this come back now?'…And so, she said maybe you need to speak to someone…. And at pretty much at the same time ended up starting the groups. (Jackson).

Thus, despite his independence he knew that he needed support to get back on track and maintain the good work he felt had already achieved.

The intensity of the internal impact of external stressors made the need to search for help and support more prominent. Whilst the participants had their own reasons for

actively seeking out help, for all participants it was about getting support with their ED. The search for the group was usually either at the encouragement of someone close to them or because of some sort of professional NHS treatment ending. What was apparent was individualised proactivity of the participants in their pursuit for help; the element of them choosing the group was evident. Once they began to attend the group, the participants had to manage the physical and emotional experience of being within it; this superordinate theme will now be explored.

Fears and Hopes: I've never been in a place like this before

Such was Alison's anxiety, not only did she delay her entry into the group, but she also needed the support of her sister 'for…a year'. As with Jane's description of a strong bodily response, Alison also had this when she first attended, demonstrated in the term 'crapping':

> I was absolutely crapping myself and I-I—it's that... It's going to sound really stupid, but I've actually only just started going on my own and I've been going for like a year first. I always took my little sister with me as support cos I didn't want to do it on my own (Alison)

The frustration in herself regarding her dependency on others was evident when she stated, 'it's going to sound really stupid' especially as she needed her 'little sister'. However, that support and commitment from others was crucial in enabling her to take the space in the group and 'do it on (her) own' leaving her emotional crutch behind.

Emma highlighted several core fears attending the group raised in her:

> …it was a room at the side of Y well you couldn't see through it …because it's like confidential … but I had no idea who would be behind it. I know, know it wouldn't be like just me and two, like, people who wanted to delve and ask lots of questions. I didn't know if it'd be full of like, really, really, really thin people. I was like, I don't know what to expect and I've never ever been to anything like that before. (Emma)

The fears of what it might mean to take up personal space in the group can be seen with her focus on the unknowns, such as the fear of having to answer 'lots of questions'. The term 'delve' indicated the fear those questions could be personally intrusive. Further, there was the unknown of those 'who would be behind' the door, fearing the group would potentially be 'full of …. really, really, really thin people'. The repetition of 'really' highlighted the extremity of her view of other's thinness compared to her own; adding to the sense of space she would take up by comparison.

She did, however, need a final nudge (physically and metaphorically) from her partner to go inside this scary environment:

> I was reluctant and. Like a push to go through the door, I think from my partner who was like go and be someone else's problem for a couple of hours please…. Luckily it was good. (Emma)

The wrench within her predicament of seeking support for her distress was apparent for she was either his 'problem' or 'someone else's'; perhaps it was no wonder this fear of being a 'problem' made her struggle to take up emotional space.

Despite this narrative of fear, hope also played a part within the internal dialogues of two of the participants' initial entry into the group. Sally on the other hand seemed to bargain with herself wherein 'hope' gave her courage to reach towards something new which might exist somewhere beyond her 'desperation':

> Hope, yeah, a lot of hope. The need of talking to someone also and… I leave it all to desperation like what can I do with this. I tried a few things, and it seems it never goes 100%. So, this is like okay, I've never been in a place like this so I'm going to see and…. Yeah, I'm going to see what happens. That was my main sort of motivation. (Sally)

Her tentativeness was still evident in the repetition of 'I'm going to see'; yet she had nothing to lose by going along to the group.

Like Sally, Daisy displayed an initial degree of reticence in attending the group; her internal dialogue differed from Sally's in that she was questioning whether she still had 'this issue':

> I think that was my earliest motivation for going, was trying to figure out in my own head do I still have this issue. And then, when I started going—at first, again, I was a bit like, oh, I'm not sure, you know, it's not that severe. Like, it could be so much worse, blah, blah, blah. (Daisy)

Here, merely talking about attending was minimized, as her ED was 'not that severe', indeed, 'it could be so much worse'. The immediate addition of 'blah, blah, blah', highlighted the minimization, as if she was going on too much about her eating distress; again, emphasising that she should not be taking up other people's time and space.

Uplifting being in the group: like I jumped out of a plane

The initial impact of the group was the key constituent of this theme. Having found the group each participant had their own internal battles related to how they felt about attending their first session. What seemed clear was they discovered ways of overcoming and challenging those initial fears. We will start with Jane who highlighted many of these processes:

> I felt like I jumped out of a plane after I came out my first session. I felt so much adrenaline. I called my boyfriend, and I was like, 'I think that's the best thing I've ever done.' I honestly felt elated because I was so nervous, and it was

> so different to what I thought it was going to be and it is so different to speaking to a professional, to speaking to other... It's almost like having an in joke with everyone in the room. They can just relate to you no matter like, you know, we all have completely different experiences. But it was very liberating I think, my first group…because it was so nerve-wracking before and that I had all of this adrenaline. And you know it's like after you do something that makes you scared, you feel great afterwards because it all just releases into your system. I just came out, I'm like, 'Oh my god. I can't believe I did that.' (Jane)

The leap of faith Jane took in initially attending was indicated through phrases such as 'jumped', 'elated', 'liberating', 'nerve-wracking', 'adrenaline' emphasising a sense of euphoria inside Jane for having taken that leap to attend. There was a sense of personal achievement that somehow freed her emotionally with the 'release' of 'adrenaline', 'into your system'; clearly this indicated a strong bodily response.

Sally described the group as 'uplift'[ing]:

> It makes me feel better. Every time I leave the group, I feel uplifted, and I come home and it's that sort of reassurance of yeah, you're fine and food is fine. Not something to fight for. And yeah, it has helped me definitely. It makes me feel a lot happier in one way, I don't know. (Sally)

It was almost as if attending the group helped her step out of a battle indicated in the term 'fight for'. This battle was with food and with herself although exactly how this happened, she does not 'know'. However, it seemed important for Sally that she attained some form of external validation via 'reassurance' and, perhaps, this offered her some internal validation which, in turn, positively impacted her emotional wellbeing.

5.5.2 The proximity of relationships

This superordinate theme was about internal and external relationships.

Self-exploration as a way/means to discover

Jackson seemed to have recognised that the group created a space for him to engage with his internal sense of agency. This space represented a new way of thinking about himself ('I learnt about myself'). There was an air of possible intrigue ('it's a way to discovery'). Being in the group kick-started a willingness inside of him to have a go at this despite feeling overwhelmed and uncomfortable ('It can be fatiguing').

By contrast Lisa berated herself for she didn't 'use the group as well as I can'. She explained why: 'because I end up talking about my family because it's easier to talk about that than what's going on for myself'. There was an air of self-honesty; perhaps she was expressing a desire to behave differently and move away from her usual modus operandi, where she stayed safe by 'talking about my family' rather than tackle her own feelings. This sounded as if it left her feeling frustrated in herself.

Unlike Lisa, Sally did not find using the group to talk about herself problematic:

> …every time I go there, and I tell how I'm feeling, just to listen to myself and seeing my focus from my own words sort of makes me realise that 'Oh, you're doing well,' you have to acknowledge that you're doing well and that motivates me to continue like that. (Sally)

The group represented a space for Sally to think about her own progress. She sounded in touch with her inner world and was able to understand her thoughts given she could 'listen to myself'. In addition, she was able to self-coach ('oh you're doing well').

Like Sally, Jane attached much value into how the group created that space for her to talk about her emotions:

> I think the group is probably the most helpful thing I've done. So, the CBT gave me like a basis, but group is much more comfortable, it's much more varied and encouraging. It's more of encouraging space I feel than a, 'Okay. So, we're here to talk about you and your problems.' And you could talk about good things. And the fear is with if you're seeing someone or you're doing something on the NHS, if you talk about good things then they're going to go, 'Okay. Well, you're fine.' (Jane)

There was a strong sense of how Jane experienced the NHS treatment that she received in the form of Cognitive Behavioural Therapy (CBT) through her evaluation of how she felt about the group. Through her use of the words 'much' and 'more' she seemed to stress the high value that she attached to the ethos in contrast to the limitations of the NHS support she received. She appeared to have created a discourse that had a script that said – do not let the NHS know you are doing too well, or they will prematurely discharge you from the service. Once she realised that the group was not like this her fear dissipated and she was able to talk freely.

For two of the participants their self-reflection picked up on the notion of short-term action. Motivation seemed a key concern for Emma. The group spurred her into action initially for 'I came back quite motivated'. She sounded disappointed and realistic as 'obviously that then fizzles out' but also positive when she acknowledged that despite the short-term benefit of the group, it was able to 'give me motivation'.

Like Emma, the group spurred Daisy into action which she described as 'commitment to action':

> …. maybe it's not been phrased like that, but I think that's an overriding theme is we all have these great ideas, and we know what we should be doing but it's how you actually put that into practice. And I can recognise a lot of my own traits in other people, like keeping really busy to avoid thinking about things, taking on too much, that kind of stuff. (Daisy)

Daisy sounded impatient with herself and others (she used the word 'we') for she felt that 'these great ideas' are all well and good but were meaningless unless they were 'put into practice'. She wanted it to be different now that she had recognised the barriers to action ('I can recognise a lot of my own traits in other people'). Seeing the lack of action in others brought this recognition into her consciousness, and now she wanted to confront it head on by demonstrating a 'commitment to act', through this there was a strong sense of determination.

This 'commitment to action' involved 'smaller, more practical goal setting'. The thinking that emerged for Daisy out of the group seemed very much linked with her finding a way to make her recovery journey achievable. So rather than getting embroiled in other people's hopes regarding weight and eating challenges ('I would like to get into a healthy weight or whatever'), she found her own way of sustaining hope in her recovery, tinged with a sense of sarcasm aimed at herself ('like good luck with that'). She made a conscious decision to focus on tangible 'smaller short-term stuff' and not directly linked to the ED. Having struggled with episodes of recovery (which is described later in the recovery reflections section), perhaps she wanted to step outside of her head and be proactive by gaining a sense of success in something.

Helpful and unhelpful aspects of relationships with others

Three layers of relationship helped to define this subordinate theme: family; partners and group members.

Several participants spoke about the strain the ED had on their functioning as a couple. Emma's partner was a key part of her desire to 'feel normal' as she felt that he 'wants me to look normal again and I just find that really hard'. The desire for normality was not without its tensions for Emma and her partner and was positioned within a context of fear ('he finds it really scary'), most likely due to her wellbeing and extreme weight loss. She did accept he had grounds for his fears for 'I do look different'. There was a sense of sadness pervading their relationship as she described an absence of activities, they used to do such as being 'spontaneous about food again…cook me a nice meal… just go wherever… grab an ice cream without there being a worry'. One gained a realistic window of what life might be like for a partner of someone with an ED. It is as if their life had also been put on hold, suspended in time and they wanted to press play so that they could start 'moving on with our lives'. It was not just the social aspects of their life together; the price was also that their plans for marriage had been put on hold for 'we were on the brink of getting engaged'.

For Alison, her ED created tension between her and her husband which subsequently led to arguments:

> And there's been quite a few arguments and stuff… Just the fact that we don't go out for one and then he thinks it's really pathetic how we can't eat meals together, and how I'm going to make myself ill and how I'm going to kill myself,

> and how if I end up in hospital he's not going to come and visit me because I've caused it myself. Just all things like this. (Alison)

It appears Alison's husband sounded despondent at 'how we can't eat meals together' and was possibly scared for his wife's health and as a result was using scare tactics to jolt her into stopping her ED ('I'm going to kill myself, …. if I end up in hospital he's not going to come and visit me'). There was also a sense of self-blame ('I've caused it myself') and partner blame ('he thinks it's really pathetic').

Both sets of couples seemed to struggle with the role that the ED had in framing the identities of Emma and Alison. This struggle was also borne out in how the parents of some of the participants engaged with the ED, for example Julie's experience of her parents' concern related to how their understanding shifted. This shift was akin to how Emma and her husband's views developed over time. At the beginning Julie's parents 'thought in black and white terms a bit…she's unwell, but she's going to get 100% better if we get her treatment'. But with time Julie felt that their perspective had changed so that they were:

> viewing recovery as something that's progressing… that has progressed the most, the most in the last 3 years and is still getting better……there were moments where my dad… thought I was never going to get better. Mum's always been a bit more positive about it. (Julie)

One wondered if this was the same belief that they all held, and they had come to a shared understanding. Mum was the one who had hope ('more positive') whilst Dad was less hopeful as he 'thought I was never going to get better'.

Several of the participants described eloquently the impact that the group facilitators had on them. Starting with Jackson who seemed initially very much in awe of them:

> the girls at the group are really good, because they just have this little way of just saying something…..They have this lovely subtle skilful compassionate way of just nudging you along. (Jackson)

It sounded like a nurturing experience for Jackson which he liked. There was a strong sense of warmth radiating from his words as he described this unfamiliar experience

Like Jackson, both Alison and Emma were inspired by the group facilitators. For Alison, knowing that there was a real person who had gone through what she was going through made recovery seem achievable and worthwhile for: 'if she could be happy in a normal size then I do look at it and I just think 'you know what? I can be like that and not have it worry me'. Suddenly recovery seemed attainable. This sense of the facilitator being real was reiterated by Emma: 'I do really me like the woman who leads, and I find her quite inspiring. She's done it and she's not just a facilitator… she shares her genuine experiences.'

The facilitators were viewed as important role models for Emma, Alison and Jackson for they were 'not just a facilitator' (Emma). It was if having facilitators who had been

through recovery was a bonus as they could 'inspire' (Emma). Emma's surprise at hearing 'genuine experiences' was a real revelation; it had an air of incredulity that such people existed.

The 'shared sense of experience' (Jane) was felt strongly by all the participants. Jane described how it felt being in 'a room full of people who understand':

> I feel there's a lot of affirmation in the group. There's a lot of nodding. Not everyone will nod but lots of people go, 'Yeah.' And it's very validating. So that's something that I noticed, and I try and do when someone's talking, to try and... That again that's a problem that you have with everyone else is they can't understand and that's fine. So, it's really valuable to go to a room full of people who do understand and to see that they understand'. (Jane)

Jane seemed vigilant to the sign that she was being understood ('nodding'). This recognition perhaps gave her a sense that her experiences and feelings were real and not just unique to her. There was a sense of reciprocity amongst the participants demonstrated through the 'nodding'; an adopted code to tell one another that they were being understood.

5.5.3 Recovery as a dynamic experience and process

This superordinate theme had two core constituents: recovery and the ED voice as saboteur. It described what recovery means or meant to the different participants as they experience or have experienced it, whilst considering the impact of the ED voice as saboteur.

Recovery reflections

This subordinate theme captured the recollections that the participants had when they were in recovery such as: 'finding life was exciting' (Daisy); 'I could see that there were so many great opportunities ahead of me' (Julie); 'being safe' (Sally) and 'acknowledging the thoughts and behaviours' (Jane).

Several of the participants described their experiences of recovery; either as someone who had had a period of recovery before relapsing or as someone currently experiencing recovery.

> It was very good, it felt very exciting as well I think, as well. It felt kind of like coming back to life again. I felt like I had a lot of—It felt quite emotional at times. ....whereas, I think, normally with my eating disorder, I was quite dull. Quite flat. So, sometimes, that was a bit hard, but it was also very exciting, I would say, because I was able to do stuff like going on holiday with my friends and properly enjoying it—I graduated obviously. It was a time of a lot of big change as well, maybe. So, that sort of period of my life was quite exciting. You graduate, you get your first job, life is that kind of thing. (Daisy)

Contrasting with 'normally' feeling 'dull' when the ED was active, transitioning into life paralleled a transition into recovery, thus, for Daisy's episode of recovery it seemed to be like a form of rebirth- a resurrection- as she was 'coming back to life again' and able to fully embrace and live it. There was a powerful emotional effect on her for she 'felt quite emotional at times'. Amid the emotion was excitement and 'life was exciting'. She was able to re-engage with life. Daisy described that period of recovery as a 'solid state of recovery'. Prior to that she has described an earlier period as a 'short term recovery'.

Lisa's recollection echoed aspects of Daisy's description. She recognised that her thoughts 'weren't as predominant':

> …like I could eat without feeling guilty or having to exercise after I've eaten… it was nice being able to no, I'm gonna have this for breakfast, this for lunch, this for dinner and I don't have to worry about it. I just have to wait for the time and then it's, and then it comes. … It was nice because…. I could go out and like have dinner and stuff with friends. I could be more social. (Lisa)

Lisa went further by articulating her episode of recovery and some of the reasons why she was unable to sustain her recovery period post treatment:

> So, I managed to kind of sustain until I kind of like got to my target weight and then I kind of when I put on a bit more, I think with everything that was happening in my life at that time as well and dealing with the weight going above my kind of target even though it's still a healthy weight above it. (Lisa)

The 'target weight' almost represented an arbitrary boundary between ill health and wellness – a goal to attain towards recovery with scope to go beyond yet once that arbitrary boundary was exceeded in the context of 'everything that was happening in my life'. It served as a trigger for weight loss. It seemed too hard to commit at this time to the need to sustain weight. This was further illustrated when she later explained why she relapsed:

> It's just kind of come across, I think kind of triggered the anorexic thoughts in my head and then I just kind of spiralled. spiralled again… like because I started feeling uncomfortable in my body that that's when it kind of started to have an impact on me like my food and stuff because I think if I well, I think I feel comfortable in myself then it would be- it would be alright. (Lisa)

Lisa's use of 'kind of' within this context implies a gradual lapse back into her ED almost like a 'spiralling' chain effect starting with her 'anorexic thoughts' then 'feeling uncomfortable in my body' and then 'an impact on my… food'. There was also a sense that Lisa displayed distorted thinking in that she believed that if 'I feel comfortable in myself', she would feel 'comfortable' in her body. There was some awareness of what she did and why in that by doing this 'it would be alright'; however, possibly the memory of being in recovery and how she felt seemed insufficient to prevent her decline.

Julie's recovery journey involved 'three or four years of in and out of inpatient hospitals'. She felt that her 'last one in [retracted name of place]..was probably a turning point'. Another example of a catalyst here with recovery more broadly was the move to '[retracted name of place] to start fresh' which seemed to activate an internal drive within Julie to start her journey of recovery. She had a purpose to get better, indeed, she could see 'great opportunities ahead'. Through this a steely sense of determination seemed evident particularly as she was 'sick of being ill' and could see that the ED was the 'one thing that was holding me back'. Reflecting realistically on her recovery to date she stated:

> ...I wouldn't say that I'm 100 percent recovered in the sense that I still do have quite a lot of obsessive traits in terms of behaviours, I guess... I still do have quite a big preoccupation with food. It...it just...nowhere near the extent that it has been in the past and I'm far healthier physically than I've ever been. And... but I think my mindset is still taking a bit of time to really shift into a healthy one. I have to very aware of what I'm doing in the sense that it's very easy for me to fall back into restrictive habits if I really wanted and…I have to really...I have to really remind myself when I have those kinds of thoughts that no, no, no, like, kind of let them come in and go, essentially. (Julie)

Julie's stage of recovery seemed to be one of remission. There was an analytic air to her assessment of her recovery and a sense that she had adopted a vigilant coaching role in her recovery where thoughts were batted back and forth like two parts of her mind playing mind tennis. Player one was the ED voice and player two was the recovery coach. For example, in the first game the ED voice reminded her that she had 'a big preoccupation with food'. The recovery coach was able to respond by reminding her that it was 'nowhere near the extent that it has been in the past'. This game was repeated and ended with the ED coach saying 'no, no. no'.

Sally's recollection of recovery was couched in terms of safety for 'the main thing for me in the recovery was that to feel safe'. This seemed to set the context so 'I could actually work later to feel better and recover'. Jane too saw herself as being in recovery. Having confirmed that she was in recovery she articulated two aspects involved in her recovery. The first was about her 'thoughts' and a recognition that these food related thoughts were 'not normal':

> I think the first thing is acknowledging the thoughts and behaviours, and that took a long time. I am still doing that. I think I am still doing that. It's noticing, 'Oh, that's not...' That's not normal to like before you go to sleep you think about everything you've eaten that day. And that's not a huge thing…. (Jane)

It was almost as though the space recovery made to increasing her self-awareness enabled Jane to make a conscious decision to start addressing what seemed to be the most intrusive aspect of her ED namely her thoughts. Through the repetition of 'I am still doing that' she emphasised that she was working hard on addressing the food related thoughts.

Jane continued and reflected on times when she had an urge to purge:

> I don't purge anymore. Occasionally, I'll get a real urge to. And I think I have the sort of one-off occasions but it's really…. like intense rather than a sort of a more everyday occurrence. It's more as a reaction to like a really intense feeling or situation. But I don't do that anymore. And I try not to restrict. I still think about it a lot. (Jane)

It seemed she was aware of the triggers; namely 'intense feelings or situations'. Fighting the urges along with not restricting meant she no longer purged.

Jane's work continued further in relation to thoughts around the interplay between eating and weight. The very act of eating was bound up in a repetitive series of four 'what's' ('what have I eaten, what can I eat, what should I eat… what I ate yesterday') indicating it was a cognitive process rather than one based on physical needs. Jane was able to identify old behaviours that she had left behind which seemed predicated on a fear of the alternative. It was as though there was a ceasefire in the number warfare ('I don't record calories anywhere and I don't record my weight'). The fear was compounded by what she might see if she started the relationship with the numbers again ('I won't like the number and then that will send me into that place'). One can surmise 'that place' is the place where war ensues, where the ED reigns and she was back in a cycle of 'purging'. One was left with a sense of the relentlessness of the thought processes that go on for her and, consequently, how hard she was working at her recovery.

Having reflected on the process of recovery Jane echoed similar sentiments to Sally in terms of learning to live with the ED and that 'it's going to be an ongoing thing' (Sally). For the first time Jane positioned her ED away from food and eating towards the label of a 'mental illness'. One wonders if this was a helpful way for her to understand her cognitive battles. For her this categorisation was not meant 'in a really sort of depressing way'. She sounded pragmatic by accepting that it was 'how your brain works' and 'that it's part of you', like an innate part of her functioning. Perhaps she was formulating these ideas out aloud whilst still expressing a degree of uncertainty when using phrases such as 'so I don't know if you'll ever….'. What she did sound clear about was that 'recovery … is not being a significant part of life' but with time the thoughts would still be there, but not so 'prominent'.

ED voice as saboteur

This subordinate theme is about 'the different voices' (Jane) that inhabits the participants' heads, which was always there challenging their attempts at recovery. It was as though the participants humanised the ED voice saboteur. This voice was like a character in the story of their lives who popped up periodically. They had to engage in an active combat with this voice so that it did not derail their recovery journeys.

> '…we have these two voices. One that's say telling us to heal and be conscious of our food intake and healthy in general and this other voice that is manipulating and very harsh' (Maria)

Perhaps Maria's use of 'we' implied that she assumed that the 'two voices' was a common experience shared by all people with an ED. In Maria's mind 'these two voices' had benign and malign qualities acting as a saboteur. There appeared to be an ongoing combat between the two voices. When the benign voice was present it was 'telling us to heal' and when the malign voice was active then 'it is manipulating and very harsh'. Given the impact of the saboteur voice clearly, she must find a way of managing them.

Maria illustrated the reality of the malign self-deprecating voice: 'I'm a giant waste of space in life sometimes'. Though Maria sounded despairing, all encompassing ('giant') and full of self-loathing, her use of the word 'sometimes' suggested that this was not a fixed view of herself and might be a state she moved in and out of.

By contrast, Emma's ED voice was different to Maria's: 'I hear of people who've recovered and they're actually really unhappy because their coping mechanism for everything has just been destroyed'. Here Emma articulated her fear of what being in recovery might mean for her. She couched the net result as a destructive one of absolute loss 'everything has just been destroyed'. One wonders who these people were and if she was afraid that she too would be one of these people.

By comparison Emma continued further by qualifying her perspective with more evidence:

> Because I think it's very easy for people to say, oh, recovered living is great, but actually, I think at first, it's really, really hard. And I think it's often pretended to people trying to recover that it will all be grass is greener on the other side, but it's not always as simple I don't think. (Emma)

Here she was expressing more doubts as if she was gearing herself up for the initial pain of recovery ('I think at first, it's really really hard') and she wanted to ensure that people stopped sugar coating recovery ('I think it's often pretended to people trying to recover that it will all be grass is greener on the other side'). It's as if she might be saying to get real here, and that she was not going to be sold this lie. There appears to be a significant amount of ambivalence present in her assertions through the word 'pretended' with some undertones of anger with the contrast of 'easy for people to say' and the reality that it was 'really really hard'.

Moments of freedom

The overriding word that encapsulated this subordinate theme was freedom and was borne out in several of the participants' recollections.

Prior to a sense of freedom, there seemed to be an engagement with a process of recognition, for example, Emma stated:

> I guess I'd been blinkered to the fact that it was happening. Maybe it, maybe I did realize it, but I don't think I acknowledged it properly, the fact that it was happening. So, I was going on long runs and then I wasn't completely eating properly, but I didn't think, 'Oh, I'm trying actively to lose weight.' I just thought, 'This is just what's going on and it's what I'm enjoying.' So then, when I recognised that it wasn't actually healthy, and it was what I was doing because I was actually really, really stressed and not particularly happy, then it was, like, that was the recognition stage, I guess. And, yeah, and the time that that becomes the recovery stage is, I guess, quite a long, drawn out process. (Emma)

This stage described the start of her ED and the behaviours that ensued, that she may or may not have been conscious of at the time. The shift from recognition to recovery occurred when she 'recognised that it wasn't actually healthy.'

Having been through her 'recognition stage', Emma seemed to have a sense of clarity as to what her hopes and dreams for recovery were, which involved a sense of freedom:

> I'm trying to see it as, like, freedom from it, from the eating disorder, from…yeah. It would be being able to come here, to a café for instance, and be like, 'Okay. I want that, like, just because I want it.' It is about intuitive eating rather than managing everything. So, so yeah. Yeah. And it's also about wanting to go for a run because I feel like it, not because I feel obliged to or because I had pasta last night, so I have to. 'That's what I guess recovery would be and therefore, as a result of all that, being able to enjoy social situations and just feel normal and not have thoughts about food and exercise…all the time. (Emma)

Emma's hopes involved: eating from the perspective of eating socially ('come here to café') and eating 'intuitively' and exercising for the right reasons. Ultimately this 'freedom' was about normality and cessation of particular thoughts, a freeing up of her mind. Alison too expressed a similar eating hope as was previously expressed by Daisy and Lisa in the section on recovery reflections.

> Well, recovery for me would be to be able to just eat three meals a day and not able to worry about it and not worry about my weight…. And to be able to go out for meals with my family and not worry about it and stuff like that... And it just not be a task 'cause there's so many more important things in life. But in

> regard to how-I'm not... I'm nowhere near that at the moment so it looks like a long way off for me at the moment... It feels a long way off. (Alison)

But this dream 'feels a long way off' for Alison, out of her reach, and she repeated this fact perhaps to re-emphasise the distance she felt she must travel. She elaborated further by describing her hope for normality. 'Being a normal person' in her mind was about the absence of the negative thoughts that occurred in relation to eating and food; it was, however, an elusive concept – 'whatever that is'. She berated the situation that she found herself in ('It's just stupid'). It was if she was implying that it should be easy not 'freaking out when I see a plate of food' and could link with her realisation that there was much work to be done if she wanted to recover from her ED.

For Maria her dream was about developing a new relationship with food:

> maybe waking up and not feeling like I had to control exactly what I'm going to eat the whole day'. And then not having that urge to take laxatives or……just feel okay, just knowing that food is nourishing and it's good for me and I actually like something. Feels like a drug you know. I have to take it because otherwise I would die. (Maria)

It was as if Maria wanted to operate outside of her restrictive way of living. One had an image of her trying to break free from her self-imposed shackles to allow the food to stay inside her body and, thus, accept its nutritional worth ('food is nourishing and it's good for me'). To be able to do that she would have to see food as a form of essential medicine ('I have to take it because otherwise I would die').

Emma's exercise hope of 'wanting to go for a run because I feel like it' was echoed by Lisa who also expressed a wish to enjoy exercise rather than see it as a chore; something that she had to do:

> I'd like to think that I wouldn't need to exercise as much because I like- I like exercise. I like walking. I like you know-I'm an active person but the reasons I'm doing it now are not for the right reasons. (Lisa)

The verb 'like' was repeated seven times by Lisa. This evoked a sense of her expressing out loud what she wanted for herself when not operating within her self-imposed rules.

To summarise, this theme captured how the participants used the ED SHG as a place to reflect about their own recovery trajectories which ended with them expressing their hopes and dreams for that recovery.

5.6 Discussion

5.6.1 Findings

The purpose of this study was to investigate the lived experiences of nine people with an ED who attended a face-to-face ED SHG relating to recovery. These findings have revealed a space; namely the ED SHG, which has interwoven dichotomies which in places can be characterised by polarised thinking that is 'either-or' (Byrne, Cooper & Fairburn, 2004, p. 154). Such thinking has been found to impact on ED recovery (Fairburn et al., 2003). The person with the ED may have thoughts such as foods that are either good or bad (Dove et al., 2009) and it can be linked to the person's sense of self, seeing themselves as either a good or bad person. Furthermore, clinicians have been exploring ways of understanding such thinking and how to assess it. This is evolving as evidenced in research carried out by Byrne et al. (2004) looking at obesity and weight gain and the psychological factors involved in that. This research has since led to a revised self-report instrument 'Dichotomous Thinking in Eating Disorders Scale-11 (DTEDS-11)' which is 'used to assess the presence of a rigid, 'black-and-white' cognitive thinking style,' involving two sub scales dichotomous thinking and dichotomous thinking related to ED (Byrne et al., 2008 p. 154). Additionally, Egan et al. (2007) found that there was a correlation between 'negative perfectionism' (p. 1813) and dichotomous thinking.

Within the framework of these dichotomies the discussion started with individual perspectives exploring internal and external struggles, and challenges faced by the participants such as transitions and barriers to entry to the ED SHG. This led onto the relational aspects which emerged from the findings such as the role of the facilitators and others supported by a discussion about the value of someone with a lived experience supporting people with EDs. Concluding the discussion there is an analysis of the trajectory responsible for the attendees leading in and out of recovery, combined with the 'ED voice as saboteur', which the findings suggested played a significant role in relapses.

Transitions

The findings in the current study identified transition as a contributory factor leading to the development, maintenance, or exacerbation of the ED of several of the participants such as moving from school into employment and leaving university. This is concurrent with existing research such as Brown et al. (2017) who posit, based on their systematic and meta-analysis that Intolerance of Uncertainty (which has its roots in anxiety) may play a role in this. For example, they found that AN in women was a means of managing anxiety uncertainty and in new situations the AN worsened. Research into transitions have identified issues related to an individual's sense of self and how an ED offers a way to deal with the difficult, hard to manage feelings that may arise, quelling them (Barth, 2021). This is substantiated by research carried out by Berge et al. (2012) who established that 'home and job transitions' preceded the onset of some of their participants' ED; supporting a considerable body of

earlier literature which identified a diverse range of factors leading to or maintaining an ED (Fairburn et al., 2003; Polivy & Herman, 2002; Treasure et al., 2003; Troop et al., 1998; Troop & Treasure, 1997).

Barriers to Entry to ED SHG

The current study's findings showed that desperation and the need to seek out support ignited a call for action (Eaton, 2020) by most of the participants. This desire to seek support led to their search for an ED SHG. Having found a suitable group for themselves, many of the participants delayed entry to the group. There were internal battles in their heads in the form of ambivalence. This manifested itself in the form of a dichotomy of self-questioning, bargaining with self, and fear. These facets of the dichotomy meant that the participants engaged in two forms of self-talk: one talking themselves out of attending (e.g.' diminishing the intensity of the illness) and the other talking themselves into attending by agreeing to attend but with a get out clause of or by bringing someone else along with them.

The ambivalence of the current study's findings echoes aspects of existing research about the ambivalent feelings of people engaged with or seeking treatment for ED. These include studies where some people with AN feel coerced into treatment (Guarda et al., 2007), another which looked at a longer term ambivalence of a young woman with an ED (Bell, 2013), an internet-based study examining the 'stages of change' in the recovery process through the online transcripts (Keski-Rahkonen & Tozzi, 2005), and an IPA study exploring what the ED meant to each participant (Fox, Larkin & Leung, 2011). What the current study's findings offer in addition is how ambivalence manifests itself when a person with an ED is seeking out informal support such as an ED SHG to support their recovery. The limited research that exists about ED SHGs does not include the pre-entry lived experience feelings and hesitation of joining a group (such as McNamara & Parsons, 2016; Stommel & Meijman, 2011; Wasson & Jackson, 2004).

Relational Recovery: being amongst others

Having navigated themselves inside the face-to-face ED SHG the next part of their recovery journey commenced. The current study's findings highlight being amongst others can be helpful in terms of reconnecting (Linville et al., 2012; Timulak et al., 2013), learning to let others in, being positively involved with others (Federici & Kaplan, 2008), recognising that you are not the only one when going through the recovery journey which is Yalom's idea of universality (Yalom & Leszcz, 2005). Furthermore, the current study's findings extend this research as it offers fuller insights into the participants' self-reflections about the ED SHG, in terms of how they use the group, how they experience being part of an ED SHG and what they have learnt about recovery from others in the group. This concurs with well documented research about how self-development and reflection occur in support groups (Koski, 2014; Laitinen et al., 2006; Yalom & Leszcz, 2005) and how participants' perspective can change as a result of engaging in a structured ED support group such as OA (Ronel & Libman, 2003).

Furthermore, the group offered a therapeutic space for members to reflect about themselves and develop their sense of self. Drawing on the field of self-psychology this is described by Kohut, as there being three needs that must be met for the self to be formed in its entirety: mirroring, idealisation and needing to be like others (Goldberg, 1998; Kahn, 2001; Kohut, 2013). Positioning this perspective within the context of the ED SHG the claim is not that the group formed the attendees' sense of self in its entirety, but that this developing sense of self was evident at times in the findings, such as when some of the participants reflected on their time in the group by using others as a type of mirror (fellow group members) or idealising the facilitator or wishing they could be like others.

Informal members

The current study identified members who were core constituents of the recovery journey. For example, the facilitator (formal member), and partners and spouses (informal members). Though partners or spouses were not formal members of the group, their presence was there implicitly by association. Several participants in the current study spoke about the guilt they felt about the impact they had on family functioning and relationships which existing research has touched on in various guises (e.g., see Pettersen et al. 2013). A parallel process can be drawn from exploring research about carers and their experiences of living with a partner or family member with an ED and the ensuing frustrations (Haigh & Treasure 2003; Highet et al. 2005; Whitney et al. 2007). Similar frustrations are borne out in the couple dyad as evidenced in the research of Linville et al. (2016). However, the current study adds an extra dimension to this existing research by recounting the challenges the partners faced through the lens of the person with the ED. Moreover, the current study also offers a broader picture of different relationships not solely the direct ones that happen inside the ED SHG.

In the current study the partners and relatives were instrumental in some cases in helping the participants find the group and start attending the group, and in some cases the participants were very keen to share their positive experiences with their loved ones. This adds to the research of Granek (2007, p. 376) who found that recovery was about 'relationships with others', through friends and boyfriends who helped to build up the women's self-esteem in their study, and how this relationship helped the women start to value themselves. Similarly, In the current study the participants were able to start their journey of recovery which, in some cases positively impacted on their sense of self.

The facilitator and the value of lived experience

It was evident in the current study that engaging with a recovered person (the facilitator), feeling supported and being inspired impacted positively on several participants. This concurs with research that in a peer group setting this is very beneficial and helpful to attendees of support groups. Research about the value that members of an ED SHG place on a facilitator's lived experience is lacking. This current study has started to address this research gap. The closest research which can be used as a mirror is research which deliberates whether a clinician with a history of an ED is beneficial for sufferers or harmful for the sufferer and clinician; there is no agreed consensus (Costin, 2002; Johnston et al., 2005; Rance et al., 2010).

Moreover, research by Johnston et al. (2005) and Audet & Everall (2003) both found that clients had concerns about their therapist when the therapist disclosed their ED history with 'overinvolvement' and 'enmeshment' emerging as two concerns. Hearing the first-hand real time account of recovery by the facilitator leading the group impacted positively on several participants in the current study. This aligns with research which found that therapist disclosure enhances the therapeutic alliance (Audet & Everall 2003; Johnston et al. 2005), and acts as a way of 'humanizing the therapist' (Levitt et al. 2016, p. 20). Therefore, being a first-hand witness of the recovery journey of the facilitators and peers instilled a sense of hope for themselves (Shepherd, G.; Boardman, J. & Slade, M, 2008).

What is recovery?

The last part of the recovery narrative is a debate about recovery. Here the last dichotomy was very real where the desire for recovery was impacted by the *ED voice as saboteur.* The findings of the current study provide an intimate window (through recovery snapshots) into the battle of staying in recovery and adds to existing research about recovery but also adds extra dimensions to the wider debate about recovery.

The first part of the debate is about how recovery is defined and what recovery involves; there was no consensus from the participants in the current study. Similarly, this lack of consensus is echoed in earlier research (Noordenbos, 2011; Rance et al., 2010). Moreover, what the current study showed is that recovery is a subjective experience for each participant which entailed a broad range of perspectives as to what recovery meant to the participants. For example, recovery involved having to give up something that they were

not quite ready to do, which touches on the earlier discussion about ambivalence. Recovery is a state of remission and is about feeling safe to enter recovery. Furthermore, when the participants in the current study did experience recovery, the overriding element was experiencing a fuller life for them such as being able to engage with people more and recognising that life was exciting,

The current study showed that some participants recognised that they were missing out on life, and this was an impetus to engage in recovery or that having experienced recovery they realised this. It is this aspect which is echoed in a study carried out by Pettersen et al. (2013) into the recovery process (the later phases). They identified a category of 'realising negative consequences', describing missing out on life as grief. Noordenbos (2011, p. 444) reviewed existing research about the views of people who formerly had an ED in relation to recovery, developing a list of eleven criteria for recovery; several of the items on that list concur in some form with what the participants in the current study expressed such as 'attitude towards food', 'social relations', 'psychological recovery' and 'emotion regulation'.

In addition, recovery for the participants in the current study was a relational experience inside the ED SHG. Being able to relate to others in the group whether it be through gaining positive affirmation for what was shared, seeing how others used the group and the feeling of being listened to others were important. These findings in the current study corroborate aspects of research carried out by Pettersen & Rosenvinge (2002) who found that 'nonprofessional care', which included meeting other 'sufferers' and engaging in SHGs was important to recovery and had positive effects. The current study has been able to add detail to what the effects of ED SHGs have on recovery in greater detail, thus adding to existing research.

Recovered versus in recovery

In this current study none of the participants described being fully in recovery but the participants further along in recovery talked about having residual type behaviours and thoughts that would be an ongoing challenge; learning to live with the ED, thus implying that recovery was an ongoing process and not fixed. These findings support the second part of the debate about whether a person with an ED is only judged as having recovered when they no longer demonstrate the relevant diagnostic criteria (American Psychiatric Association, 2022; Noordenbos, 2011). This view implies that recovery is a fixed entity, you are, or you are not recovered. Moreover, such a black and white view of recovery may negatively impact a person's sense of self as it implies there is no middle ground (Rance et al., 2010).

A different perspective, which the participants in the current study also described, is to view recovery as something which is ongoing, whereby the person with the ED is described as in recovery with a recognition that some people with an ED will move in and out of recovery and retain some ED related behaviours and thoughts (Johnston et al., 2005).

Vandereycken (2012) offers a slightly different contribution to the debate about recovered or in recovery, the idea of spontaneous recovery from an ED. The implication is that there is a belief amongst some professionals that the reporting of ED recovery by an individual with an ED is not valid unless authenticated by a professional using a set of pre-determined criteria.

Recovery and the ED Voice

Several participants in the current study experienced relapse when they had periods of moving in and out of recovery, and as mentioned previously each had their own subjective experience of this process. These experiences add to the large body of literature about relapse and its complexities (Grilo et al., 2012; Keel et al., 2005; Kordy et al., 2002).

Furthermore, the current study's findings show the dichotomy of wanting to get better and how the ED voice as saboteur impedes this, for no matter what the impact was on their daily functioning, family life, and relationships the voice remained powerful for the participants. The ED voice is well documented in literature concerning the anorectic voice which is often presented as one that is critical and humanised (Pugh, 2016; Pugh & Waller, 2017). The battles with the voices in the current study mirror aspects of research carried out by Musolino, Warin, Wade & Gilchrist (2016) who found that some of the participants in their research struggled with 'cultural understandings of healthy eating' (p. 6).

However, the notion of the ED voice with respect to AN has been critiqued as possibly being unhelpful and sustaining the AN (Pugh 2016). The current study added a new contribution to research regarding the ED voice at two levels. The findings showed that the voice was present at the start of the journey when joining the ED SHG and the ED voice had a positive impact on the participants responding positively to a live version of a recovered person inside the ED SHG and to other members inside the group.

5.7 Implications

The findings of the current study have several implications. Four such implications will be examined in detail: recovery; the role of the facilitator; and the place of ED SHGs within support packages.

Recovery

The first implication is about recovery. The findings of the current study highlighted the importance that the participants gave to the non-criterion-based characteristics of recovery, thus potentially reinforcing the need to have such aspects at the core of any uniform criteria that is developed to 'measure' recovery. The meta-analysis carried out by de Vos et al. (2017, p. 10) supports the findings from the current study in that they found issues related to self-development and a desire to address feelings and behaviours associated with the ED. Overall they recommend that 'psychological dimensions in definitions of ED recovery' should feature as criteria when considering ED recovery.

Furthermore, there are instruments that do exist which include the 'Eating Disorders Recovery Questionnaire' (EDRQ) which Bachner-Melman et al. (2021) assert as a reliable measure of assessing recovery from an ED as it incorporates a breadth of criteria including going beyond 'the absence of ED symptoms'. Saunders et al. (2019, p. 494) examined a different instrument, the Body, Eating, and Exercise Comparison Orientation Measure-Revised (BEECOM). They adapted it by altering its structure by removing questions to create a shortened version BEECOM-R, with a view to encompass the 'nature of social comparisons tendencies' which they purport to be an important aspect of the recovery process.

What seems apparent from the findings of de Vos et al (2017) and the two examples of instruments, is that there has been a real desire to move beyond the diagnostic model of recovery towards an instrument that interrogates other factors linked with recovery. This has ramifications for the type of therapy that is offered to a person with an ED. Juarascio et al. (2013) carried out an empirical study exploring the use of Acceptance and Commitment Therapy (ACT) to treat EDs. It is important to note that what ACT does not do is engage in the polarised thinking, described earlier in section 5.6.1, but instead allows for any thought to be permissible as a way of helping lead to a fuller life and to support an individual being able to think more flexibly (Hayes et al., 2006). Building on that notion, Juarascio et al. (2013) purport that ACT offers a way of helping people with EDs learn how to manage the difficult internalised feelings that they experience by learning to create a 'psychological distance' (p. 461) from them and thus enable them to function in their everyday lives. The learning to live alongside the ED was something that participants in the current study expressed which ultimately for some would help them gain ownership of their life (Shepherd et al., 2008). Moreover, this would lead to a situation where: 'patients' values are integrated with the best research evidence and clinical expertise, clinicians and patients will form a therapeutic alliance that optimises clinical outcomes and quality of life' (de la Rie et al., 2006, p. 667).

The role of the facilitator

The second implication relates to the people who run the group; the facilitator who will need the requisite skills and knowledge to ensure the smooth running of the group (Waller et al., 2020). Arguably, some inexperienced facilitators may require training so they can, for example, facilitate group dynamics and the effective use of time (Waller et al., 2020). At present technically anyone can set up an ED SHG without any formal training. Many MHGs which include ED SHGs are established by people in a voluntary capacity, with lived experience who may or may not use self-disclosure. This self-disclosure can be a way of building up a therapeutic alliance and trust. However, for self-disclosure to be effective and safe there needs to be a clear framework which includes training, guidance and boundaries (de Vos et al., 2017; Wasil et al., 2019).

The author of the current study benefitted from mentoring which included co facilitation alongside an experienced group therapist, in addition to training through the national charity BEAT during the late 1990s and early 2000s. The training was part of the

then Eating Disorders Association Self Help Network (Blades, 2004). This training created opportunities to network with other ED SHG facilitators. It no longer occurs due to the cessation of government funding. Thus, the consequences are that groups who may have previously relied on the charity's support, are left to work independently, resulting in limitations in building professional networks with clinicians. However, what the charity does helpfully offer is a gratis HelpFinder[2] database for groups and any ED provision to advertise their services. Other ED charities offer something similar such as Talk ED formerly known as Anorexia and Bulimia Care[3] who charge to advertise on their help Directory. Arguably, what is needed is government funding for ED charities or ED clinical settings to support the training of facilitators and the building up of a network which is kitemarked for quality. Knowledge on the part of both facilitator and professional would require mutual sharing about one another's services.

This can perhaps be achieved by fostering a partnership between ED SHGs, ED clinicians and ED settings, where there is a mutual sharing of information about one another's services. Thus, accurate information could be shared between both and any misconceptions that do exist (Seebohm et al., 2013) might be lessened and the professionals fear of harm could be mitigated.

The Place for ED SHG within support packages

Many MHGs including ED SHGs rely entirely on fees paid by its members to cover the operational costs associated with running the group. This makes them vulnerable especially if the attendee numbers fluctuate as funding relies on members attending. This is the case for the group facilitated by the author of the current study. Seebohm et al. (2013) found that some SHGs ran out of funding and group leaders used their own funds to keep their group running. The same type of vulnerability can be applied to the group facilitator with their lived experience. If the group facilitator becomes unwell then the group could be at risk of becoming non-operational. These two points are addressed later in this thesis. For example, chapter eight has carried out a study of the experiences of ED SHGs facilitators and chapter nine contains a SROI of an operational ED SHG and its economic and social value.

Finally, unstructured ED SHGs need higher visibility and recognition by organisations (this is explored further in chapter seven of this thesis). The government National Institute for Health and Care Excellence (NICE) 'Care planning and discharge' (NICE, 2020) make no reference to peer support such as ED SHGs for patients leaving treatment. Similarly, several years prior to that, 'The Joint Commissioning Panel for Mental Health Guidance for commissioners of ED services' (jcpmh) omitted ED SHGs when describing services for adults

[2] Database managed by the charity BEAT which allows ED SHGs and other professional to advertise.

with reference to the role of the voluntary sector in adult ED care (Joint Commissioning Panel for Mental Health, 2013). Their visibility is timely considering the rise in numbers of individuals with EDs. The recovery experiences of the participants in the current study attest to the fact that individuals with an ED often learn to live alongside their ED. Therefore, support needs to be in place to facilitate this and reduce the likelihood of relapse, as this requires more intense and costly care at a time when resources are limited.

5.8 Suggestions for future research

Future research examining the role of facilitators further would be beneficial to better understand the individuals who volunteer in this role and what support they receive.

A larger scale study of individuals with an ED who have attended an ED SHG could act as a way of building on the findings of the current study is another direction for future research. The use of a wellbeing instrument may help to better understand the impact on aspects of their QoL and whether attendance at an ED SHG improves wellbeing.

5.9 Strengths and Limitations

Although this study was informative there are some limitations that merit discussion. Firstly, the number of participants involved in this study was deliberately small which is in keeping with the chosen methodology of IPA, as it allowed for the richness of each of the participants' lived experiences to be heard; IPA does not aim for generalisability (Smith et al., 2009), but it does aim for case-to-case generalisation (Treharne & Riggs, 2015)

Secondly, the influence of the researcher and in the case of this current study is two-fold. IPA by its very nature means that the researcher will influence the data through the process of interpretation (Smith et al., 2009). Additionally, some of the participants were recruited from the group that the author of this study facilitated. Furthermore, the duality of occupying a position of researcher and facilitator means that there was a possibility of the participants from the author's group wanting to please her in their responses to their experience of the group. Another explanation might be due to a desire by the participants to wanting to share their positive experiences for the good of others and themselves, what McCann, Campbell & Entwistle (2010, p. 1) term as 'conditional altruism'. The opportunity afforded the participants to tell the author on a one-to-one basis how they were experiencing the group and what they had learnt. The findings demonstrated commonalities across the experiences of all participants across the three groups, for example in terms of the fears of attending, how it felt attending the group and their own self-discoveries. provides more details about the quality assurance processes that took place to mitigate for the potential researcher bias.

Thirdly, this current study only captured experiences of self-selected participants who had had a positive experience of attending an ED SHG. This is replicated in other studies of ED SHGs such as McNamara & Parsons (2016) and Wasson & Jackson (2004). Despite this there have been studies that have reported on some of the surmountable challenges that attendees of support groups have encountered such as comparing their

bodies with others and members monopolising the time such as Waller et al. (2020). Fourthly one male was recruited out of the nine participants which represents 11% of the participant group. The charity BEAT (n.d.) put the estimated figure at 25% of UK people with an ED being male. This estimate was not accompanied by a source. In a review Sweeting et al. (2015) found that statistics for prevalence of EDs in men ranged between 10% and 25% of the estimated ED population, depending on the publication. There is a consensus however that more women than men are diagnosed with an ED.

The key strength of this current study is that the findings presented a continuum for how a person with an ED engages with a face-to-face ED SHG. This continuum started with the subjective experience of the onset of their ED, their search for a group, their attendance which was not always immediate, through to their own personal recovery experiences. Such a continuum appears absent from existing research to the author's knowledge.

5.10 Conclusion

To the author's knowledge this current study is the only IPA study which has captured in detail the lived experiences of people with an ED who have attended a face-to-face ED SHG in relation to recovery. What has been apparent is that there is a scarcity of research into how ED SHGs support recovery, how people with an ED find them and the various structures of ED SHGs that exist. The attendees' recovery was across a series of phases: the beginning of recovery (contemplation); post relapse and post treatment. The *ED voice as saboteur*, a term developed by the author of this current study played a pivotal role in explaining relapses and the ebb and flow of recovery. The key thread running through this study has been the relational aspects of being in the group and experiencing recovery.

The group was not about keeping people with the ED in a 'need for constant vigilance' as purported by Koski (2014, p. 85) and others who fear that they may cause harm. What the current study evidenced is that an ED SHG has a potentially vital role in maintaining successful outcomes.

Key findings

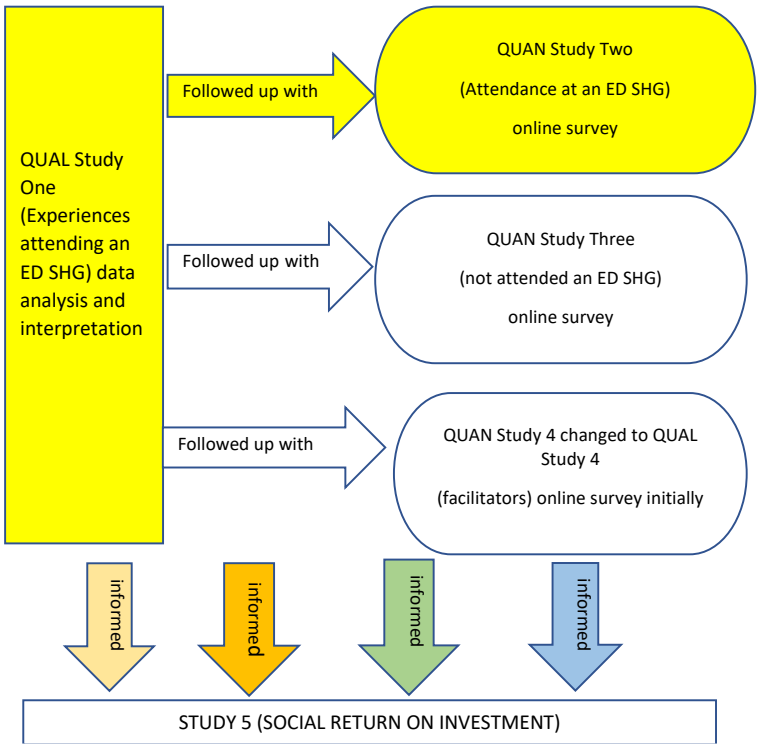
- The reinforcement of the social value of being amongst others through attending the group
- The group acting as a catalyst for attendees to seek support
- The support from friends and family to attend the group
- The group offering a space for self-exploration and self-reflection
- Participants' value of facilitators' lived experience of recovery

Chapter 6: ED SHGs and what matters in recovery (Study 2)

6.1 Study Overview

The previous study (chapter five) involved the gathering of qualitative data using IPA about the lived experience of nine people. Direct words, phrases, and experiences of those participants formed two of the key constructs; experiences of being a member in an ED SHG and their relationship with recovery, of this quantitative online prevalence survey. This was the first explicit point of integration as per the exploratory sequential design which was the chosen methodological approach (see Figure 4.1 with the highlighted boxes) below.

Figure 4.1: Diagram of The Research Exploratory Sequential Design



As alluded to in chapter four, an exploratory sequential design involves the acquisition of data from a qualitative study to inform data in future quantitative studies (Onwuegbuzie & Leech, 2005). This point of integration acted as a way of examining whether the qualitative findings of the previous study (chapter five) were replicated across a larger population, or if the findings were unique to that group of participants.

Furthermore, the chapter five study found that self-questioning was a barrier for some joining the group straightaway. Such ambivalence has been noted in research related to how patients engage with treatment (see Guarda et al., 2007; Bell, 2013; and (Keski-Rahkonen & Tozzi, 2005). The narrative review (chapter three) provided limited insights into the hesitation of some individuals when joining a group (see McNamara & Parsons, 2016; Stommel & Meijman, 2011; Wasson & Jackson, 2004). What appears absent from literature

is detailed data of the experiences of people who initially delayed their entry to an ED SHG, their reasons why, and how long that delay was.

Moreover, the chapter five study confirmed the social value of being in a group with others who have the same condition in supporting their recovery journey (Federici & Kaplan, 2008); a form of relational recovery. It found that the group created a space for self-reflection and self-development which has been noted in other support groups (e.g. Linville et al., 2012 and Koski, 2014). More research with larger populations into the benefits of ED SHGs in supporting recovery are needed, to add to the limited knowledge base.

Notably, the experience of recovery in the previous study found that there was an ebb and flow to recovery and that none of the participants described themselves as fully recovered. Some attested to the belief that recovery was about learning to live with their ED which aligns with existing research such as Johnston et al. (2005). This perspective is under researched within the context of attendees of ED SHGs and would benefit from a deeper exploration of this with a more diverse range of individuals.

The aim of this current study focussed on:

- participants with an ED who had experience of attending an ED SHG;
- their views and experiences of recovery, and
- their wellbeing.

6.2 Methodology

This section is about the design of the study and includes information about how the study was created.

6.2.1 Research design

An online prevalence survey was created to collect quantitative data which entailed participants answering 15 questions (Table 6.1) (Appendix 6.1: full survey questions), with opportunities for participants to add qualitative comments. Qualtrics Software was used to create the survey and produced the initial data set (Qualtrics, Provo, UT). The data were analysed using IBM SPSS Statistics (version 27).

Ethics

Before any data were collected, full ethical approval was sought and approved by the University of Hertfordshire's Health and Human Sciences Ethics Committee with the protocol number of LMS/PGR/UH/04306 (see chapter four).

Table 6.1: Overview of survey questions

Question Focus/Type	Rationale for inclusion
Demographic data including ED diagnosis and type of support (formal and informal) accessed	-To capture background of participants to see if the respondents were representative across the population in terms of gender, ethnicity
Journey to ED SHG including length of delay to gain entry to the SHG (quantitative and qualitative)	-To understand how they found the group and their reasons for seeking one. -To find out what they did when they got the information and if they delayed going why and for how long
Experience inside the SHG -Likert scale (agree, neutral, disagree). List of 13 choices were developed from study one participants' experiences) (quantitative)	-To quantify the participants' experience of: - how it felt attending the group - the challenges of attending - impact of others in the group - positive personal self-development - impact on engaging with professionals
Experience of attending SHG using a sliding scale rating (quantitative)	- to gather quantitative data about the participants' overall experience of attending an ED SHG
Support recovery. Choice from a prepopulated list (quantitative)	-to find out about the types of informal or formal support participants have or are in receipt of
Beliefs about recovery using Likert scale (agree, neutral, disagree). 24 statements recovery (choices were developed from participants' experiences from study 1) (quantitative)	- To gather quantitative data about when they were/are in recovery - challenges of recovery - how it feels/felt being in recovery - feelings about own recovery progress - engagement with recovery - ED behaviours
Wellbeing using WEMWBS (14-item version)	-to gather data about the wellbeing of participants at the time they completed the survey

Recruitment

Recruitment of participants took place over a period of 20 months. The study was advertised in a variety of places including: social media such as Facebook, Twitter, and LinkedIn; ED Networks including the national ED charity BEAT and British Eating Disorders Society; and contact was made with several NHS trust ED services two of whom agreed to circulate the advert amongst their ED patients. All potential participants needed to be over the age of 18, have or have had an ED and have attended or were attending some form of ED SHG.

6.3 Results

Participants

Participants who had answered at least one question over and above the characteristic questions were included as part of the analysis. The median number of participants was 76 and the range was between 76 and 106 (Table 6.2). It was more important to capture as many responses as possible for each question as the analysis for the survey was split into three areas (ED SHG, recovery, and wellbeing) and each area was not reliant on the responses from previous areas.

Table 6.2: Response rate by question type

Focus	No: of participants who answered question	No: of participants who answered question (%)
Demographic	106	100
Finding ED SHG and reasons why	106	100
Actions on finding ED SHG	97	92
Attendance at ED SHG	89	84
Experience of Recovery and support for recovery	77	73
Wellbeing	76	72

Demographics

The gender distribution was 94% female (n=99) and 5% male (n=5) (Table 6.3).

Table 6.3: Gender Characteristics

Gender	Frequency	Percent
Male	5	4.7%
Female	99	93.4%
I would prefer to describe my gender myself	2	1.9%
Total	106	100.0

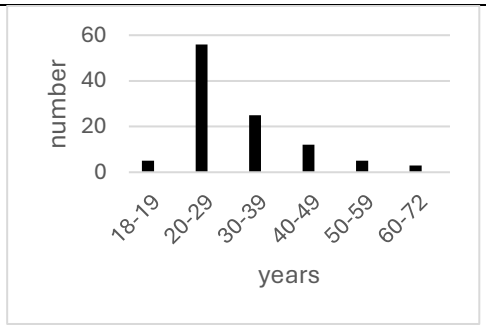
The survey was completed by a broad range of ages (n= 106); the most popular ages being in the 20s age bracket. The data (Table 6.4) revealed a skewness of 1.7 and kurtosis of 3.2. Due to the large sd (10.7) care was taken when drawing on the data in Table 6.4, as it indicated that the mean (31) was likely to be an error, so the median which was 27 was likely to be the better measure of central tendency due to the very broad range (18 to 72 years). The data were not normally distributed due to the kurtosis value (3.2) (Kallner, 2017).

Table 6.4: Age Statistics

N	106
Mean	31 (sd error 1)
Median	27
Mode	25
Std. Deviation	10.7
Skewness	1.7
Kurtosis	3.2
Minimum	18
Maximum	72

When grouping the data into age bands (see Figure 6.1) it was apparent that 53% of the participants were in the 20s age bracket, 19% were over 40 years old and 8% were over 50 years old (Appendix 6.2: detailed breakdown of age).

Figure 6.1: Grouped representation of ages



age	no:	%
18-19	5	5
20-29	56	53
30-39	25	24
40-49	12	11
50-59	5	5
60-72	3	3

Based on The Office for National Statistics (ONS) ethnicity descriptors 87% of the participants identified themselves as from a white background (n= 92). The subset who indicated that they were 'other' white included several self-described descriptions (Figure 6.2). 13 participants identified themselves as from a non-white or mixed ethnic background (12%). Appendix 6.3: detailed ethnic breakdown.

Figure 6.2: Ethnicity self-description

Spanish	English German	White American
White Italian	German	French British North American
Italian	Czech	New Zealander
French	German European	Mixed European/North African
Polish	Caucasian	Half Spanish
Eurasian	Scandinavian	Half mix of many things
	Mediterranean	Central European

Some of the questions included a free text box for respondents to add any qualitative comments. When this applied some of those comments have been included to further support the analysis of the quantitative data.

6.3.1 Experiences of seeking and attending an ED SHG

This section addresses the participants' experiences of how they found the ED SHG they attended; why they looked for one; what happened when they found it; how they experienced their first sessions; and what it felt like being in the ED SHG.

How participants found out about the ED SHG

Table 6.5 shows that the internet proved to be the most important source of information. The internet search (n=45) accounted for 48% of the count and the professional category (n=23) accounted for 33% when excluding the 'the other' category. These two sources were the most important ways of finding the ED SHG or being provided with information about the ED SHG. The 'other' category represents a large proportion of the cumulative data (n=23). Some participants added extra information like: 'I called BEAT' and 'Counsellors UK' or 'I was told by someone at work'.

Table 6.5: How participants found the ED SHG

Answer	%	% (excluding 'other' category)	Original Count
Internet search	39%	48%	45
Someone showed me	8%	10%	9
I was told by a professional such as a nurse, doctor, therapist etc.	27%	33%	31
I was told by friends or family or partner	4%	5%	5
I was told by someone at work	3%	3%	3
Sub Total (excluding 'other')			93
Other	20%		23
Grand Total			116

Why participants sought the ED SHG

Table 6.6 shows the top three reasons that participants chose for seeking an ED SHG from a prepopulated list.

Table 6.6: Motivations for seeking an ED SHG

Answer	%	Count
My treatment ended	10%	21
There was a long wait for treatment	8%	17
I was put on a waiting list	8%	17
I was waiting for treatment after an assessment	4%	9
I was getting panicky about my ED	17%	37
Things were spiralling out of control	20%	46
I was using my food more to deal with my emotions	14%	32
I was told that I was not ill enough by a specialist ED service to receive help	5%	10
Other	14%	32
Total	**100%**	**221**

These reasons were due to: 'things spiralling out of control' (n= 46); 'getting panicky about ED' (n= 37); and 'using food more to deal with emotions' (n= 32). These three reasons could be described as emotive reasons, and when grouped together (n= 105), they represent 56% of the total responses when excluding the category 'other' in this calculation. Moreover, if matters relating to delays in treatment are considered as one area i.e., waiting for treatment after an assessment (n=9); not being ill enough to receive treatment (n=10); long wait for treatment (n= 17); and being put on a waiting list (n= 17) the aggregated total is 28% (the category 'other' has been excluded in this calculation).

The qualitative data that emerged from the 'other' category qualified some of the quantitative data; there were over 30 qualitative responses. These ranged from a short sentence or phrase to longer paragraphs elaborating further on why an ED SHG was sought. It became apparent that some of the groups were part of a treatment unit, but the general sense of the comments would imply that this was in the minority. The responses have been organised under the following broad theme headings (Table 6.7, overleaf), exemplified by some of the participants' words. Appendix 6.4: Reasons for seeking group (extra qualitative comments)

Table 6.7: Reasons for looking for the group (themed qualitative comments)

Emergent Theme	N	%	Exemplar comment(s)
Signposting to support	5	16%	-My therapist recommended I attend a support group to work alongside my therapy sessions.
Lack of professional support	7	22%	-I was told that my other mental health problems meant I wasn't eligible for ED treatment, and that my weight at the time was too low for community treatment but too high for inpatient treatment. (I have recently started having treatment, but it has taken me more than 3 years to be able to access it).
Self-realisation	5	16%	-Realised I wasn't fully recovered -I couldn't manage my eating myself and I hated putting on weight -Sick of having an eating disorder
A desire to share with others	5	16%	-I just wanted to share with people with similar experience. -I was in treatment but wanted to speak to other people in the same situation.'
Choosing the group	5	16%	-I found groups helpful in day treatment and wanted to continue -There is very little support for overeaters that is not a specific weight loss group. I thought it might be helpful
Miscellaneous	5	16%	-Covid Restrictions -There were no services in NHS at the time.

Actions on finding the group

Participants (n=97) were asked to choose the description that best matched their experience of what they did when they found out about the group (Table 6.8) and the length of delay (Figure 6.3).

Table 6.8: Actions on finding out about the ED SHG

Answer	%	Count
I attended the next scheduled group straightaway when I got the details	26%	45
I delayed my entry to the group because I was worried about my body size	11%	19
I delayed my entry to the group because I was feeling anxious	18%	32
I delayed my entry to the group because I was worried about what would happen	13%	22
I delayed my entry to the group because I was worried about who would be there	11%	19
I delayed my entry to the group because I was feeling scared	14%	25
Use this box to add any further comments if you wish to do so	7%	12

The percentage of participants attending the next scheduled group after finding out about it was 46% (45/97), suggesting that 54% (54/97) did delay their entry. The delay time had a range of 1 week to 1 year with the modal average being between 1 to 6 weeks. The individual responses were grouped into bands (Figure 6.3). What the data do not specify is if they continued attending after the first group as that question was not directly asked. However, the qualitative comments linked with this question and with the subsequent

survey questions imply that most did continue attending post their first entry into the group.

Figure 6.3: Length of delay in attending the ED SHG

Length of time	N	%
Can't recall	3	6%
More than a year	5	11%
More than 3 months but less than a year	6	13%
Up to 3 months	9	21%
1-6 weeks	24	51%

The qualitative comments which explained the reasons for delaying entry to the ED SHG in more detail revealed issues related to possible ambivalence in addition to worry as exemplified by the following two comments:

> I delayed contact because I was still trying to come to terms with having an eating disorder, despite inpatient treatment I thought I had things more under control, but I didn't!!!! So, I put off going to a support group for a while. I also didn't know anyone else going to the support group to start with, so it felt very scary not knowing be what to expect or how to behave (what would the rules of the group be etc).

> I put off self-referral for about 6 months because a) I was maybe a bit in denial b) I thought it was too busy and didn't have enough time c) the pandemic started.

Furthermore, worry was articulated as 'I was worried I wasn't sick enough to attend, and everyone would think I was a fraud'.

Some participants admitted that their ED behaviours had impacted attendance: 'I delayed my entry because it clashed with my (admittedly very excessive) exercise programme' and 'My bingeing and purging was out of control and the anxiety of attending got me stuck at home with the behaviours'.

This respondent captured the essence of several other responses in terms of the length of delay, ambivalence, and a need to ask for help:

> 'It took best 6 months for me to physically attend a group meeting from first becoming aware of a self-help group. I felt scared & wanted to do it by myself. Admitting I couldn't do it alone, was in extreme suffering and asking for help by going to a self-help group was a key step'.

Further reasons can be found in Appendix 6.5: Reasons for delaying entry (all comments)

What happens inside the group

89 participants responded to the question. The use of a Principal Component Analysis (PCA) was considered as a way to reduce the number of factors (items), to generate new factors and aid the analysis of the responses (Cattell, 1978; Ringnér, 2008). A Kaiser-Meyer-Olkin Measure of Sampling Adequacy (KMO) and Bartlett's Test of Sphericity were generated to ascertain if a PCA was suitable, i.e., that there was a relationship between the data (Abdi & Williams, 2010). The KMO statistic (0.77) was above the minimum of 0.5; this was an indicator that confirmed that the data sample were sufficient for PCA. The closer the KMO is to 1 the better (Kaiser & Rice, 1974). Equally Bartlett's Test of Sphericity (df = 77) is 336.098 and $p < .001$ is significant, again confirming that a PCA was suitable (Hogarty et al., 2005)

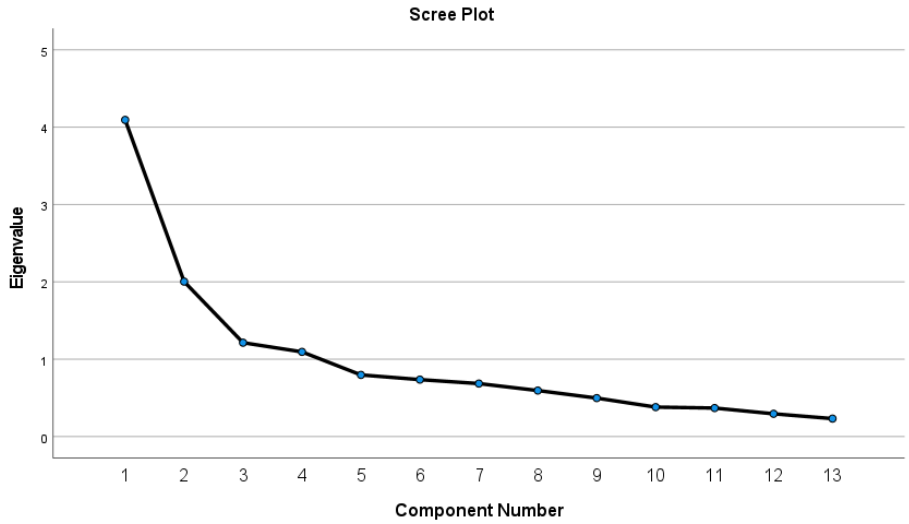
A PCA was used to see if the existing number of factors could be reduced. In determining the number of factors to be extracted a Scree plot (Figure 6.4) was generated and examined, in addition to identifying the number of factors with Eigenvalues >1. There were four factors with Eigenvalues >1 (Eigenvalues were 4.095, 2.004, 1.214, 1.095) (Table 6.9). The first two scored highly but all four were above 1 so met the threshold for a PCA (Jolliffe, 2002).

Table 6.9: Total Variance Explained (Group)

	Initial Eigenvalues			**Extraction Sums of Squared Loadings**		
Component	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	4.095	31.497	31.497	4.095	31.497	31.497
2	2.004	15.417	46.914	2.004	15.417	46.9
3	1.214	9.339	56.253	1.214	9.339	56.3
4	1.095	8.427	64.680	1.095	8.427	64.7

Additionally, the point of inflexion on the Scree plot indicated a possible 4-factor solution giving 64.7% variability explained in the 4-factor model. However, the point of inflexion on the Scree plot indicated a possibility of reducing the 13 factors down to 3 factors. The 3-factor solution accounted for 56.3% of the variance in questionnaire responses. Appendix 6.6: Three factor solution (group).

Figure 6.4: Scree Plot (group)



A pattern matrix was carried out and Figure 6.5 indicates how well the new factors loaded onto the existing factors (a cutoff point of greater than 0.4 was accepted). All the new factors loaded onto the existing factors.

Figure 6.5: Factor loadings for 4 factor solution, groupings, and definitions (group)

Original Factors	4-factor solution			
	A	B	C	D
1. I learn things about myself	.547	.255	-.211	-.066
2. I feel that I don't always use the group as well as I want to	.059	.061	.879	-.180
3. I find it hard to talk about myself	-.038	.129	.824	-.068
4. I find myself talking about my family	-.014	-.096	.212	-.866
5. I find it an encouraging space	.605	.057	-.247	-.194
6. I can talk about anything I want to	.243	.051	-.287	-.427
7. I leave the group feeling motivated	.690	.130	-.045	-.149
8. I feel a commitment to action	.650	.102	-.113	-.317
9. I can recognise a lot of my own traits in other people	.820	-.180	.163	.327
10. I am able to tell myself I'm doing well	.180	.183	-.485	-.213
11. I have found out how to access treatment	.105	.853	.166	.004
12. I have learnt about what help I am entitled to	-.104	.828	-.082	-.162
13. I have sought professional help as a result of attending the group	.007	.792	.060	.261

Factor	Revised Factor name	Original factors	Definitions
A	Motivation/ intrapersonal	1,5,7,8,9	Learning about oneself and from others. Being motivated and ready for action.
B	Help seeking	11,12,13	Learning about how to access treatment. Seeking help as a result of attending group.
C	Personal difficulties inside group	2, 3, 10R[4]	Internal personal frustration in not feeling able to use group in the hoped-for way
D	Talking	4,6	Talking about family and having the space to talk about anything.

[4] This indicated a reverse relationship. It was decided not to reverse the question but keep it in its original format to maintain the essence of the question.

A Communalities Analysis was carried out to ascertain the level of extraction i.e., the 'estimates of the variance in each variable accounted for by the factors in the factor solution' (IBM). This showed that the new factors had an agreeable level of variability ranging from 0.467 to 0.762 (Appendix 6.7: detailed communalities analysis breakdown). Each of the four new factors can be considered normally distributed i.e., the skewness value was below 1 and the kurtosis value was below 2, except for the first factor (motivation/ intrapersonal) which was slightly skewed with a value of 1.17 (Table 6.10). Appendix 6.8: Detailed descriptive statistics of generated factors (group).

Table 6.10: Descriptive statistics of generated factors (Group)

		Statistic	Std. Error
Motivation/ intrapersonal	Mean	-.5711	.05425
	Median	-.60	
	Std. Deviation	.47	
	Skewness	1.17	.276
	Kurtosis	.86	.545
Help seeking	Mean	.1886	.07183
	Median	.3333	
	Std. Deviation	.62618	
	Skewness	-.273	.276
	Kurtosis	-.925	.545
Personal difficulties inside the group	Mean	.0044	.07453
	Median	.0000	
	Std. Deviation	.64977	
	Skewness	.025	.276
	Kurtosis	-1.255	.545
Talking	Mean	-.0395	.07301
	Median	.0000	
	Std. Deviation	.63647	
	Skewness	.152	.276
	Kurtosis	-.986	.545

A rotated component matrix which rotated in 9 iterations, showed that the components were more highly correlated with eleven of the items as indicated in Table 6.11. The acceptable cut-off point that was used was 0.4 (Guadagnoli & Velicer, 1988). The results suggested that Items 6 and 10 could potentially be dropped from further analysis as they did not highly correlate with any of the components (as there was a cut-off point below 0.4). However, it was decided to keep items 6 and 10 as they could be loaded onto several of the revised four factors e.g., item 6 could be loaded onto motivation and talking. As expected, many factors were interrelated.

Table 6.11: Rotated Component Matrix (group)

	New Factors			
Original Factors	**Motivation / intrapersonal**	**Help Seeking**	**Personal difficulties inside the group**	**Talking**
1. I learn things about myself	.660			
2. I feel that I don't always use the group as well as I want to			.833	
3. I find it hard to talk about myself			.791	
4. I find myself talking about my family				.811
5. I find it an encouraging space	.725			
6. I can talk about anything I want to	.439		-.319	.405
7. I leave the group feeling motivated	.759			
8. I feel a commitment to action	.778			
9. I can recognise a lot of my own traits in other people	.652			-.423
10. I am able to tell myself I'm doing well	-.391		.498	
11. I have found out how to access treatment		.835		
12. I have learnt about what help I am entitled to		.820		
13. I have sought professional help as a result of attending the group		.759		

6.3.2 Recovery

This section addressed two aspects of recovery, the support that participants drew on to support their recovery and their agreement response as regards to what happens during recovery based on a set of 24 statements.

Support for recovery

The data were grouped into 'professional' and 'informal and nonprofessional' support (see Table 6.12) as part of the analysis. Informal and nonprofessional support accounted for 65% of the total count (255/393) compared to a figure of 35% for formal support (138/393). Combining ED SHG and Online Support Group together gave a count of 23% (91/393). Moreover, the data indicate that therapists and ED SHGs are the most important source of support for recovery; one would maybe expect the ED SHGs to score highly as the survey was about people who had attended an ED SHG. However, informal and nonprofessional support like self help books and workbooks seemed important and that the participants reached out to a range of other support. Moreover, 'Partner, Family, and Friends' (n=84) were an important part of supporting their recovery (21% of the total). However, the qualitative data generated from this survey did not offer any insight into the 'Partner, Family, and Friends' response as no participants explicitly elaborated on this.

Table 6.12: Things and people that have supported recovery

Types of support	%	Count	
The ED Self Help Group	14%	54	Informal & Nonprofessional support
ED Self Help Book	5%	18	
ED Self Help Manual/Workbook	3%	12	
Online Support Group	9%	37	
Recovery App	3%	11	
Recovery Coach	2%	7	
Recovery Blog	2%	8	
My partner or family	10%	40	
My friends	11%	44	
ED Charity e.g., BEAT, ABC etc	6%	24	
GP	7%	28	Formal support
Dietician or nutritionist	8%	30	
Psychiatrist	6%	23	
Therapist	15%	57	

What happens during recovery

This subsection provides an analysis of the participants who rated 24 statements (items) in relation to when they were in recovery or had been in recovery based on a Likert scale (agree, neutral and disagree). See Figure 6.7 which lists the 24 statements in full. The questions were couched in the present and past tense. Participants who had not experienced recovery or been in recovery were advised to skip the question. It may have been prudent to have included an option to capture those who had not been in recovery, but it may have separated the group into subgroups that would be too small to analyse. 77 participants answered this question.

The use of a PCA was considered as a way to reduce the number of factors to generate new factors and aid the analysis of the responses (Ringnér, 2008). Before that could take place, a KMO of Sampling Adequacy and Bartlett's Test of Sphericity were generated to ascertain if a PCA was suitable i.e., that there was a relationship between the data. The KMO statistic (0.743) was above the minimum value of 0.5; this was an indicator that confirmed that the sample was sufficient for PCA (Hogarty et al., 2005; Ringnér, 2008). Bartlett's Test of Sphericity (df = 276) is 882.492 and $p < .001$, is significant, confirming that a PCA was suitable (Hogarty et al., 2005).

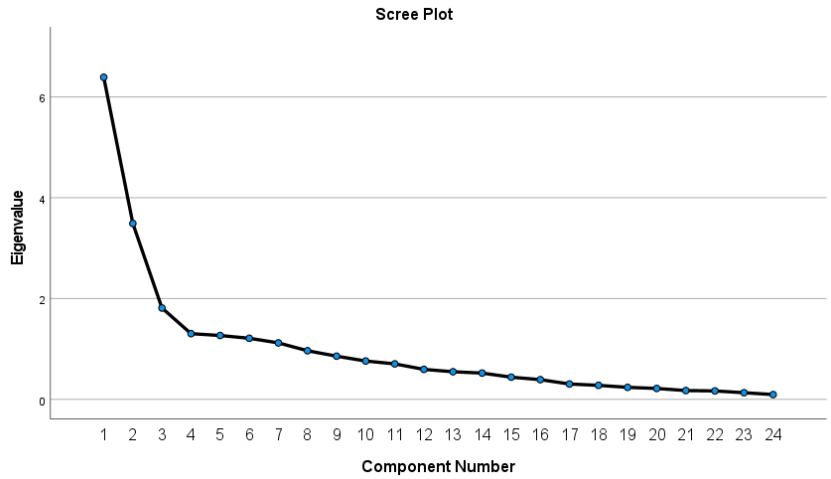
In determining the number of factors to be extracted, a Scree plot (see Figure 6.6) was generated and examined, in addition to identifying the number of factors with Eigenvalues >1. There were seven factors with Eigenvalues >1 (Eigenvalues were 6.39, 3.49, 1.81, 1.30, 1.27, 1.21 and 1.12) as indicated in Table 6.13. The first two scored highly but all seven were above 1 so met the threshold for a PCA (Jolliffe, 2002).

Table 6.13: Total Variance Explained (Recovery)

Factor	Initial Eigenvalues			Extraction Sums of Squared Loadings		
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	6.391	26.630	26.630	6.391	26.630	26.630
2	3.490	14.543	41.173	3.490	14.543	41.173
3	1.813	7.555	48.728	1.813	7.555	48.728
4	1.304	5.434	54.162	1.304	5.434	54.162
5	1.268	5.281	59.443	1.268	5.281	59.443
6	1.213	5.053	64.496	1.213	5.053	64.496
7	1.121	4.671	69.167	1.121	4.671	69.167

The analysis converged in 24 iterations. Additionally, the point of inflexion on the Scree plot indicated a possible 7-factor solution giving 69.2% variability explained in the 7-factor model. However, the point of inflexion on the Scree plot indicated a possibility of reducing the 24 factors down to 6 factors. The 6-factor solution accounted for 64.5% of the variance in questionnaire responses but it failed to converge; it is therefore not useful for the analysis.

Figure 6.6: Scree Plot (recovery)



A pattern matrix was carried out and Figure 6.7 indicates how well the new factors loaded onto the existing factors (a cutoff point of greater than 0.4 was accepted). All the new factors loaded onto the existing factors.

Figure 6.7: Factor loadings for 7 factor solution, groupings, and definitions (recovery)

Original Factors	New Factors						
When I am in recovery/when I was in recovery….	A	B	C	D	E	F	G
1. I feel/felt excited	-.728						
2. It feels/felt good	-.793						
3. it feels/felt like coming back to life again	-.829						
4. I feel/ felt emotional at times		.741					
5. I recognise/recognised how life is/was quite dull when I have/ had my ED		.708					
6. I can/could eat without feeling guilty				.470			
7. I can/could eat without having to exercise				.719			
8. it is/was nice being able to eat without having to worry				.637			
9. I find/found it hard to sustain my recovery at my target weight							.900
10. I am/was sick of being ill and restricting						.538	
11. I can/could see there were many opportunities ahead of me	-.658						
12. I can/could see that my ED was holding me back	-.572	.418					
13. I still have/had wobbles			-.639				
14. I believe/believed that recovery is/was an ongoing thing				.606			
15. I am not 100% recovered; I still have a lot of obsessive traits			-.891				
16. Recovery is/was easy for me to fall back into restrictive habits			-.798				
17. I don't/didn't really know what it is/was to be fully recovered			-.806				
18. I do purge/I did purge						.692	
19. I still think about what I can eat/ I thought about what I had eaten or could eat			-.773				
20. I do record calories/ I did record calories					.895		
21. I do record my weight/did record my weight					.644		
22. I am/ was scared to weigh myself because I am/was worried I will/would not like the number		.518					.497
23. I do count numbers/did count numbers					.710		
24. I have/ had ups and downs during my recovery		.542					

Factor	Revised Factor name	Original factors	Definition
A	Impact on self	1,2,3,11,12	Experiencing the benefit of recovery on own life and seeing a reason to recover.
B	Self-recognition	4,5,12,22,24	Acknowledging the less than positive impact of ED has/had on living a full life, and the ups and downs of recovery.
C	Struggles	13,15,16,17,19	Having ongoing struggles with managing ED behaviours and thoughts, as well not knowing what full recovery is/was.
D	Freedom to eat	6,7,8,14	Eating without compensatory behaviours to mitigate for it but being mindful that recovery is an ongoing process.
E	Weight and calories	20,21,23	Engaging in ED behaviours concerned with weight and calorie record keeping
F	Behaviours	10,18	Being sick of being ill, restricting and purging.
G	Sustaining recovery	9,22	Difficulties of sustaining recovery and the fear attached to weighing self.

A Communalities Analysis was carried out to ascertain the level of extraction. This showed that the new factors had an acceptable level of variability ranging from 0.58 to 0.84 (Appendix 6.9 for a detailed breakdown). Three of the seven new factors were normally distributed (Impact on self; Behaviours; Sustaining recovery) due to the skewness and kurtosis values. Two were kurtosed and right skewed (Self recognition and Struggles). One factor (Freedom to eat) was slightly left kurtosed. The remaining factor (weight/calories) was moderately left skewed (see Table 6.14 for the exact figures and Appendix 6.10 for a more detailed breakdown).

Table 6.14: Descriptive statistics of new factors (recovery)

		Statistic	Normally Distributed?
Impact on self	Mean	-.3184	Yes
	Median	-.4000	
	Std. Deviation	.58531	
	Skewness	.473	
	Kurtosis	-.808	
Self-recognition	Mean	-.6875	No
	Median	-.7500	
	Std. Deviation	.40440	
	Skewness	1.542	
	Kurtosis	2.037	
Struggles	Mean	-.6816	No
	Median	-1.0000	
	Std. Deviation	.50510	
	Skewness	1.776	
	Kurtosis	2.236	
Freedom to eat	Mean	-.1743	No
	Median	.0000	
	Std. Deviation	.58312	
	Skewness	-.144	
	Kurtosis	-1.219	
Weight/calories	Mean	-.1754	No
	Median	-.3333	
	Std. Deviation	.71487	
	Skewness	.358	
	Kurtosis	-1.088	
Behaviours	Mean	-.2237	Yes
	Median	.0000	
	Std. Deviation	.58535	
	Skewness	.382	
	Kurtosis	-.266	
Sustaining recovery	Mean	-.4211	Yes
	Median	-.5000	
	Std. Deviation	.60029	
	Skewness	.779	
	Kurtosis	-.318	

The rotated component matrix shows that the components were highly correlated with all the 24 variables as indicated in Table 6.15. The acceptable cut-off point that was used was 0.4 (Guadagnoli & Velicer, 1988).

Table 6.15: Rotated Component Matrix (recovery)

Components	Revised Factors						
	1	2	3	4	5	6	7
1. I feel/felt excited		.722					
2. It feels/felt good		.814					
3. it feels/felt like coming back to life again		.815					
4. I feel/ felt emotional at times				.758			
5. I recognise/recognised how life is/was quite dull when I have/ had my ED				.653			
6. I can/could eat without feeling guilty		.420			.577		
7. I can/could eat without having to exercise					.739		
8. it is/was nice being able to eat without having to worry					.716		
9. I find/found it hard to sustain my recovery at my target weight						.876	
10. I am/was sick of being ill and restricting							.611
11. I can/could see there were many opportunities ahead of me		.654					
12. I can/could see that my ED was holding me back		.628		.417			
13. I still have/had wobbles	.678						
14. I believe/believed that recovery is/was an ongoing thing					.539		
15. I am not 100% recovered; I still have a lot of obsessive traits	.837						
16. is/was easy for me to fall back into restrictive habits	.796						
17. I don't/didn't really know what it is/was to be fully recovered	.779						
18. I do purge/I did purge							.635
19. I still think about what I can eat/ I thought about what I had eaten or could eat	.800						
20. I do record calories/ I did record calories			.842				
21. I do record my weight/did record my weight			.657				
22. I am/was scared to weigh myself because I am/was worried I will/would not like the number				.576		.490	
23. I do count numbers/did count numbers			.718				
24. I have/ had ups and downs during my recovery	.411			.598			

6.3.3 Wellbeing

The WEMWBS scale employs a 1 to 5 Likert scale of questions about wellbeing which are worded positively (Tennant et al., 2007). These questions required the participants to rate their 'feelings and thoughts over the last two weeks' (Appendix 6.11a: Prevalence survey WEMWBS detailed results and 6.11b: Statistics of WEMWBS question responses). The data from the 76 participants' responses were normally distributed: mean (42), median (41) and a high sd (10.5), indicating that the range was broad (49). Additionally, the skewness was less than 1 (0.259) and the kurtosis (-0.242) was between -2 and +2. Based on the range and the sd, the median was the best central tendency to use to represent the average value for the data set. The mean and median were almost identical.

The participants (n=76) who completed this part of the survey had a lower mean ($\bar{x}$=42) than the general UK population in the WEMWBS study whose mean is higher (μ=51). It can be surmised therefore that the 76 participants who completed the prevalence survey were not representative of the WEMWBS general UK population.

The Modelling Process

A Generalised Linear Modelling approach was used to analyse the responses to the wellbeing WEMWBS questions, using Forward Conditional Binary Logistic Regression (BLR). This was deemed to be the most efficient way of considering which covariates should be used to predict the dependent variable, as the covariates had different underlying characteristics.

The following regression equation was used:

$$Y = \beta 0 + ax1 + bx2 + cx3 + \ldots\ldots.$$

Where β0 represents the intercept, i.e., the constant (where the line crosses the y axis) and regression, and ax1, bx2, etc. represent the regression coefficients / covariates.

The WEMWBS wellbeing survey data which were continuous data, were recoded to create binary data for the BLR. The aim of BLR was to identify if any of the independent covariates previously collected, i.e., the 11 output factors generated from the PCA (4 relating to experience in the group and the 7 related to recovery), along with age and ethnicity, were predictors of wellbeing (see Table 6.16). For the purposes of the BLR the ethnicity data was recoded into three groupings due to the small sample size and the diversity of responses within the 'white' category where some responses only had 1 or 2 responses against certain descriptors.

Table 6.16: Independent Covariates used for BLR

BLR Independent Covariates	Details
Age	
Ethnicity	White (1,2,3*) Mixed (4,5,6,7*) Black, Asian, Not specified (8-13*) *Relate to the ethnicity categories on the prevalence survey
PCA Covariates (related to group experience)	Motivation / intrapersonal Help seeking Personal difficulties inside group Talking
PCA Covariates (related to recovery)	Impact on self Self-recognition Struggles Freedom to eat Weight and calories Behaviours Sustaining recovery

BLR modelling was undertaken three times to investigate the effect of variable cut points e.g., positive wellbeing; high wellbeing; and very good wellbeing.

Model A: Using the Survey mean $\bar{x}$ =42 as the cut point value

There was almost an even split in the sample of those coded as having less than positive wellbeing (n=39) and those exhibiting positive wellbeing (n=37). The regression constant (β= -0.53) is not significant (p=0.819) so was not required to be kept in. The odds risk ratio (0.949) is less than 1. (Appendix 6.12: Original classification table for step 0).

The model summary (see Table 6.17) presents three different ways of assessing the reliability of each step. The Nagelkerke R Square data was used as this was deemed a more reliable indicator of goodness of fit as the Cox & Snell R square makes no adjustments (Harrell, 2010). The Nagelkerke R Square shows that for Step 1, 39.4% of the variability is explained and that this model would be accurate 39.4% of the time, which means that at least 60.6% is not explained.

Table 6.17: Step Summary for cut point value of 42

Step	-2 Log likelihood	Cox & Snell R Square	Nagelkerke R Square
1	78.662[a]	.296	.394
2	65.719[a]	.406	.541

Based on the data, Step 2 is the better model as 54.1% of the variability is explained suggesting that if the prevalence study was replicated it would be accurate 54% of the time

for people with the condition, in this case the wellbeing predictor. This result is good when consideration is made for the small cohort size.

Table 6.18 (below) shows that in Step 1, taking the mathematically correct significant figure, the constant is part of the model. 'Impact on self' is the only covariate that appears. The odds ratio- the risk factor (0.08) is less than 1 which indicates that 'Impact on self' might contribute a positive effect on wellbeing; possibly having a protective factor on wellbeing. Neither the odds ratio nor the Confidence Interval (CI) (0.025 - 0.256) crosses over 1 which implies that there is a high precision for the Odds ratio (Tenny & Hoffman, 2025).

For Step 2, the constant is present. 'Personal difficulties inside the group' is the first covariate in the model followed by 'impact on self'. 'Personal difficulties inside the group' has a high odds ratio, and a CI which is above 1 both of which suggest that these may be predictors that 'Personal difficulties inside the group' may present a 6-fold risk (i.e., an enhanced risk) of this impacting negatively on wellbeing. Overall, the model has shown two parameters going in opposite directions.

Table 6.18: Variables in the equation (cut point value of 42)

		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I. for E(B)	
								Lower	Upper
Step 1[a]	**Impact on self**	-2.530	.596	18.022	1	<0.005[5]	.080	.025	.256
	Constant	-.956	.365	6.843	1	.009	.384		
Step 2[b]	**Personal difficulties inside the group**	1.819	.563	10.445	1	.001	6.168	2.046	18.593
	Impact on self	-2.277	.665	11.726	1	.001	.103	.028	.378
	Constant	-.887	.405	4.805	1	.028	.412		

a. Variable(s) entered on step 1: impact on self
b. Variable(s) entered on step 2: Personal difficulties inside the group

Appendix 6.13: Classification Table (42 as cut point value) and Appendix 6.14 for variables not included in the equation for steps 1 and 2.

[5] P=0.000022

Model B: Using a nationally published mean (taken from WEMWBS), μ= 51 as the cut point value

The regression constant (β=-1.099) is significant (p = <0.005) so it needs to be kept in the model. The odds risks ratio (0.333) is less than 1. Appendix 6.15 for the variables not in the equation at Step 0. Appendix 6.16 for the original classification table.

The Nagelkerke R Square (see Table 6.19) shows that if the study was replicated it would only be accurate either 18.7% of the time if Step 1 is used, or 26.5% of the time if Step 2 is used. The results suggest that neither model would provide an accurate predictor of which covariates are indicators of wellbeing.

Table 6.19: Step Summary for cut point value of 51

Step	-2 Log likelihood	Cox & Snell R Square	Nagelkerke R Square
1	75.224[a]	.126	.187
2	70.491[a]	.179	.265

Table 6.20 shows that in step 1 the only covariate that has been included is 'Personal difficulties inside the group' which is significant (p=0.004). The odds ratio (4.218) is greater than 1 and the confidence interval crosses over 1 (1.605-11.088) which means that 'Personal difficulties inside the group' has a negative impact on wellbeing.

For Step 2, two covariates have been included 'Personal difficulties inside the group' and 'Struggles'. As for step 1 'Personal difficulties inside the group' has an odds ratio greater than 1 (3.420) and CI crosses over 1 (1.271- 9.198). Similarly, 'Struggles' has an odds ratio greater than 1 (3.220) and the CI crosses over 1 (1.089 to 9.517). Thus, suggesting that these two covariates have a negative impact on wellbeing (Appendix 6.17: the classification table for the two steps).

Table 6.20: Variables in the Equation (cut point value of 51)

		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I. for Exp(B)	
								Lower	Upper
Step 1[a]	**Personal difficulties inside the group**	1.439	.493	8.520	1	.004	4.218	1.605	11.088
	Constant	-1.311	.316	17.252	1	p<0.005[6]	.270		
Step 2[b]	**Personal difficulties inside the group**	1.230	.505	5.933	1	.015	3.420	1.271	9.198
	Struggles	1.169	.553	4.472	1	.034	3.220	1.089	9.517
	Constant	-.541	.471	1.321	1	.250	.582		

[6] p=.000033

Model C: Using the prevalence survey 25% quartile with 35 as the cut point value

The initial aim of this model was to explore the top and bottom quartiles. The middle quartile was almost identical to the mean (see Model A). Additionally, the 75% quartile gives a cut point value of 51 (which was explored in Model B previously). The 25% quartile gives a cut point value of 35, where a score of 35 or above represents high wellbeing. In Step 0, 76.3% of the participants were correctly classified as having high wellbeing. The regression constant (β= 1.170) is significant (p= 0.000014) and has been included in the model. The odds risk ratio (3.222) is above 1.

Table 6.21: Model Summary Step 1 (cut point value 35)

Step	-2 Log likelihood	Cox & Snell R Square	Nagelkerke R Square
1	74.057[a]	.113	.170

This model contains one step only (see Table 6.21). There is 17% of the variability explained suggesting that if the model was replicated it would only be accurate 17% of the time. This implies that this model is not a reliable model to use to identify which covariates may predict wellbeing.

Table 6.22: Variables in the Equation (cut value point 35)

		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I. for EXP(B)	
								Lower	Upper
Step 1	**Impact on self**	-1.445	.509	8.069	1	.005	.236	.087	.639
	Constant	.881	.293	9.063	1	.003	2.413		

Variable(s) entered on step 1: impact on self.

Table 6.22 shows that the constant is significant (p= .0003) and that the only covariate that appears is 'impact on self'. The odds ratio (0.236) is below 1 and the CI (0.087 to 0.639) does not cross over 1. 'Impact on self' is the only covariate included in the model and based on the odds ratio it would suggest that it possibly has a protective factor on wellbeing (Appendix 6.18: Original classification table and Appendix 6.19: Variables not included in the equation).

In summary, Table 6.23 shows the three covariates that appeared across the three models and whether they were protective or not based on the odds ratio.

Table 6.23: Overview of covariates that appeared in the models

	Model A (cut value 42)	**Model B (cut value 51)**	**Model C (cut value 35)**
covariates that appeared in the BLR	Personal Difficulties inside the group (high risk factor)	Personal Difficulties inside the group (high risk factor)	Impact on self (protective)
	Impact on self (protective)	Struggles (risk factor)	

6.4 Discussion

6.4.1 Findings

The objective of this current study was to explore 'ED SHGs and what matters in recovery' from an online prevalence survey of individuals with an ED who had attended a group. The findings revealed the intersectional relationship between the experience of attending an ED SHG, recovery, and the wellbeing of the participants who completed the survey.

The discussion of the current study's findings has been organised under three broad areas commencing with a deeper exploration of the ED SHG in terms of what happens outside and inside the group. This then leads into examining the benefits of recovery contrasted with the struggles that recovery raised for the participants. Finally, there will be a reflection on the nature of nonprofessional sources of support and the value that the participants attached to this.

Finding an ED SHG

The current study offered new insight, which is not evident in research, about how individuals with an ED tried to locate an ED SHG, revealing the internet as the most popular approach used. The body of literature which aligns is research about ED OSGs and how they are used by individuals with an ED to gain support from their peers (e.g., Eichhorn, 2008; Mccormack, 2010; Stommel & Meijman, 2011).

Moreover, the current study's findings attune with aspects of existing research about the motivations that lead individuals to seek out the support of an ED SHG. Treatment: in terms of it coming to an end, the long wait for treatment and being put on a waiting list, was one of the higher scoring reasons for seeking the ED SHG in the current study. This complements existing research which has documented the rise in the number of individuals with an ED which has led to longer waits for treatment due to the shortage of resources, and long waiting lists (BEAT (n.d); PwC, 2015). Yet, the situation has been exacerbated by the Covid-19 pandemic, nationally and internationally (Devoe et al., 2023; Rodgers et al., 2020; Taquet et al., 2022).

Similarly, Hamilton et al. (2022), in their Australian study, reported that their respondents had average delays of 5.28 years before they sought treatment. When analysed by type of ED, they found individuals with BED and BN, on average, had longer delays than individuals with AN, as much as over eight years difference. The longer delay for individuals with BED may be explained by low esteem, something which Darcy & Dooley (2007) found in their research examining the clinical profile of individuals attending an ED OSG.

The current study's findings about the participants' self-reported delays in attending an ED SHG is synonymous with research about treatment delays. These findings have added extra dimensions to the literature base through researching about the length of the delay in attending an ED SHG and identifying the possible contributory intrapersonal reasons. Fear of not knowing what would happen and who would be attending could explain why some delayed entry, which was between one week up to a year. The frequent time span reported was one to six weeks. Noticeably, nearly half of the participants in the current study attended the ED SHG straightaway when they found the details of the group which may have indicated a readiness for action (Eaton, 2020). Furthermore, the research of Prochaska et al. (1992) about the change process within the context of addiction, is arguably commensurate with this idea.

Additionally, the findings from the current study aligns with the limited research about reasons for seeking the support of an ED SHG, such as 'things spiralling out of control'; 'getting panicky about ED' and 'using food more to deal with emotions'. Russell-Mayhew et al. (2010, p. 35), for example, reported that individuals with an ED in their research had identified the reasons for attending their ED SHG as 'reaching the end of the line'. Similarly, participants in a study carried out by Pettersen & Rosenvinge (2002) spoke about 'crisis point' that led them to hope for recovery.

Inside the ED SHG

Having examined the length of delays and the reasons behind this the discussion focuses on what happens inside the group. The four factors generated as part of the PCA: 'Motivation/interpersonal'; 'Help seeking'; 'Personal difficulties inside group'; and 'Talking'), form the framework for the discussion about what happens inside the ED SHG (see figure 6.5). Gaining an understanding of the participants' experiences inside the group may help understand what function the ED SHG plays or can play in supporting recovery.

'Motivation/interpersonal' (Learning about oneself and from others. Being motivated and ready for action) and 'Help seeking' (Learning about how to access treatment and Seeking help as a result of attending group) both resonate with aspects of existing research about the change process. For example, a study carried out by Blake et al. (1997) which explored the 'stages and processes of changes in EDs', drew on the work of Prochaska and DiClemente (1992) in terms of the processes of change (Figure 6.8). Blake et al. (1997) examined the stages of change in patients with AN and BN. Based on their analysis they

found patients with BN were at the action (A) stage; in comparison with patients with AN who were at an earlier stage, precontemplation / contemplation (P/C) stage. Applying this idea to the context of the current study may serve as a useful perspective into which attendees could benefit the most from the ED SHG based on the constituency, and the ensuing dynamics that may prevail in terms of levels of motivation and action.

Figure 6.8: The change process of Prochaska and DiClemente (1992)

[as presented by Blake et al., (1997)]

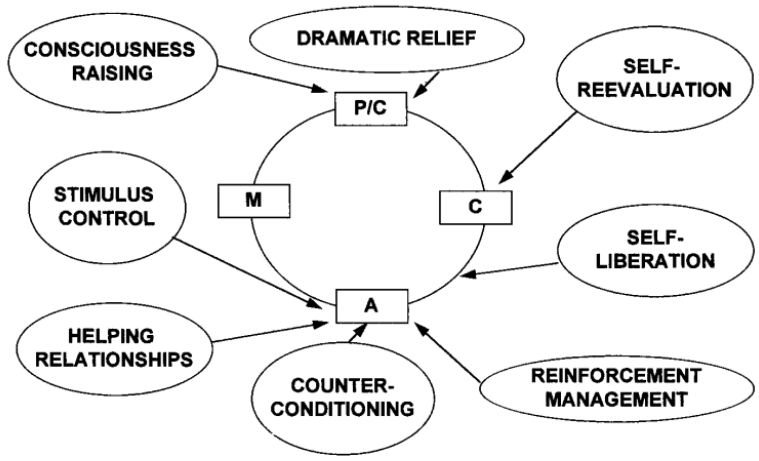


Figure 1. Processes of change. P/C, precontemplation; C, contemplation; A, action; M, maintenance

Moreover, Sjogren's (2017, p. 3) review reflected on the idea of motivation further, through considering Motivational Enhancement Therapy (MET) within the context of AN, asking if it can be enhanced. This approach would be employed to ascertain at what stage of change the person with AN is at 'to support the clients use their own resources in the process'. Furthermore, they worked on the premise that individuals with AN are not motivated in weight restoration and recovery. They posit that MET may have more success in 'nonclinical populations' more so than in clinical ones. Additionally, it has been suggested that individuals with BN are likely to be motivated to change more so than individuals with AN (restrictive type) (see Fairburn, 2008; Vitousek et al., 1998).

The third factor of the current study's findings: 'Talking' (Talking about family and having the space to talk about anything) is in keeping with existing research about the importance and value of having a space to talk to others with the same conditions. For example, some of the participants in Reid et al.'s (2008) qualitative study about patients' views of an ED outpatient service valued having the space to talk freely and be listened to. A similar finding was echoed in research by Evans et al. (2011) within the context of their participant's experience of help seeking where feeling able to talk about the ED without feeling judged was important. Ki (2011) noted this too within their research conducted within an ED Art therapy support group context. They found that some attendees felt part of a community and happy that they did not always have to talk about their ED; there was a freedom to talk about what they wanted to. Furthermore, individuals with an ED have

identified being able to express themselves with confidence as an important criteria in the recovery process (de la Rie et al., 2007; Noordenbos, 2011; Noordenbos & Seubring, 2006).

By contrast, the fourth factor 'Personal difficulties inside the group' (Internal personal frustration in not feeling able to use group in the hoped-for way) in the current study's findings from the BLR, identified a potential risk factor to the wellbeing that attendance might present; albeit an intrapersonal one (see table 6.28). This notion generates a potential new perspective around ED psychopathology and wellbeing as it has been considered through the lens of an ED SHG. Several studies based in the Netherlands have been carried out exploring patients' ED and aspects of wellbeing. One such study was a comparative one carried out by de Vos et al. (2018) between female ED patients and the general population in the Netherlands of pathological symptoms and wellbeing. They found that ED patients had lower levels of wellbeing satisfaction (which they termed 'languishing') than the general population. However, they did find that some of those patients had high levels of wellbeing (which they termed 'flourishing'). The second was carried out by de la Rie et al. (2007) who examined QoL where wellbeing was a domain that was referred to as important by research participants but was not cited as the most important.

Moreover, risk factors with reference to Covid-19 is an important consideration that merits discussion as the current author's data regarding wellbeing were collected partly during that period. There is a growing body of evidence around the risks that Covid-19 have presented to the ED population. Areas of their life such as living arrangements, choice of what to eat, deterioration of mental health and wellbeing have impacted and can impact on ED recovery and an increase in ED behaviours (Branley-Bell & Talbot, 2021; M. Cooper et al., 2022; Giel et al., 2021). However, according to Devoe et al., (2023), who carried out a review of 53 studies about Covid-19, eight studies contained results where individuals with an ED had no increase in their symptoms.

Recovery

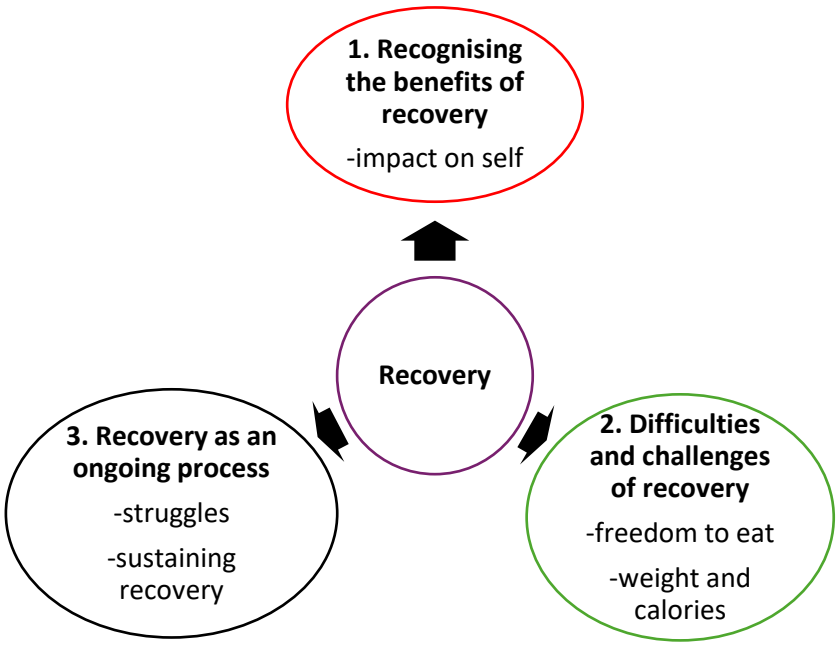
Hower et al. (2022) posit that defining recovery is influenced by the methodological stance of the researchers. However, there have been suggestions that the lived experience of individuals with an ED should feature as part of the criteria (see Kenny et al., 2022; Kenny & Lewis, 2021) (see chapter two and five for further examination of recovery).

The lived experience of the participants in the current study offered new insights into their personal relationships with recovery. The discussion draws on this and has been structured around the seven PCA factors (see Table 6.24) which have been grouped together under three discussion strands as outlined in Figure 6.9.

Table 6.24: Seven Recovery themes with definitions

Title	Definition
Impact on self	Experiencing benefit of recovery on own life and seeing a reason to recover.
Self-recognition	Acknowledging the less than positive impact of ED has/had on living a full life, and the ups and downs of recovery.
Behaviours	Being sick of being ill, restricting and purging.
Struggles	Having ongoing struggles with managing ED behaviours and thoughts, as well not knowing what full recovery is/was.
Weight and calories	Engaging in ED behaviours concerned with weight and calorie record keeping.
Sustaining recovery	Difficulties of sustaining recovery and the fear attached to weighing self.
Freedom to eat	Eating without compensatory behaviours to mitigate for it but being mindful that recovery is an ongoing process.

Figure 6.9: Recovery Discussion Strands



Recognising the benefits recovery

The 'Impact on self' was a factor that arose out of the current study's findings and will be considered in terms of the benefits of recovery. There was a self-understanding and realisation by the participants in the current study about the impact that the ED had on their life, echoing similar perspectives of participants in other studies who did not want the ED to dominate or take over their life (such as Pettersen et al., 2013; Pettersen & Rosenvinge, 2002; Reid et al., 2008). In the current study the BLR identified this as a potential protective

wellbeing factor towards recovery. Moreover, it has been found that individuals with an ED tend to have a poor QoL. For example, de La Rie et al. (2005, p. 1519) found that both former and current ED patients had poorer QoL than the 'normal reference' group in their study. Furthermore, what appeared significant was that ED patients had significantly poorer QoL than the former ED patients related to aspects of emotional and social functioning and the persistence of 'physical, psychosocial and social wellbeing, even after recovery of symptoms'. So, 'when health-related quality of life is the important outcome…the primary interest is focused on how well the different treatments improve the patient's physical function, social function and psychological well-being rather than just relapse rate' (Vergel & Sculpher, 2008, p. 176).

Difficulties and challenges of recovery

Two factors from the current study's findings: 'Freedom to eat' and 'Weight and calories' were two aspects of the difficulties and challenges of recovery faced by the participants. The participants in the current study had a desire for *normalcy* around eating without feeling a need to resort to compensatory behaviours; this is in accordance with existing research. For example, patients in research carried out by Noordenbos & Seubring (2006) who rated which criteria were important for recovery, ranked highly not engaging in compensatory behaviours post eating. Likewise a number of participants in Linville et al.'s (2012) research found the focus on learning how to eat different foods and recognising the signs of hunger as part of their treatment useful. Similarly, in a review by Noordenbos (2011) of patients' criteria for recovery, eleven criteria emerged, three of which could be construed as being behaviours and attitudes linked to *normalcy* around eating. For example, being able to eat in a regular way without needing to use compensatory behaviours like purging, exercising etc., being able to eat socially, and willingness to try new food.

The participants in the current study identified compensatory behaviours around managing weight and calories record keeping. This aligns with aspect of research such as Linville et al. (2012, p. 22) who identified themes and sub themes from their research with twenty two 'recovered' women with an ED in recovery; three of which related to weight: 'weight as a recovery barometer, being weighed and hurtful comments about weight' as impinging on their recovery. Similarly, six out of the eleven recovery criteria created by Noordenbos (2011) mention areas such as cessation of negative feelings towards wanting to lose weight, being of a 'normal weight' and weight not being a determiner of self-worth. However, research has found that those receiving treatment or support for their ED would prefer that professionals do not focus on weight restoration at the expense of supporting self-worth development (Barko & Moorman, 2023; Maurel et al., 2024).

Recovery as an ongoing process

From the current study's findings, the two themes: 'Struggles' and 'Sustaining recovery', are in concordance with existing research. Such as research regarding the management of ED thoughts (e.g., self-criticality), ED behaviours (e.g., purging), and the preoccupation with

weight that individuals recovering from an ED often have, which can impede the sustainment of recovery (Fairburn et al., 2003; Pettersen et al., 2013; Treasure, 1997). Moreover, the gaining of and maintenance of weight during and post treatment have been found to be contributory factors to relapse (de la Rie et al., 2005; Fairburn et al., 2003; Musolino et al., 2016). Thus, presenting a possible risk factor to successful recovery which was identified in the current study's findings.

Additionally, some individuals within the current study described themselves as 'recovered' or 'in recovery'. The 'in recovery' state could possibly be construed as partial recovery. This is in line with aspects of some areas of existing research. For example, Strober et al. (1997) drawing on the ideas of Morgan & Russell (1975) categorised partial recovery as 'good, intermediate and poor outcome' as part of their research measures. These categories were linked with menstruation restoration and weight with respect to patients with AN. Additionally, the poor category was linked with the patient 'exhibit[ing] bulimia nervosa'. They saw the link between fuller recovery and improvement in psychosocial functioning (in patients with AN) but found no variables to predict relapse post full recovery. Clinically they found that 'weight loss following discharge and ''switches'' to binge eating' had an impact on recovery. This links with the notion of transdiagnostic diagnosis purported by Fairburn et al. (2003) and the notion that EDs like AN and BN share similar features and that the person with the ED may move between disorders. Moreover, Strober et al. (1997) views partial recovery as a 'transitional state' leading up to being fully recovered.

The interplay between recovery and nonprofessional support

The current study found that participants drew on a range of sources of nonprofessional support in addition to the ED SHG to support their recovery. These findings are important and novel in terms of understanding the breadth of nonprofessional support that individuals who attend an ED SHG engage with. These sources have been grouped under three broad headings: the promotion of recovery; friends and family; and guided self help (GSH) materials.

The promotion of recovery

Participants in the current study indicated they had made use of recovery coaches in addition to the peer support offered through the group. This aligns with current research which has noted that peer recovery support services and the use of recovery coaches are frequently being embedded in the practice of some mental health fields, such as in addiction and are often peers who have a lived experience of the condition and of recovery (Eddie et al., 2019; Jack et al., 2018). In a similar way sponsors are used in OA settings to promote and support recovery from food addiction and are drawn from its membership (Wasson & Jackson, 2004). Moreover, the use of lived experienced recovery stories has gained impetus and are a key feature used by ED charities such as BEAT and Talk ED on their websites. Talk ED, for example, provide 'real stories' from individuals who describe themselves as recovered or in recovery.

Likewise, ED recovery is promoted via individuals on online platforms; this may be, for example, in the form of recovery blogs (Gies & Martino, 2014; Wolf et al., 2013) and Instagram posts (Au & Cosh, 2022; Goh et al., 2022). Au & Cosh (2022) found in their research that the community aspect was important, offering a source of support in the absence of treatment for some participants in their study. Goh et al. (2022) who evaluated posts using the hashtag: '#EDrecovery and #EatingDisorderRecovery' on Instagram noted the community aspect too (such as the sharing of challenges and recovery journeys).

However, their analysis did find that though some spoke positively about their experiences of treatment and the difficulties they faced conforming to treatment requirements, only a small minority of posts appeared to actively promote seeking professional support. Similarly pro ANA websites which too affords its member support have been perceived to be harmful in terms of sustaining the illness and not promoting recovery (Brotsky & Giles, 2007). Other writers have suggested that such sites provide an important role in providing a space for women with AN to hold onto the values that are important to them (e.g. Firkins et al., 2019) and offer social support. Furthermore, Mulveen & Hepworth (2006) noted in their IPA study that users of pro ANA sites valued the social support and the freedom that such sites allowed for them to say whatever they wanted. They noted too that there were opportunities for members to learn more healthier eating practices.

Friends and family

Participants in the current study rated the support of friends and family highly in aiding them with their ED recovery. This concurs with existing research about the significance of others in supporting someone with their ED recovery. Granek (2007), for example, who carried out research with five women with AN, found that the 'male influence' and their families was a positive presence for the women, due to the women feeling looked after by them: showing concern and feeding them in a healthy way. Male partners also positively supported the women's emerging sense of self.

However, caring for someone with any mental health illness has an impact on the mental health of the person involved in the caring (Haigh & Treasure, 2003; Stefanini et al., 2019). Therefore, support for carers of individuals with an ED is very important. Moreover, some of the interventions available to support carers, have been the feature of several studies or analyses (such as Hibbs et al., 2015; Treasure & Nazar, 2016). A research informed intervention such as 'The New Maudsley Model' (Treasure et al., 2015) is ideal in offering a space for carers to learn practically from clinicians and a 'paid recovery guide' (a former patient with AN who has recovered) as to how to support their loved one, as well as how to look after themselves in a workshop setting.

Guided self help materials

Participants in the current study identified that they had drawn on self help material like ED self help books, workbooks and manuals. For example, this is in keeping with a systematic review and meta regression carried out by Traviss-Turner et al. (2017), who identified thirty

studies featuring GSH. They noted that most GSH approaches used printed literature such as manuals and workbooks. There was variability in the individuals who were involved in supporting the delivery or guiding of the GSH, including GPs, facilitators (not trained formally), and doctoral students.

Moreover, an IPA study of users' experiences of ED GSH (Plateau et al., 2018), though only involving four participants with BN or BED complements this in terms of revealing that the clinician support (assistant psychologist) was an important aspect of the successful engagement with the ED GSH. This was in addition to the users having had prior experience of CBT. Initial engagement for some was challenging in terms of how such an approach may not have the same level of value as direct treatment. There exist other forms of GSH such as Dialectical Behaviour Therapy GSH (DBT- GSH) for BED, which have been the focus of research studies to understand the impact of such interventions, for example Carter et al. (2020). It should be noted that some GSH literature, written by clinicians, is readily available for anyone to use independent of professional support (for example Cooper, 2009; Fairburn, 2013; Schmidt & Treasure, 2007). One can surmise that participants in the current study may have used them personally or as part of a treatment programme.

6.5 Implications

The data that have emerged from this current study raised several implications pertaining to accessibility and diversity. Hower et al. (2022, p. 7) have proffered concerns about the ED population who are not represented in most research relating to ED recovery for example 'non-binary people, higher weight individuals and, children', and the fact that majority of research is of 'thin, white females' based in clinical settings.

Accessibility of ED SHGs

The overarching implication is the accessibility of ED SHGs in terms of gender and ethnicity; the data collected focussed on these two areas. The demographic data from the current study presented a picture of a lack of ethnic diversity as regards who attended ED SHGs; predominantly females from a white background , in their 20s, concurring with Hower et al. (2022). Further studies would merit considering other areas of accessibility in terms of disability and other genders for example.

Galmiche et al. (2019) assert that more women than men have an ED. Only five men engaged in the current study, which is a low number compared to the number of men with an ED, where a figure of 10% has been cited (Robinson et al., 2013; Sweeting et al., 2015; Weltzin et al., 2005). Weltzin et al. (2005) cite a breakdown by ED suggesting 10% of individuals with AN and BN are male, with a higher figure of 25% for BED. EDs has historically been presented as a female disease/ illness (Galmiche et al., 2019) and the low uptake of the survey may be an indicator that men may possibly be reluctant to attend what may be perceived as a female environment. This notion is borne out in several research studies. For example some of the men in qualitative research by Robinson et al. (2013) articulated that they found the ED service they were using 'gender excluding' and the

materials that were on offer not appropriate to their needs. In a similar way, Bohrer et al. (2017) found that men were less likely to ask for treatment for an ED.

Within the current study individuals with an ED from a non-white or mixed ethnic background accounted for a small fraction of the participants in the current study. One participant in this study summarised the issue succinctly:

> I'm a brown Pakistani girl, there are hundreds of us with EDs but we're not given that support and time. I'm lucky I have been given it but it's disorienting to be in a room of white girls.

Clinician bias was found in research carried out in the US by Becker et al. (2003) in terms of ethnicity, finding that those from a non-white background were less likely to be referred for further clinical support by their doctor or asked as often as those from a white background. This has been echoed in numerous other studies such as Becker et al., 2003; Gordon et al., 2002; and Sala et al., 2013.

Nevertheless, clinicians and professionals (such as doctors and therapists) were scored highly in the current study in terms of signposting participants to an ED SHG. This is despite research about MHGs implying that some professionals may feel undermined by groups run by the individuals with the condition (Seebohm et al., 2013) or that such groups are potentially harmful (Salzer et al., 2001; Timulak et al., 2013). Moreover, if the premise is that professionals see value in ED SHGs then research such as this study can help to enlighten more professionals as to the value of such groups for its attendees, enabling professionals to signpost their patients or clients in an informed and knowledgeable way.

6.6 Suggestions for future research

Future research into the individuals who run ED SHGs could complement and expand on the research debate as to whether clinicians with an ED should be working in ED clinical settings with ED patients and whether they should share their experiences with patients (see Audet & Everall, 2003; Audet & Everall, 2010; Costin, 2002; Johnston et al., 2005; Rance et al., 2010). Additionally, such research may encourage more individuals post recovery to consider facilitating or being involved in ED SHGs.

6.7 Strengths and Limitations

Low uptake of the survey may have been due to the period when the data were collected (2020-22), which was during the early stages of the Covid-19 pandemic (Institute for Government; World Health Organization). At that time there were restrictions on movement and gatherings due to government lockdown (Institute for Government). These factors may have impacted on engagement by possible participants whose regular in-person support such as an ED SHG may have ceased or reduced. A three-point Likert scale was used for this survey taking into account the nature of the participants who would be completing it; the aim was not to overtax the participants. It was designed as a blunt tool to gather their

experiences more so than to gather nuanced data that a longer Likert scale such as a 5-point or 7- point scale may have gathered.

Notwithstanding the cited limitations, three core strengths were apparent. The first is the unique aspect of considering and identifying the potential risk factors of how an ED SHG may impact on an attendee's wellbeing both positively and negatively, using PCA and BLR modelling. To the author's knowledge this has not been documented in this way. The second strength was the collection of primary quantitative and qualitative data from a range of individuals with an ED who had attended or are attending an ED SHG. This created a safe anonymous space for them to be honest thus supporting integrity in allowing them to be as open as they chose to. The third revolves around experiences of recovery. Through the prudent use of a PCA, the 24 recovery factors that emerged from the analysis of data were reduced to seven factors leading to the creation of three core recovery themes. This presented succinctly what matters in recovery for individuals who attend or have attended an ED SHG.

6.8 Conclusion

This current study has examined the experiences of individuals who have attended an ED SHG and what their perspectives on recovery were. The results provided important insights into the ED SHG; the motivations of why individuals with an ED sought out an ED SHG and the fact that attendance was not always immediate. The analysis of the data as to what happens inside the ED SHG provided a novel insight into a potential risk factor to the individuals' wellbeing that the intrapersonal experience of the ED SHG presented, alongside the positive space to talk that the ED SHG created.

Moreover, recovery was revealed as an ongoing process that was linked with not wanting the ED to take over their life but to create a sense of freedom and *normalcy* around eating. However, sustaining recovery and the management of the ED behaviours and thoughts were potential risk factors to wellbeing that may lead to a relapse. Support with the ED and for recovery outside professional support encompassed a range of sources, such as guided self help (GSH) material, friends and family and engaging with recovery apps and blogs promoting recovery.

The key recommendation that has emerged out of this study is a better understanding how an ED SHG alongside other sources of nonprofessional and professional support can interplay to support the recovery of an individual with an ED.

Key Findings

- Reasons for seeking help
    - Things spiralling out of control
    - A sense of desperation
    - A motivation to change
- The journey to ED SHG involved
    - An intrinsic motivation to attend

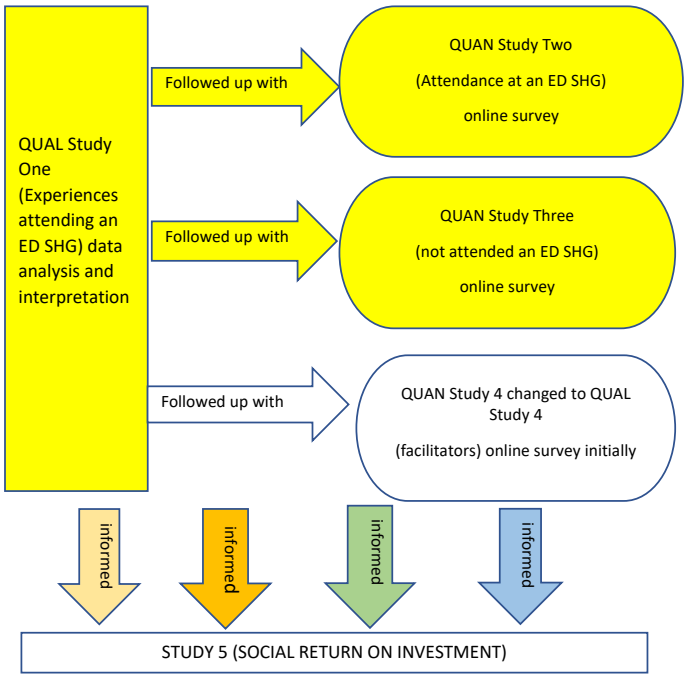
    - Suggestions by professionals and friends and relatives
- Barriers to entry
    - Delaying entry before joining (ranged from one week to one year)
    - Reasons for delays included: personal perceptions about validity of being 'allowed' to attend e.g. not believing that one is sick enough.
- What recovery involves
    - Attendees learning to live with some of the residual behaviours (seeing it as an ongoing process)
    - 'Struggles' (one of the PCA recovery factors) was identified as a possible risk factor to the wellbeing (WEMWBS instrument was used), as evidenced through BLR modelling
    - 'Impact on self' (one of the PCA recovery factors) was identified as potentially having a positive effect on wellbeing (WEMWBS instrument was used), as evidenced through BLR modelling
- The ED SHG supports recovery
    - By attendees seeing others experiencing recovery,
    - Through offering a space for self-reflection by the attendees' on their own recovery,
    - By attendees recognising a need for specialist support.
    - BLR modelling identified that one of the PCA factors 'Personal difficulties inside group' was a potential 6-fold risk factor to wellbeing (WEMWBS instrument was used)

Chapter 7: What matters in recovery: Adults with an Eating Disorder who have never attended an ED Self Help Group (Study 3)

7.1 Introduction

The previous two studies explored the mainly positive experiences of attendees who had attended ED SHGs which was also echoed in existing research. However, there appears to be no research which has explicitly examined the experiences of individuals with an ED who have never attended an ED SHG or who are reluctant to do so. This current study complements some of the findings from chapter six particularly around views on recovery and represents the next point of integration as per the highlighted yellow boxes in Figure 4.1.

Figure 4.1: Diagram of The Research Exploratory Sequential Design



There is a body of literature however, which has offered insights into a variety of support group contexts about the negative experiences attendees have attested to and some of the reasons why some choose not to attend. One such experience is around group leadership and management. For example, Dyregrov et al. (2014, p. 55) found that some participants in a grief group raised disquiet about the group leader whom they felt overshared and colonised the time in sessions due their 'unresolved own grief'. Further concerns lay around the competency of the group leader not having sufficient subject knowledge around grief or the skills to manage group processes. Commensurate issues were noted by Ussher et al. (2008) whose participants in a cancer support group complained about how controlling the group leader (a professional) was in terms of monitoring what was allowed to be spoken about.

Furthermore, the structure and organisation of groups was an area of disquiet. Some of the groups were open groups which meant new members could join at any time. Some participants in a grief group described having to repeat the same stories feeling that the group stagnated and did not move forward (Dyregrov et al., 2014). Interestingly, one newcomer in the same study described finding it hard to join especially if there was a core group of members, due to feeling shy (Dyregrov et al., 2014).

Another concern was around the impact of hearing others' stories and experiences. Participants in a study carried out by Palant & Himmel (2019) situated in an Inflammatory Bowel Disease (IBD) support group setting, found talking about their condition raised uncomfortable feelings such as anxiety about relapse especially if they were in remission from their condition. Likewise, Dyregrov et al.'s (2014) participants described a stress response listening to others' stories in the group. Similarly, some participants in a grief group perceived that the group might be a negative space where difficult topics such as death might be raised and there was also a sense of fear of being burdened by other people's situations (Ussher et al., 2008)

The length of time individuals have lived with a condition appears to significantly influence their engagement with support groups. Kalichman et al. (1996) found that people living with HIV/AIDS were more likely to attend support groups if they had been seropositive for a longer period. This suggests that over time, individuals may become more open to seeking the support of a group, possibly as their initial fears and reservations subside.

Some participants who have never attended the grief group appeared pragmatic about attending, stating that as they have never needed one before they do not need to attend one now. There is an implication that support groups are for those without their own support to draw on (Ussher et al., 2008). By contrast, Gage & Kinney (1996) found that non-attenders with HIV/AIDS were fearful about stigma, privacy around confidentiality which led to a reluctance in engaging for fear of the social repercussions at disclosure. Moreover, Davison et al. (2000) found that stigma related to a condition was a determinant as to whether someone would seek out support.

A common theme that transcends several support group contexts is each participant's personal relationship with their identity around their condition. For some being amongst others with the condition reinforced their illness status when what they wanted was to move beyond that. For example, Ussher et al. (2008) found that some participants from the cancer group expressed a desire not to be defined by their condition, especially if they had recovered. They no longer saw themselves as a cancer patient, with a mindset of learning to live with cancer. Similarly, Palant & Himmel (2019) observed that individuals with IBD often avoided support groups because they did not want to be constantly reminded of their condition, especially during periods of remission.

These findings suggest that non-attendance is not solely about not needing the group but may also be perpetuated on intrapersonal issues around the participants' fears

and anxieties, attendance being intertwined with their identity and how they manage other people's distress and struggles. For some, the stage they were in terms of their illness was also an indicator of engagement with support groups. For others it was about how they viewed their illness. This was about not still being identified by their illness, but this was something that would be a backward step as they moved from illness to recovered or in remission. This has implications for the setting up and the structuring of groups especially in terms of the leadership of the group and the proposed aims of the group.

The aim of this small-scale study entitled 'What matters in recovery: Adults with an Eating Disorder who have never attended an ED Self Help Group' was to:

- Understand the experiences of individuals who have never attended an ED SHG,
- Explore the possible reasons why they have never attended an ED SHG and to see whether attending an ED SHG was something they would consider engaging with
- Gain insights into their experiences of what matters in recovery.

7.2 Methodology

This section is about the design of the study and includes information about how the study was created.

7.2.1 Research design

The online prevalence survey was created to collect the data which entailed participants answering ten questions which are contained within Appendix 4.18 with opportunities for participants to add qualitative comments. Table 7.1 (overleaf) provides an overview of how the survey was structured.

Ethics

Before any data were collected, full ethical approval was sought and approved by the University of Hertfordshire's Health and Human Sciences Ethics Committee with the protocol number of LMS/PGR/UH/04873 (see chapter four for further details).

Table 7.1: Overview of survey questions

Question Focus	Detail
Demographic data	-To capture background data about: - age, gender and ethnic group (using ONS descriptors) - ED diagnosis and mental health and other related issues
Access to support	-To find out what access there is to: - informal support - formal support
Recovery	-Identical questions that were used in Study 2 about experiences of recovery with the exception that 'not applicable' was added to the Likert scale to act as a way of comparing this group with the study 2's participants' responses to see if there are similarities and/or differences.
Attending an ED SHG	-To understand the reasons for not attending an ED SHG. -To explore considerations of possibility of attending an ED SHG

Recruitment

Recruitment posters invited anyone aged 18 or over who had an experience of an ED but who had not attended an SHG to contact the researcher. These posters were advertised in a variety of places such as: social media such as Facebook, Twitter, and LinkedIn; ED Networks including the national ED charity BEAT and British Eating Disorders Society. This took place over 18 months.

7.3 Results

All data have been rounded up to the nearest whole number so there may be rounding errors.

7.3.1 Participants

There were 31 participants (n=29 completed all questions and n=2 opted not to complete the last two questions pertaining to recovery and non-attendance at an ED SHG). All data were included as part of the analysis.

Demographics

Table 7.2 outlines the demographic constituency of the participants.

Table 7.2: Demographic data

Gender	frequency	%
Male	4	12.9
Female	23	74.2
I would prefer to describe my gender myself	2	6.5
prefer not to say	2	6.5
Age band	**frequency**	**%**
18 to 24	13	41.9
25 to 34	13	41.9
35 to 44	3	9.7
over 55	2	6.5

Ethnic description	frequency	%
White English/Welsh/Scottish/Northern Irish/British	20	64.5
White Irish	3	9.7
Any other White background, please describe	5	16.1
Mixed/Multiple ethnic groups: White and Black Caribbean	1	3.2
Asian/Asian British: Pakistani	1	3.2
Black/ African/Caribbean/Black British: Caribbean	1	3.2

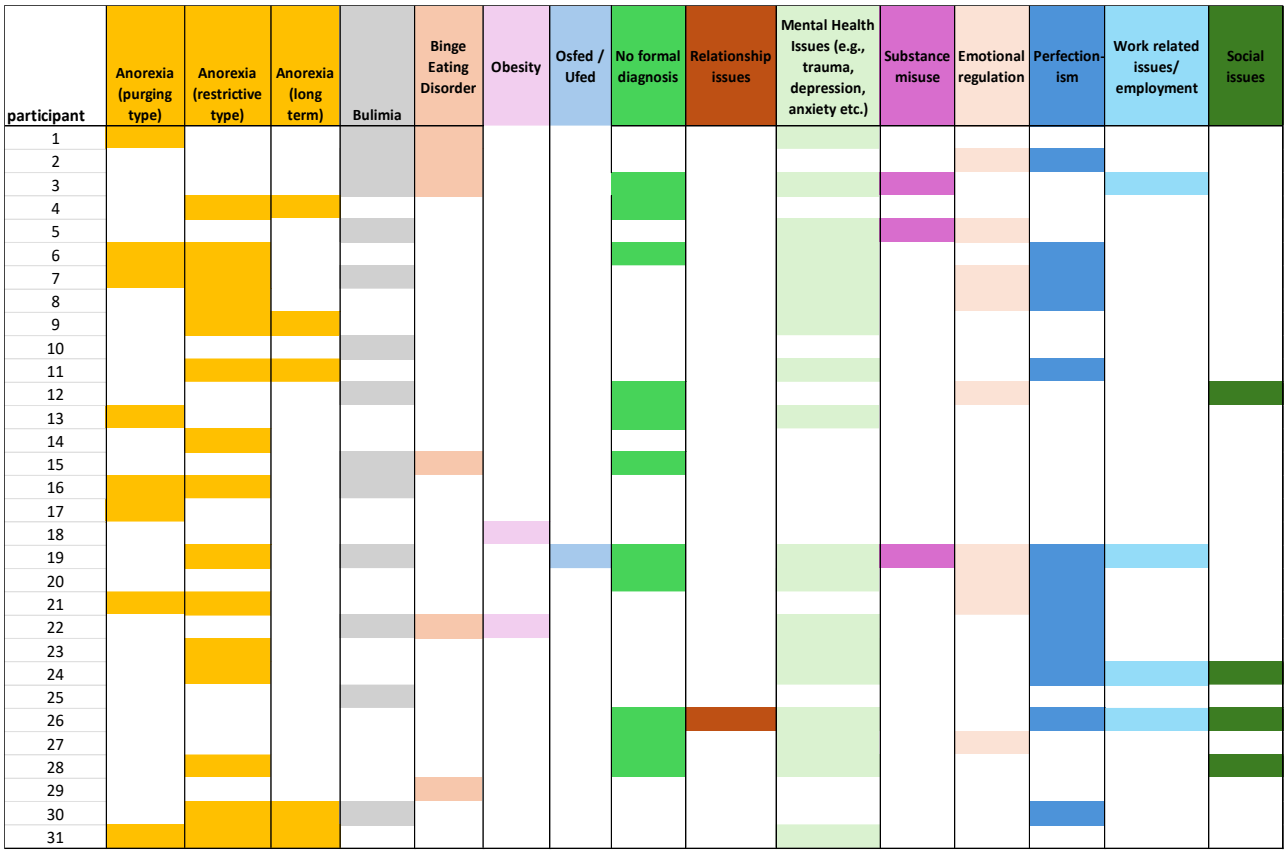
The participants were mainly female and situated predominantly in the 18-24 and 25-34 age bands. Additionally, they were mainly white (74%, n= 23) if White English/ Welsh/ Scottish/ Northern Irish/ British and White Irish were combined. The other White background 16% (n=5) were: Ashkenazi Jewish, German, French, Polish and white European. The remaining 10% included 1 person for each of White and Black Caribbean, Asian (Pakistani), and Black British (Caribbean).

Some of the questions included a free text box for respondents to add any qualitative comments. When this applied some of those comments have been included to further support the analysis of the quantitative data.

Participants' ED diagnosis and other related issues

Table 7.3 provides an individualised visual overview for each participant. It shows that 81% (n= 25) of the participants self-reported as having more than one ED diagnosis (this was not contingent on an official clinical diagnosis), 16% (n=5) as having one ED diagnosis (AN x 3, obesity x 1, bulimia x 1), and one participant as having no formal diagnosis. Four participants added separate entries under the 'other' category.

Table 7.3: Participant ED diagnosis and other related issues



participant	Anorexia (purging type)	Anorexia (restrictive type)	Anorexia (long term)	Bulimia	Binge Eating Disorder	Obesity	Osfed / Ufed	No formal diagnosis	Relationship issues	Mental Health Issues (e.g., trauma, depression, anxiety etc.)	Substance misuse	Emotional regulation	Perfection-ism	Work related issues/ employment	Social issues
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3															
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In addition, Table 7.4 provides an overview of the types of ED that the participants as a cohort ticked. It indicated that many of the participants ticked more than one choice as regards type of ED. What is not clear is whether the participants had multiple diagnoses over a period, or they were unsure of what type of ED they had been diagnosed with. The participants who ticked a named ED e.g. AN and no formal diagnosis may be indicating that they have self-diagnosed themselves as having the specific ED or they had a time when they had no formal diagnosis.

Table 7.4: ED diagnoses

ED diagnosis	N	N	%
Anorexia (purging type)	**7**	**28**	**43**
Anorexia (restrictive type)	**16**		
Anorexia (long term)	**5**		
Bulimia	13		20%
Binge Eating Disorder	10		15%
Obesity	2		3%
Osfed/Ufed	2		17%
No formal diagnosis	11		17%
Total	66		101%

The choice of ticking other MH issues was designed to gain an indicative understanding as to whether the participants had other co-occurring conditions related to their MH. There were other named choices such as emotional regulation and perfectionism in addition to work related and social issues (see Table 7.5).

Table 7.5: Other related issues

Other related issues	n
Relationship issues	2
Mental Health Issues (e.g., trauma, depression, anxiety etc.)	18
Substance misuse	3
Emotional regulation	9
Perfectionism	13
Work related issues/employment	4
Social issues	4
Environmental issues	0
Other (please specify)- conditioned mentioned by participants ‘Body dysmorphia’; ‘RSD’, ‘Autistic + ADHD’; ‘homelessness’; ‘diabulimia’; ‘autism’	4

MH is an all-encompassing term which may explain why it scored the highest out of all the concerns when considered in isolation. Moreover, MH with emotional regulation when grouped together, accounts for the most pressing concern. Most of the participants who had ticked perfectionism also had a diagnosis of AN (11/13, 85%). Work/employment related issues did not feature strongly. Perhaps it may have been due to participants not being in employment or them having found a way of managing their ED in the workplace. Social issues appeared not to be a concern for the participants which seems at odds with research which has noted the social isolation that many individuals with an ED experience.

7.3.2 Support

This section addresses the type of support that participants identified that they accessed or

Informal support

When the choices that the participants were offered were grouped into 'new categories' the results showed that social media was the most popular form of informal support (see table 7.6). The results also showed that close people was another popular form of informal support. There appeared to be an underlying theme of connections either through social media or close people. In addition, education (self help books) is another important source. The 'other' category comments revealed that some participants potentially did not access informal support, and that friends/people were an important source of support.

Table 7.6: Informal Support that has been accessed

Choice	New grouped category	N	% (including 'other')
Instagram	Social media	15	35%
Facebook		4	
Twitter		7	
Self Help Books	Books	7	14%
Other books not self help		3	
Eating Disorder Charity e.g., BEAT, ABC	Charity	5	8%
BEAT; BEST CCI; First Steps x2			
Mental Health Charity e.g., Mind, Sane		1	
Family e.g., parent(s), Carer(s), sibling(s) etc.	Close people	7	18%
Partner e.g., husband, wife etc.		6	
Recovery Coach		1	1%
Employer		1	1%
University wellbeing service		2	3%
Work colleagues		1	1%
Pro Ana Websites		3	4%
Other (please state below) A couple of friends; Friend; Friends, but I didn't seek support during my eating disorder, Other autistic women that I have met through social media therapist x3, nowhere, none Tumblr Generalised support website (7 cups of tea), and Centrepoint		11	9% (friends/ people/ therapist) 3% (no one) 3% (other sources)
		74	

Professional support

Participants were offered ten options to choose from. Table 7.7 shows that talking therapy accounted for 58% of the count when collating counsellor (15%), psychotherapist (16%), psychologist (11%) and CBT therapist (11%) together followed by GP support (26%). This was followed by specialist ED treatment with 21% when grouping specialist ED therapist (5%), ED inpatient treatment (5%) and ED outpatient treatment (11%) together.

Table 7.7: Professional Support that was accessed

Type of professional support	N	%
Counsellor	9	15
Psychotherapist	10	16
Psychologist	7	11
CBT therapist	7	11
Specialist ED therapist (Please say a little more below). -Family therapist; talking therapy via ED project (TH)	3	5
GP	**16**	**26**
Dietician	7	11
ED inpatient treatment. (Please say a little more if you wish to below). -In general hospital for ng feeding, not edu	3	5
ED outpatient treatment. (Please say a little more if you wish to below). -I had both outpatient and day hospital treatment; I was part of an outpatient surgery but refused treatment; Day patient group; Day patient services; CAMHs support as a 16–18-year-old,	7	11
I am on a waiting list for specialist ED treatment. How long have you been waiting? (Please say a little more below). -8 months waiting list for NHS. Was rejected over the BMI at first as was still in healthy range (all be it at the lower end) but hair was falling out, constantly cold, brain fog, sleep issues, then I started to pay for my own counsellor, but she isn't an ED specialist. My GP referred back in and now have been accepted but waiting on the list; 1 week; 9 months; 16 months	4	6

7.3.3 Recovery

There were 31 participants who were able to answer the question (Appendix 7.1: The 24 recovery statements). Due to the design of the question with the inclusion of not applicable on the Likert scale, 14 responses were recorded as missing as they did not have full responses to all statements that could be coded. This left 17 participants who had 'valid responses' i.e., a full set of scores for every sub question which could be analysed.

Participants in the current study were asked the same questions about recovery as participants who had attended an ED SHG (see study 2, chapter six). This was to enable a direct comparison of their recovery experiences. The PCA outputs from study two which generated seven recovery factors (see Table 7.8) from the 24 recovery statements were used to code the responses of the current study's participants' responses.

Table 7.8: Recovery factors generated from Study 2

Factor	Revised Factor name	Original statements	Definition
1	Impact on self	1,2,3,11,12	Experiencing the benefit of recovery on own life and seeing a reason to recover.
2	Self-recognition	4,5,12,22,24	Acknowledging the less than positive impact of ED has/had on living a full life, and the ups and downs of recovery.
3	Struggles	13,15,16,17,19	Having ongoing struggles with managing ED behaviours and thoughts, as well not knowing what full recovery is/was.
4	Freedom to eat	6,7,8,14	Eating without compensatory behaviours to mitigate for it but being mindful that recovery is an ongoing process.
5	Weight and calories	20,21,23	Engaging in ED behaviours concerned with weight and calorie record keeping
6	Behaviours	10,18	Being sick of being ill, restricting and purging.
7	Sustaining recovery	9,22	Difficulties of sustaining recovery and the fear attached to weighing self.

This generated means and standard deviations for each factor for both sets of participants, enabling an independent sample T-test to be performed using SPSS to compare the two different datasets (see Table 7.9). The means showed that those who had not attended an ED SHG positively rated the 24 statements in comparison to those who had attended an ED SHG where all means were negatively rated. Furthermore, Table 7.9 includes Levene's Tests for equality of variances which found that two of the recovery factors ('Freedom to eat' and 'Behaviours)' did not have equal variance which also showed that the degrees of freedom (df) figure were not whole numbers. Cohen's d for effect size was used, showing a large effect size for weight and calories and lower effect sizes for 'Self-recognition' and 'Struggles', with the remainder showing a medium effect size.

Table 7.9: T-test

	Mean		**Standard Deviation**		**Levene's Test for Equality of Variances**		**t-test for equality of means**		**Effect Size**
Recovery Factor Names	**Not attended ED SHG** (current study)	**Attended ED SHG** (study 2)	**Not attended ED SHG**	**Attended ED SHG**	**f**	**sig**	**t**	**df**	**Cohen's d**
Impact on self	.0948	-.3117	.60213	.58444	.010	.922	3.166	104	.58926
Self-recognition	.6207	-.6916	.33421	.40331	.449	.504	15.606	104	.38593
Struggles	.9224	-.6857	.13731	.50307	17.958	<.001	25.630	98.572	.43591
Freedom to eat	.1437	-.1786	.53494	.58046	.743	.391	2.601	104	.56856
Weight and calories	.4023	-.1818	.72034	.71235	.022	.882	3.752	104	.71451
Behaviours	.3214	.2078	.76029	.59797	4.206	.043	3.328	39.798	.64449
Sustaining recovery	.7069	-.4286	.52640	.59997	1.583	.211	8.969	104	.58108

a. Equal variance assumed except for 'Freedom to eat 'and 'Behaviours' so adjustments were made.
b. Reference range for effect size : 0.2 (small), medium (0.6) and large (0.8) (J. Cohen, 2013)

There were 17 qualitative comments (see Table 7.10) that the participants made in relation to how they experienced recovery. Grouping them under three broad areas: revealed that despite the positive rating of the recovery statements the participants experienced difficulties with their recovery and were ambivalent towards the idea of recovery and how it felt out of reach for some support.

Table 7.10: Recovery Qualitative Comments

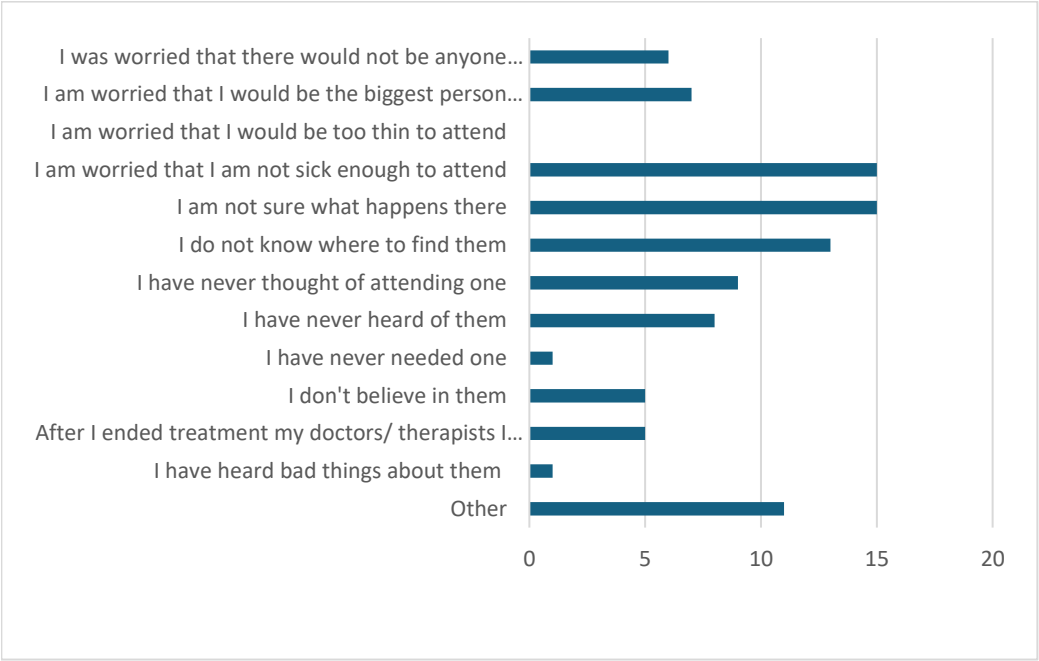
Theme	Qualitative Comments
recovery as something that is not attainable	-I don't know if I have ever been in a recovery. Life seems to be a vicious circle -I will never be recovered. I will always vomit when I've binged. It won't end. -I believe recovery is incredibly personal. For me recovery means maintaining a weight and eating at a level that keeps me out of hospital. I discharged myself from services before being weight restored and have absolutely no interest in being weight restored. I am perfectly content keeping my disorder at a point where I am still actively engaging in behaviours but not to a point that I can't function in everyday life. -I have not managed it yet. As I have never received help, I swing between eating normally and not depending on life happenings. -I don't ever see a time where I'll be fully recovered, I think there will always be residual thoughts and hyper awareness.
The ongoing nature of the struggles and challenges of recovery	- Without my support I wouldn't know how to cope whilst waiting for the NHS -I thought I had almost got to 'recovered' but then the pandemic and other life stuff happened, and I found myself resorting to ED behaviours again. I think I will probably always be 'in recovery' but how active this is/how much effort it takes etc will fluctuate -It feels very challenging, especially with the weight gain and people assuming you're 'better' -Ongoing struggle since 16 years old varying intensity. Sometimes binge eating sometimes bulimia and calorie counting. Not always debilitating. Triggered by stress -It's hard with no support network and everyone just sees the happy you, but you are crumbling inside, especially with the stresses of studying -It's early days and I'm realising it's not linear. I'd just started to go out with friends for food- often preparing by looking at the menu ahead of the event. Now calories are on menus that's stopped me going now. I feel like I'm so easily triggered. -It is a continuous battle and sometimes very difficult to stay focused and remember why I began my recovery journey in the first place -Not a linear journey. Very much ebb and flows. -There is a history of bulimia in my family. Part of my ongoing recovery was finding other autistic women who experienced body dysmorphia and the shared experience of ED alongside neurodivergence. Many of my ED issues include sensory processing difficulties, and interoception (so I cannot tolerate the feeling of being full).
Reluctance of recovery	-It feels forced almost like recovery isn't the way I want to live -I had an ED as a result of sexual assault leading to control issues. I was very against recovering because I liked it and liked the control- it took a partner expressing concern for me to try and recover. Now, a few years on, I only get the urge to restrict or purge when going through times of acute stress. -I found it difficult to accept recovery as I found it difficult to let go of restrictive eating. It was a mechanism of control, and I felt it was keeping other aspects of my mental health under control. I still don't know how I recovered as I refused all formal help and was often in denial.

7.3.4 Attending an ED SHG

Reasons for non-attendance

Figure 7.1 below presents the results.

Figure 7.1: Reasons for not having attended an ED SHG (quantitative results)



Reasons	N	% (excluding 'other' category)
I was worried that there would not be anyone there like me	6	7%
I am worried that I would be the biggest person there	7	8%
I am worried that I would be too thin to attend	0	0
I am worried that I am not sick enough to attend	15	18%
I am not sure what happens there	15	18%
I do not know where to find them	13	15%
I have never heard of them	8	9%
I have never thought of attending one	9	11%
After I ended treatment my doctors/therapists never suggested I attend one	5	6%
I have never needed one	1	1%
I don't believe in them	5	6%
I have heard bad things about them	1	1%
Other	11	

Grouping some of the choices under four new subheadings (see Table 7.11) revealed that 'uncertainty about an ED SHG' accounted for the largest proportion of the count at 42%. This was followed by 'being worried' (33%), 'not a consideration' (17%) and 'ideology' about ED SHGs (7%).

Table 7.11: Reasons for not attending an ED SHG under grouped sub headings

Sub heading name	Choices	% count	Total % count
Uncertainty about an ED SHG	I do not know where to find them I have never heard of them I am not being sure what happens there	15% 9% 18%	42%
Being worried	I am worried there would not be anyone there like me I am worried I would be the biggest person there I am worried I am not sick enough	7% 8% 18%	33%
Not a consideration	After I ended treatment my doctors/therapists never suggested I attend one I have never thought of attending one	6% 11%	17%
Ideology	I don't believe in them I heard bad things about them	6% 1%	7%

There were 11 qualitative comments in the 'other category' to support the quantitative data (see Table 7.12). These comments have been grouped into three broad strands: 'shame', 'recovery', and 'resistance and reluctance'.

Table 7.12: Reasons for not having attended an ED SHG (qualitative comments)

Strand	Comments
Shame	-shame/fear that recovery means gaining weight, which I cannot envisage ever feeling happy about. -I am ashamed of myself. - There are none in my area - also I feel because of my age (41) that I'd be the oldest there. I live in the XX of the UK where there doesn't appear to be any groups. I would consider online group with people of similar age. I also feel ashamed because I'm a teacher and foster carer and worry I'd be judged or if a parent of a child I teach was there or an ex-student. It feels safer online because I can choose whether to have my camera on in the first instance.
Recovery	-Full recovery is encouraged too much and being in partial recovery and being perfectly fine with being there is looked down on/discouraged. -I felt too young at the time when it would have been most useful, now I feel 'too recovered' to engage in ED spaces. -Actively didn't want to recover, it made me feel safe and in control.
Resistance and reluctance	-Until recently, I denied having an ED. Perhaps harder to access without a formal diagnosis. -I was resistant to accepting I needed help. -Not something I culturally I felt I could talk openly about. -I don't want to gain weight. -I don't want to share details of my lifestyle.

Attending an ED SHG: consideration of attending one

Table 7.13 shows that there was an almost equal split between those who would consider attending an ED SHG versus those who would not.

Table 7.13: Outcomes of participants who would consider attending an ED SHG

Response	Frequency	Percent	Valid Percent
Yes (please tell us why)	13	41.9	44.8
No (Please tell us why)	12	38.7	41.4
I would rather not say	4	12.9	13.8
Total	29	93.5	100.0
Missing responses	2	6.5	

An exploration was carried out to see if there was any overlap between those who would consider attending versus those who would not attend (see Tables 7.13 and 7.15 overleaf). This revealed two overlapping core reasons which scored highly were selected by participants who would or would not consider attending an ED SHG (see Table 7.14).

Table 7.14: Reasons for not attending an ED SHG and consideration of attending an ED SHG

	I am not sure what happens there	I am worried that I am not sick enough to attend
Yes, I would consider attending an ED SHG.	7	9
No, would not consider attending an ED SHG.	6	6

Table 7.15: Cross tabulation of reasons for not attending and YES, would consider attending (participants)

Participant identifier	I have never heard of them	I was worried that there would not be anyone there like me	I was worried that I would be the biggest person there	I am worried that I am too thin to attend	I am worried that I am not sick enough to attend	I am not sure what happens there	I do not know where to find them	I have never thought of attending one	I have never needed one	I don't believe in them	After I ended treatment my doctors/ therapists never suggested I attend one	I have heard bad things about them	other
3			1		1	1	1				1		
5							1						1
6													1
9	1				1	1	1	1					
11													1
12	1		1		1	1	1	1			1		
13		1			1								1
14		1	1		1	1							
17			1		1		1						
18					1	1	1				1	1	
19	1				1	1	1	1					
20							1						1
28	1				1	1	1	1					
	4	2	4	0	9	7	9	4	0	0	3	1	5

Table 7.16: Cross tabulation of reasons for not attending and NO, would consider attending (participants)

Participant identifier	I have never heard of them	I was worried that there would not be anyone there like me	I was worried that I would be the biggest person there	I am worried that I am too thin to attend	I am worried that I am not sick enough to attend	I am not sure what happens there	I do not know where to find them	I have never thought of attending one	I have never needed one	I don't believe in them	After I ended treatment my doctors/ therapists never suggested I attend one	I have heard bad things about them	other
2		1											
4	1				1	1	1	1	1				
8		1				1							1
10			1										1
15					1	1		1		1			1
16	1					1	1	1					1
21										1			1
23		1			1	1				1	1		
24										1			
25			1		1						1		
26			1		1			1		1			1
27					1	1	1	1					
	2	3	3	0	6	6	3	5	1	4	2	0	6

As regards the qualitative responses (Appendix 7.2: all qualitative comments), the recurring reasons cited by those who said yes, they would consider attending an ED SHG was linked to support ('I feel the group environment can be really supportive', 'To gain support and to feel less alone') and a way to connect to others ('Good way to connect with support and people who understand, constant support'). For others it was about adding in extra support on top of existing or previous support ('I've recently been using twitter a lot for support/hearing other people's stories', 'I think attending a support group would be helpful way to connect and engage with people who have had similar experiences', 'I could still use a support system for when I have wobbles with my ED').

For those who stated no, there was a belief that the group was not the right thing for them because it might be harmful due to competition ('for me a self-help group would possibly turn into a competition of who was the sickest, and if others were worse than me I would strive to be the sickest rather than getting better') or an idea of needing to be ready for the group ('I need to lose weight first'). For some there appeared to be a clarity about a group not being a helpful or useful place for them due to 'I don't think I would find it useful'. For others it seemed linked to where they were in their own recovery journey, for they felt that they were 'fully recovered now' or being 'past the point where it would be most beneficial for me. I am coping with recovery on my own now'.

7.4. Discussion

The aim of this current study was to investigate some of the reasons why individuals with an ED have not attended an ED SHG or whether they would consider attending one, in addition to understanding what matters in recovery.

7.4.1 Findings

The core findings of the results demonstrated that two of the most popular reasons non-attendance at the group was about the lack of information about what happens inside a group and feeling not sick enough to attend. When considered alongside whether participants would or would not attend an ED SHG the results showed that those two reasons scored highly.

Moreover, the current study builds on earlier research (see chapter six) which identified the importance of making others aware of the existence of ED SHGs; using the internet to find the group was the most popular method of finding one. By contrast not knowing where to find an ED SHG accounted for 15% of the responses in the current study. Furthermore, uncertainty about what happened inside an ED SHG was a highly scored reason for non-attendance, with 42% of the count indicating this. Comparably, the chapter six study observed that participants delaying entry to their ED SHG between one week and one year (table 6.5).

In the current study the participants highlighted that none of their professionals suggested an ED SHG. There could be several reasons for this such as professionals not

knowing about them, feeling potentially undermined, or seeing a perceived threat to their position as the knowledgeable one (Constantino & Nelson, 2009; Salzer et al., 2001; Seebohm et al., 2013). By contrast others have noted the value of ED SHGs alongside existing professional support such as Bolzan et al. (2001) and Yalom & Leszcz (2005).

Furthermore, the participants had access to or accessed a range of professional support such as their GP and ED specialist input in addition to informal support with social media being the most popular. However, four indicated that they were on a waiting list.

Findings from the current study showed that those who had not attended an ED SHG positively rated the recovery statements whilst those who had attended SHGs negatively rated them (see chapter six). It is important to note that no baseline of what the starting point for recovery was taken for either group of participants. Therefore, it is not clear where they were in their recovery journey. What can be inferred is that being in self help means they are in receipt of informal support through the group. Perhaps those who did not attend an ED SHG were at a better stage in their recovery. However, the qualitative comments (see Table 7.12) would suggest otherwise as many cited ongoing struggles, challenges and a view of not wanting to recover.

The analysis of the results has been organised thematically to focus on the core findings from the data. Therefore, the findings will address three strands:

- Reasons for not attending an ED SHG: not being sick enough to attend
- The potential benefit that a group might offer
- Experiences and views of recovery

Reasons for not attending an ED SHG: not being sick enough to attend

In the current study some participants appeared to think they needed to be more severely ill or have a lower weight to seek an ED SHG. They identified that not being sick enough was a reason not to attend. This may have come from experiences of seeking treatment where body weight has been a barrier for individuals seeking support for their ED, as some have been turned away for treatment due to their BMI not being low enough to meet the threshold for specialist ED treatment. This was something that some participants in the current study commented on. This adds to the ongoing discourse about BMI being used as a criterion for treatment. For example, Hamilton et al.'s (2022) research regarding access to treatment noted that individuals with an ED who had a BMI within the normal range category had a three times longer wait to get treatment in addition to clinicians holding negative biases towards such individuals. Similarly, participants in a study by Eiring et al. (2021) shared how others close to them did not believe that they had an ED and that their weight was a factor in whether they were able to access treatment. Comparably, participants in another study expressed a fear of their problems not being taken seriously by professionals either because they did not ask about their concerns, or that they did not look ill due to not having a low enough body weight (Evans et al., 2011).

By contrast, guidance published by NICE has advised that 'BMI or duration of illness' should not 'determine whether to offer treatment for an eating disorder' (NICE, 2020, p. 11). However, despite this, media reports such as an article in the Guardian online in 2021 would suggest that this guidance is not being adhered to. In this featured newspaper article, Agnes Ayton, chair of the Royal College of Psychiatrists' ED faculty raised concerns that BMI is being used as way to decide who gets access to treatment. The use of BMI to decide who receives treatment may explain why some of the participants in the current study felt that they needed to lose weight before they would attend an ED SHG; they may have had personal experiences of being turned away from services. Some commented on the fact that they were still on waiting lists.

Moreover, a feeling of not being sick enough could potentially be likened to the anorectic voice. This has been defined as a critical internal dialogue, an accepted feature noted in EDs (see Pugh, 2016) who provided a useful overview of the research base and how understanding of this has developed). Notably, the demographics of the current study's participants showed that the vast majority had had a diagnosis of AN. Moreover, the current study's findings contribute an extra dimension to the existing research body of knowledge in this area, as the perspective was gained from participants who had not attended an ED SHG. It concurs with existing research, such as a study carried out by Waller et al. (2020) who found the some participants who had attended a professionally-led ED support group had expressed feeling impacted by the body sizes of other members, leading to direct self-comparison.

Experiences and views of recovery

The current study expands on and challenges the notion of the perceived benefits of social support within a non-professional context such as an ED SHG. Some of the participants in the current study expressed a fear that if they attended an ED SHG, they would be required to be pro recovery. These findings echoes existing research about the notion of partial recovery noted in various studies such as Bohrer et al. (2020) who found that some of their participants described themselves as being partially recovered.

Additionally, the current study is in accordance with research about the ambivalence that some individuals with an ED felt about recovery such as not believing they would ever fully recover which was sometimes linked to the ED voice or fears about being made to gain weight (Jenkins & Ogden, 2012; Pugh, 2016; Pugh & Waller, 2017). Moreover, this implies that some of the current study's participants possibly held a preconception that ED SHGs were places that *forced* them to recover. This aligns in part with research that has documented that some patients receiving ED treatment relapse because they struggle with some aspects of what is expected of recovery such as weight restoration and maintaining a weight that clinicians feel indicates recovery (Bell, 2013; Fox et al., 2011; Guarda et al., 2007).

Building on this idea further, some participants in the current study expressed a lack of readiness to recover, not wanting to recover and not believing that they would ever recover. These perspectives contribute to the literature base about relapse and recovery such as Grilo et al. (2012); Keel et al. (2005); and Kordy et al. (2002). By contrast, elaborating further on the earlier discussion about not being sick enough to attend an ED SHG, the current study's participants also indicated that they were sick of being ill. This supports existing research such as Federici & Kaplan (2008) who found that their participants were sick of being ill and were motivated to get better. Likewise, Pettersen & Rosenvinge (2002) also noted the same and that their participants were motivated to get better to improve their lives.

The potential benefit that a group might offer

Although participants in the current study had never attended a SHG, some indicated a willingness to consider attending an ED SHG believing that it potentially offered a space where they might 'gain support'. This reinforces existing research such as that of Pettersen & Rosenvinge (2002). Like the participants in the current study, their participants identified the positive benefits of being amongst others with an ED, as they felt understood by others in the same situation as themselves, and that seeing others in recovery offered them hope. This is further echoed in the breadth of research about the value and importance of social support for recovery, (for example, de la Rie et al., 2006, 2007; Federici & Kaplan, 2008; Linville et al., 2012). Furthermore, the participants in the current study believed that an ED SHG might offer them somewhere to help to lessen isolation and help them connect with others. This is in accordance with research about the value of support groups such as the research of Ki (2011), set within an arts based support group for adults living with ED, where the participants described a sense of feeling of being connected, belonging, and feeling welcome within that setting.

7.5 Implications

The findings have raised two broad implications.

Promotion of groups

The first implication is how to raise the visibility of ED SHGs with a view to demystifying what happens inside of them. One way is through social media, as it was the most popular form of informal support identified by the participants in the current study. Positioned alongside this is a potential opportunity to capitalise on the 45% of participants in the current study who would consider attending an ED SHG. Moreover, this research can contribute to the demystification of what happens inside a group alongside the previous two studies. This can be achieved through attendees sharing the perceived benefits of attending and how it felt making that initial step to attend. In addition to the personal challenges, some experienced internalised barriers, for example hesitancy around attending and feeling not sick enough to attend.

As noted in the previous study the promotion of recovery via online platforms and individuals sharing their stories has grown (section 3.3.3). More recently researchers and mental health campaigners have raised concerns about the negative impact and potential harm of social media platforms, particularly ones that are 'image-based' on the mental health of children and young people (Au & Cosh, 2022; Dane & Bhatia, 2023; Saul et al., 2022; Vandenbosch, 2017). Linked with this is the fact that social media companies are aware but do not appear to engage with such concerns and in some cases potentially exacerbate the issue through their use of algorithms (Harriger et al., 2022; Raffoul et al., 2023). Criticism is not only of social media platforms but also applies to fitness and health apps such as MyFitnessPal, which have proved triggering for some individuals with an ED, negatively impacting on their recovery as borne out in the research of Eikey (2021) and Pater et al. (2019).

Expanding further upon this debate is research about how to mitigate for the harm that social media may cause. Authors such as Mazzeo et al. (2024) examined research regarding interventions that had been attempted. For example, the research of Guest et al. (2012) around the use of an appearance game with 259 mainly white children in the UK. It was found that the game did not yield any changes in areas such as body appreciation. Furthermore, much of the research around interventions is skewed towards US females and white individuals to the exclusion of minority ethnic groups (Mazzeo et al., 2024).

Another approach has been social media literacy such as a pilot study (involving teenage girls) which was carried out by McLean et al. (2017). They found that it had the potential for mitigating for some of the risk factors for developing an ED, as their participants showed some positive changes as regards body image and esteem. Building on this further is the idea of integrating questions about ED patients' use of technology as part of the initial assessment and their treatment. Pater et al. (2019), as a part of their research, expressed concern and surprise at the fact that this was not a part of clinical practice. Thus, this is an important consideration too for facilitators in terms of how they manage conversations about social media and fitness and diet Apps amongst attendees, whilst ensuring a safe recovery space for all that is not triggering.

Nevertheless, there are opportunities for facilitators of ED SHGs to offer psychoeducation around safe recovery, despite the possible apparent dissenting voices of other communities such as pro ana websites which for some possible attended of groups is a reality. A study by Firkins et al. (2019) provides useful insights about how the study's participants 'disengaged' from such sites and their sense of loss at leaving a community which offered them much, their shifting identity, and a lingering need to still visit the site despite deciding on recovery. ED SHGs can provide a different community which offers an alternative perhaps safer voice around ED recovery.

Furthermore, as most of the participants in the current study had access to professional support it would be prudent for ED SHG facilitators to try and foster collaborative relationships with professionals. However, many ED SHGs operate

independently with limited or restricted budgets so outreach work may represent a financial barrier.

ED and Autism

The second implication pertains to autism. Several participants in the current study indicated that they were autistic. There has been a growing body of research about the link between AN and some of the traits often associated with autism. For example some of the key findings of a review of literature carried out by Carpita et al. (2022) noted that the autistic traits were more pronounced and evident in people with AN (see Huke et al., 2013) whose review of eight studies noted this prevalence but also identified that there were limitations as to how individuals had been screened for autism). By contrast however, there has been an ongoing debate as to whether the autistic behaviours are attributable to the impact of starvation or a combination of both (Carpita et al., 2022; Kerr-Gaffney et al., 2021). Additionally, Mandy & Tchanturia (2015) have questioned whether issues around social and flexibility difficulties in patients with EDs is genuinely autism or undiagnosed autism. The author of the current study, drawing on their 30 years expertise in running an ED SHG has found that autistic attendees in the past have displayed hesitancy around attending due to their diagnosis, sometimes predicated on their negative experiences in seeking help and their autism not being understood by gatekeepers and those assessing their treatment needs.

7.6 Suggestions for future research

The current study has opened several trails which would merit deeper exploration. For example, researching the experiences of those who run ED SHGs such as facilitators to better understand who they are and the type of support and training they receive or have received. This area of research seems absent. Furthermore, this could be broadened to examine how facilitators advertise their groups and the relationships they have with professionals or other services. Additionally, researching the lived experience of individuals with autism who have attended an ED SHG, exploring the positive and less than positive experiences is another potential area to pursue. The findings of such research could inform possible attendees and facilitators.

7.7 Strengths and Limitations

The results of the current study raised several limitations. The first relates to the small study size which means that no generalisability can be applied to a wider population. Secondly, the demographics of the participants. The cohort was mainly female with men accounting for 12% of the cohort size which is lower than most recent estimates putting it at 25% (BEAT (n.d)). By contrast Mangweth-Matzek (2024) have asserted that EDs are rare in men. However, the data from the current study could be deemed to be in keeping with other data which has the estimate at 10% (Robinson et al., 2013; Sweeting et al., 2015; Weltzin et al., 2005). Additionally, most of the participants in the current study identified as white; this is in keeping with existing research. For example Waller et al. (2009) noted in their research

that people from groups such as those from an afro Caribbean background were underrepresented in ED services relative to the proportion from a white background. Notably, many of the participants had some form of AN diagnosis which may have possibly skewed the answers to some of the questions.

A key strength of this current study is the uniqueness of the research in finding out why individuals with an ED have never attended an ED SHG, the reasons, and potential ways to address this. To the author's knowledge there has not been such a study. The second strength pertains to the small cohort size. This meant that a more granular approach to tracking participants' responses across questions was possible. The third pertains to recovery and being able to directly compare experiences of recovery from two distinct groups; those who have attended an ED SHG and those who had not. The findings added a novel perspective to the debates around what matters in recovery; raising the question of at what point in recovery might someone with an ED seek informal support for themselves.

7.8 Conclusion

The current study sought to ascertain what some of the reasons were as to why individuals with an ED did not attend an ED SHG. What was found was that the main reasons why they did not attend lay with not knowing enough about the groups in terms of their existence, what happens inside an ED SHG and whether they were ill enough to attend. However, despite this, a significant proportion did identify that they would consider attending one and were able to articulate how it might benefit their recovery and social functioning, this seemed linked to their stage of recovery. Therefore, it is important that professionals and individuals with an ED are fully educated about all aspects of an ED SHGs and how to find one.

Key findings

Barriers to entry:

- Personal perceptions about validity of being 'allowed' to attend e.g. not believing that one is sick enough.
- Not knowing that ED SHGs exist or where to find them.
- Uncertainty about what happens inside an ED SHG and where to find them.
- A belief that ED SHGs promote recovery.
- A reluctance to get better due to not wanting to gain weight and resistance to accepting help.

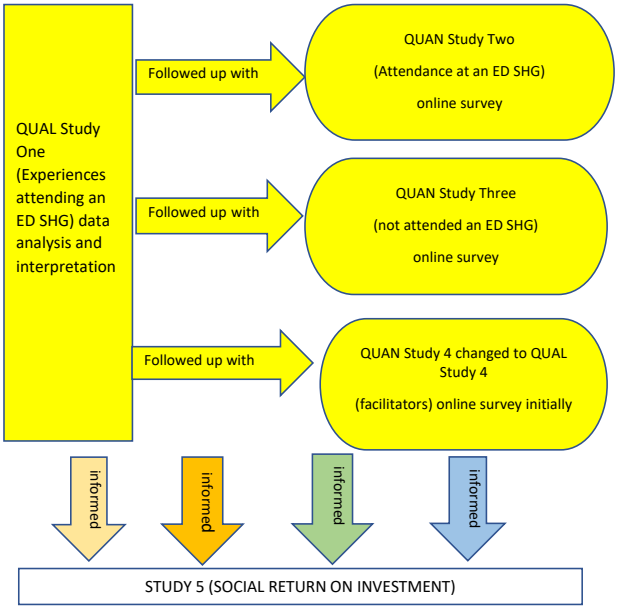
Chapter 8: What matters in recovery: Exploring facilitators' perspectives of Eating Disorder Self Help groups (Study 4)

8.1 Overview of Study

The research title for this study is 'What matters in recovery: Exploring facilitators' perspectives of Eating Disorder Self Help groups'. With a rise in the number of individuals with an ED, people with a lived experience of an ED can be a useful resource to support those in treatment (Duvall & Hanson, 2024). Facilitators of ED SHGs can thus carry out such a role. Furthermore, it has been found that facilitators of ED SHGs can play several other important roles within their respective groups such as ensuring the safety for the participants through their management of the group (Waller et al., 2020). Additionally, the review noted that they can provide psychoeducation to its attendees (Peterson et al., 2009; Rathner et al., 1993). Furthermore, they can promote recovery as an ideal outcome (McNamara & Parsons, 2016). What has been clear is that there are no comprehensive studies about facilitators for ED SHGs and what happens in these unstructured and often unregulated groups.

The aim of this study was to understand this role from a facilitator's perspective. It complements the findings from earlier studies (see chapter five) which touched on the value that some attendees attached to the facilitators' own experience of having an ED. It is the next point of integration as per the highlighted boxes in Figure 4.1.

Figure 4.1: Diagram of The Research Exploratory Sequential Design



8.2 Literature Review

Peer mentoring

There is limited literature which uses and features the role of facilitators within an ED SHG. The closest comparable terminology is around the notion of peer mentoring. Moreover, there is a rich body of work within a therapeutic context, which features studies about peer support and mentoring by individuals with a lived experience supporting peers who have the same condition and who wish to have support with their recovery. For example, a study by LaMarre et al. (2024, p. 11) about the ED lived experiences of individuals and carers who were either peer mentors or who were recipients, offered rich insights into the recovery process through these two lenses; identifying 'the inner and outer ingredients of recovery'.

However, often the focus has been on the individual in receipt of support as opposed to the individual offering the support. The number of studies set within an ED context, however, appears to be lacking. Examples of the type of research over and above that which was found in the narrative review (see chapter three) which do exist includes evaluative studies such as pilot studies about peer mentoring (e.g., Beveridge et al., 2019; Hanly et al., 2020); systematic reviews with a focus on lived experience (e.g., Lewis & Foye, 2021; Pellizzer & Wade, 2023); and peer support for parents (e.g., Grennan et al., 2022). None of these reviews noted peer mentoring within an ED support group context. What was important about these studies was the relationships that were built and the value of the lived experience of the person offering the mentoring.

Lived experience and experts by experience

Revisiting the idea of EBE which was discussed in the narrative review (chapter three) is the fact that the Care Quality Commission (CQC) makes use of EBEs to support their inspections of health services (see CQC website). As mentioned previously in chapter three, EBEs have been used to support the education of a range of professions such as nurses to help them gain empathy and to deliver aspects of the curriculum (see Happell et al., 2021, 2022; Horgan et al., 2013) and social workers (see McLaughlin, 2009). Neither context, however, is about EBEs supporting others who need support with recovery. What seems important is a question about how someone with a lived experience positions themselves as an EBE or peer mentor and what constitutes sufficient 'recovery' from a condition before an individual can use their lived experience to support others. Roennfeldt et al.'s (2020) exploration as to 'how much lived experience is enough' provides some useful insights where participants in that study suggested that recovery is not fixed, and it is hard to quantify. Having someone assess is not easy as recovery is a subjective experience. Lewis & Foye (2021) noted that some studies in their systematic review required those who were placed in a position as an EBE or as a peer mentor were required to directly share their own personal experiences of their condition, with some occupying paid positions. Some studies in that review noted how long the lived individual had to have been in recovery, ranging from one year to three years; for example Beveridge et al. (2019) cited one year for their pilot study.

However, Toikko (2016) has suggested that having a lived experience of a condition was not sufficient for someone to be described as an EBE. They suggest that the lived experience combined with other aspects that an individual brings, contributes to an individual's ability to be an EBE such as professional competencies gained elsewhere or as part of their work. Moreover, Pellizzer & Wade (2023, p. 414) assert that it is important not to apply a 'one size fits all model' as regards how long recovery should be before someone embarks on a peer support role. Furthermore, Lewis & Foye (2021) found some safeguards apparent in several studies that formed their systematic review in terms of how to support the wellbeing of those who use their lived experience. These included screening of individuals, psychiatric evaluation, ongoing monitoring, and implementation of wellness plans.

Moreover, there have been debates around the use of practitioners with lived experience working with ED patients to support their recovery, their usefulness, and the potential of harm for both. There is no agreed consensus (Costin, 2002; Johnston et al., 2005; Rance et al., 2010). Research by Johnston et al. (2005) and Audet & Everall (2003) found that clients had concerns about their therapist when the therapist disclosed their ED history with 'overinvolvement' and 'enmeshment' emerging as two concerns. Furthermore, research has found that therapist disclosure enhances the therapeutic alliance (Audet & Everall 2003; Johnston et al., 2005), and acts as a way of 'humanizing the therapist' (Levitt et al. 2016, p. 20). The research of King & Russon (2023) provides further insight into the benefits through the lens of how therapists with an ED lived experience made use of their sense of self when treating patients. The therapist believed that their lived experience affected positive changes for their patients through, for example, their understanding of the non-linearity of recovery based on their own experiences of treatment. This they believed enhanced their working alliance with their patients. However, this can present challenges for practitioners as noted by Maguire (1985) who questioned how doctors and nurses when working with dying patients can provide the necessary care whilst ensuring that their emotional wellbeing is not impacted negatively. This is even more evident if a patient's circumstances echo aspects of their own life outside of the setting. The same could be said for those with a lived experience working with ED patients.

Professionals' Perceptions of Mental Health Groups

Another area to consider is the limited and ill-informed view that some professionals hold about the benefits of SHGs which are run by non-professionals (Borkman, 1976; Salzer et al., 1999). It is unclear how many professionals have participated in an MH group as there are limited studies providing such data. Therefore, as there is a paucity of data about the views that professionals hold about ED SHGs it has been necessary to draw on wider data around MHGs to try and understand the issue, which means that the fuller picture of professionals' views about ED SHGs is not fully understood.

The professionals' views will be examined through two narratives. The first narrative concerns expertise; the lack of professional expertise, and professionals believing that their

expertise is being undermined if the person with the condition takes ownership for their treatment and recovery (Seebohm et al., 2013). The second pertains to the notion that professionals may feel fearful of the potential of harm that groups not led by professionals might do, such as perpetuating the illness and thus helping attendees to remain ill rather than promote recovery (Salzer et al., 2001; Timulak et al., 2013).

The first narrative pertaining to expertise appears to be aligned to a hierarchical view of knowledge where professionals are more likely to respect groups run by fellow professionals, maybe in part due to their view of what constitutes appropriate treatment and recovery (Bolzan et al., 2001). Salzer et al. (1999) suggest that professionals have constructed an ideology around the notion that MHGs are seen solely as an informal social group which affords the opportunity to meet people with the same condition. Secondly, MH groups are professionally led groups that are more focused and based on a methodology linked to recovery and occupational health. However, as discussed previously in chapter three, there is a suggestion that within an MHG or SHG there exists two forms of knowledge: 'experiential and professional' (Borkman, 1976, p. 448) and a unique 'expertise' (Yalom & Leszcz, 2005). Furthermore, there is the implication that MHGs can draw on that knowledge and expertise and thus rely less on the professionals.

Returning to professionals' concerns about their expertise being possibly undermined by MHGs, Yalom & Leszcz (2005) suggests that there is space for both peer-led groups and professionally led groups and that fellow group therapists should see such groups as something which can support their work as opposed to something that is in competition. Moreover, this could then create a space for professionals and individuals with an ED to consider a hybrid approach where both can work harmoniously together, perhaps in a similar way to a movement in Germany called Self Help Friendliness (SHF) (Kofahl et al., 2014). This is where SHGs work in partnership with professionals in an embedded way, so that SHGs are part of the support package for patients. However, it has been suggested that SHF might only be beneficial with certain types of SHGs in terms of the type of ideology the mental health professionals have towards mental illness in terms of how they are trained (Constantino & Nelson, 2009; Emerick, 1990).

Two practical considerations ought to be borne in mind. The first is that some professionals have been taught that they should keep a professional distance away from the patient (Constantino & Nelson, 2009). This strand is explored further later in this chapter. Therefore, such training would impede professionals engaging positively with SHGs. Secondly, Constantino & Nelson (2009) believe that telling professionals about SHGs is not sufficient for engagement. It is important to note that there are effective relationships between SHG/MH group attendees and professionals in existence, but one must not overlook the power imbalances that will exist. Constantino & Nelson (2009) found in their research that professionals seemed oblivious of the power they held, for example in terms of economic power relative to the SHG attendees who were poorer than them. This explicit and implicit power that professionals hold is an important consideration when establishing

partnerships (Constantino & Nelson, 2009; Seebohm et al., 2013). However, there is a different type of power which the person who attends the SHG/MHG has, which is EBE. Therefore, a two-way education process is key on the part of both parties if any effective partnership is to be built on trust and mutual respect (Constantino & Nelson, 2009; Kofahl et al., 2014; Stewart et al., 1995).

Also to be considered is the concern that some professionals hold about the harm that SHGs that operate outside of them can cause; this is the second narrative that will be examined. The issue of harm was discussed in chapter three with respect to safety and recovery messages. The limited research that is available raises a concern about misinformation possibly being given to members by non-professionals (Naslund et al., 2016). This misinformation could also take the form of conversations between members which may be perceived as potentially harmful but not being addressed by moderators of such groups. This was evidenced in an OSG (Stommel & Meijman, 2011). The misinformation may come from other communities such as pro anorexic (or pro ana) groups and websites. However, there are two schools of thought emerging from the literature regarding pro ana websites. One has articulated the fears around the perceived 'anti-recovery' message that they perpetuate (Brotsky & Giles, 2007) such as supporting self-starvation (Roberts Strife & Rickard, 2011). The strength of the community is echoed in research carried out by Granek (2007) who examined the subjective experiences of five women with AN. Their findings, one aspect of which they termed 'Relational Anorexia' (Granek, 2007, p. 5) identified the importance of the social circle for these women with AN and how it was an embedded part of their daily functioning, being amongst others who had some form of ED. This therefore acted as a way of sustaining their AN.

Furthermore, there is a different school of thought which suggests that the sites provide a space for the person with the ED to hold onto the values that are important to them (Firkins et al., 2019). In addition, they offer a sanctuary for the women with AN according to Dias (2013), writing from a feminist perspective. Firkins et al. (2019) suggest that the professional community visit the sites to better understand them. Likewise, professionals could be encouraged to do the same with respect to ED SHGs.

Based on their findings from several research studies, Kelly & Yeterian (2011) suggest that if professionals engage positively with MH groups, they can influence whether their patients participate in them. This was described for example in a study by Sisson & Mallams (1981) whereby a professional created a wraparound approach to helping their client attend an AA group. This was through a phone call in the session, offering to bring the client to the group and the AA group reaching out to the client. This had a positive impact for the client in terms of their continued attendance. Such an approach is labour intensive if it were to be repeated for every client. By contrast in a study of a peer support group set up for renal care it was found that most clinicians failed to signpost their patients to the peer support group or did not signpost again if the patients turned down the offer the first time (Wood, 2015). They seemed to lack the tenacity of the clinicians in Sisson & Mallams' (1981) study, and this

resulted in a low uptake of the service. The research authors acknowledge a range of causes as to why this occurred such as many staff not promoting the service or not knowing when to offer the service. These two examples highlight the influence that clinicians and professionals can have on how their patients and clients engage with SHGs. However, care must be given as to how best to do this so that all staff are engaged, any strategies are time efficient, and everyone understands what is on offer. Moreover, this issue has been explored through an MH group lens as opposed to an ED SHG lens. This is due to the lack of research into this area. Despite this the narratives clarify the potential value SHGs offer.

8.3 Methodology

Research Design

This research took a qualitative approach with IPA being identified as the most appropriate methodology, as much of the data were related to reflections on a personal lived experience. The subject matter was very close to the author of this study's lived experience as a facilitator. It was therefore it was important that quality assurance was an integral part of the design of the study. Therefore, to add a layer of robustness and to mitigate for potential bias another researcher was engaged to carry out part of the research (the semi structured interviews). Additionally, a reflective diary was kept by the author of this study to capture reflections and feelings that arose during the collection and analysis of data. To further address the issue of potential bias the research was assessed against the 'eight big tent' criteria for assessing the quality of qualitative research devised by Tracy (2010) (see Table 8.1).

Table 8.1: Quality Assurance Criteria

Criteria for quality (end goal)	**Description of the criteria**	**Evidence for meeting the criteria**
1-Worthy topic	The topic of the research is: - Relevant - Timely - Significant - Interesting	-Very few studies in the field related to research question. - Timely as there is a rise in the number of EDs and more people may need to make use of ED SHGs. This may result in a need to recruit more facilitators to run such groups. -Liaised with co-workers of ED SHGs about the relevance of study and a clinical psychologist who is experienced in EDs. -Both supervisors have worked in the field of EDs. -Researcher works in the field as a facilitator of an ED SHG and as a psychotherapist/counsellor. -Researcher carried out an IPA research study (unpublished) involving four former attendees who became co-workers and/or facilitators who endorsed the subject matter. - As the literature appears limited in this field it is interesting to hear about the lived experiences of current facilitators.

2-Rich rigour	The study uses sufficient, abundant, appropriate and complex: - Theoretical constructs - Data and time in the field - Samples - Contexts - Data collection and analysis processes	-Gathered data from eight in-depth interviews from across different ED SHGs and from facilitators with different levels of expertise to endorse findings. -Demographic data about all participants is provided -Data were collected over three months through one-to-one semi structured interviews which were transcribed and analysed.
3-Sincerity	The study is characterized by: - Self-reflexivity about researchers' values and biases - Transparency about methods and challenges	- The researcher's personal and epistemological position is clearly articulated early on into the thesis, regarding methodology, and concerning the participants' experiences of facilitating their ED SHG -This inclusion enables the reader to gain a fuller picture of the researcher and reflect on the researcher in relation to the position and values they occupy and the impact on the double hermeneutic of how the participants' accounts are understood by the researcher. -As is good practice with IPA a reflective diary was kept and there were ongoing discussions with the researcher's supervision team. This supported the author of the study to reflect on how their own personal experience as a facilitator may impact on the analysis and interpretation of the data.
4- Credibility	The research is marked by: - Thick description, concrete detail, explication of tacit knowledge - Triangulation or crystallisation - Member reflections	-The findings section, using direct quotes from the participants, supports the themes developed by the researcher. In some cases, the titles of the themes are the participants' exact words or variations of them. Furthermore, this demonstrates that the researchers' analysis is grounded in the participants' experiences. -The main supervisor was involved in ensuring the credibility of the analysis of the interviews by reviewing the development and creation of and the ongoing refinement of the themes. This supported the researcher in staying true to the data that emerged from the interviews i.e., the participants' words rather than being over analytical and losing the essence of the participants' words.
5-Resonance	The researcher influences, affects, or moves readers or a variety of audiences through: - Aesthetic, evocative representation - Naturalistic generalisations - Transferable findings	-The researcher carefully selected quotes from the eight interviews that they hoped would move and connect with readers who may have never facilitated or attended an ED SHG. -It has the potential to reach out to professionals inside and outside the field of ED to help them learn more about the individuals who facilitate ED SHGs and any support they may need as well as the value they can bring. -The researcher ensured that they accurately captured the participants' words and represented them accurately and sensitively.
6-Significant contribution	The research provides a significant contribution: - Conceptually/theoretically - Practically	-The findings of this research contribute to a field where there is a shortage of research into the individuals who offer support for recovery from an ED through their facilitation of unstructured ED SHGs.

	- Morally - Methodologically - Heuristically	-There is a place for this research to contribute to government policy into ED SHGs being seen as a pathway for support pre and post specialist treatment and the potential training that facilitators may need.
7-Ethics	The research considers: - Procedural ethics (such as human subjects) - Situational and culturally specific ethics - Relational ethics - Exiting ethics (leaving the scene and sharing the research)	- Ethical approval was granted by the University's ethics committee following a successful application. A protocol number was attached to the research. - Potential distress was considered at the development stage of the research and a debrief sheet was provided for all participants post interview. -A reflective diary was kept. Regular supervisory meetings and communications were a key feature of the interview and analysis stages of the research. -Any ethical issues which arose were addressed immediately through the appropriate channels.
8-Meaningful coherence	The study: - Achieves what it purports to be about - Uses methods and procedures that fit its stated goals - Meaningfully interconnects literature, research questions, findings, and interpretations with each other	- The Methods chapter of the thesis outlines why IPA, the chosen methodology was the most appropriate method to use in addressing the research question for this study (chapter 4). -The Discussion section articulates how the findings address the research question. -The Findings section represents the culmination of ideas from across the eight interviews which enabled the researcher to create the superordinate and subordinate themes. Furthermore, the researcher sought to present the uniqueness of each interview staying true to each participant's perspective whilst identifying where the data across the eight participants diverge.

(Drawn from 'Big Tent Criteria for Excellent Qualitative Research' by Tracy 2010, p. 840)

8.4 Recruitment

Recruitment process

An advert outlining the nature of the study including eligibility criteria was created. The eligibility criteria required that all potential participants were over the age of 18 and had facilitated or was currently facilitating an ED SHG. This advert was used to recruit potential participants through a variety of channels including through direct email to ED SHGs advertised through the charity BEAT's 'Self Help Finder database', social media, and word of mouth. This yielded ten expressions of interest. As a result of email and telephone conversations nine facilitators agreed to participate in interviews. However, only eight were interviewed as the ninth facilitator failed to respond to reminder emails. It was decided that eight would be enough to proceed with.

The Sample

Eight suitable participants were recruited. All were female. There was a breadth experience and ages. There appeared to be a broad corelation between age and length of experience in terms of the younger participants had less experience (see Table 8.2).

Table 8.2: Participants' Experience

Pseudonym name	Gender	Length of experience as a facilitator	Type of lived experience
Kelsie	Female	9 months	Someone who had an ED
Sonia	Female	9 years	Had a sibling with an ED
Katherine	Female	9 months	Someone who had an ED
Mary	Female	20+ years	Parent of child who had an ED
Paulette	Female	20+ years	Parent of child who had an ED
Anna	Female	3 months	Someone who had an ED
Rowena	Female	6 months	Someone who had / has an ED
Fran	Female	6 years	Parent of child who had an ED

Ethics

Full ethical approval was sought and approved by the University of Hertfordshire's Health and Human Sciences Ethics Committee (Protocol number: LMS/PGR/UH/05154).

Interview schedule

All interviews took place online via Zoom, and all but one (interview 8) was carried out by a co researcher (not the author of this PhD). The participant with the shortest interview time (Kelsie) was offered two interviews (which she accepted) as they initially struggled answering questions. The lead researcher and the interviewer met after the first interview to identify approaches to try and gather more information from Kelsie. As for the previous IPA study, a semi structured interview approach was identified as the most appropriate approach due to its flexibility (Smith et al., 2009). This creates opportunities for participants to go off in a direction that the researcher may not have thought of, resulting possibly in much fuller data (Smith et., 2009), enabling participants to be in charge and be the expert (Eatough & Smith, 2017).

The questions (see Figure 8.1) went through several iterations which involved input from the lead supervisor. They were also derived based on the some of the emerging findings from the first two studies. Additionally, the questions were reviewed and piloted with an existing facilitator. As a result, question nine was adjusted; the original question was 'What has been your own personal experience of eating disorders over your life?' and was changed to 'Do you have a lived experience of an eating disorder and are you happy to tell me about it?'. The addition of the phrase 'lived experience' felt more in keeping with the literature surrounding ED experience.

The interview range time was 27 minutes to 61 minutes with mean=50.25, median=54 and SD=10.6 (Table 8.3)

Table 8.3: Interview times

Pseudonym name	Time in minutes
Kelsie	27
Sonia	55
Katherine	54
Mary	54
Paulette	57
Anna	61
Rowena	50
Fran	44

All interviews were transcribed by an external company who signed a confidentiality agreement (Appendix 8.1).

Figure 8.1: Interview Questions

1. Can you tell me about your experience of facilitating an eating disorder self help group?
2. Can you describe the reasons why you facilitate this group? (prompt do you do this on your own or with others)
3. What are the helpful and difficult aspects for you about facilitating a group? (prompts: training and professional knowledge; resonance with personal experience; logistics)
4. What eating experiences and challenges do members of the group talk about and explore in your group?
5. What other issues not related to eating disorders specifically do members of the group talk about and how do you manage these?
6. What has your experience been around managing emotional experiences within group members? (prompts: sadness, anger, anxiety)
7. What has your experience been around managing conflict and arguments between group members? (prompts: specific examples)
8. What support do you provide for members around their eating or other issues?
9. Do you have a lived experience of an eating disorder and are you happy to tell me about it?
10. What impact does facilitating a group have on your own life?
11. How did you find facilitating the group during the experience of lockdown during the COVID-19 pandemic? (prompts: online v face to face; attendance;)

Analysis

As for the first study (see chapter five) the same framework as defined by Smith et al (2009) was used. Fuller details about IPA have been discussed in chapter 4.

8.5 Results

This section presents the outcomes of the analysis of the data. As a result of the analysis three superordinate and nine subordinate themes were created and these are captured in Table 8.4. Each theme is described and then illustrated with verbatim quotes and a commentary.

Table 8.4: Superordinate and subordinate themes

Superordinate	Subordinate
Motivations for becoming a facilitator	Lived experience: knowing and understanding the impact on self or family Giving back: providing a nurturing role
The positive and challenging aspects of being a facilitator	Helping others: An enriching and rewarding experience When things resonate: how it makes me feel Making a commitment: balancing and juggling demands
The importance of facilitator knowledge and skills	Training and group process: Knowing what to do and when Boundaries: creating a safe and / or confidential space Being a container of distress The importance of self-care

8.5.1 Motivations for becoming a facilitator

This superordinate theme was supported by two subordinate themes which focussed on the lived experiences of the participants and how that experience impacted their decisions to become facilitators.

Lived experience: knowing and understanding the impact on self or family

This subordinate theme encapsulated the reality of the participants' lived experience based on their direct or indirect relationship with an ED such as that of a parent, sibling or someone who had had an ED.

For participants who had had an ED, the age of onset revealed that it commenced in their teen years and had impacted their lives. For example, Kelsie had her ED for five to six years and recalled that: 'it became a problem when I was about 15/16 and it probably continued to be a problem until I was 21 or 22'.

Like Kelsie, Katherine's ED started around aged 16. For her it 'was a really tough time like, I felt really out of control… It was my way of coping with stress and any overwhelming emotions…it was a really difficult time'. With the repetition of 'really' and emotive language, such as 'tough', 'out of control', 'overwhelming', one can sense the struggle that ensued when the ED developed given the purpose her ED served in helping her manage challenging feelings yet 'I gained a lot of weight very quickly'.

Moreover, a need for intervention was a strand touched on by Katherine, Paulette, and Mary. For example:

> …so I think it, it was never really like highlighted to me, like nobody ever said, do you think you have an eating disorder, which I'm kind of shocked about because I have been mental health campaigning since I was like, sixteen/seventeen and I've always been very open about my experiences, I've done a lot of media experience, but nobody actually turned round to me and said, I think you have an eating disorder, and I think it just shows the lack of awareness and education about them really. (Katherine)

Thus, Katherine was critical that those around her took no action, punctuating her point with an air of incredulity when she repeated that no one directly asked her about an ED; indeed, even within her campaigning role within a mental health field, she seemed emphatic ('it shows') about a 'lack of awareness and education' from others.

Conversely, Paulette did try to intervene in the case of her daughter:

> We had to encourage her to get help and things, and we only knew what she was willing to tell us, and that's a problem. We could see that she [her daughter] had a problem, but she was in denial and of course, she was over eighteen, so I was, what was frustrating that we couldn't actually do anything about it. (Paulette)

Paulette seemed mindful that her daughter had her own personal sense of agency which she had to respect despite this feeling 'frustrating', yet her frustration implicated a sense of helplessness that she could not help in the way that she wanted to; especially given her daughter was an adult who 'was in denial'. Mary's need for intervention was about the stark reality of having to vicariously witness her young daughter being close to dying:

> All I knew was that my daughter had an eating disorder, and she was going to die, but she did go down to a critical level at twelve years old and that was the most horrendous time of our lives, we nearly lost her and since then we nearly lost her four times in her journey, so, so, so basically early intervention is key. (Mary)

Terms such as 'critical' and 'horrendous' evoked a powerful sense of the intensity of that experience for them both. As facilitators with lived experiences watching from the sidelines, both Paulette and Mary conveyed a sense of helplessness, as their daughters became ill. This seemed to underpin their motivation to aid others and thus become a facilitator. This notion is continued in the next subordinate theme.

Giving back: providing a nurturing role

This subordinate theme had an altruistic and reparative quality in so much as it explored the participants' desire to use what they had learnt through their own family's experience, to help others or themselves via facilitating an ED SHG. For example, reparation was apparent in Mary's account:

> if we could help one person or parent, or whatever, to stop you know, for not to go through what our daughter went through, and we went through, it would be worthwhile…. when we couldn't get the help that we needed, really onset us to think, right, what are we doing to make a difference and how can we bridge those gaps. (Mary)

This seemed to ignite an internal call to action through bridging 'gaps'. Mary appeared able to protect others from distress and ensured other families never had to experience the challenges she had faced.

Likewise, Paulette wanted to make things better for group members and other parents:

> I wish I could make them, you know, all well really, I wish they didn't have the problem, because that's very difficult when you can see parents are very distressed, they're loving parents… So you know, you, you wish that you could wave a magic wand and make everything right. (Paulete)

Paulette conveyed how hard it was to see others experiencing what she had. The repetition of the word 'wish' three times and reference to waving a 'magic wand' potentially created a sense of a fairytale world with the removal of pain, and a subsequent happy ending. This was especially as they're 'loving parents', questionably who possibly deserved better. One could ask oneself if she was also expressing not just a wish for them but something she had hoped for herself when her daughter was very ill.

Sonia too recognised the potential value that attending an ED SHG would have afforded her family given 'this was the kind of thing that my family and my sister would have really benefitted from'. This then appeared to motivate her into getting involved as a facilitator: 'So, I, you, you know, I wanted to do something that would have, under other circumstances, been a real help for our family'.

For facilitators who used to attend for their own ED, the value of attending an ED SHG appeared evident, such as Kelsie:

> I used to attend it for myself, and that was a few years ago, and I thought it was brilliant. I didn't think there was anything like it in the community. So, when I got a bit better myself, I wanted to kind of give back and part of that for other people. (Kelsie)

This first-hand positive experience of an ED SHG in her own ED recovery journey seemed to have fuelled her desire to 'give back' This was an underlying narrative for most of the facilitators as to why they became facilitators. The next superordinate theme examines the positives and challenges that they faced in that role.

8.5.2 The positive and challenging aspects of being a facilitator

This superordinate theme was supported by three subordinate themes, which had an emphasis on the intrapersonal aspects of the facilitator role and the value attached to being in the role.

Helping others: An enriching and rewarding experience

This subordinate theme captured a variety of reflections about the added value that being a facilitator afforded to different areas of the facilitators' lives such as their own intrapersonal and career development. For example, two of the facilitators identified how their self-confidence grew such as Katherine. She reflected on the realities of how anxiety impacted on her way of functioning, drawing on an image of light and dark. This evoked an image of the night, 'a really dark time', emerging into day, 'sunlight'. Her use of the world 'really' appeared to emphasise how tough that dark period was for her. This was in contrast with her subsequent use of 'really' describing how 'it's really nice to get to use those personal experiences'; there seemed to be an air of delight in being able to do that.

Sonia, too echoed a growth in her confidence:

> I get more from them in many ways than they get from me……. It's given me the confidence to be quite vocal in other settings, about what may or may not be appropriate, and to challenge other people's behaviour. (Sonia)

Sonia was able to be more assertive with people. Perhaps she was suggesting that this was something she had not been able to achieve in the past.

Likewise, there was a positive gain for Paulette:

> I mean in a strange way it's enriched my life. You know it's made me think that you have to appreciate what you've got, even though I have a daughter that has suffered with eating disorders…. So, I just feel that you know, it's given me a sort of the empathy to understand other people's suffering. It doesn't matter what it is, it's just made me a better person in some ways. (Paulette)

With self-development seeming to occur in terms of developing empathy, Paulette seemed grateful for the difficult experience despite the challenge of her daughter's ED. Her reference to 'suffering' twice had an air of pain; the pain that her daughter went through which seemed to enhance Paulette's understanding of 'other people's suffering' and maybe understanding her own suffering as a parent.

Similarly, Mary appeared to articulate a compulsion to facilitate the group for it 'would be criminal' if she was not able to *save* people and educate them:

> the people who come are full of admiration for the group they're attending, and the support, they get through it, and you know, they feel

> as if often it's their lifeline...as long as I can help people, I will continue doing it… I think it helps me personally, to know that these people aren't slipping through the net, and I think that's one of the main things for me, is that you know, they are getting more educated, and they are understanding what the importance of somebody with an eating disorder is. (Mary)

Mary's reflection appeared partly metaphorical for the reference to 'lifeline' which had a preventative quality with her having a desire to ensure attendees do not come to harm by not 'slipping through the net'.

Furthermore, several facilitators viewed the potential benefits for their own career trajectories. For example, volunteering as a facilitator seemed an opportune moment for Rowena as she was 'considering going into either counselling or some related career':

> …so I, I thought I wanted to experience it, doing similar kind of work, and, and I suppose yeah, I just wanted to see if this was something that, that I could do and, and, and develop, and I guess whether I'd be good enough at it to be able to offer that, that, that service and that space to people who are you know, recovering from an eating disorder. (Rowena)

Rowena seemed to express uncertainty in her own capabilities. The repetition of the word 'that' appeared to convey a sense of hesitancy and perhaps a lack of confidence too.

By contrast Kelsie was already working in an aligned field. She saw the role as:

> …motivating for me, and I think it's, I work in the mental health field, so I think it' been brilliant experience for me to learn in a, in a voluntary setting as a facilitator of a group, to then go into a clinical setting. I think it's; it's had a good effect on that aspect of my life as well' …. I enjoy it, it's nice to feel that I have an extra purpose. I look forward to it, I enjoy going. (Kelsie)

Moreover, the role appeared to create several areas of value for Kelsie. For example, it offered a way to perhaps enhance her skills set for the next stage in her career development and a sense of worthiness ('have an extra purpose').

When things resonate: how it makes me feel

This subordinate theme was about how the facilitators responded when things resonated for them when they were carrying out their role in the ED SHG. For example, Anna was able to recognise how she felt:

> …if something did touch me: I think there were certain times when there were things people were saying that I'd, did sit there and I was kind of like, this is really rubbish and complex, and I guess being able to, to say that and feel that in the group, without it being about me, again I think is,

> is really important. I guess to show that I am human as well, and that things can impact us, and again, I think there's something within practitioners being able to do that, that actually can be quite helpful for the other person, but obviously not to a point where the things are about you and the group's about you, but yeah, at times I can remember it, it definitely being hard especially when certain questions were getting asked, and more of kind of feeling, I guess I was overwhelmed in a way of, of kind of, this is a lot, you're all bringing a lot. (Anna)

Anna's rationale seemed to be about a need to show her humanity and vulnerability. It was important that she was able to recognise and acknowledge her distress, a way of indirectly processing what was occurring internally for her within the context of the group. Moreover, the demands put on her 'when certain questions were getting asked', was too much for her. However, she appeared to reiterate that considering how she was feeling was not to the detriment of the group. There was maybe an inferred assumption that 'obviously' one would know that and, there was an internal battle of managing her own feelings, whilst at the same time being present emotionally within the group.

By contrast Mary recounted a time when:

> I think I've shed a tear once in a meeting and, and it really got to me, and, and I've only ever done it once in twenty odd years, but I don't think it's right for a facilitator to show that, that, that emotional exposure if you like, because they are looking to you for support and I don't think you're in the right place if you're going to be crying about everything that they're going to be saying. I mean you know, I'd find it a bit off putting if, if the facilitator [laugh] was in tears every few minutes, so I wouldn't be very, very sure of her capabilities [laugh] really. (Mary)

Thus, Mary appeared to chide herself for showing emotion. One wondered if she was possibly projecting her beliefs about how a facilitator should conduct themselves, into the group members, citing what they would be expecting. She further intimated that such conduct would suggest a lack of capability for displays of emotion in her mind perhaps would not be received well by the group. One was left with an overall sense of Mary being fearful of being judged and being seen as not good at her role, as well as possibly worried that she may present that same momentary lapse of a display of emotion again, so she had to put a stop to it, and it worked as 'I've only ever done it once in twenty odd years'. She appeared proud to state that.

Similarly, Kelsie acknowledged:

> Obviously, some things affect me, but I feel like I'm able to kind of keep a straight face and kind of keep my emotions at bay until I've walked out after the, the meeting's over, and I can always just try and like take a few

> deep breaths and kind of put it to the back of my mind**.** Yeah, I don't feel it, it impacts my ability to, to do it. (Kelsie)

It felt important that Kelsie let one know that despite how material may have stirred things within her she remained professional. The use of 'obviously' seemed to imply that one would know that: that it was a given. One pondered how hard it was for her to mask how she may have been feeling when material in the group stirred up feelings for her. Additionally, one wondered too if the 'deep breaths' provided a physical way of exhaling out the emotions and parking them.

Fran too acknowledged being impacted:

> Well I suppose when I'm talking to them, I don't, I, I, it might be difficult, but it's never been so upsetting that I, I sort of can't sleep that night or anything, you know, makes me concerned for the person that's talking, but it, it doesn't so far, hasn't sort of left me in a situation where I feel I need to go and talk to somebody about it. (Fran)

Fran's response differed from Kelsie and Mary in that despite experiencing some form of resonance, it was manageable for her.

Rowena's resonance however, appeared to differ markedly from the other facilitators in so much as:

> I think I was so nervous about making it work, that I wasn't even that engaged with my own experience in the moment. So I think in terms of [pause] I guess my difficulties were of, [sigh] how can I put it, being concerned that something might be distressing for a person in the group, and [pause] so yeah, I guess for me the things that would have been difficult, that would come up, were more things that would, that would be making me doubt my competence as a facilitator rather than taking me back somewhere in my own sort of, journey with the eating disorder. (Rowena)

Rowena highlighted the nuances in her experiences which seemed related to two aspects of the role: the experience of the group members and her competence as a facilitator. This seemed to be the essence of her resonances.

What appeared apparent overall was that for most of the facilitators there was a preoccupation with ensuring that they were seen to be competent at their job. That seemed to mean holding any emotions that the group evoked within them in abeyance.

Making a commitment: balancing and juggling demands

The facilitators discussed the competing demands on their time. This theme elaborated on what those demands were and how the facilitators felt about that. For several of the facilitators, such as Sonia, they were able to 'build my other social commitments around it'.

She appeared happy to commit to the role as 'it is only once a month'. One felt that she sounded quite pragmatic that the commitment was minimal in terms of the impact on her life 'if I want to do social things, I just avoid those dates' and doing this role monthly was a fruitful use of her time as 'I'm not in front of the telly'.

Mary, like Sonia, also protected the group date in her diary as 'we try not to you know, book a holiday when it's, it's the first Monday'. There was an acknowledgement that facilitating the group has 'its restrictions' which Mary seemed resigned to as 'it's just you know, it's just the way we are you know'. Moreover, the rule of 'we try not to … book a holiday when it's the second Monday in the morning' seemed sacrosanct.

Similarly, Fran too decided to adapt an aspect of her social commitments to fit in with the group:

> Actually on a Tuesday night, which is the, when we do it, is not hugely convenient because I actually do something else on a Tuesday night, but it was the best night for it to do it, so it's been, but actually that doesn't stop me doing it, do you know what I mean, I, so that's an impact, but it's not actually a serious impact, otherwise I, it would, I wouldn't be doing it, so I prefer to try and help than anything else…but it's, basically I do a YYZ course, and have done so for several years, and that's a Tuesday night. So, but they just know that on the third Tuesday of the month I won't be there, you know, it's, it's absolutely fine. (Fran)

Despite the inconvenience Fran seemed to have decided that the group was important and that she could forgo missing her course once a month. One had a sense of her possibly weighing up the impact of missing her longstanding commitment, versus her desire to, and on balance the clash 'doesn't stop me doing it'. She had been able to find a practical way of making both work; resulting in her course members perhaps embracing the fact that she would suddenly not be there once a month. They were impacted too as they had been used to Fran attending regularly. Her final comment may have been another confirmation for herself that it was indeed 'absolutely fine'.

By contrast, Paulette and Rowena offered insight into the practicalities of overseeing the group. For example, Paulette was concerned about succession planning and had questioned her capacity to continue as 'I don't know how long I'll be able to run the group':

> People say you know, will you hand over to someone or do anything and I mean, people do come on a regular basis, and they want to support me and …, they like to sort of come on a regular basis, but they don't want to take over the actual commitment of running the group every month, which I find is what you need really. (Paulette)

Paulette described a picture of people wanting to help around the periphery and one assumed that these people were people who possibly facilitated but that was not clear.

Nevertheless, it appeared that no one wanted to or felt ready to take ultimate responsibility for managing the group in the same way that Paulette had done so. One questioned whether there was an etch of disappointment as she identified her fear as to the future of the group.

Rowena's concern was about the group-related tasks she did away from the group:

> The communications were a bit stressful as well. I mean because things were, we didn't have so much of the different platforms that we have now, so it was all email and I think for me, I was the one responsible for checking the email and having the phone on a Sunday night and I felt, I don't know, I just felt very responsible and kept checking things when I shouldn't have done, and, and if people phoned at times when the phone wasn't on, even though it was publicised that the phone was only on at set times, I'd feel really guilty about that. (Rowena)

One had an impression that Rowena seemed overwhelmed by some aspects of the role, having acknowledged the enormity of what she was expected to do around the group communication. One pondered how it was agreed that she would have responsibility for both forms of communication. Despite trying to be externally boundaried she seemed compelled to keep 'checking things when I shouldn't have done'. This led to her stating that 'I'd feel guilty'. This suggested that she knew that it was not helpful to keep behaving in the same way, but because of her sense of responsibility she carried on breaking her own boundary.

8.5.3 The importance of facilitator knowledge and skills

This superordinate theme had four subordinate themes which pertained to the knowledge and skills that the facilitators had been taught or acquired to enable them carry out their role effectively, whilst ensuring the safety of the group, as well as considering their own self-care.

Training and group process: Knowing what to do and when

This subordinate theme was about the training that the facilitators did or did not receive. Additionally, it explored the sense that some made of the training and how this was borne out in their facilitator style.

Some facilitators spoke about how they interpreted the body language of attendees in the group to help them understand the group process. For example, this was something that Kelsie articulated. She described her training as having 'improved my ability to look at body language'. Furthermore, she continued by explaining how this was borne out in a session. There was an emphasis on 'show[ing]'. It was about being attuned to 'someone showing signs of upset' which then necessitated 'showing understanding', and then 'showing that you're willing to listen', almost like a chain reaction. It was as if the facilitator had to match the body language communication of the group attendee with their own display of

body language – an unspoken form of communication -displaying a 'willing[ness]' to engage and say: 'you're willing to help without saying you know'. The body communication was perhaps more important than verbal communication within that context.

Like Kelsie, Paulette also tried to make sense of the attendees' body language:

> you can see their body language and the way they sit, and if they're fiddling and, so I try and watch you know, their body language and just to sort of, just gently talk to them and just make them feel just calm and relaxed, and that we're not there to judge them, we're there to just release our feelings and to help one another. (Paulette)

Paulette appeared adept at noting body language indicators. She then seemed to use that information to respond as a facilitator with warmth with the aim to help 'them feel just calm and relaxed'. The description that it evoked for one, was of a space that was both nurturing and supportive.

Moreover, Anna's focus was similar but more analytic:

> I think that's where I kind of, work mostly with that kind of experience, that kind of emotional stuff anyway. I guess more of, not thinking about specifically the eating disorder, but actually what's going on underneath and what emotion's coming up, and what are we trying to avoid, to kind of look at. So, I think for me doing that within the group when someone brought something up that was interesting, and I kind of enjoyed doing it. (Anna)

Thus, Anna's training, one inferred, seemed different to that of the other facilitators in terms of her analytic approach which focused on group processes. Furthermore, she appeared to want to explore more deeply what might be going on in the group experientially. Moreover, one had the impression that she was thinking psychotherapeutically about the group process ('what are we trying to avoid') in terms of what might be occurring 'when someone brought up something that was interesting'. This appeared to spark her interest.

By contrast two of the facilitators appeared disappointed by the training and support they did or did not receive, for different reasons. For example, Rowena raised the fact that as an inexperienced facilitator she had wished that she had received some support in the form of supervision from 'the charity that we were actually working on behalf'.

> My overall feeling looking back is that we were both two inexperienced facilitators and probably needed to be working with somebody more experienced. It, it was quite stressful, we never entirely felt confident in ourselves, I think. We did have the good fortune of having Greta to supervise us, I think it was once a month she'd meet with us to talk about how things were going, which was really helpful. There was nothing like

> that provided by the charity that we were actually working on behalf of. (Rowena)

One felt that Rowena's reflection was tinged with an air of disappointment. One wondered if she had had 'somebody more experienced' supporting her, she may have been more secure in her facilitator role. The support she did receive from Greta seemed to bring into her consciousness a deficit in other support that she felt was lacking.

Conversely Fran did receive training from the charity that Rowena had alluded to, but appeared not to feel that it was needed as they were 'telling us what we already knew':

> But it was also how to perhaps raise questions, which a lot of us already sort of knew, and conversations to have, things to avoid discussing. [pause] Not putting ourselves in sort of vulnerable positions, so they would sort of, it was sort of role play occasionally, certain scenarios or what have you, but I think it was more based as, as well, some of it, on having larger groups than we actually had there. (Fran)

Fran seemed to highlight a mismatch between her level of competence and what the charity offered her.

Boundaries: creating a safe and / or confidential space

This subordinate theme was about how safety and confidentiality were considered by the facilitators and how this was borne out in practice. For example, Fran and Katherine's approach involved the sharing of expectations at the outset of each group session. One aspect was confidentiality as in the case of Fran who appeared to conceive this as involving three strands.

Firstly, Fran appeared to want to clarify at the onset, the safety and sanctity of the confidential space where what was spoken about would not be shared more widely for 'what's said in the group stays in the group'. The second seemed linked to conduct, reminding members the type of behaviour to be expected reinforced using 'no' before describing what not to do such as 'no sort of side conversations' and 'no eating in the group'. The third pertained to language: 'no, no talking about weight, BMI and things like that'; this seemed to show an awareness of recognised potential triggers and thus wanting the group to feel as safe of possible.

Katherine too wanted to 'reinforce it's a safe place':

> confidentiality is there unless, obviously we believe that they are a harm to themselves or others, so I, I think just trying to make it a warm environment and for them to know that it is a safe space to talk about whatever they choose to. (Katherine)

Ensuring group safety for Katherine, was linked to the limits of confidentiality. Interestingly safety appeared to be equated also with 'trying to make it a warm environment', offering a space for group members to express themselves freely.

Similarly, Mary too had an emphasis on confidentiality. She emphasised the delineation between the group and the charity it sat within as 'we never discuss anybody who has been to the group, you know, it, the confidentiality is a given'. One wondered whether it was something that it was important for the service users of the charity to know so that they would feel safe coming. One felt like there was an instructional quality to how Mary described this: 'you don't share the fact that somebody has been to your group with you know, over a cup of coffee', in terms of how one might something new to the setting in a support role.

By contrast Rowena offered a slightly different perspective to the other facilitators:

> unless you have an established cohort already there with at least a few people who you know are going to be there week by week, it becomes quite hard to provide that sense of stability and safety that I think people are generally looking for when they come to a group like that.

Rowena appeared to be frustrated that she did not have a core of regular attendees that is 'an established cohort' attending the group. This seemed a challenge for her to do what she set out to do which was to ensure a secure foundation, which was something she believed group members 'are generally looking for when they come to a group like that'. Perhaps that belief may have been informed by Rowena's own lived experience of having previously attended an ED SHG:

> In any group, even the most established like the one I used to go to, I have actually, I've recently come back to, is that even, even then there are, there are lots of people who come only once or who come occasionally, and that's fine if you're in a group where you've got at least four to six people who you can pretty much guarantee are going to be there, because then new people come and they're part of a stable community and they, they can decide they, they want to join it, but I think without the sense of this being a, a stable group who know each other and are here every time, I think it just feels a bit insecure for people. (Rowena)

There was an emphasis on the word 'stable' (which was alluded to twice) and this seemed to be at the core for what Rowena's ideal conditions would be for someone attending a group. Moreover, one speculated as to whether this was what she felt that she needed when she had attended a group herself. One had a sense of her need to feel safe (if one worked on the premise that she was describing what she personally found helpful) through her description of how there needed to be an established core of attendees being there, whilst allowing space for new people to come and go.

Being a container of distress

This subordinate theme was about how the facilitators described what was or would be required of a facilitator if anyone in the group exhibited distress and how they contained this.

For example, Sonia's approach if 'somebody was really distressed' seemed to be about giving the person who was distressed a private space to talk ('let's come and have a separate chat with me') and perhaps an opportunity to process things outside of the group setting. One wondered if that approach was only for when attendees were 'really distressed'.

In a similar way to Sonia, one aspect of the approach that Katherine would take hypothetically if someone was distressed within the group, revolved around offering space for 'a bit of one-to-one time'. She appeared to have a sense of clarity as to why conflict might arise ('because they're upset and distressed'), and how to support the person concerned by offering an opportunity to talk with the facilitator on their own ('one-to-one time'). This seemed framed within a rationale of ameliorating the situation ('de-escalating') and taking a person-centred approach ('meeting the person where they're at') to reassure the group attendee ('I am here for you like, I'm here to support you'). Katherine appeared to express an air of relief however that 'thankfully, we've never had to deal with that', perhaps suggesting that there may have been potential anxiety around theory (what she may have been taught) versus actual reality.

Kelsie too would take the distressed person(s) away from the group to talk:

> there's always two or more facilitators in there, so one of us would pull one of the people in the argument aside, we'd take them out of the room while it calmed down and we'd both discuss with each of the people involved, what was said, how they felt and just give them a chance to kind of breathe and maybe get them some water or something, and if, if it calmed down from there, then brilliant, we'd, we'd resume the group. If not, we'd sit with them and then we could always carry on without that involvement. We can't have the argument affect the entire group.
> (Kelsie)

Like both Sonia and Katherine, Kelsie's approach to contain any distress in addition to creating private spaces for the individuals to talk. She seemed to have a range of strategies she would draw on to calm the situation down. Her aim, it seemed, was to ensure the continued smooth running of the group. Kelsie's last comment: 'we can't have the argument affect the entire group', possibly revealed how she might have wanted to speak to the persons involved if she was allowed to, that is to gently remonstrate them.

By contrast Anna's approach to containing distress was focused on 'body and regulating':

> so I would, and I'm trying to think if I ever did it and I, maybe I did do, but I guess talk to them, to be able to talk about something more specifically, in terms of the emotional, something that had gone… So just helping them note if they're looking kind of more anxious or they're speaking a lot faster, what's going on, and me being able to I guess, co, co-regulate with them.

Thus, one felt that Anna's approach seemed grounded within a psychoeducation philosophy. For she seemed to educate the group members in understanding more about how their body and voice ('speaking a lot faster') reacted to anxiety or emotional distress through guided talk. Having supported them to gain that recognition in terms of a change in state, she appeared to support them to manage their emotional state as a joint enterprise ('co-regulate with them').

Paulette appeared to present a type of facilitator methodology.

> I think you, you can switch off, because if they're getting upset you have to be strong for them, so you have to carry what they're holding in their, in their mind really, and you have to be the one to give them understanding and empathy, and if you get too involved well then, you're not really doing your job properly.

Through her repeated use of the words 'you have to', Paulette seemed assured that there were three core *demands* required of a facilitator when containing distress.

The first *demand* was 'you have to be strong for them'. This strength seemed linked to ensuring that emotional distance was kept for 'if you get too involved well then you're not really doing your job properly'. The second pertained to being a container of distress: 'you have to carry what they're holding in their, in their mind really'. The third *demand* required the facilitator to 'have to be the one to give them understanding and empathy'. When considered as a whole, the three demands could perhaps be perceived as a form of facilitator role descriptor.

The importance of self-care

The demands of being a facilitator raised the notion of self-care for some facilitators. This subordinate theme therefore explored how the facilitator made use of supervision and how some reflected about the importance of their own self-care. For example, Sonia spoke about the value of having a co-worker ('that's one of the advantages of there being two facilitators') and supervision and how that was a source of support. She also seemed very conversant as to the processes that afforded her opportunities to potentially access support for herself. Her support appeared to culminate in three stages. The first was informal 'after the end of each session we'd have a bit of a debrief between the, the two of us'. The second created an opportunity to alert her supervisor to 'any causes for concern, including for ourselves'. The last was 'formal supervision so that we can kind of deal with those issues as

well'. Thus, these layers of support could be potentially construed as creating a framework to keep Sonia emotionally safe in her facilitator role.

For Katherine, 'it's really important to stay on top of your own self-care…you could slide incredibly quickly if you weren't'. This seemed to have an air of a warning not only to herself but to others. One pondered if there had been a decline in her own self-care in the past and her warning came from a place of a personal lived experience. Furthermore, she reflected that 'I can't do my job if I am not well myself'; this highlighted again that she was maybe talking from a place of knowing. It appeared as if she had adopted a shift in perspective from seeing self-care as good in theory 'I just viewed self-care as a kind of like, good thing to do', to raising it to a higher profile as something that was crucial. The shift appeared to have yielded positive benefits for her 'as it's really helped me to restructure my life and find a lot more balance between work and like, enjoyment as well'.

Similarly, Anna too spoke about a need to 'remember to take care of myself':

> because I think doing a group is a lot of work. I kind of, what you put into it, kind of the, even the practical paperwork side of it, with all the group members, such as taking, I guess taking care of myself is important, kind of outside of that and not just dedicating every ounce of time to the groups. (Anna)

It seemed as if Anna came to a realisation that self-care was important and had to perhaps nudge herself to remember that. However, at points she appeared to be convincing herself ('I guess taking care of myself is important'), perhaps rationalising the reasons why through quantifying the activities she did. Nevertheless, this insight appeared to help her decide that she no longer wanted the group to subsume her life.

Paulette's version of self care lay around being 'able to switch off':

> In the last few years I mean I know my boundaries anyway, and I, I manage to be able to switch off because I realise you do what you can within that group, and if anybody rings up or sends an email I, I do what I can to help them, signpost them to other help, and I feel, well I do what I can at that time, and then I have to switch off, but it does take a little while to get to that point. (Paulette)

Paulette perhaps had struggled in the past to switch off from her facilitator role. This was qualified twice with 'I do what I can', and examples of how she achieved this. This possibly implied that she had maybe gone through a period of accepting that there was a finite amount of time that she could give to the group. Moreover, a further reference to being able to 'switch off' punctuated her description with how she managed to establish those boundaries. One felt that the 'I have to switch' phrase sounded like a mantra that she may have had to say to herself on several occasions.

These findings will be discussed in the next section with reference to existing research.

8.6 Discussion

8.6.1 Findings

The current study aimed to explore 'facilitators' perspectives of ED SHGs and what matters in recovery', which arose out of two earlier studies (see chapters five and six). The limited research that exists about facilitators of ED SHGs seems to imply that facilitators can play several important roles such as promoting ED recovery as an ideal outcome through providing hope (McNamara & Parsons, 2016), ensuring the safety of participants by how they manage the group (Waller et al., 2020), and through providing psychoeducation (Peterson et al., 2009; Rathner et al., 1993).

The use of lived experience of recovery as someone who had an ED or that of a relative, was something that all facilitators brought to the role. These experiences helped to shape the type of facilitator they were and fuelled their motivation to fulfil the role. This brought personal altruistic benefits with a desire to give back to others, similar to the participants in research of LaMarre, Wozney, et al. (2024) about the experiences of peer mentors who offered a range of mentoring support. Like participants in the current study, they reflected on how they wished they had had that same support for their recovery. Additionally, they too felt a sense of being valued by those whom they were supporting.

However, the facilitator role brought personal challenges of how to manage resonances, which led some to implement some form of emotional distancing and self-care. This could be perceived as a form of psychological protection of their wellbeing. This is in keeping with other caring professions such as nurses. Research into emotional distancing within healthcare has been given growing consideration within literature such as research about how nurses interact with their patients and clients (e.g., Allan & Barber, 2005; Bakker & Heuven, 2006; Kim et al., 2020; Van Sant & Patterson, 2013; Wilstrand et al., 2007). Managing the volunteering role and their own personal lives emerged as another area of self-care that needed the facilitators' attention. This was something they were cognisant of and proactive in addressing.

Using lived experience to support recovery

The current study's findings revealed what it felt like for the participants to use their lived experience as group facilitators to support others with their recovery. All the participants spoke about some of the positive benefits of being a facilitator and the learning they personally gained from group members, vicariously in some cases. This echoes some of the findings from research by Beveridge et al. (2019) whose peer mentors found that they too gained much from the role as well as a space for self-reflection, being able to use their lived experience of their ED in a positive way. This was how some of the participants in the current study positioned themselves with respect to their lived experiences in terms of wanting to give back to others. This further aligns with a study by Hanly et al. (2020) who found that reciprocal gains was something that the peer mentors in their study had positively identified. One such gain was that of having a sense of feeling good by supporting

someone else. Correspondingly, the positive impact of hearing about the facilitators' ED lived experiences of recovery was raised by some of participants in the first study (see chapter five).

Furthermore, the current study adds an extra dimension in that the results offer a more in depth understanding of the motivations behind the desire to support others with their recovery. Insomuch as some of the facilitators in the current study felt a sense of responsibility to share their ED experiences with others based on their own or that of their relative's history. This was sometimes tinged with a sense of wanting to protect others from experiencing the same feelings they had had, and to ensure they received their equivalent positive experiences of attending an ED SHG.

Additionally, the current study's findings are in line with aspects of existing research by Salzer & Shear (2002) who discuss the experiences of peer support specialists within a substance misuse program. Some of the participants in the current study, for example, reflected on how they had learned much from group attendees and how this learning had enhanced some of the skills needed for their career. Some were either already working in mental health or aspired to do so and wanted to explore the suitability of such a career. This is commensurate with findings from their study such as those linked with 'job-related' benefits like professional growth. Similarly, participants in a study by Toikko (2016) who were training to be EBEs were able to draw on their own professional backgrounds and utilise what they learnt from their own lived experience to support them in their EBE role.

Moreover, the current study builds on existing research about individuals who have a lived ED experience as a carer supporting other carers. Much of existing research has been situated in settings where parents are seeking support for their child, such as a study by Grennan et al. (2022) which involved some parents being trained to act as facilitators of the support group. That study presents findings about how the attendees benefitted from the group. The current study's findings by contrast, presents new insights, as there are data about the facilitators themselves who are carers, including details of the emotional aspects of their current and past lived experiences. In some cases, the facilitators (especially those who had been parents of a child with an ED) seemed to describe a protective aspect that the role gave to them which acted as an internal driver to volunteer.

Self Care and Emotional Distancing

As well as the role of facilitator being a rewarding one, participants in the current study reflected on some of the challenges that the role presented. They appeared to feel a need to find a way of emotionally distancing themselves from difficult feelings linked to any personal resonances they experienced which emerged during or post the group and the responsibility of sometimes having to be a container of group attendees' distress. There are a variety of forms which could be associated with the overarching term of emotional distancing which has been referenced in research such as 'boundary consciousness' (Van Sant & Patterson, 2013), 'emotional dissonance' (Bakker & Heuven, 2006), 'emotional

boundary' (Allan & Barber, 2005) and 'emotional regulation' (Powers & LaBar, 2019). Maguire (1985, p. 1711) suggests that 'distancing tactics' are about 'emotional survival', based on their observations of nurses and doctors involved in working with patients who are dying.

The facilitators in the current study employed a range of strategies to emotionally distance themselves including switching off after the group and taking deep breaths, trying to deflect any feelings that emerged. These approaches and philosophy echo aspects of existing research, for example research carried out by Wilstrand et al. (2007, p. 75) about nurses caring for patients who self-harmed, noted how they developed ways of managing their feelings towards patients when faced with difficult circumstances such as 'shutting off feelings' or deflecting their feelings through 'joking and irony' with their patients. This seemed to infer that this was a way to protect themselves emotionally.

Similarly, facilitators in the current study opted to address resonances through working on not showing feelings externally and keeping them hidden, by trying to put them to the back of their mind. This was not always the case as some facilitators were able to acknowledge the feelings and give themselves time to process them. Another response was to chastise themselves for showing feelings, locating the reasoning for doing this based on a perception that it would be frowned upon by the very people they were supporting. This further concurs in part with research carried out by Allan & Barber (2005) where participants ideologically deflected feelings back to the patient in the belief that the emotions belonged to the patients and as such they should take ownership of them. This was set within the context of the forming of emotional boundaries.

Furthermore, the current study attunes with existing research around the interplay between emotional distancing, and competency. The facilitators in the current study were clear that any emotional responses to material that arose in the group did not impact on their ability and capacity to be a facilitator. This is noted in a similar way in other studies such as Maguire (1985) who found that the healthcare workers feared admitting to their peers that they were struggling, as they worried that they would be perceived as not competent to work in that setting. Similarly, Kim et al. (2020, p. 600), have suggested that emotional distancing 'enables healthcare workers such as nurses to put their feelings aside and be more straightforward about what subsequently needs to be done'. Being able to do this, creates a situation whereby the person involved is able to function effectively in their role, through the act of shutting off their feelings (Wilstrand et al., 2007).

Moreover, the participants in the current study may have linked competency with a sense of how professionals are required to behave, as some had expressed a wish to enter the field of mental health. This is partly in accordance with some of the findings in the research of Yanay & Shahar (1998). In that study they found that some of their participants also expressed beliefs around which feelings were permissible within the setting and why, and the optimum position was about controlling such emotions. The authors suggested that

this was linked in part to their professional aspirations to become therapists, in a similar way to participants in the current study who also held such aspirations.

Despite a need to emotionally distance themselves, the facilitators in the current study found that the role gave them a sense of worth and value which may have provided a protective factor, meaning that the resonances did not appear to overwhelm them. This is in line with a study by Hage et al. (2021) which found that staff working on an ED unit who employed some form of emotional distancing had high levels of satisfaction due to the engaging nature of the work. It was this that protected against burnout.

Self-care and work life balance

Continuing the idea of self-care further, there was a recognition by the facilitators in the current study to proactively implement this further to establish a good work life balance for themselves. This was partly in response to a recognition that wider tasks outside of the direct role of facilitating the group were monopolising their time, and for some knowing the boundaries in terms of how much support they could offer within the time. This is in keeping with the notion of work life balance which can be defined as constituting the proportion of an individual's time that is spent at work versus the time left for other personal social pursuits outside of work (Brough et al., 2020; Gröpel & Kuhl, 2009). It has been suggested in many research studies that there is a correlation between work life balance and burnout across a plethora of professions. This can impact negatively on role performance, productivity, and job satisfaction in areas such as the medical field (Kanwar et al., 2009; Maeran et al., 2013; Paredes & Cochran, 2020; Troppmann & Troppmann, 2017).

Furthermore, the facilitators in the current study ensured that they established boundaries to make space for family and friends and their hobbies. There was a sense of self warning for some that it was something they needed to do. This mirrors existing research by Thompson et al. (2011, p. 157) involving trainee counsellors which noted that participants in their study also initiated deliberate actions to support their own self-care. This involved connecting with networks of people outside of their work setting which 'replenished their energy levels'.

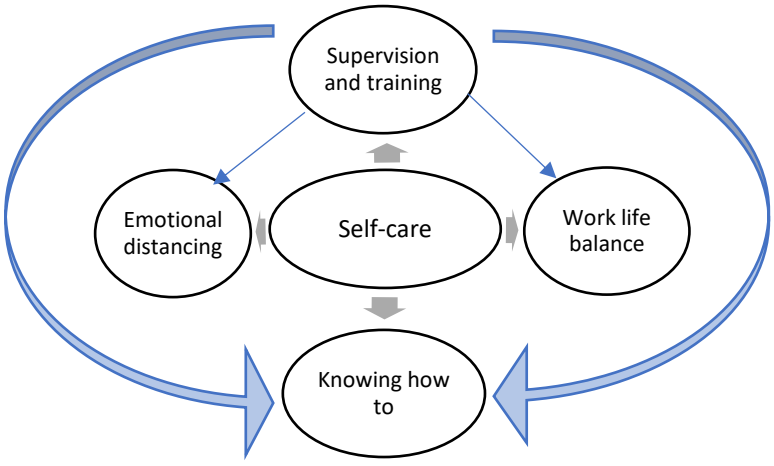
However, not all facilitators in the current study were able to successfully do this. There were tensions for one in terms of how much support is enough and for another not being able to adhere to their own self enforced boundary around the required admin tasks needed to run the group. This further concords with some of the findings of a study carried out by Kemp & Henderson (2012) whose participants were paid peer workers who were not fully cognisant with the administrative burden involved. Thus, the facilitators in the current study subsequently created boundaries around the administration which involved setting times when they would answer calls and emails.

The value of supervision and training

The current study highlighted that supervision was an important element in self-care and support. Those facilitators who spoke about supervision noted the value they attached to having the space to debrief with co-workers and their supervisor after group meetings. It seemed apparent that supervision was available for those facilitators whose groups were part of a bigger organisation. Similarly, Thompson et al. (2011) noted in their research with trainee counsellors that those who had supervision valued it. The environment created at one level of the organisation was one where self-care was an embedded part of supervision. Conversely, at another level within the organisation supervision was not offered. This gap in support was also evident for the facilitators in the current study.

To summarise, one of the facilitators in the current study summarised the interplay between self-care and the notion that she would not be able to perform her duties if she was not well and ensured that she engaged in self-care. Linked with this is the importance of training and supervision (see Figure 8.2). This has resonances with existing research. An appropriate work life balance has been found to improve mental health wellbeing functioning within the workforce which can lead to staff feeling positively about their job. This was noted for example in a cross cultural study carried out by Haar et al. (2014). It has been proposed that counsellors who are experiencing some form of burnout or who are not implementing good self-care should not be practising as it raises ethical considerations around competency (Coaston, 2017; Thompson et al., 2011).

Figure 8.2: Facets of Self Care



8.7 Implications

The current study's findings revealed several implications.

Training and supervision

The first such implication is around the competency and how training and supervision can support voluntary facilitators of ED SHGs in the absence of a regulatory framework. It appeared evident that because of the training they had received many of the facilitators in the current study were competent and able to operate within a framework that ensured the safe running of their groups. This non regulatory framework ensured that they were secure in describing the boundaries and structures that they followed or had created to keep their members safe, enabling them to articulate confidently what they would do if challenges arose within the group and how confidentiality would be maintained. This contributed to their self-care. However, the current study has highlighted that the support that facilitators received was not consistent, as some commented that they not all received training or supervision.

Moreover, those who had been in receipt of training in the current study were appreciative and saw its worth as they commented on what they had learnt such as being able to interpret body language during the group. In addition, they used supervision as a place to process group concerns as well as their own. Several literature reviews have noted the positives of training for facilitators such as a meta analytic review of dissonance -based ED prevention programs by Stice et al. (2019), who noted that facilitators who had received about seven hours of training produced positive outcomes. Similarly, a systematic review by Delisle et al. (2016) about training programmes for peer facilitators noted the benefits for those who had received training, enabling them to effectively facilitate their groups and other aspects of the role.

Additionally, the current study's findings indicate that facilitators whose ED SHGs were embedded as part of a bigger charity offering other services and not just a standalone, seemed to have established supervision structures. Furthermore, a most recent systematic review about the effectiveness of lived experience involvement in ED treatment highlighted several important points about training and supervision (Pellizzer & Wade, 2023). One such point was the fact that it was not well evidenced in research, with only 27% of the eleven papers mentioning training and supervision. This, therefore, raises the question as to what happens to facilitators who are not supported through training and supervision and what the resultant outcome might be. The implication being that training and supervision need a higher profile within the peer support sector; a point which was raised by Kemp & Henderson (2012). This is important particularly within the field of ED SHGs to safeguard the wellbeing of group facilitators and the vulnerable people who attend.

Potential facilitators who operate without that support are vulnerable as are the people they are supporting and the longevity of the group. One of the facilitators in the current study who had set up a group had to close it, due to low numbers. They were

disappointed that the charity that had helped them set up did not offer any training and subsequently they felt left without the knowledge and skills to facilitate the group effectively. This impacted on their ability to maintain boundaries of managing their time around the admin side of the role which then impacted on their self-care.

One possible model for training could involve new facilitators being supported by more experienced facilitators, learning through observing them, as was the case in a study of a parent-led ED support group (see Grennan et al., 2022). The parents who were in receipt of this training positively acknowledged its value. Another approach may involve looking at groups or organisations who have a structure of training of support such as the OA organisation. What can be gleaned from the paucity of research that exists is that there is an in-house training structure which *generates* facilitators or leaders of groups globally. Yet, OA does not readily welcome outside researchers as informed by the author's enquiry (see narrative review, chapter three).

Sustainability of ED SHGs

The second implication highlighted in an earlier study (see chapter five) is about the place of ED SHGs within support packages and the sustainability of groups. Expanding further on this, sustainability is associated with the personnel who run the group, namely the facilitators. In the current study one facilitator spoke about the struggle she was having to find someone to hand over the running of the group. There appears to be a real danger of groups folding if groups are run by one key person for a long time and succession planning is not built in. Therefore, to attract volunteer facilitators, clarity as to what the role entails is an important consideration.

Therefore, Jacobson et al.'s (2012) idea of a job description for a peer support worker is an important one. As a result of their evaluation to better understand what peer workers do, they concluded that having a lived experience was not sufficient. Their research identified the breadth of the role. The current study's findings concur with this; in that it offers qualitative data about how the participants felt about carrying out the tasks and the impact on their lives.

8.8 Implications for future research

The current study identified competency and the variability of training that the facilitators received. Some found their training not geared to their needs, one received none, and others spoke about how it helped them to better understand aspects of their role such as how to interpret body language. Therefore, it may be opportune to research further about the content of training that facilitators receive and where there may be deficits to enquire what training they would like and why. This aligns with the recommendations of Barak et al. (2008) post their research about peer mentors who offered home mentoring. They suggested that these mentors needed training to learn how to establish boundaries with their mentees.

8.9 Strengths and Limitations

There exist several limitations which merit further consideration. Firstly, the number of participants involved in this study was deliberately small which is in keeping with the chosen methodology of IPA, as it allowed for the richness of each of the participants' lived experiences to be heard; IPA does not aim for generalisability (Smith et al., 2022). Additionally, the participants were a homogeneous group in terms of ethnicity (white British) and gender (all female). It could be argued that this demographic is in keeping with data about EDs being seen as a female illness and that underrepresented groups are not visible within such settings (see chapter six), being mindful that over half of the facilitators were individuals who had had an ED and the other had had a relative with an ED.

A key strength that was apparent for this current study is its uniqueness as it has examined the role of the facilitator of an ED SHG through the eyes and words of facilitators. This contributes to the knowledge base about ED SHGs that the author of this study has already added to in the earlier studies. There exists several studies about clinicians who have a lived experience of an ED who are working or have worked in an ED setting (Costin, 2002; Johnston et al., 2005; Rance et al., 2010). However, the current study expands on this as it is, to the best of the author's knowledge, the only IPA research study which has explored in detail the personalised journey from lived experience (either as someone who had an ED or someone whose family member and an ED), personal motivations through to the day-to-day practicalities and challenges of facilitating an ED SHG.

8.10 Conclusion

This study explored facilitators' perspectives of ED SHGs and what matters in recovery.

It has shown that the facilitators' own personal lived experiences either as someone who had had an ED or that of a relative, was instrumental in why they chose to carry out the role. Together with that was the personal value they attached to the role which had an altruistic element as it created an opportunity for them to give back to others, through offering support with recovery. There were personal gains as regards their self-development as part of their own recovery, the building of self-confidence and career development (through the acquisition of skills and knowledge in the mental health field).

Moreover, due to their ED lived experience (some of which were painful) their personal management of how to deal with resonances was an important aspect of their own self-care; this they did through emotional distancing as well as ensuring a good work life balance. In addition, the commitment to be a facilitator required personal sacrifices related to their free time and other regular commitments. Sometimes this caused conflict in ensuring the establishment of boundaries related to the administrative aspects of the role, which meant some felt overwhelmed and experienced self-doubt.

Furthermore, all facilitators operated within a professional framework either because of their own self-belief as to how to behave in the role, or as part of the training that they had received. There was a recognition of the value that supervision had as a

reflective space where facilitators could process issues arising from the group. However, not all facilitators were in receipt of training and/or supervision, and this raised implications for the necessity for this to be in place to support the wellbeing of the facilitators and the safe running of the group. For those who had not received appropriate training and support, they noted how it impacted on their ability to manage their group.

Key research findings

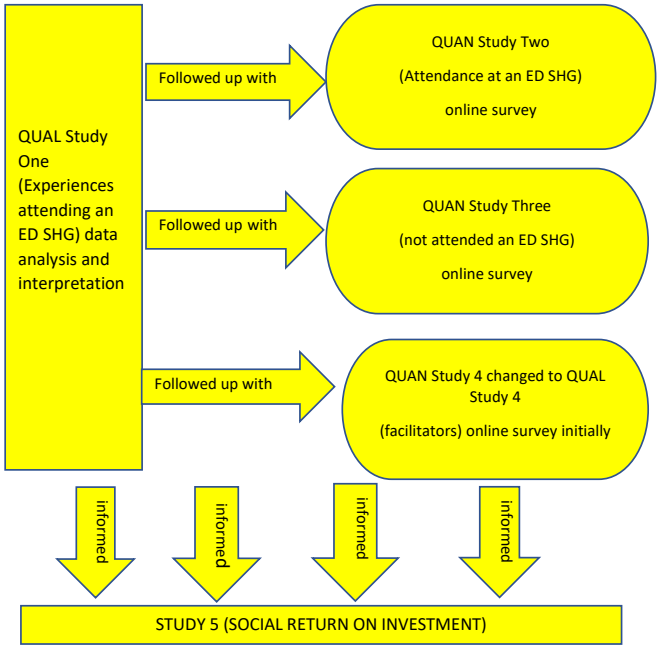
- Participants' value of the facilitators' lived experience of recovery
- Facilitators lived experience providing motivation to support group members
- The importance of facilitator self-care
- The importance of facilitators self-managing personal resonances with participants through emotional distancing, training and supervision

Chapter 9: An evaluation of the central London SHG for adults with an ED (Study 5)

9.1 Introduction

This Social Return on Investment (SROI) offers an innovative and unique study which evaluates the economic and social value that an operational ED SHG affords to its key stakeholders and society. It was conducted on the Central London SHG for Adults with an ED by the group contact who is also one of the facilitators of the group, drawing on data gathered from current stakeholders of the group. It has three strands which focusses on: the stakeholders' experience of the group; their views on recovery; and how the group may have impacted their wellbeing. It represents the final part of the exploratory sequential design methods approach of this thesis as highlighted in Figure 4.1

Figure 4.1: Diagram of The Research Exploratory Sequential Design



Previous studies in this thesis have informed the content of the SROI (see chapters five and six). The salient key findings which emerged from these studies included the importance of the social value that such groups offer its attendees; the relational aspects of recovery; and being amongst others who understood them. Furthermore, study two offered insights into how ED SHGs might impact wellbeing. Various factors were constructed out of the data as either contributing positively or negatively towards an attendees' wellbeing. The 'impact on self' which concerned about attendees experiencing the benefit of recovery on their own lives and seeing a reason to recover, was one such factor which was identified as a protective factor. Conversely, the PCA factor 'personal difficulties inside the group' was identified as a six-fold risk factor to wellbeing (as evidenced through the BLR). This was

about attendees being frustrated with themselves for not being able to utilise the group how they wanted to (see chapter six to review this in more detail).

Furthermore, the economic and social cost of EDs has been the focus of several key reports. Three such reports were reviewed in terms of the costings that have been calculated that offers a picture of the costs of an ED for an individual, their families and the public purse. Pro Bono (2012, p. 4), an economics-focussed charity produced a 'comprehensive view of the overall costs to society of key eating disorders in England', focusing on young people. They also reviewed disability-adjusted life-years (DALY) using 'premature mortality and reduced 'quality of life' from illness' (Pro Bono, 2012, p. 26) within the scope of disease burden. Table 9.1 provides a final economic estimation.

Table 9.1: Final Economic Estimation of disease burden (Pro Bono)

Value	Cost
healthcare treatment costs	over £80 million
present value of reduced GDP (conceivably perhaps twelve times this figure	over £230 million
value of reduced length of life and health (conceivably up to seven times this figure	over £950 million

Assumptions had to be made about costs such as how many visits an individual with an ED might make to a GP, prevalence of EDs, how deaths from an ED are recorded as there are other comorbidities which may mean that the death is attributed to another co existing condition.

Several years after the Pro Bono report, the national ED charity BEAT commissioned PricewaterhouseCoopers (PwC), (2015, p.4) to carry out an assessment of the costs of EDs. The nature of the report differed from that report as their focus assessed 'the cost to society of this debilitating condition including treatment and wider social costs'. Their economic cost was an estimate of £15 billion per annum. The report was punctuated with quotes from some of the 537 respondents to the survey and / or who had been interviewed as part of the information gathering process. Based on the data gathered, the authors were able to calculate financial and economic costs for an individual related to having an ED (see Table 9.2) as well as a broader picture.

Table 9.2: Average costs linked to having an ED (PwC, 2015)

	Aspect	Cost per annum for individual with an ED		Cost per annum for someone caring for an individual with an ED
Financial costs	Expenditure on private treatment	£831		£920
	Expenditure due to NHS treatment	£43		£51
	Travel costs for treatment	£220		£723
	Other	£1233		£2040
Economic costs	Loss of income due to taking time off work	£109 (under 20s)	£4,897 (over 20s)	£3463
	Loss of income due to impacted educational or professional development	£553 (under 20s)	£4,613 (over 20s)	£2468

More recently Virgo et al (2021) published an online report written by a range of experts. It presented a holistic picture of the costs as well as unit costs for some services that individuals with an ED may use, drawing on a plethora of sources including some of the same data sources as Pro Bono and PwC, international and national research, NHS data to model the cost of EDs to individuals, carers and the state (see Table 9.3).

Table 9.3: Assumptions of ED unit Healthcare costs 2020 (Virgo et al, 2021)

Area	Unit cost £	Comments
specialist ED inpatient adult	£455.00	107 days
specialist ED inpatient child	£510.00	138 days
specialist ED inpatient private	£700.00	
specialist ED outpatient (AN and BN adult)	£148.00	30 sessions per year
specialist ED outpatient (AN and BN child)	£262.00	20 sessions per year
GP Costs	£39.23	2.15 visits per year
Blood tests	£7.00	2 per year primary and outpatients
DEXA scan	£77.00	once per year
Private Care	£150.00	30 sessions

The three reports together present a picture of the challenges of identifying the numbers of individuals with an ED, the social, economic, and emotional costs to them and their families and friends, and the cost to the public purse. There are gaps in the data as there appears not to be a systematic approach to the gathering of and the analysis of the data.

This section has presented an overview of the value of ED SHGs and contextualised the economic costs of EDs. The following section will explore aspects of this in practice though the lens of an existing ED SHG.

9.2 The Central London Self Help Group

Founded in the 1970s, the Central London SHG for adults with an ED, was initially a group for both carers and people with an ED and operated as a charity. This was the case study that was used for this SROI to address the question about value and impact. There are limitations to this approach as this ED SHG will not necessarily be representative of all groups, so one will have to exercise caution about any assumptions that are inferred. The subsequent section describing the group demonstrates that the group will show that the group is not diverse in its intake (e.g., gender and ethnicity) and as such one may need to reflect on the potential impact of the group if it did reflect a broader diversity. It is to be noted that the group was dissolved as charity in 2001.

The author of this thesis is the group contact and a co facilitator and has been involved with the group for over 30 years. During this period the group has had a complex relationship with the national ED charity BEAT. This has included affiliation of their group 'Self Help Network', working in partnership with them, and now most recently advertising on their self help database. The status of the group is that it is an independent body with financial agency and is regarded as a society. Its funding is entirely generated by attendees' fees.

The group purpose (who it is for)

The primary purpose is to support attendees with their ED recovery. There is a group purpose that is read out at the start of every session (see Figure 9.1) articulating the parameters the group operates within. This was developed by group members and was most recently updated at the request of a longstanding member. This was in response to a newly formed committee that was created post Covid-19. It is an open group meaning that members can choose to attend when they want to.

Figure 9.1: Purpose of the Central London Self Help Support Group

Purpose of the Group

The primary purpose of the group is to help ourselves recover from an eating disorder, and to assist others to achieve recovery. We can best support one another by sharing feelings, experiences, and suggestions in an open, honest, and non-judgemental way. Whilst it can be challenging to do this, we have found from experience that the more one can get involved the more one gets out of the group. We don't have all the answers; everyone has their own emotional and situational difficulties, and although many of these are shared, one may need to find individual therapy or counselling to deal with these issues more thoroughly. However, the problem we have in common is a troublesome relationship with food, and/or body image; and participation in the group has helped many of us to overcome this. Everyone makes a valuable contribution by being here and listening. That said, we hope you will join in when you feel like it. Whatever you say, it may help someone as well as yourself.

As a group, we avoid talking about numbers that may be triggering for others. If you do mention numbers and someone needs to remind you, please know that this is to respectfully call you in, not to call you out. Examples: Number of calories; Body weight/BMI; Amount of food in grams; Hours between meals/snacks; Weight lifted; Hours/minutes exercising; Distance travelled whilst exercising; Clothing sizes etc.

Updated October 2021

The Management of the Group

The group has four main volunteers who contribute to its running (see Table 9.4 for an overview of the roles). Each person has some form of lived experience as someone who may have recovered from an ED or been a carer of someone with an ED. The group contact who is a qualified practising psychotherapist/ counsellor has lead responsibility for the group and is supported by three other volunteers. All those involved in the management of the group have attended for at least two years and been involved in some capacity before taking on the voluntary role as a facilitator.

Table 9.4: People who Support the Management of the Group

Role	Key Duties
Group contact	-Lead facilitator for all groups. -Oversees the team of facilitators. -Responsible for the administration of the group such as management of group email, communication, renting of room, development of policies, and maintenance of database of members. -Has responsibility for safeguarding and professional indemnity insurance
Facilitator	-Volunteer who co facilitates the group. -Supports at least one group monthly.
Trainee facilitator	-Longstanding group member who has a good period of recovery.
Steering Group member	-Longstanding members of the group. -Meets periodically with the group contact to review how the group is running and to make suggestions about changes and discuss any organisational issues. -Welcomes new members to the group and supports breakout groups during meetings.

How the group functions

Access to the group is via self-referral (email or telephone). The person initiating contact may have found the group themselves via the internet, the BEAT Self Helpfinder database or a recommendation by a healthcare professional who may know of the group. Anyone wishing to participate must use an online booking form to indicate their wish to attend and to pay the attendance fee. This captures their name and contact details. There are two groups a month, each lasting up to 90 minutes. The group that is held on the second Wednesday of the month is face to face in person and the group that is run on the fourth Wednesday of the month is an online group. People pay a small fee to participate (£5 for the face-to-face group and £3 for the online group). The fees support the yearly room hire cost.

The group has a 'loose' structure. One of the facilitators shares the limits of confidentiality and when it would be broken and how, in relation to harm to themselves or others and matters relating to the law. Some regular members like to send apologies if they are unable to attend and these are shared at the start. Each attendee checks in and provides a short update (up to five minutes and depending on the size of the group). The group then decides how to spend the time. If the group is small (up to six people) then it may stay as one group. If it is bigger there may be smaller breakout groups for part of the time guided by the facilitators. There are at least two facilitators at each group to guide conversations, ensuring the safety of the group and that everyone has space to take time for themselves.

Each person has an opportunity to share what they would like to during the session. Attendees support one another by feeding back on what they have heard, sharing ideas and own experiences with others. A wide range of topics are discussed in the group (see Table 9.5 for examples). The facilitator will bring others in or comment on what has been heard and may signpost to help and raise concerns about someone's safety e.g., if they are at medical risk. The facilitators are conscious of the time. A special feature of the group is that there are people at different stages of recovery who can offer their experiences to those at the start of their recovery and can help them reflect on how far they have moved in their own personal journey.

Table 9.5: Examples of conversations that occur in the group

Topic	**Examples**
Recovery	Relapses, goals, emotional aspects, practical strategies that have helped, self help
Everyday life experiences	Pregnancy, bereavement, family ill health
Relationships	Family, partners, dating, marriage
Workplace	Returning to work, taking time off due to ill health, occupational health meetings, informing boss or colleagues about ED
Accessing support	Long waiting lists, experience of initial assessments, entitlement to treatment, speaking to GP, experience of specialist treatment programmes
Self help	Strategies, ideas gleaned from therapists, books, podcasts, people to follow on Instagram

Investment required for the group to function

Table 9.6 outlines two types of investment that are required to run the group. The actual cost is what is paid out each year; the room rental for the in-person group, which is £618.75. It also captures the volunteer investment. If the group was not run by volunteers, the annual running cost of the group would £6,649.75. Therefore, the group is only financially viable with volunteers.

Table 9.6: Time and financial Investment required for group to function

Item	Unit cost/ unit time	actual total cost	Volunteer investment	Comments
Room rental (September to July inclusive) for in person group	£37.50	£618.75		50% discount given by landlords
Group contact: admin function 6 hours a month answering emails, sending out booking link, sorting out room hire, updating policies etc	£60	£0.00	£360.00	Group contact is a volunteer and does not charge for their time
Group contact: facilitator role- qualified therapist (3 hours per month- 11 months)	£60	£0.00	£1980.00	Group contact volunteers their time
3 Facilitators- volunteers (1.5 hours per month per volunteer)	£40	£0.00	£1,980.00	All volunteers give their time for free
Travel costs for 2 facilitators	£10	£0.00	£220.00	
Travel costs group contact	£35	0	£385.00	taxi cost due to group contact having disability
Travel time for 2 facilitators	£40	£0.00	£880.00	
Indemnity Insurance to use hired space	£61	£0.00	£61.00	Cost borne by group contact
Zoom Group licence for online group	£15	£0.00	£165.00	cost borne by group contact
	Total	£618.75	£6,031.00	

9.3 Methodology

This SROI project is an exploratory and evaluative one, as it is being conducted retrospectively (Nicholls et al., 2012) and using an existing ED SHG as a case study. The broad aim was to explore the value that ED SHGs offer the main stakeholder, i.e., those who attend the group, and to ascertain what social and economic value and impact that can be ascribed to it (Nicholls et al., 2012). There is a paucity of research about ED SHGs as evidenced in the narrative review (chapter three), but there are some reports which have attempted to calculate the economic and social costs of EDs for individuals, friends and families, and the government.

All SROI projects usually adhere to a set of principles as Social Value UK (see chapter four for more details about SROIs):

1. Involve stakeholders
2. Understand what changes
3. Value the things that matter
4. Only include what is material
5. Do not overclaim
6. Be transparent
7. Verify the result
8. Be responsive

9.4 Stakeholder Research Process

The nature of the scope is narrow as this is the first attempt at such an evaluation within this field. Additionally, it maintains its robustness and credibility. One acknowledges that the nature of this SROI could have been broader looking at areas such as the impact on health services and friends and families. Gathering data from such sources would have been problematic due to accessibility of data in the field. Therefore, the key stakeholders for this SROI are group attendees as they are the only ones directly impacted by the group. Table 9.7 outlines an audit of stakeholders who are either direct or indirect beneficiaries of the group.

Table 9.7: Stakeholder audit

Key Stakeholder Type	**Reason for inclusion**
Attendees of the group	People who are expected to gain the most benefits.
Excluded Stakeholders (indirect beneficiaries)	**Reason for exclusion**
Public Health (NHS) and allied health services and professionals	Hard to identify the benefits due to scale and lack of direct access to this group of stakeholders.
Volunteer facilitators	Instrumental for the running of the group but not direct recipient of benefits.
Friends, families, and carers	Are impacted by stakeholders but not direct beneficiary of the group

The Research Design

The SROI was designed to gather qualitative and quantitative approaches to the collection of data. Firstly, possible outcomes that people who have attended an ED SHG might experience were identified see (Table 9.8). These outcomes were drawn from two earlier research studies of the experiences of individuals who had attended an ED SHG, using some of the qualitative data and themes (see chapters five and six). Secondly, a quantitative approach in the form of Likert scale type questions was employed to measure those outcomes and to

identify change. Additionally, the quantitative data were drawn on when deciding on suitable figures for deadweight and attribution. Such an approach is in keeping with the development of an SROI where qualitative comments are gathered from stakeholders and then the outcomes are measured using a quantitative approach.

Table 9.8: Possible outcomes for Attendees of ED SHG

Outcome	Quotes from studies 1 and 2 (people who have attended ED SHGs)
Becoming more open to talking and sharing with others	-I just wanted to share with people with similar experience. -I was in treatment but wanted to speak to other people in the same situation.'
Getting extra support due to unavailability of professional services	-I was told that my other mental health problems meant I wasn't eligible for ED treatment, and that my weight at the time was too low for community treatment but too high for inpatient treatment. (I have recently started having treatment, but it has taken me more than 3 years to be able to access it.) -I needed extra support while being in outpatient treatment, there was not therapy available for ED and the psychiatrist was useless
Feeling excited at starting the process of attending an ED SHG	-I felt like I jumped out of a plane after I came out my first session...I honestly felt elated because I was so nervous, and it was so different to what I thought it was going to be and it is so different to speaking to a professional, to speaking to other... -It makes me feel better. Every time I leave the group, I feel uplifted, and I come home and it's that sort of reassurance of yeah, you're fine and food is fine -I think the group is probably the most helpful thing I've done. -I think when I come away, I feel this kind of positive boost. It's like a recovery booster
Overcoming initial feelings of fear about attending	-It took best 6 months for me to physically attend a group meeting from first becoming aware of a self-help group. I felt scared & wanted to do it by myself. -Admitting I couldn't do it alone, was in extreme suffering and asking for help by going to a self-help group was a key step'. -I delayed contact because I was still trying to come to terms with having an eating disorder, despite inpatient treatment I thought I had things more under control, but I didn't!!!! So I put off going to a support group for a while. I also didn't know anyone else going to the support group to start with, so it felt very scary not knowing be what to expect or how to behave (what would the rules of the group be etc)'. - I was worried I wasn't sick enough to attend and everyone would think I was a fraud'.
Raising of uncomfortable feelings being in the group and about the group	-I felt anger, shame and blame- irritated by all aspects, the structure, people talking positively and sharing, that I was attending & that I was the position. I often looked down or up to others in the group- I thought I was unique. -its impact is more temporary. So that evening I came back quite motivated to do well the next day. Obviously, that then fizzles out, but it gives me motivation for some amount of time. -other days I go there, and I just feel really overwhelmed and more stressed than what I did when I went in because it makes me think loads of things and I'm a bit of a... My head goes a bit, you know, I just think too much and then I go off in all these different directions and sometimes it just makes me a bit more stressed.

Lessening feelings of isolation	-I was feeling lonely and isolated due to the ED. -I feel there's a lot of affirmation in the group. There's a lot of nodding. Not everyone will nod but lots of people go, 'Yeah.' And it's very validating. So that's something that I noticed, and I try and do when someone's talking -it's really valuable to go to a room full of people who do understand and to see that they understand'.
Creation of opportunities for self reflection on own recovery progress	-Because every time I go there, and I tell how I'm feeling, just to listen to myself and seeing my focus from my own words sort of makes me realise that 'Oh, you're doing well,' -Commitment to action, maybe it's not been phrased like that, but I think that's an overriding theme is we all have these great ideas, and we know what we should be doing but it's how you actually put that into practice. -And I can recognise a lot of my own traits in other people, like keeping really busy to avoid thinking about things, taking on too much, that kind of stuff - Viewing recovery as something that's progressing… that has progressed the most, the most in the last 3 years and is still getting better……there were moments where my dad… thought I was never going to get better
Recognising a need support with recovery	-Realised I wasn't fully recovered -I couldn't manage my eating myself and I hated putting on weight -I needed extra support while being in outpatient treatment, there was not therapy available for ED and the psychiatrist was useless -Sick of having an eating disorder -My therapist recommended I attend a support group to work alongside my therapy sessions. This is like abnormal… everything I'm hearing and then I've never really thought I had a problem. I suppose it has kind of made me realise that I do have a problem but then I'm at the point now where I'm like ignoring it. -it's like you don't have to be really, really severely underweight to still have a problem.

This led to the development of an online survey to gather mainly quantitative data which entailed stakeholders answering eleven questions and three demographic questions (Appendix 4.30). The eleven questions were broadly grouped under five areas as outlined in Table 9.9 which describes the rationale for the type of survey questions. They related to the impact of the group on personal functioning and recovery were included to help one better understand what were possible contributory factors that led to a change in the stakeholders' wellbeing pre and post the group.

Table 9.9: Rationale for quantitative survey questions

Question Type	Rationale for inclusion
Demographic data including ED diagnosis and access to professional support	-To capture background of stakeholders to see if the stakeholder group is comparable with data about attendees of ED SHGs carried out by author of thesis
Journey to the group	-To understand motivations for attending group and length of engagement with the group
The impact of the group on personal functioning (10 sub questions) Likert scale to rate levels of agreement	-To quantify the stakeholders' experience of: - how it felt attending the group - the challenges of attending - impact of others in the group - positive personal self-development - impact on engaging with professionals
The impact of the group on recovery (7 sub questions) Likert scale to rate levels of agreement	-To quantify the amount of change experienced in relation to: - feelings about own recovery progress - engagement with recovery - the benefits gained from others in the group (strategies learned and see others' progress) - how group supports recovery post discharge from professional services
Change in wellbeing using Short Warwick-Edinburgh Mental Well-Being Scale (S)(WEMWBS) (Tennant et al., 2007)	-To measure the change in stakeholders' wellbeing pre and post attending the group

Ethics

Before any data were collected, full ethical approval was sought and approved by the University of Hertfordshire's Health and Human Sciences Ethics Committee with the protocol number of LMS/PGR/UH/05633. Fuller details can be found in chapter four.

9.5 Findings

All data have been rounded up to the nearest whole number so there may be rounding errors. The questions that were asked can be found in Appendix 4.30.

9.5.1 Information about the stakeholders

Table 9.10 outlines the demographic constituency of the stakeholders. The data revealed a homogeneous group in terms of gender and ethnicity.

Table 9.10: Participants' Demographic Data

Gender	**frequency**	**%**
Female	12	92
I would prefer to describe my gender myself. Nonbinary.	1	8
Age band	**frequency**	**%**
25 to 34	9	69
35 to 44	1	8
45 to 54	2	15
over 55	1	8
Ethnic description	**frequency**	**%**
White English/Welsh/Scottish/Northern Irish/British	9	69
Any other White background, please describe	3	23
Mixed/Multiple ethnic groups: White and Asian	1	8

The stakeholders were mainly female (n=12, 92%); this is reflective of the ED internationally (see Galmiche et al., 2019). The group has on occasion had male attendees but they represent a small percentage, under one percent which does not tally with data which shows a rising picture of men diagnosed with an ED (Robinson et al., 2013; Sweeting et al., 2015).

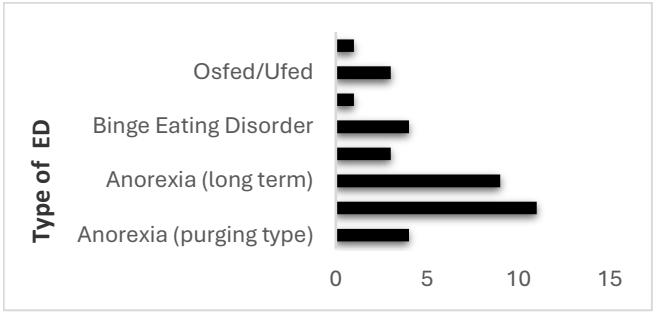
The majority ethnic group was white / other white background (n= 12, 92%). This is reflective in research such as Hower et al. (2022). The low uptake of stakeholders from an minority ethnic background is comparable to existing research that has found that individuals with an ED are sometimes subject to clinician bias and thus less likely to be referred for treatment (Becker et al., 2003; Gordon et al., 2002; Sala et al., 2013).

The most popular age band was 25-34 years (69%, n= 9). This appeared to be in keeping with existing data such as estimated figures collated by the Institute for Health Metrics and Evaluation (IHME) which suggested that 1.29% of the ED population in the United Kingdom of Great Britain and Northern Ireland for 2021 was aged between 25 to 29 and 1.06% for the 30-24 age band (IHME, 2024).

ED background of stakeholders

The outcomes are evidenced in Figure 9.2 The most prevalent ED indicated by the stakeholders was AN where 85% of the stakeholders (n=11) had a diagnosis of restrictive AN. Furthermore, 67% of the total responses were for all forms of AN combined. Binge Eating Disorder (BED) was the next most popular ED; this was only a small proportion of the cohort. Three of those with AN had both AN and BED. This trend differed to existing data as regards the estimated cases of AN and BN in 2021 in the UK as reported by the IHME whose estimated figures suggested 206, 713 cases for BN and 72,857 for AN (IHME, 2024). This would imply that the stakeholder group are not reflective of the UK ED population.

Figure 9.2: ED Background of Stakeholders



Type of ED	N	% of total responses
Anorexia (purging type)	**4**	
Anorexia (restrictive type)	**11**	**67%**
Anorexia (long term)	**9**	
Bulimia	3	8%
Binge Eating Disorder	4	11%
Obesity	1	3%
Osfed/ Ufed	3	8%
Other (please specify) Arfid	1	3%

Access to Professional ED Support

91% (n=10) of the stakeholders indicated that their GP was a source of professional support, and this was the most popular source (see Table 9.11). This is not unusual as the GP is a gatekeeper to enable patients to access to NHS professional support. Additionally, 54% (n=7) had access to specialist ED support, with 23% (n=3) being on a waiting list for specialist ED treatment. The range of ED specialist input appeared broad in terms of the type of interventions they had experienced. Two such treatments: MANTRA and CBT- ED are two treatments recommended by the National Institute for Health and Care Excellence (NICE, 2020).

Table 9.11: Stakeholders' Access to ED Specialist Support

Type of Specialist Support	N	Additional Comments Made by Stakeholders
GP	10	
Specialist ED therapy	7	• CBT-E • I have weekly private dynamic therapy specialising in ED recovery and OCD • CBT-E and MANTRA • CBT, MANTRA, DBT, art therapy, music therapy, 'movement therapy', general counselling, mindfulness, briefly EFT • 3 x CBT, 1x MANTRA • CBT, psychotherapy • CBT with a clinical psychologist for past 6 months
non-ED therapy	8	
Dietician	7	
ED inpatient treatment.	2	• 10-month admission (most of the aforementioned ED therapy took place in this admission, mostly in group settings)
ED outpatient treatment.	7	• Day patient treatment • Clinical management via ED team • CBT/general psychotherapy
I am on a waiting list for specialist ED treatment. How long have you been waiting?	3	• 6 weeks • 18 months • 26 months
Other	1	• Counselling

9.5.2 Findings on stakeholders' reasons for attending the group

All were current members. Over half of the stakeholders (n=7, 54%) had been attending the groups for more than three years (see Table 9.12) which suggests that they were an established core membership of the group.

Table 9.12: Length of time been member of the group

Period	number	% (rounded up)
Less than 6 months	3	23%
6 to 12 months	2	15%
1 to 3 years	1	8%
More than 3 years	7	54%

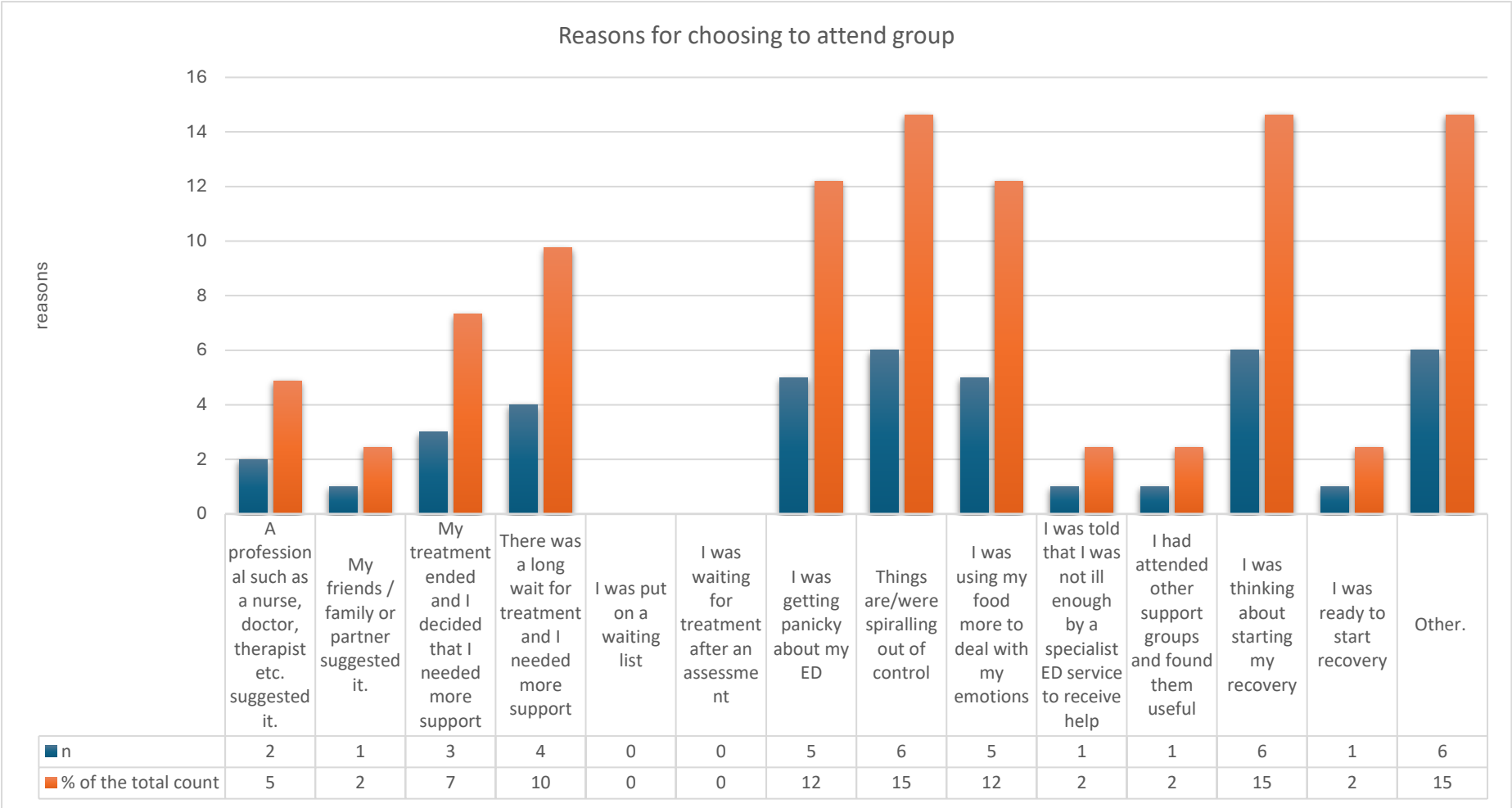
Figure 9.3 presents an overall summary of the results and Table 9.13 presents a themed grouping of the reasons. The stakeholders identified that emotive reasons were the main reasons why they chose to attend the group accounting for 39% of the total responses. This would possibly suggest a sense of desperation as they indicated issues like feeling panicky, using food and things getting out of control. This is supported by one of the six additional comments: 'I thought I was going to die soon if I didn't get help' Despite these strong emotive responses, the stakeholders were able to seek out a group and attend it.

Table 9.13: Reasons for attending the group (themed)

Reasons	Theme	% of the total count
A professional such as a nurse, doctor, therapist etc. suggested it. My friends/family or partner suggested it.	People	7%
There was a long wait for treatment, and I needed more support. My treatment ended and I decided that I needed more support.	Treatment	17%
I was getting panicky about my ED. Things are/were spiralling out of control. I was using my food more to deal with my emotions.	Emotive Reasons	39%
I was thinking about starting my recovery. I was ready to start recovery.	Recovery	17%

Furthermore, reasons related to recovery and treatment were highly scored at 17% each. This would perhaps imply that the group was seen as somewhere to offer support pre and post treatment. One stakeholder commented on the absence of support: 'I hadn't had support with my ED in a very long time and traditional healthcare ED experiences weren't very positive'. Another thought that despite 'experiencing a relapse', they were not 'sick enough for NHS treatment'. Additionally, there appeared to be a further indication of proactivity by some of the stakeholders, as they seemed to signify a potential desire to commence their recovery.

Figure 9.3: Reasons for attending the group



	A professional such as a nurse, doctor, therapist etc. suggested it.	My friends / family or partner suggested it.	My treatment ended and I decided that I needed more support	There was a long wait for treatment and I needed more support	I was put on a waiting list	I was waiting for treatment after an assessment	I was getting panicky about my ED	Things are/were spiralling out of control	I was using my food more to deal with my emotions	I was told that I was not ill enough by a specialist ED service to receive help	I had attended other support groups and found them useful	I was thinking about starting my recovery	I was ready to start recovery	Other.
n	2	1	3	4	0	0	5	6	5	1	1	6	1	6
% of the total count	5	2	7	10	0	0	12	15	12	2	2	15	2	15

9.5.3 Findings on stakeholders' experience of the group

The stakeholders' rating of the ten statements (Figure 9.4) showed that they agreed with 80% of the statements (mode of 2 (agree)). The remaining two statements were linked with professional support. One statement pertaining to the group leading to them to seek professional help received an overall neutral rating response (mode=3) with three stakeholders opting for not applicable. 'Does not apply 'was excluded from the final presentation of the data in Figure 9.4.

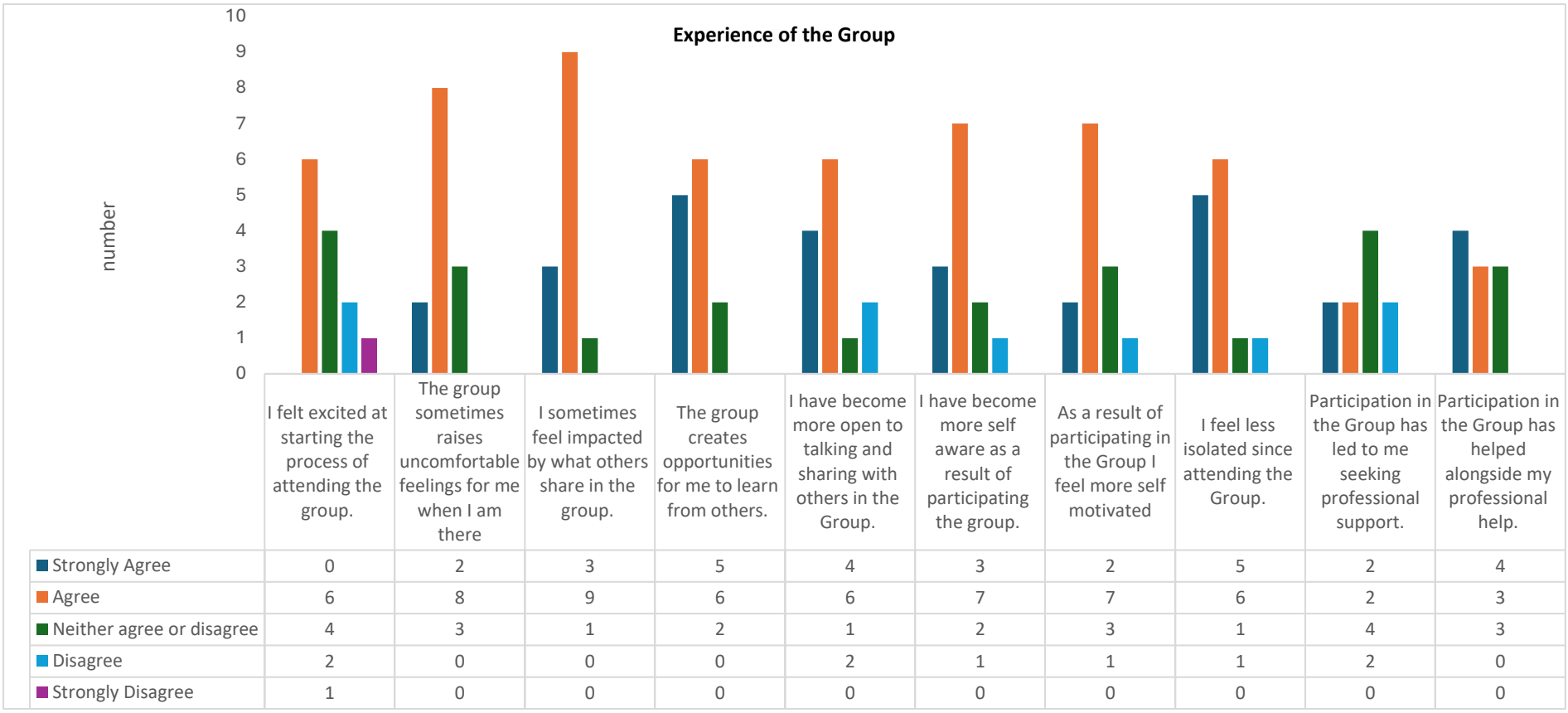
By contrast, there was strong agreement by the stakeholders as regards the group helping stakeholders alongside professional help (mode =1 (strongly agree)) with three stakeholders indicating that the statement was not applicable. There were several additional comments which qualified this:

'Taking part in the group helped me realise that I needed to seek out professional help again'

'The group has been very validating for me and has been crucial in helping me liaise with and engage with services and fight for treatment'

Another stakeholder whilst acknowledging the positive aspects of the group ('the group has been super helpful for me. I've gained a lot from connecting with others that have been through similar things.'), noted the challenges and internal battles that the group presented for 'sometimes I can find what others say a little triggering, not because of specifics, but if I feel like I'm in an okay place, and someone else isn't, the ED voice tries to make sure I go 'backwards''. Fear of being triggered by others has been raised in research into the potential 'harm' that groups might raise in terms of SHGs not promoting recovery (Salzer et al., 2001; Timulak et al., 2013).

Figure 9.4: Experience of the Group



	I felt excited at starting the process of attending the group.	The group sometimes raises uncomfortable feelings for me when I am there	I sometimes feel impacted by what others share in the group.	The group creates opportunities for me to learn from others.	I have become more open to talking and sharing with others in the Group.	I have become more self aware as a result of participating the group.	As a result of participating in the Group I feel more self motivated	I feel less isolated since attending the Group.	Participation in the Group has led to me seeking professional support.	Participation in the Group has helped alongside my professional help.
Strongly Agree	0	2	3	5	4	3	2	5	2	4
Agree	6	8	9	6	6	7	7	6	2	3
Neither agree or disagree	4	3	1	2	1	2	3	1	4	3
Disagree	2	0	0	0	2	1	1	1	2	0
Strongly Disagree	1	0	0	0	0	0	0	0	0	0
mean	2.8	2.1	1.8	1.8	2.1	2.1	2.2	1.8	2.6	1.9
mode	2	2	2	2	2	2	2	2	3	1

Similarly, another stakeholder shared their experience about the difficulties they experienced in attending the group:

> I think if I was in a better headspace the group would have been more helpful for me. I am currently not receiving any 1 to 1 support, so I found that I would attend the group, open the floodgates and let out things I'd maybe been storing up for too long, but there realistically (by no fault of the group or its structure) would not be time or professional support to patch that up again, so I would go home feeling drained and not particularly better.

This revealed the limitations of having a space to share feelings and then not having the subsequent follow up to process anything that may arise. Thus, leaving them feeling perhaps not better. It raises an implication that the group in isolation may not enough for those without professional support or a wider network of support outside that they can draw on. There is an importance of ensuring that attendees of any support group feel contained in a therapeutic sense (Bion, 1962; Miller-pietroni, 1999) so that they are kept safe. This type of containment often requires the skill of a practitioner who is professionally schooled in this area such as a psychotherapist or psychologist (Jacobs, 1993)

Moreover, the lessening of isolation was a strong emergent feature in the additional qualitative comments which helps to illuminate the reason for the strong agreement with the survey statements. For example, one stakeholder with ASD mentioned feeling 'really accepted and not isolated'.

Seeing how others have developed in the group was important for several stakeholders. For example:

> I've gotten to see the long-term outlook of the people I care about who are also suffering with EDs I often feel that most therapeutic settings give a brief window into an ED person's lived experiences, but the long game is so incredibly inspiring. I've seen people change in in heartwarming and tragic ways. It's the reality of our disease, and group is a place where we can honour those extremes and everything in between.

9.5.4 Findings on stakeholders' experience of recovery

Figure 9.5: Impact of Group on Recovery

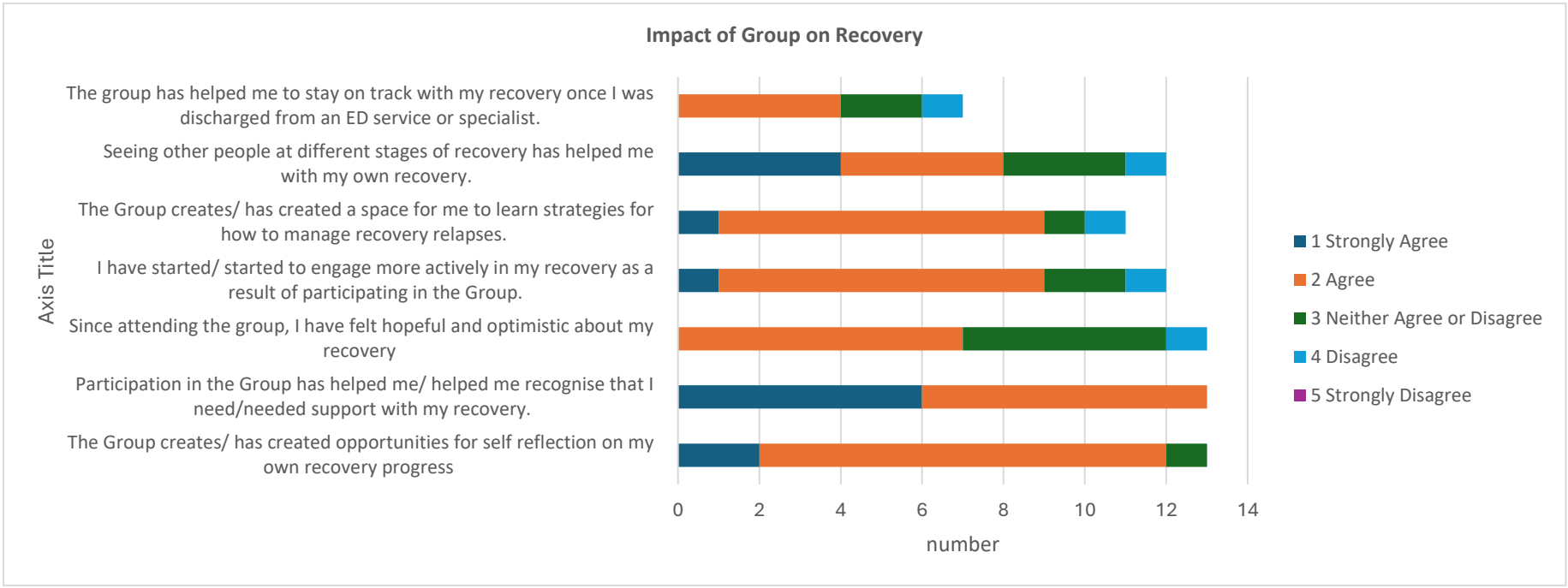


Table 9.14: Impact of Group on Recovery (with averages)

Statements	1 Strongly Agree	2 Agree	3 Neither Agree nor Disagree	4 Disagree	5 Strongly Disagree	Mean Score	Mode Score
The Group creates/ has created opportunities for self-reflection on my own recovery progress.	2	10	1	0	0	1.9 (agree)	2 (agree)
Participation in the Group has helped me/ helped me recognise that I need/needed support with my recovery.	6	7	0	0	0	1.5 (agree)	2 (agree)
Since attending the group, I have felt hopeful and optimistic about my recovery	0	7	5	1	0	2.5 (agree)	2 (agree)
I have started/ started to engage more actively in my recovery as a result of participating in the Group.	1	8	2	1	0	2.3 (agree)	2 (agree)
The Group creates/ has created a space for me to learn strategies for how to manage recovery relapses.	1	8	1	1	0	2.2 (agree)	2 (agree)
Seeing other people at different stages of recovery has helped me with my own recovery.	4	4	3	1	0	2.1 (agree)	1 and 2 (strongly agree/agree)
The group has helped me to stay on track with my recovery once I was discharged from an ED service or specialist.	0	4	2	1	0	2.6 (agree)	2 (agree)

Figure 9.5 (see previous page) and Table 9.14 (above) demonstrate that overall, there was agreement with the seven statements. However, there were different levels of agreement. Optimism around recovery and keeping track with recovery once being discharged from an ED service or specialist, were two that scored at the lower end of the agreement spectrum (scoring a mean of 2.5 and 2.6, respectively). One stakeholder commented on 'seeing some people become more optimistic about their future has helped me to see that things can get better, and that also applies to me'. Seeing someone else experiencing recovery offered hope for this stakeholder which complements findings from this study and existing research such as Federici & Kaplan (2008) and Reid et al. (2008) about how stakeholders value being amongst others. Another stakeholder specifically mentioned the importance of group post treatment as it 'helped me stay on track when I was discharged'. It is important to note that only seven stakeholders answered that question, and six ticked did not apply which could thus account for the lower scoring.

In addition, the data showed that the areas where there was strongest agreement were linked with the group creating a space for self-reflection about the recovery progress and needing support with recovery. This was substantiated by some qualitative comments: 'It's helped me accept I'm still struggling with an ED and I can take some control back and 'it gives me the time and space to think about recovery and related strategies'. This concurs with existing research about how self-development can occur in support groups (see Koski, 2014; Laitinen et al., 2006; Yalom & Leszcz, 2005). Possibly this may have led to them being more open to learn strategies to support their recovery, or that they were motivated to attend the group to do so. This led to one stakeholder acknowledging that 'despite still living with an eating disorder even though I have attended for a few years I have achieved small goals in my recovery'.

Furthermore, it seemed evident that seeing others going through recovery was important for the stakeholders as this statement received high levels of agreement (mean=2.1). The qualitative statements suggested that this was linked to a lessening of isolation and being part of a community:

> 'I greatly appreciate the resource that Sue has created with the group; she has been running it in some fashion for almost as long as I've been alive. I hope that there will always be a place like group where people can go for community; isolation is where eating disordered thoughts fester'.

> 'I value the sense of community it brings to ED recovery, and it is much more inclusive than other SHGs e.g. ABA'.

This sense of feeling valued and accepted are two of Yalom's curative factors of groups (Yalom & Leszcz, 2005) and builds on existing research about the importance that members of SHGs attach to belonging such as (Bolzan et al., 2001; Ki, 2011).

9.5.5 Findings on stakeholders' wellbeing

A baseline score was needed for the SROI calculation. As there was no existing baseline data, pre and post group data was collected about stakeholders to identify what their wellbeing was like before they started attending the group and what their wellbeing was like now. This approach involved the stakeholders being reflective about their progress, drawing on a historical recall of experiences from several years ago.

The use of pre and post-test surveys have been widely used in a plethora of research across a variety of fields such as education learning gains (Domenghini et al., 2014) and health (Davis et al., 2018). However, there are benefits and possible limitations to using a pre and post-test survey design as the stakeholders drew benefits such as efficacy and helping to address potential survey fatigue have been noted (Porter et al., 2004). However, there is the issue of bias and the validity of the results and a need to exercise caution when analysing or interpreting the results. (Marsden & Torgerson, 2012; Nimon, 2014) This can be due to the possibility of participants overestimating how much change has occurred (Davis et al., 2018) or participants reporting change as they believed that this was an implicit reason for a particular intervention in addition to the limitations of their accurate recall (Kowalski, 2023).

Table 9.15 shows the pre and post group data and the overall outcomes in terms of change. As a shortened version of the 14-scale WEMWBS was used it is advised that this SWEMWBS (as per their online guidance) be converted for:

> the seven items have superior scaling properties to the 14 items, but in order to take advantage of this and to compare results with those of other studies using the 7-item scale SWEMWBS, raw scores need to be transformed'

The data showed that ten of the thirteen stakeholders had a meaningful positive change. Despite three not having a meaningful positive change there was no meaningful negative change for any of the stakeholders. Additionally, the mean average self-reported wellbeing WEBWMS score for the stakeholders before they attended the group was 16.3 (baseline score) and the mean average score after attending the group was 21.2. This represents a change of 4.9 which is a significant change in wellbeing, suggesting good value for the group when considered alongside the other analysed data on experiences and how the group supports recovery.

Table 9.15: Stakeholders' Wellbeing Scores

Baseline (Pre attending the group)										Since attending the group (post group)										Change		
I've been feeling optimistic about the future	I've been feeling useful	I've been feeling relaxed	I've been dealing with problems well	I've been thinking clearly	I've been feeling close to other people	I've been able to make up my mind about things	Total baseline SWEMWBS Score	After conversion of the SWEMWBS score	Level of wellbeing	I've been feeling optimistic about the future	I've been feeling useful	I've been feeling relaxed	I've been dealing with problems well	I've been thinking clearly	I've been feeling close to other people	I've been able to make up my mind about things	Total follow up SWEMWBS Score	After conversion of the SWEMWBS score	Level of wellbeing	Change from baseline	Meaningful positive change?	Meaningful negative change?
1	2	1	1	1	3	3	12.0	14.1	Low	2	1	3	2	2	3	2	15.0	15.8	Low	3.0	yes	no
3	2	1	2	2	3	3	16.0	16.4	Low	4	3	2	3	4	2	3	21.0	19.3	Low	5.0	yes	no
1	1	1	1	2	3	4	13.0	14.8	Low	3	3	1	3	3	4	4	21.0	19.3	Low	8.0	yes	no
3	1	3	1	3	2	5	18.0	17.4	Low	4	4	3	5	5	5	5	31.0	28.1	High	13.0	yes	no
2	1	2	1	2	4	3	15.0	15.8	Low	2	1	1	2	2	4	5	17.0	16.9	Low	2.0	no	no
3	4	2	2	2	4	2	19.0	18.0	Low	4	4	3	4	3	2	4	24.0	21.5	Mod-erate	5.0	yes	no
2	2	2	2	2	2	2	14.0	15.3	Low	4	4	3	3	4	4	4	26.0	23.2	Mod-erate	12.0	yes	no
3	2	2	3	3	2	2	17.0	16.9	Low	3	3	3	4	4	3	3	23.0	20.7	Mod-erate	6.0	yes	no
1	2	2	2	2	2	2	13.0	14.8	Low	2	3	2	3	3	2	3	18.0	17.4	Low	5.0	yes	no
1	2	1	2	2	2	2	12.0	14.1	Low	2	3	1	3	3	2	3	17.0	16.9	Low	5.0	yes	no
1	3	1	2	2	2	2	13.0	14.8	Low	3	3	2	3	2	3	3	19.0	18.0	Low	6.0	yes	no
2	3	2	3	3	3	2	18.0	17.4	Low	4	3	2	3	3	3	2	20.0	18.6	Low	2.0	no	no
4	3	4	4	4	3	3	25.0	22.4	Mod-erate	3	3	2	4	4	3	4	23.0	20.7	Mod-erate	-2.0	no	no

9.6 The SROI calculation

Calculating the SROI: Giving outcomes a value

A decision was made to use WEMWBS as it is a well-tested and validated tool adding a level of robustness for the SROI when placing a monetary value on the outcomes of the group. Furthermore, the stakeholders' wellbeing in its entirety rather than individual components of wellbeing was utilised when deciding which outcomes to monetise for the SROI calculation.

The concept of a Wellby (Wellbeing-Year) was used as the valuation tool. It is defined as 'one point of self-reported life satisfaction measured on a 0-to-10 Likert scale for one individual for one year' which is a 'measure of social value and progress' (Frijters et al., 2024, p. 1). The notion was developed by Frijters et al. (2020) and has been 'endorsed' by HM Treasury (Frijters et al., 2024). A financial figure can be attributed to it. It is based on the ONS life satisfaction 10-point scale (0-10). As the SWEMWBS is a 7-35 scale it was rescaled to fit into the 0-10 ONS Life Satisfaction scale as illustrated in Table 9.16. Furthermore, Frijters et al. (2024, p. 2) suggest that its wide use is due to 'its simplicity' in terms, user-friendliness, and the transparent model of the 'theory of change'. In addition, it is informed by a strong evidence base.

Table 9.16: Rescaling SWEMWBS measure

ONS Life Satisfaction	WEMWBS
0	7
1	9.8
2	12.6
3	15.4
4	18.2
5	21
6	23.8
7	26.6
8	29.4
9	32.2
10	35

Table 9.17 shows each stakeholder's change in SWEMWBS wellbeing score represented in WELLBYs, where one WELLBY is a one-step increase in ONS life satisfaction. The mean average WELLBY increase on the ONS life satisfaction scale was 2.

Table 9.17: Stakeholders' change in baseline in WELLBYs

SWEMWBS Change from baseline	WELLBY	WELLBY rounded to nearest whole number
3	1.071428571	1
5	1.785714286	2
8	2.857142857	3
13	4.642857143	5
2	0.714285714	1
5	1.785714286	2
12	4.285714286	4
6	2.142857143	2
5	1.785714286	2
5	1.785714286	2
6	2.142857143	2
2	0.714285714	1
-2	-0.714285714	-1

Calculating the SROI: Impact

Attribution and Deadweight

In identifying the impact of an activity within an SROI, one must consider two aspects of any claims that are made: deadweight and attribution. This is to ensure that one does not overclaim about the impact and value attributed to the activity; in this case the Central London SHG. According to Nicholls et al. (2012) this is a crucial aspect of any SROI.

The two terms can be defined in the following way:

- Deadweight: 'A measure of the amount of outcome that would have happened even if the activity had not taken place'.
- Attribution: 'An assessment of how much of the outcome was caused by the contribution of other organisations or people.'

(Nicholls et al, p. 84)

Within this study the outcome relates to three areas of impact. These were considered when deciding on the figures for attribution and deadweight:

- The attendees' experience of the group
- How the group impacted on their recovery
- The impact of the group on their wellbeing

Deadweight

The deadweight figure was reached through analysing the outcomes data of three areas of the surveys. The wellbeing of the stakeholders was collected to capture a baseline starting point and post group outcomes. It showed that the wellbeing starting point was low for nine attendees and moderate for four of the attendees. The shift between the baseline and the post group scores showed some meaningful positive change for 77% (n=10) of the stakeholders (see Table 9.15).

There was no negative meaningful change. This would suggest that the group had some impact on their wellbeing, which might not have happened had they not attended the group: especially when considered alongside their perception of the group and the group's impact on their recovery (see sections 9.5.3 and 9.54 for a fuller discussion and graphical representation of the findings of the survey responses). Based on this information, a deadweight figure of 50% was decided upon as this was reflective of a need not to overclaim and recognised that 50% of the stakeholders' personal change in wellbeing would have happened despite the group.

Attribution

The demographic data of the group attendees informed how the figure for attribution was reached. The data revealed that 91% of the attendees had accessed their GP (n= 10), seven had had some access to specialist ED treatment and eight had had non ED therapy input Three were on a waiting list, but it was not clear if this was their first request for treatment or not (see Table 9.11). This would suggest that access to medical support (primary via the GP and secondary via the hospital) would have contributed to the stakeholders' support for recovery and wellbeing. Therefore, the attribution takes account for 75% of the net change.

9.7. Results and conclusions

The calculation structure and process has been informed by a social value and management consultancy organisation, Envoy Partnership (Kempton & Gawin Warby 2021) who have a wealth of experience in working in the field of SROI. Their SROI calculator template was adopted for the current study.

Total value created

The process of calculating the value created by the group was as follows:

- Identifying the amount of change created

The overall amount of change created was 1.5 using the WEMWBS outcome scores.

This figure was arrived at through the following calculation:

4.9 (21.2-16.3) ÷ (35-7) x 8.66667 (average number of stakeholders) = 1.5 (post SWEMWBS score minus the pre SWEMWBS score, converted to a 0-1 scale)

- Using the deadweight proportion (50%) and the attribution proportion (75%) to identify the final **impact figure** was computed as 0.57 (to 2 d.p).

Calculation: 1-0.5 (deadweight) x 1.5 (amount of change) x 0.75 (attribution)= 0.6 (rounded to 1 decimal point)

NB: The deadweight calculation of 1-0.5 indicates that 0.5 of the outcome is being removed.

- A financial proxy of £130,000 was used based on the Central WELLBY value figure of £13k per 1 point on the life satisfaction scale per year (Frijters et al., 2024). This was multiplied by the impact figure of 0.6. A discount rate of 3.5% as per Her Majesty's Treasury Greenbook Guidance (H M Treasury, 2022) was built into the final calculation. The benefit period considered was one year.

The total attributable value is £130,000 x 0.6 x 0.965 (the discount) = £ 71,437

The SROI ratio showed that for every £1 invested in the group there was approximately £11 of value created. This was based on £71,437 ÷ £6,650 (the financial and volunteer investment). It is important to note that the monetary values or the estimated value of the group are not real pounds per se as the only 'actual' cost is the yearly rent and the rest of the investment is volunteering time and payment for other resources paid for by volunteers.

The SROI ratio of £1: £11 shows a significant return and thus suggests that the group represents good value. The return based on the lower and upper WELLBY values also showed a good return (see Table 9.19), with ratios of £1: £9 and £1: £14.

Table 9.18: Financial Proxy using different WELLBY figures

	WELLBY figure per 1 point	SROI Ratio Calculation
Lower	£10,000	£100,000 x 0.6 x 0.965 (the discount) = £ 57,900 **Ratio is £1: £9** (£57,900 ÷ £6,650)
Central	£13,000	£130,000 x 0.6 x 0.965 (the discount) = £ 71,437 Ratio is £1: £11 (£71,437 ÷ £6,650)
Upper	£16,000	£160,000 x 0.6 x 0.965 (the discount) = £92,640 **Ratio is £1: £14** (£92,640 ÷ £6,650)

9.8 Strengths and limitations

The main strength of this SROI study is its uniqueness in terms of the subject matter. There appears to be no other such studies about an ED SHG in existence to the best of the author's knowledge, having perused the database on Social Value UK.[7] It has provided insight into the experiences of direct stakeholders and attributed a value to changes in their wellbeing. Moreover, it builds on two other studies that the author has carried out (see chapters five and six) to present an in-depth analysis of how an ED SHG can support ED recovery. A further strength is the use of established and robust measures, namely the use of WEMWBS and WELLBY to inform the monetary calculation. This means that the study has scope for other ED SHGs to replicate aspects of this.

However, there are some limitations which warrant further exploration. One such limitation is that of bias. There is a recognition that there may have been a conflict of interest and potential bias as the author of the SROI is the key person involved in the running and facilitation of the group. This had the potential to influence the deadweight and attribution figures as it could be construed that the author may have wanted to present the impact of the group in the best light possible. However, to mitigate for bias, consideration was given to:

- the type of data collected (Likert scales, the use of the WEMWBS Wellbeing instrument, and quantitative and qualitative data)
- how the data were collected (anonymously)
- how they were analysed (calculation of population baseline scores and arithmetic averages as applicable).

[7] Social Value UK are a professional body for social value and impact management in the UK according to their website (https://socialvalueuk.org/).

Moreover, the simplicity of the model has meant that only broad generalisations could be formed, and several assumptions were made as only one ED SHG with a small number of stakeholders was considered. In addition, the stakeholders were homogenous in terms of gender and ethnicity. The model was not designed to account for variables such as the treatment history and associated costs in detail. However, 'what is important is that the measures adopted capture a large part of the concept they were designed to capture' (Frijters et al. 2020, p. 128).

9.8 Considerations

Two key considerations have arisen out this SROI. The first relates to the estimated value for money. It was noted that the current cost of running the group is £618.75. If this cost was borne by Public Health England, they would get a good return for their money as for every £1 invested in the group there would hypothetically be a return of approximately £11. Stakeholders currently invest in the group in that they pay a small fee each time they attend. If there was external funding more individuals might attend, working on the premise that the 'entry' fee might be prohibitive for those on a low income.

The second pertains to the value of volunteering. Table 9.6 showed that volunteers contribute £6,031 to the running of the group. In addition, they contribute over 200 hours of their own personal time annually. An earlier study carried out by the author about facilitators of ED SHGs noted how enriching the process of being a facilitator was. However, it also found that facilitators found it challenging at times to juggle the competing demands on their time, and the personal sacrifices that they had to make to enable them to carry out their volunteer role (chapter eight). This SROI has confirmed, like the facilitator study (chapter eight) did, the importance of support for facilitators of ED SHGs. The wider consideration is that there may be a role for Public Health England to invest in the training and support of facilitators.

Future research might wish to consider a larger scale study over a longer benefit period to better understand the impact on wellbeing and how it might support relapses post treatment. Indirect stakeholders could be built into the model such as the NHS and friends and carers.

To conclude, this study showed the potential economic and social value of the Central London ED SHG. The data from stakeholders have demonstrated the personal value for each one in terms of how it supports their wellbeing and their recovery from their ED.

Key findings

- The significant return in terms of economic value that were calculated.
- The meaningful positive change in the wellbeing of attendees according to the SWEMWBS pre and post attendance survey scores.
- The benefit in supporting attendees' recovery including seeing others experiencing recovery, space for self-reflection on their own recovery, and recognising a need for specialist support.
- The group acting as a catalyst to seek support

Chapter 10: Conclusions and Discussion

This chapter will revisit the main research aim and questions. It will then synthesise the key findings from across the five studies. This will be followed by sections outlining the implications, strengths and limitations. Finally, there will be some considerations regarding future research directions.

10.1 Revisiting research aims and questions

This thesis sought to address the following research question:

'Who or what contributes to an individual's recovery from an ED?'

This was supported by four supplementary questions:

I. What role do ED SHGs play in supporting an individual's recovery?
II. How do individuals use and experience ED SHGs as part of their recovery?
III. What constitutes recovery from an ED?
IV. What economic and social value do ED SHGs offer?

Table 10.1 (overleaf) presents the key findings and outlines how these questions were addressed by the five studies.

Table 10.1: Key research results and findings

Key Research Findings	Study
Main research question: Who or what contributes to an individual's recovery from an ED?	
-Participants' value of facilitators' lived experience of recovery	1,4
-Facilitators lived experience providing motivation to support group members	4
-The importance of facilitator self-care	4
-The importance of facilitators self-managing personal resonances with participants through emotional distancing, training and supervision	4
-The SROI value of facilitators providing a sense of community	5
-The support from friends and family to attend the group	1
Research question I: What role do ED SHGs play in supporting an individual's recovery?	
-Reinforces the social value of being amongst	1,2,5
-Provides opportunities to talk with others	1,2,5
-Creates a safe place for self-exploration and self-reflection	1,2,5
-BLR modelling identified that one of the PCA factors 'Personal difficulties inside group' was a potential 6-fold risk factor to wellbeing (WEMWBS instrument was used)	2
-Provides a catalyst to seek support- a type of call to action	1,5
Research question II: How do individuals use and experience ED SHGs as part of their recovery?	
-The reasons to seek help:	
-Things spiralling out of control	1,2
-The sense of desperation	1,2
-A belief that the group might help with recovery	1,2
-A motivation to change	1,2
-A desire to connect with others	1,2
-The journey to ED SHG:	
-An intrinsic motivation to attend	1,2
-Suggestions by professionals and friends and relatives	1,2
-Barriers to entry:	
-Delaying entry before joining; personal perceptions about validity of being 'allowed' to attend e.g. not believing that one is sick enough.	1,2,3
-Not knowing that ED SHGs exist or where to find them.	3
-Uncertainty about what happens inside ED SHGs and where to find them.	3
-Belief that ED SHGs promote recovery is a reason not to attend an ED SHG.	3
-Reluctance to get better due to not wanting to gain weight and resistance to accepting help.	1,2,3
Research question III: What constitutes recovery from an ED?	
-Giving up something whilst not being quite ready to do so	1
-A state of remission	1
-Feeling safe to enter recovery	1
-The experience of a fuller life and a recognition that life is exciting	1
-A wish to have a freedom to eat	1,2
-Learning to live with some of the residual behaviours (seeing it as an ongoing process)	1,2
-Managing the ED voice as saboteur	1,2
'Struggles' (one of the PCA recovery factors) was identified as a possible risk factor to the wellbeing (WEMWBS instrument was used), as evidenced through BLR modelling	2
-The PCA recovery factor 'Impact on self' was identified as potentially having a positive effect on wellbeing (WEMWBS instrument was used), as evidenced through BLR modelling	2
Research question IV: What economic and social value do ED SHGs offer?	
The positive impact the Central London ED SHG had was evident due to:	
-The significant return in terms of economic value that were calculated.	5
-The meaningful positive change in the wellbeing of attendees according to the SWEMWBS pre and post attendance survey scores.	5
-The benefit in supporting attendees' recovery including seeing others experiencing recovery, space for self-reflection on their own recovery, and recognising a need for specialist support.	1,2,5

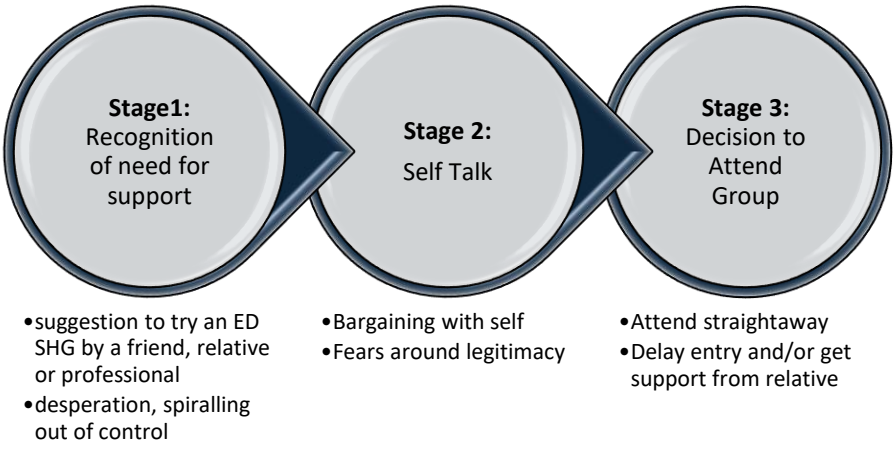
10.2 Key findings in the context of existing research

Three overarching themes emerging from the findings will be discussed with reference to research: joining an ED SHG; value; and recovery.

Joining an ED SHG

The thesis makes several noteworthy and unique contributions to the limited research body around how individuals with an ED decide to join an ED SHG and what subsequently happens. Figure 10.1 outlines this as a series of three stages. One such contribution lies around the barriers to entry post the initial recognition of a need for support (stage 1). For example, individuals who had or who had never attended an ED SHG identified intrapersonal reasons for delaying entry or not attending, linked with beliefs around legitimacy of possible membership (see studies two and three). This corroborates and goes beyond existing limited research noted in the narrative review (chapter three) which noted hesitancy in joining an online forum (Stommel & Meijman, 2011) and some of the emotive reasons why members had joined an OA group (Russell-Mayhew et al., 2010).

Figure 10.1: Stages of joining an ED SHG



Furthermore, the thesis extends existing research as study two (chapter six) found that some delayed entry between one week and one year due to reasons including coming to terms with an ED, denial, and not believing they were sick enough (stage 2). Similarly, individuals who had never attended an ED SHG cited some of the same reasons, particularly around the belief about not being sick enough to attend. Additionally, reasons such as not knowing of their existence and what such groups involved (discussed in chapter seven) precluded attendance.

In the absence of comparable research in this area, the closest research which aligns with this is around barriers to treatment and readiness to change. For example, Hamilton et al. (2022) noted average delays of 5.28 years with lengthier delays linked with the type of ED. Some delays in accessing treatment according to existing research, was sometimes attributed to not being believed (often due to body weight) by friends and relatives (see Eiring et al., 2021) or not being taken seriously by professionals (see Evans et al. 2011) or the internal critical voice described in literature such as the anorectic voice (see Pugh, 2016).

Value

The findings from the thesis demonstrated different types of value that the ED SHG afforded its attendees. For example, it provided opportunities for them to connect with others who were affirmative and understanding; thus, helping to dissipate their sense of isolation (see chapters five, six and nine). This aligns with existing literature such as an appraisal by Salzer et al. (1999) of SHGs who noted the positive impact on the social aspects of life. Furthermore, research by Longden et al. (2018) identified the uniqueness of the support its members felt they received from their peers. Bolzan et al. (2001, p. 322) describes this as being 'amongst equals'. Additionally, the thesis added a new dimension to research through measuring changes in wellbeing of a group of attendees (see chapter nine). This specificity linking wellbeing and attendance at an ED SHG is not evident in research to the best of the thesis author's knowledge.

Moreover, the thesis highlighted that group attendees started to recognise that they had a problem and/or that they were not fully recovered due to hearing others speak in the group (see chapters five and 6). This concurs with research about the value of being in the presence of those who have had an ED and hearing from those who have recovered. For example, in the research of Wasil et al. (2019, p. 1), who coined the phrase 'recovery self disclosures (RSD)', clinicians shared their lived experience. This acted as a form of motivation for the women in their research.

Additionally, the thesis found that the group created a self-reflective space about what the attendees needed to do for their own recovery allowing opportunities for personal growth (see chapters five, six and nine). This is in keeping with existing research such as the research of Laitinen et al. (2006) with women suffering depression learning about what was important for their own self-development.

However, the thesis' findings identified a new dimension to research as regards the intrapersonal process of self-development (PCA factor: 'Personal difficulties inside the group') represented a potential risk factor to wellbeing (six-fold factor) of those attending an ED SHG (see chapter six). This was due to some perceiving that they were not using the group how they wanted to. For example, some were frustrated that they focussed on talking about their family when they wanted to focus on themselves. This is an important consideration for facilitators of groups in terms of their skills and confidence in being able to facilitate the process of supporting the attendees in addressing this. Chapter eight (study

four) of the thesis found that those facilitators who had training were able to confidently interpret group processes and dynamics.

Notably, the thesis showed the economic value that facilitators in addition to their ED lived experiences brought. This was exemplified through the evaluation of an operational ED SHG which showed that their volunteering time represented excellent value for money (as described in chapter nine). This adds an original contribution to research as no such findings appear in literature or on sites such as Social Value UK.

Recovery

The experiential aspects of recovery, in addition to an evolving definition of recovery emerged out of the thesis. Study two, for example, generated seven recovery components which corroborate with existing research about recovery criteria (Noordenbos, 2011; Noordenbos & Seubring, 2006; Rance et al., 2010) alluded to previously in chapter two.

It further addresses the call for such criteria to be grounded in research (Bardone-Cone et al., 2018). The thesis research, through four studies, has analysed the experiences of a range of individuals who have had different forms of treatment and types of support and their views on what matters in recovery to them.

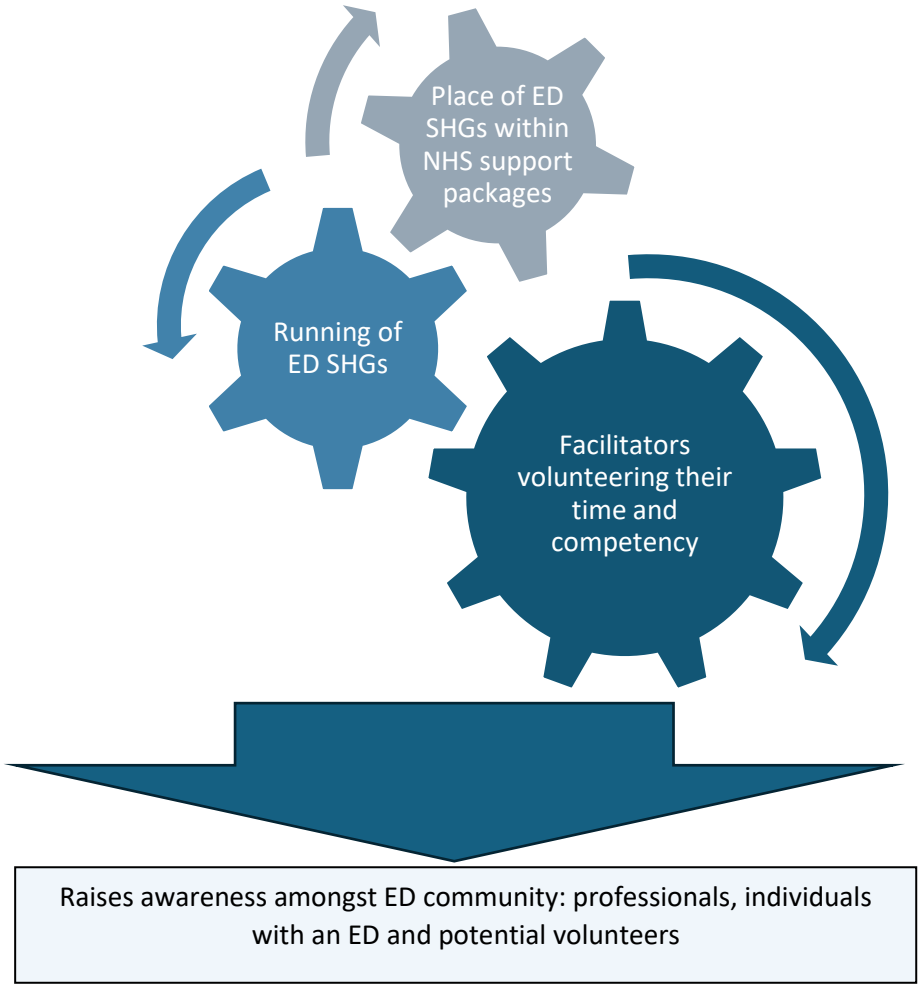
Importantly it has contributed current research knowledge on existing accounts of the subjective recovery experiences of individuals with an ED set within an ED SHG context. This builds on existing accounts such as Matoff & Matoff (2001) and Pettersen & Rosenvinge (2002).

10.3 Implications

Changing Landscape

The thesis author has noted the changing landscape of ED SHGs attendees based on her data collection over the past twenty years. Attendees seem to be presenting with more complex presentations of their ED alongside co-occurring conditions which perhaps could be attributed to the long waits for assessment and treatment. Attendees have cited waits of a year for their initial assessment followed by waits of up to two years before reaching the top of the waiting list for treatment. Additionally, more attendees have disclosed their neurodivergent conditions such as ADHD and autism. This raises several key implications as to the place of ED SHGs which have been outlined in Figure 10.2 (overleaf). The moving cogs represent key elements that were borne out across the narrative review and the five studies.

Figure 10.2: The place of ED SHGs



The effective facilitation of an ED SHG is contingent on volunteer time and competency, especially as all the facilitators in study four were EBEs due to their ED lived experience. This competency thus relies on effective training and supervision (as discussed in chapter eight) which in turn also ensures safety for both attendees and facilitators. Moreover, there is an importance on ensuring that attendees of any support group feel contained in a therapeutic sense (Bion, 1962; Miller-pietroni, 1999). This containment often requires the skill of a practitioner who is professionally schooled in this area such as a psychotherapist or counsellor (Jacobs, 1993). There may need to be a recognition that some potential attendees are not well enough to attend the group and need referring to another service. This may involve additional volunteer time over and above the facilitation of the group.

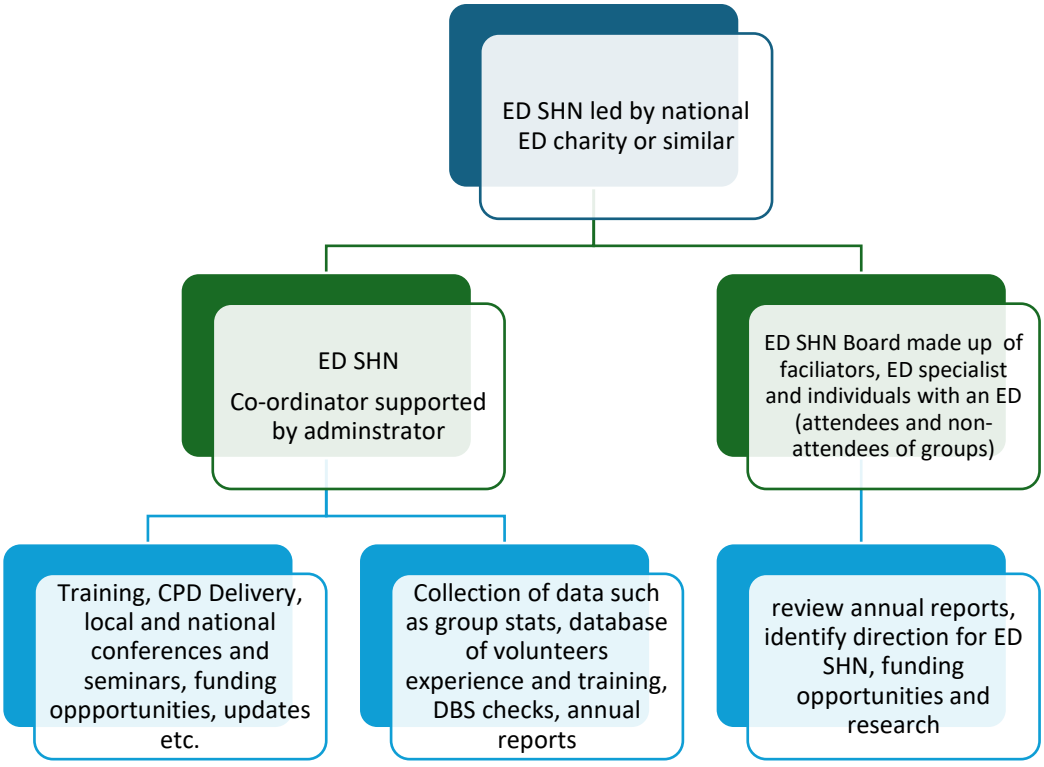
Moreover, having suitably qualified/trained facilitators who promote safe recovery will help to assuage the fears that some professionals have voiced around safety (Breuer & Barker, 2015; Salzer et al., 2001; Timulak et al., 2013). Likewise, it may also address

concerns around the perceived lack of expertise. This in turn may help to raise the esteem of ED SHGs with NHS policy makers when considered alongside the thesis qualitative and quantitative data regarding impact, outcomes and the social value they bring. This will help to demystify what they are, how they are run and who attends and why. Thus, helping ED SHGs become embedded within NHS support packages and promoted as a valuable resource that can support individuals with an ED pre and post treatment. This may lead to the sustainability of groups through helping with active participation, from those who need support and new volunteers with a lived experience who may want to set up their own group or get involved with existing groups.

10.4 Key recommendations

The first recommendation pertains to the possibility of the setting up of an ED Self Help Network (ED SHN) for new and existing groups which are led by lived experience facilitators (as outlined in Figure 10.3).

Figure 10.3: Possible Eating Disorders Self Help Network Model



Benefits of an ED SHN

The thesis author was fortunate to have benefitted from an ED SHN group which was led by a national charity in the early stages of when she became a facilitator. The benefits she noted included:

- Offering a type of kitemark for the groups to indicate that they were working in partnership with the charity.
- being able to call herself an X charity trained facilitator.
- help raise the esteem of the group with local GP Patient Participation Groups and local ED services.
- recognising the value of volunteers through sending out certificates during national volunteering day.
- connecting with other local ED SHGs and facilitators.

Building further on the first recommendation, the second pertains to a need for ongoing funding for the ED SHN and buy-in from NHS services who can see the value of ED SHGs. Moreover, new groups may require start-up funding with initial costs such as rent and public liability insurance. This would help with the scalability of groups as there would be a centralised organisation with a remit to support groups and their growth as well as building up a database of potential new facilitators. The thesis author's group has been in a fortunate position to have benefitted from being able to generate facilitators from within the group through a process of mentoring.

10.5 Potential avenues for future research

- Research examining what matters to ED SHG attendees in terms of their impressions of the ED SHG facilitator, with respect to the importance they attach to the lived experiences of facilitators. This would add an extra perspective to the debate regarding whether practitioners with lived experiences should be working with patients with an ED.
- A longitudinal study which could track the recovery of a cohort of ED SHG attendees. Such a study could check on their wellbeing, their recovery journey, and how the group supports their recovery over a period of three years.
- The replication of the SROI evaluative study which examined the impact of ED SHGs on recovery and wellbeing (chapter nine). This would add to the Social Value UK database and build on the body of work around the economic and social value of ED SHGs, which is under researched as demonstrated by the thesis.
- An examination of the experiences of individuals who might find it challenging to attend such as those with autism. A stakeholder in SROI study five mentioned that they felt 'welcomed and less isolated' in their group. Another individual in study three (non-attender of an ED SHG) mentioned that part of their 'recovery was finding other autistic women'. By contrast a study two participant from a minority ethnic group expressed concern about the lack of diversity and how it felt 'being in a room

of white girls'. There is a need for more published research about minority ethnic groups with an ED as such groups are currently underrepresented (Halbeisen et al., 2022).

10.6 Strengths and limitations

The thesis has several limitations. The first pertains to how study three (chapter seven) was advertised and constructed, leading to a small response rate relative to the estimated ED population. On reflection, it may have been more prudent to have framed the research question in more general terms asking potential participants about their experiences of ED recovery with a sub question interrogating why they had not attended an ED SHG. Asking a question that is about absence of criteria i.e. not attending an ED SHG may not have been attractive to someone from the ED community. Secondly, there was a reliance on self-reporting about recovery and ED diagnosis. The use of existing instruments may have added an extra layer of robustness. However, as the focus of the thesis was on ED SHGs, which is under researched, this may have mitigated for this.

Thirdly, the sample sizes were modest in two of the studies. This means that caution must be taken in terms of the generalisability of results and findings. However, the findings can be used a framework for an enhanced understanding of ED SHGs and what matters in recovery. Fourthly, the thesis author interviewed participants known to her (chapter five) and gathered anonymous online data from group members from the group she co-facilitated (chapter nine). She may have unconsciously or consciously not pursued more information about how participants felt about the facilitators for fear of hearing or reading something critical or positive about herself and her fellow co facilitators. This may have resulted in missed opportunities for the gathering of more in-depth data about the role of the facilitator and how attendees felt about them. However, this was mitigated for, by using another interviewer for the fourth study about facilitators (see chapter eight).

The main strength of the thesis is the MMR approach which enabled a kaleidoscopic enquiry into what ED SHGs are, how they function and how they support recovery. Another strength is the diversity of the five studies including one study (chapter seven) which focused on a hard-to-reach group of individuals who had never attended an ED SHG which offered insights into the potential intrapersonal and external barriers to attending. The final strength opened a potential line of enquiry as to why a group situated in central London with a diverse population (chapter nine) is frequented by a homogeneous group. Moreover, the author has analysed more recent data and has seen an increase in men regularly attending and less so with respect to minority ethnic attendees. This has raised questions as a group contact and facilitator as to whether this pattern on lower engagement from minority ethnic groups is related to stigma with such communities and replicates what happens more broadly in MH in terms of potential structural barriers.

10.7 Final thoughts

At the start of my PhD journey, I hypothesised that ED SHGs can support recovery, and I believe that this thesis has shown this through the innovative mixed methods approach methodology. Its findings have been impactful for me as I have found myself reflecting on my own practice as a psychotherapist/counsellor and as a group facilitator of an ED SHG. I feel that I have been in a unique position to have been able to implement theory into practice for the duration of writing this thesis. For example, I have been able to weave in research about what is recovery when the topic matter has been raised by group attendees. As a group we have discussed the external realities of long waits for treatment, good and bad experiences with professionals, and what informal support they have accessed such as self help books and recovery coaches.

Furthermore, I have observed the importance of the lived experiences of the attendees, myself and fellow co-facilitators on how the group functions and how that has created a community of learners all supporting one another, where over time the newcomers learn from the oldcomers (the more experienced attendees) through a process of legitimate peripheral participation (Lave & Wenger, 2001). Moreover, there is an active interchange of knowledge that does not just sit with me, but also with the members who feel able to share their experiences (professional and experiential). It has been instrumental in why I have sustained my thirty-year engagement with the group, and I will continue with this commitment.

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