The importance of social identities in the management of and recovery from 'Diabulimia': A qualitative exploration

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ABSTRACT

Introduction: A significant barrier to recovery for individuals with co-morbid eating disorders and type 1 diabetes is the way in which group members self-categorise. Nonetheless, identity issues are neglected during the recovery process. The aim of this paper is to explore how group memberships (and the associated identities) both contribute to and hinder recovery in this cohort.
Method: Transcripts from five online focus groups with 13 members of an online support group for individuals with 'Diabulimia' were thematically analysed.
Results: Findings suggested that those with whom one shares a recovery identity can be well placed to provide psychological resources necessary for successful recovery although such connections can be damaging if group norms are not managed. Members recognised that other important relationships (including family and friends and health professionals) are also key to recovery; these other group memberships (and the associated identities) can be facilitated through the recovery identity group membership, which allows for external validation of the recovery identity, provides encouragement to disclose the illness to supportive others, and provides information to facilitate positive service interactions.
Conclusions: While clinical interventions typically focus on eliminating disordered behaviours, we suggest that these should also include strengthening important group memberships that promote recovery.

1. Introduction

Individuals with Type 1 Diabetes Mellitus (T1DM) are at increased risk of developing an eating disorder (Custal et al., 2014; Jones, Lawson, Daneman, Olmsted, & Rodin, 2000; Peveler, 2000). A defining behavioural feature of eating disorders in individuals with T1DM is the practice of deliberately and chronically withholding insulin specifically and only for weight loss (Custal et al., 2014; Murray & Anderson, 2015; Pinhas-Hamiel, Hamiel, & Levy-Shraga, 2015; Tierney, Deaton, & Whitehead, 2009). As weight loss itself increases in importance to the individual, he or she tends to also routinely engage in other weight management strategies (Balfe et al., 2013) commonly associated with anorexic or bulimic behaviour (Allan, 2015; Custal et al., 2014; Murray & Anderson, 2015). While there has been limited research with this population, Custal et al. (2014) found that apart from insulin misuse, individuals with co-morbid eating disorders and T1DM do not differ from individuals with eating disorders on other eating disorder-related

behaviours and psychopathology (such as drive for thinness, body dissatisfaction, and perfectionism).

Once diagnosed, this cohort tends not to respond to standard eating disorder treatment and is at very high risk of serious complications linked to the eating disorder and the resulting poor glycaemic control (Colton, Olmsted, Wong, & Rodin, 2015; Peveler & Fairburn, 1992; Tierney et al., 2009). Compared to individuals with eating disorders but without diabetes, this cohort shows lower partial and full recovery rates and individuals are more likely to drop out of treatment at an earlier stage (Peveler & Fairburn, 1992). Poor clinical outcomes are primarily explained as a result of low levels of persistence and motivation to change (Custal et al., 2014). However, recent research suggests that an important barrier to recovery is the way in which this cohort self-categorises as an illness group (Allan, 2015; Allan & Nash, 2014).

Within mental health in general (e.g. British Psychological Society, 2013) and eating disorders in particular (e.g. Fairburn & Cooper, 2014), there remains a critical discussion about the validity of diagnostic terminology for understanding facets of human distress. Nevertheless, for people experiencing such difficulties, group identities are commonly organised around diagnostic labels (e.g. Espíndola & Blay, 2009), and the issue of identity also lies at the heart of recovery for individuals with both diabetes and eating disorders. The diabetes community uses the

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term 'Diabulimia' to describe what they see as a unique illness identity that should be distinguished from other eating disorder subtypes (Allan, 2015; Allan & Nash, 2014; Custal et al., 2014; Murray & Anderson, 2015; Tierney et al., 2009). However, this is neither a recognised diagnostic category, nor is it used in the academic literature (Allan & Nash, 2014).[1] This absence of identity recognition can hinder recovery due to lack of tailored health services and professional training (Tierney et al., 2009), misunderstanding on the part of family and friends (Pinhas-Hamiel et al., 2015), and the inability to form connections with other individuals participating in group eating disorder interventions (Colton et al., 2015). Cruwys, Haslam, Fox, and McMahon (2015) found that in such group programmes individual progress often occurs in the context of newly forged ideas of normative changes within a group identity; however, someone with Diabulimia may not be able to share the group's recovery identity due to their perceptions of the unique nature of their particular difficulties, thus making the acceptance of newly formed group norms a much harder task.

Over time the eating disorder forms an important basis for self-definition (Abbate-Daga, Amianto, Delsedime, De-Bacco, & Fassino, 2013). Consequently, a shift from an illness to a recovery identity is an essential part of successful recovery (Bowlby, Anderson, Hall, & Willingham, 2015; Espíndola & Blay, 2009; McNamara & Parsons, 2016). However, identity change is typically conceptualised as occurring at the individual rather than the group level (Malson et al., 2011). Recent research in the area of substance misuse has highlighted the importance of social identity transition for successful recovery from addiction. It is proposed that dis-identification with an 'addict' group alongside identification with a recovery group fosters recovery and positive health outcomes (Best et al., 2016; Dingle, Stark, Cruwys, & Best, 2015; Frings & Albery, 2015). Recovery identities have been associated with lower relapse rates (Buckingham, Frings, & Albery, 2013), treatment engagement (Beckwith, Best, Dingle, Perryman, & Lubman, 2015), and greater duration of abstinence (Tomber, Shahab, Brown, Notley, & West, 2015).

It has been argued that eating disorders are a form of addiction (Davis, 2001; Davis & Claridge, 1998). From a clinical perspective, the core behavioural components of eating disorders closely resemble those of substance abuse (Davis, 2001). For those living with Diabulimia, the act of insulin omission and the performance of other disordered eating behaviours become progressively entrenched and individuals report feeling unable to cease these behaviours in spite of experiencing adverse medical consequences (Balfe et al., 2013). Given the addictive components associated with Diabulimia and the complex identity issues involved, it is argued here that the approach espoused by the Social Identity Model of Cessation Maintenance (Frings & Albery, 2015) and the Social Identity Model of Recovery (Best et al., 2016) might be effectively applied to recovery from Diabulimia.

Recent research by McNamara and Parsons (2016) has illustrated that connections with similar others online can promote recovery in individuals with eating disorders through the construction of a shared recovery identity that promotes illness disclosure and treatment engagement. However, a shared recovery identity, while central to treatment success, is only one part of successful recovery. The newly-acquired recovery identity needs to be seen in the context of other groups that are also crucial to recovery and that have implications for how individuals self-define. Therefore, the aim of the current paper is to explore the ways in which important group memberships (and the social identities derived from them) both contribute to and hinder the process of recovery in individuals with Diabulimia.

1.1. The role of social relationships in recovery

Social relationships are important in providing a context conducive to recovery, namely, one where the individual does not feel judged on the basis of their disorder identity but feels understood, accepted and perceives their issues are taken seriously by their social networks (Federici & Kaplan, 2008; Leonidas & dos Santos, 2014).

The Social Identity Model of Identity Change (SIMIC) proposes that group memberships have an important role to play in adjusting to change (Haslam et al., 2008; Iyer, Jetten, Tsivrikos, Postmes, & Haslam, 2009). Life transitions often involve leaving one social group to join another – a process that can be experienced as extremely stressful (Haslam et al., 2008). SIMIC proposes that the negative effects of transition can be attenuated, in part, through the adoption of a new social identity which provides the individual with a sense of meaning, purpose, and behavioural guide (Haslam et al., 2008; Iyer et al., 2009). This model forms a key element of the social identity approach to addiction and has informed both the Social Identity Model of Cessation Maintenance (Frings & Albery, 2015) and the Social Identity Model of Recovery (Best et al., 2016). These models propose that a shared sense of identity with others who are also in recovery facilitates the identity transition necessary for successful recovery. Alongside receiving social support from other group members, the recovery group membership acts as an important meaning-making tool that guides behaviour and provides the individual with specific goals and motivations that offer a sense of purpose post-transition (Buckingham et al., 2013; Frings & Albery, 2015; Dingle, Stark, et al., 2015; Jones et al., 2012).

The eating disorder literature has tended to focus on how connections with similar others, particularly those forged online, maintain disordered behaviours rather than promoting recovery (Riley, Rodham, & Gavin, 2009). Nonetheless, recent research in this area suggests that a shift away from a positively-valued eating disorder identity is facilitated by the support and understanding of similar others (Ison & Kent, 2010; Linville, Brown, Sturm, & McDougal, 2012; McNamara & Parsons, 2016; Ransom, La Guardia, Woody, & Boyd, 2010). While research on this topic is even more scarce for those dealing with Diabulimia, a qualitative study by Balfe et al. (2013) suggested that moving away from disordered behaviours was facilitated by contact with similar others which allowed participants to acknowledge the severity of their disorder. However, there is no insight into how recovery identities might promote positive health outcomes in this cohort. Given the comparative rarity of the comorbidity of eating disorders and type 1 diabetes, the potential of online groups in particular to facilitate the construction of a shared recovery identity necessitates further investigation.

Although relationships with similar others can be helpful, relying on such identities may keep individuals within the world of mental illness and addiction indefinitely, preventing a full recovery (Tew et al., 2012). While the social identity approach to recovery has recognised the importance of dis-identification with groups that promote addictive behaviours, it has yet to consider in detail how to incorporate into the recovery process group memberships that may have been negatively affected by the individual's disorder identity but are a vital part of recovery. This is an important avenue of research as the desire to repair important relationships, particularly those with family and friendship groups, can be a catalyst for recovery (Dingle, Cruwys, & Frings, 2015; Leonidas & dos Santos, 2014; Linville et al., 2012).

Family and friendship groups represent potentially important identity groups that have existed prior to the onset of the individual's addictive disorder and should be present after recovery (Haslam et al., 2008; Tew et al., 2012). These can provide a sense of identity continuity to the individual which is an important determinant of a successful identity transition (Haslam et al., 2008). The formation of a recovery identity might also be seen as more compatible with these identities – again another important determinant of a successful transition (Haslam et al., 2008). While individuals with eating disorders can withdraw from valued support networks (Leonidas & dos Santos, 2014), it is important

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that such identity networks are preserved (or re-established) during recovery.

However, support from family and friends is not always positively experienced by individuals in recovery from an eating disorder (Leonidas & dos Santos, 2014; Linville et al., 2012). There can be a mismatch between an individual's support needs and the support offered such that it is experienced as inadequate at best or hurtful at worst (Linville et al., 2012; McNamara & Parsons, 2016). Family and friends may believe that the disorder is controllable by the individual. This misperception can result in tense interactions that ultimately damage relationships (Linville et al., 2012). Those living with Diabulimia have described family and friends as "imperfect supports" (Balfe et al., 2013, p. 2033) in that dysfunctional family relationships could contribute to the development of the disorder but also that family members can reinforce disordered behaviours due to the value placed on weight loss (Balfe et al., 2013). Given the mixed findings in this area (Leonidas & dos Santos, 2014), it is important to investigate how such broader identity networks can be effectively incorporated into the recovery process alongside the recovery-oriented group.

Finally, support also comes from formal services. Issues around identity and service engagement have been investigated to a limited extent within the social cure tradition. Walter, Jetten, Dingle, and Parsell (2015) argue that engagement with some services (specifically those for homeless individuals) necessitates the adoption of a stigmatised identity which might not necessarily be associated with positive outcomes for the individual. Nonetheless, there is evidence that identification with services can enhance wellbeing in this group (Walter, Jetten, Dingle, Parsell, & Johnstone, 2016), suggesting that self-categorising in terms of a stigmatised identity might not always be negative. However, service interactions can become a site of identity conflict (Stevenson, McNamara, & Muldoon, 2014). The stigma associated with a group of service users can undermine relationships with service providers by undermining a sense of shared identity between both parties. This lack of shared identity combined with service users' anticipation of negative treatment from service providers undermines trust in services and could ultimately contribute to individual service disengagement (Stevenson et al., 2014).

Such issues are particularly pertinent for the current context. First, as mentioned earlier, healthcare professionals do not formally recognise the Diabulimia identity (Allan & Nash, 2014). Individuals with Diabulimia have reported negative experiences with professionals when they used this term with their identity being dismissed as "made up on the Internet" (Allan, 2015, p. 100). This dismissal of an individual's identity can lead to difficult interactions with professionals and a refusal to engage with treatments that are not perceived as identity-congruent (Colton et al., 2015). Furthermore, individuals with eating disorders are routinely stigmatised by professionals (Byrne, 2000; Currin, Waller, & Schmidt, 2009; McNicholas, O'Connor, O'Hara, & McNamara, 2016). They are described as difficult to treat and are not viewed as a group that clinicians enjoy interacting with. This is also the opinion displayed toward those with diabetes, thus those presenting with both conditions may be doubly-disadvantaged (Tierney et al., 2009).

However, as with family and friends, those with Diabulimia do mention strong therapeutic relationships with health professionals as important to recovery (Balfe et al., 2013; Tierney et al., 2009). Thus, as with informal support sources, it is important to determine how these relationships can also be effectively incorporated into the recovery process and understand how they exist alongside other valued identity groups.

To summarise, poor treatment outcomes for individuals with Diabulimia are typically explained in individualistic terms, neglecting the role of social factors in recovery. Group memberships (and the social identities derived from them) are at the core of the identity transition process necessary for successful recovery (Best et al., 2016; Dingle, Stark, et al., 2015). These identity networks form the context in which

recovery occurs and can both facilitate and hinder this process (Haslam et al., 2008). The social identity approach to addiction recovery has so far investigated the role of identity groups relevant to the addict and recovery identity (i.e. similar others) but has paid less attention to the role of other identity groups that are crucial to recovery. Therefore, the aim of the current paper is to investigate the role played by multiple identity groups in the recovery process. Specifically, we are interested in exploring (1) how a sense of shared identity with similar others online enhances wellbeing and promotes recovery from Diabulimia and (2) how important identity networks can be successfully incorporated into the recovery process.

2. Method

2.1. Participants and recruitment

Thirteen members of an online support group for individuals who self-categorise as recovering from Diabulimia participated in this study. Of those who reported demographic information, all were female and ranged in age from 18 to 67 years (mean age = 34.9 years). Nine participants were British and two were from the USA. Participants were recruited through an advert posted on the online group's homepage. Those that indicated their willingness to participate were provided with a detailed participant information sheet by the research team which indicated that the research was being conducted as part of the requirements of the first author's Bachelor's degree. Participants were informed that their participation in this study would not affect the service they received from the online group. Informed consent was obtained from all participants prior to the focus groups. The study and its procedures were approved by an ethics committee at the lead author's institution.

2.2. Data collection

Five online focus groups (Gaiser, 1997) comprising two to four participants were facilitated by the first author using a secure chat room accessible only by study participants and the facilitator. The facilitator had sufficient preparation for the process through completion of core research modules and preparatory conversations in academic supervision. She had no additional relationship with the participants beyond the recruitment to – and conduct of – the focus groups. Each participant was issued a unique screen name when they logged in at the beginning of the focus group session to preserve anonymity. A semi-structured schedule was developed from a literature review and consisted of fourteen open-ended questions that explored participants' experiences of the online support group (e.g., "what have you found most useful about being part of the group?"), their impression of support services available for individuals with Diabulimia (e.g., "what other support services did you try before this group?"), and their experiences of seeking help and support for their disorder from family, friends, and healthcare professionals (e.g., "what do you find most challenging about talking to people who do not have the illness?"). Focus groups lasted for approximately 1 h each. Transcripts of chat sessions were subsequently downloaded and entered into NVivo text tagging software for analysis.

2.3. Analytic approach and procedures

A theoretical thematic analysis (Braun & Clarke, 2006, 2013) was conducted on the data as we were interested in exploring participants' experiences of recovery and the online group through the lens of the social identity approach. A contextualist epistemological approach (Braun & Clarke, 2013) was adopted in this study. This approach views knowledge as signifying the researcher's theoretical position and experience in addition to being 'true' in the data collection context (Braun & Clarke, 2006).

Analysis followed the steps outlined by Braun and Clarke (2006). Transcripts were read repeatedly for familiarisation purposes before all data relevant to the research question were coded, being as inclusive as possible. Themes articulating the most salient patterns occurring across the dataset were formed by grouping similar codes together. Through the use of deviant case analysis (Silverman, 2001), instances which did not fit the broader patterns were used to revise the thematic structure so that it could account for the data in its entirety. All data pertaining to each theme were collated once the thematic structure was finalised.

Braun and Clarke (2006, 2013) advocate that the process of coding and initial analysis is built upon the individual researcher developing a deep familiarisation with the data; within this methodological position, the concept of inter-rater reliability to coding is not an appropriate expectation, and so the initial stages of coding were conducted primarily by the first author without seeking to perform inter-rater reliability checks. However, samples of transcript were reviewed by the second author in her role as academic supervisor. Discussions were held at all stages of the analytical process to create an iterative process through which the analysis reflected the original data in a coherent manner that had been considered from the multiple perspectives of the different researchers.

3. Findings and analysis

Four themes were identified from the data. Superordinate and subordinate themes are provided in Table 3.1. These are discussed below with extracts provided to illustrate identified themes. We begin by articulating how identity can lead to a perception of being driven away from mainstream supports (including other service users and professional services) and subsequently seeking validation in the online group. While this group can assist in symptom management and enhance wellbeing, group members must also manage the risks presented by the community. Finally, we detail how the validation provided by the online group allows reintegration into other valued groups.

3.1. Theme 1: not like everyone else

3.1.1. Self-distinction from other patients

Participants saw themselves as having a distinct (as they termed it) "Diabulimic" identity and the lack of recognition of this identity by others acted as a significant barrier to support. Participants saw insulin omission as a defining feature of their illness identity that distinguished them from other eating disorder groups and which prohibited them from developing a shared sense of identity with other individuals with eating disorders. In extract 1 below, participants discussed their experiences with either eating disorder-only or diabetes-only groups – neither of which is able to support them in the way they needed. Being directed

Table 3.1
Superordinate and corresponding subordinate themes.

Superordinate theme	Subordinate themes
Theme 1: not like everyone else	Self-distinction from other patients
	Dismissal of healthcare professionals
Theme 2: shared identity online promotes recovery	Acceptance and validation of Diabulimic community
	Facilitation of symptom management
	Shared learning
Theme 3: threats to recovery	Self-management – when Diabulimic is not a helpful identity
	Group self-regulation
Theme 4: recovery outside of the Diabulimia group	Accessing services
	Talking to non-group members
	Owning the group identity

to this form of support is reflective of the current treatment protocol, whereby illnesses are seen as co-morbid and both are treated separately (Allan & Nash, 2014; Custal et al., 2014). However, participants did not view this as helpful for recovery:

Extract 1
Focus group 1
User81 […]the other patients did fail to grasp the effect diabetes had to play in my situation, they didn't understand the complexity of it, so it was easy to feel alone even when surrounded by support, as through no fault of their own, they could not fully understand
User58 Plus they were all non-diabetics, and didn't know what MY issues meant. There was one diabetes group, but all that happened is that the nurse scolded me for not improving my BGs[a] in a week, and THAT set me off to the point where I wouldn't go back.
User81 Sometimes I felt people would be thinking 'oh here she goes again, on about her sodding diabetes'
[a] Blood glucose levels.

3.1.2. Dismissal of healthcare professionals

The fact that this combination of difficulties is not well encapsulated within existing diagnostic frameworks meant that medical help was also perceived to be inadequate which led to difficult interactions with healthcare professionals (as alluded to in Extract 1). Participants felt a lack of empathy from clinicians regarding the hold that the eating disorder had over them:

Extract 2
Focus group 3
Int   What smaller things do you feel the professionals don't get?
User12 That just how randomly and dramatically blood levels can fluctuate, even when you are putting in 200%, how small things can really have a massive impact on your day and your ability to do the right thing, that making the right choice, no matter how insightful you are is still very fucking hard.

While this sentiment has been expressed in research with individuals with eating disorders (McNicholas, O'Connor, McNamara, & O'Hara, 2015), our participants also faced the lack of formal recognition of their disorder as well as a lack of professional knowledge and training (Allan, 2015; Tierney et al., 2009). This added an extra barrier to receiving what they perceived to be effective and appropriate treatment, in spite of their efforts to engage with the services offered to them:

Extract 3
Focus group 2
User93 I've tried counseling and therapy (for eating disorders) but none of them had a clue what Diabulimia was so weren't much help whatsoever. Everyone I tried to explain to they'd just ignore me and talk about other eating disorders that I may have.

This inability to find appropriate support resulted in a strong feeling of isolation among participants. While they shared that they had a strong desire for recovery, they felt that this could not be achieved without support from similar others (Best et al., 2016; Frings & Albery, 2015) and professionals who were informed about their disorder.

3.2. Theme 2: shared identity online promotes recovery

3.2.1. Acceptance and validation of Diabulimic community

The sense of identity as 'Diabulimic' operated as a social identity that formed the basis for seeking out similar others online to access the support that they felt would be more helpful and conducive to recovery than that received from those who did not share this identity (Best et al., 2016; Frings & Albery, 2015; Haslam, Jetten, O'Brien, & Jacobs, 2004; Haslam, Reicher, & Levine, 2011; McNamara & Parsons, 2016; Read, Morton, & Ryan, 2015). Participants described the strong sense of community and sense of shared identity among the online group. This was reported to combat feelings of isolation and group members formed a key part of participants' social networks (Best et al., 2016):

Extract 4
Focus group 2
User1   I've got some of my best friends from it
User3   Yeah I have made some really close friends through the support group, in fact a whole new social circle offline

Focus group 3
User12   It's given me true valuable friendships with people who get it.

Similar to research in addiction recovery, Extract 4 above illustrates that as the individual wished to recover, their social networks increasingly included others in recovery (Best et al., 2016; Dingle, Stark, et al., 2015). Interactions with group members were much different to those described earlier:

Extract 5
Focus group 2
User10   I think the chance to really say all on my mind, to rant and just get it all out because a lot of the time healthcare professionals don't provide that space, or don't know where you're coming from. also you bond with people online, and strike up friendships, so the mutual support is really valuable. you can say your most honest shit but it's not the unbalanced relationship of a healthcare professional and client.

Focus group 5
User20   I do have support from other areas but it's not the same here I can come and rant and rage be depressed or proud of myself feel rubbish or great. No one judges or tries to tell me "I mustn't do this or that" or says "if you carry on behaving like this you'll be crippled with this disease by the time you're 50".

The support offered by those who share a sense of identity was perceived as qualitatively different from that received from those outside the group (Haslam et al., 2011; Linville et al., 2012; McNamara & Parsons, 2016). Specifically, participants felt that they could share experiences without being judged and that they could receive the emotional support and encouragement from group members that was absent from their other support networks (however well-intentioned the support offered may be).

3.2.2. Facilitation of symptom management

It was apparent from the data that the group provided a social context within which members could learn to manage their disorder and face the challenges of recovery (Best et al., 2016; Dingle, Cruwys, et al., 2015; Dingle, Stark, et al., 2015). The group was seen as a vital source of information about the illness and how to manage it. This was especially important given the aforementioned lack of knowledge among many clinicians (Tierney et al., 2009). Participants described the group as their primary source of advice:

Extract 6
Focus group 5
User81   It's like the start point do I look it up on google or go to the GP, no I ask the group if that makes sense, it's like the first thing I do
Int   That's great, and why is it the first place you go to over other places?
User81   Because no one knows more about Diabulimia than Diabulimics

3.2.3. Shared learning

Aside from information on medication and coping strategies, it was clear that learning about the consequences of the disorder and its complications from trusted others had an impact on participants' willingness and motivation to improve their own self-care (Frings & Albery, 2015; Haslam et al., 2004). This is exemplified below when participants were asked about the type of informational support received from the online group:

Extract 7
Focus group 1
User81   Mostly insight into the devastating impact of it
User93   Yes definitely the consequences of it all, people sharing their experiences first hand. It's a real eye opener.
User81   I knew the facts, but nothing like hearing first hand experiences
User58   Exactly, 81!

Thus, it would seem that a shared sense of identity with similar others assists in the successful management of the disorder, including finding comfort in the encouragement from others and having a trusted source of information and advice (Best et al., 2016; Frings & Albery, 2015; Haslam et al., 2004). It also suggests, similar to Balfe et al. (2013) that such connections can assist in individuals appreciating the negative consequences of disordered behaviour patterns related to their eating disorder.

3.3. Theme 3: threats to recovery

3.3.1. Self-management – when Diabulimic is not a helpful identity

While the group experience was generally a positive one, there could be some drawbacks whereby interactions with the group could have a negative effect. At times, group members felt that they had to regulate contact with the group if they perceived it was having a negative impact on mood:

Extract 8
Focus group 4
User61   I had to take a step back after my baby was born though as I was feeling very vulnerable and didn't find it helpful focusing on anything ed related.
Int   That makes sense, so can sometimes an online group make you think more about the illness?
User95   Yes. You are definitely more mindful. Sometimes that's a good thing but sometimes not. Think that depends on your frame of mind/mood.
User61   Yes. Sometimes it can be very helpful but personally I've found that if I'm feeling vulnerable and lots of people are really struggling the general mood can decline and it is easy to dwell on the negativity. But overall I've found online groups a positive experience.

This illustrates the potential for such groups to present threats to recovery, requiring the individual to regulate their contact with the group (Haas, Irr, Jennings, & Wagner, 2011; Mulveen & Hepworth, 2006). It also provides further support for the recommendation by Frings and Albery (2015) that such groups comprise a mix of participants at different stages of the recovery process.

3.3.2. Group self-regulation

Participants pointed to the importance of group norms (or "guidelines" as they were referred to) to highlight how the group itself can respond to instances where online group interactions can contribute to individual vulnerability and threaten the recovery of its members (Frings & Albery, 2015). Participants believed that it was important for group norms to be centred on recovery and for these to be enforced in group discussions:

Extract 9
Focus group 4
User61   I think it's important for there to be guidelines in place and for all members to stick to them as otherwise the group can go from being supportive to encouraging people to further their ed
Int   Thats true, so what helps to keep an online group a positive experience rather than negative?
User95   I like that [name of support group] has goals. And people are open in the group.
User61   Partially a good admin team and partially members taking responsibility for what they post and understanding the purpose of the group.

This suggests that participants understood the group identity to revolve around the principles of recovery; these principles informed the group's normative beliefs and values and were reflected in the guidelines and the agreed purpose of the group. When these norms were

violated, there were adverse consequences for group members' recovery (Cruwys & Gunaseelan, 2016; Frings & Albery, 2015). However, both group leaders and members were held jointly responsible for ensuring a group environment that was conducive to recovery.

3.4. Theme 4: recovery outside of the Diabulimia group

3.4.1. Accessing services

Recovery occurs in the context of other social relationships and also relationships with healthcare professionals. As previously mentioned, the recovery group was generally viewed as providing the understanding and emotional support needed to promote recovery. This was in contrast to other valued social networks. However, successful recovery involves engaging with formal support services and making (or renewing) connections outside of the treatment milieu (Best et al., 2016; Dingle, Cruwys, et al., 2015; Frings & Albery, 2015; Tew et al., 2012). In our data, we noted that the online group did not just provide psychological resources necessary for managing symptoms and understanding the disorder but also provided resources that assisted in managing relationships with other valued groups.

First, many participants reported that the group had successfully impacted on their engagement with clinicians. A number of participants reported that they had increased engagement with health services as their group membership increased their motivation to recover and encouraged them to engage with health services (McNamara & Parsons, 2016). There was one exception to this broader pattern whereby one participant reported a reduction in the number of medical appointments attended but clarified that this was due to improved self-care.

It was also clear that group membership influenced interactions with clinicians in a number of ways, as exemplified below:

Extract 10
Focus group 2

Int	Because you're getting information from the online group do you feel you see health professionals more or less than you did before using online groups?
User1	More
User10	More
User1	Some of the ppl I talk to give me the encouragement I need to face hcp[a]
User10	Because i am taking control so am more motivated
User3	More but also my appointments are more useful so I see them at the right time and I'm asking them the right things

[a] Health care professionals.

As outlined in this extract, group members felt that participation in the recovery group not only gave them the motivation needed to engage with formal services (McNamara & Parsons, 2016; Read et al., 2015) but also allowed them to more appropriately manage their interactions with professionals (Read et al., 2015). In Extract 10 above, group members spoke about how their membership of the group helped them to manage their medical appointments so that they were useful and effective. In this way, participants may derive a greater sense of personal control over their health outcomes from their online group membership (Greenaway, Haslam, Cruwys, Branscombe, & Ysseldyk, 2015). Importantly, participants saw the online group as complementary to, rather than as a replacement for, health service engagement.

3.4.2. Talking to non-group members

Articulating how group membership might impact on interactions with friends and family was not as straightforward. Consistent with previous research, these social networks were not perceived to be uniformly supportive (Balfe et al., 2013; Linville et al., 2012). This could lead some to withdraw completely from these groups or only engage with select members, as exemplified below, when participants discussed whether engaging with the online group encouraged them to speak to family and friends more often about their disorder:

Extract 11
Focus group 1

User58	I'm speaking to them a little more, but it has been VERY difficult to open up. I'm still not revealing the total extent of it, but I do think I'll get there. And I'm not sure that it's because of the group, or because I really AM in recovery.
User93	I feel like others have encouraged me to open up to my family and friends more but it's still hard and I still can't say everything I want to.
User81	Not much difference there I don't think.
User89	Friends definitely, and my husband. My folks or siblings, no. They don't get it, and they have made zero effort to become involved. I have tried but to them, if they don't talk about something, then it doesn't exist. And I asked for their support a year ago when I left for treatment. But my good friends are understanding and my husband tries to be supportive.

The practice of 'selective disclosure' described here has been shown to have positive associations with mental health and can therefore be an effective strategy for managing the effects of belonging to a stigmatised group (Ilic et al., 2014).

3.4.3. Owning the group identity

As outlined above, some participants felt the group was pivotal in their increasing ability to speak to those friends and family members who they judged would be supportive. Participants suggested that the group facilitated relationships with important others, either by providing an alternative avenue of support or by providing a way of validating their illness identity to others:

Extract 12
Focus group 2

User3	In fact I think I continue to have wonderful friends because I can go to the group and say things that I need to say in a social space but that I don't really want my friends who I meet down the pub to know so it makes my other relationships easier, I don't feel like Im burdening them or wishing they would understand because I know there is a huge group of people who do understand online…

Focus group 4

Int	Since joining an online support group have you felt able to speak to your friends and family about your illness more or less than before?
User95	Much more! It's more validated now it has recognition. Recognition from other sufferers rather than medical. I can share [support group's facebook] status'. People can see what it is for themselves too.

Focus group 5

User20	I'm not sure. Those people I do talk more to I have also told about the online group and shared some of the things I have read/learnt on here
User81	Yeah I'm the same probably like it's not just me thinks that makes me feel more confident

This latter aspect of group membership, namely, that it provides validation of the illness identity was particularly important in the absence of formal medical recognition (Tierney et al., 2009). Showing friends and family that the individual is "not the only one" with this disorder, but that it is an identity that is shared with others, can serve to legitimise their identity in the eyes of important others. Therefore, this suggests that recovery identity-relevant relationships can help to maintain other important group memberships that will persist after recovery.

4. Discussion

The aim of this paper was to explore the ways in which important group memberships (and the social identities derived from them) impact on recovery from Diabulimia. Our findings suggested that identity-based support from similar others is a key part of the recovery process (Best et al., 2016; Frings & Albery, 2015). A shared recovery identity formed the basis for the provision of psychological resources necessary to manage symptoms and cope with the challenges associated with recovery – in particular the lack of understanding and knowledge that exists both within informal and formal support networks. In addition, this group membership was seen as complementary to other

identity networks that were crucial to recovery and was perceived to help facilitate interactions with those who might misunderstand the nature of the disorder.

4.1. Including important group memberships in the treatment and recovery process

Clinical services in mental health often use group programmes as a means of achieving therapeutic change (e.g. Cruwys et al., 2015). However, the nature of difficulties presented by the participants in this study may make face-to-face group programmes an impractical solution, as the comparative rarity of the co-occurring difficulties of diabetes and eating disorders would not allow a sufficient critical mass of Diabulimics in one locality to meet with regularity. Nevertheless, the findings of this study imply the importance of clinical services who treat such individuals undertaking efforts to somehow incorporate social networks successfully into the treatment and recovery process. The accounts of these participants suggest that clinicians should not be afraid of supporting individuals to access online fora for this purpose, and perhaps future service developments could consider how such groups could be formally created and endorsed within the wider service context.

In such cases, developments require a clear understanding of the identity dynamics involved. These groups should facilitate the identity transition necessary for successful recovery (Best et al., 2016). This implies that not only should they endorse norms reflecting health-enhancing behaviours (and avoid emphasising the importance of a particular body shape or dieting, etc.) (Best et al., 2016; Cruwys et al., 2015; Cruwys & Gunaseelan, 2016; Frings & Albery, 2015), but they should also create a social context in which the individual affected feels that they are accepted and their issues are taken seriously (Leonidas & dos Santos, 2014; Linville et al., 2012).

The findings of the current study are reflective of previous research on the role played by social networks in eating disorder and Diabulimia recovery. First, our findings indicate that this cohort has developed a strong illness identity that is perceived to be separate from other eating disorder subtypes (Allan, 2015; Allan & Nash, 2014). Similar to those in recovery from addiction, establishing connections with similar others to construct a recovery identity was seen to be a crucial step in the recovery process (Best et al., 2016; Buckingham et al., 2013; Dingle, Stark, et al., 2015; Frings & Albery, 2015). The sense of shared identity established in the online group facilitated the provision of important psychological resources including emotional support, strategies for managing symptoms, and information relating to the adverse consequences of continuing to engage in disordered behaviours, such as insulin omission. However, our data does suggest that connections with a recovery-oriented group are not free from the potential to hinder recovery. Our findings emphasise the importance of establishing an identity based on the principles of recovery and ensuring enforcement of group norms related to this in order to ensure online (or any form of support group) interactions foster health-enhancing, rather than maladaptive, behaviours (Cruwys & Gunaseelan, 2016; Frings & Albery, 2015; McNamara & Parsons, 2016). These findings also echo research into the effective processes within group programmes, whereby individual changes occur in the context of newly forged ideas of normative changes within a group identity (Cruwys et al., 2015; Frings & Albery, 2015).

Second, consistent with previous literature, family and friends were not perceived as uniformly supportive (Leonidas & dos Santos, 2014; Linville et al., 2012). Clearly such networks cannot connect on the basis of a shared recovery identity and this limits the extent to which support offered can be seen as appropriate to the needs of the individual in recovery (Haslam et al., 2011; McNamara & Parsons, 2016). However, participants did acknowledge that friends and family members who understood and were willing to empathise with them were an important source of support (Linville et al., 2012). Similarly, engagement with

health professionals was also recognised as essential for recovery. However, to the extent that professionals dismissed (or were hostile to) participants' identity, the support offered was perceived as unhelpful and even detrimental to recovery (Stevenson et al., 2014; Tierney et al., 2009). This lead in some instances to participants reporting that they disengaged from support services that were not viewed as identity-congruent. Access to services is often dependent on assuming a certain social category (Walter et al., 2015). In this instance, participants resisted the category imposed by services and wished to engage with services on the basis of their 'Diabulimic' identity. Further research is needed to investigate the extent to which identification (or not) with diagnostic categories impacts on certain groups' willingness and ability to access the services necessary for health and wellbeing. Such issues are applicable to groups beyond that discussed in the current study and include those with stigmatised identities such as those with mental illness and substance abuse disorders.

Finally, one concern typically associated with membership of online groups is that they can become an inappropriate substitute for real-world relationships (Jetten, Haslam, Haslam, & Branscombe, 2009). Furthermore, identifying with a group oriented toward illness might limit the development of a complete recovery identity (Federici & Kaplan, 2008; Tew et al., 2012). Our findings address both of these issues. First, the online recovery group was seen to complement rather than replace health service engagement. Group membership facilitated positive interactions with health professionals by providing information that could be used to structure appointments and ensure that participants made the "best use" of this time (Read et al., 2015). Second, some participants also suggested the group facilitated conversations with supportive friends and family members by providing them with a validation of their illness identity and the confidence to disclose their difficulties, not just online, but to their important social relationships. While some caution is noted given the potentially damaging impact of online interactions (Haas et al., 2011; Mulveen & Hepworth, 2006), the associated norms of engagement with outside relationships could be built upon to promote the creation of links with groups that are not eating disorder or Diabulimia related to ensure the move to a recovery identity that is not based on a disordered identity (Federici & Kaplan, 2008; Tew et al., 2012).

4.2. Strengths and limitations of the current study

There are a number of strengths to the current study. First, there is a dearth of research on the role that social relationships play in eating disorder recovery (Leonidas & dos Santos, 2014; Linville et al., 2012). Furthermore, to our knowledge, there is no research on the experiences of this particular cohort in seeking support from social relationships during recovery. This study moves beyond understanding poor treatment engagement as a consequence of personality factors and considers the role played by group memberships and associated identities. Consistent with previous research in this tradition, the current study illustrates that connections with similar others can promote recovery and that during recovery, these connections become an important part of the individuals' social networks (Best et al., 2016; Dingle, Cruwys, et al., 2015; Dingle, Stark, et al., 2015; Frings & Albery, 2015). It also includes an exploration of the role played by other important formal and informal support networks that are crucial to recovery but that are not always fully incorporated into the recovery process. In particular, the current study illustrates the importance of identity-congruent support services to facilitate the construction of these connections and demonstrates the potential of the recovery group membership to assist in the maintenance of connections with other groups necessary for successful recovery. We suggest that these processes are not just relevant in the context of Diabulimia but are likely to be applicable across a range of addictive disorders as well as other forms of mental illness.

Second, this study highlights the importance of identity content to the recovery process. Recovery-oriented groups that engage in

discussions or behaviours that are not consistent with recovery may impede the identity transition. This is consistent with the growing literature on social identity and recovery (Best et al., 2016; Dingle, Stark, et al., 2015; Frings & Albery, 2015; McNamara & Parsons, 2016). Third, this study supports previous research by Stevenson et al. (2014) highlighting the corrosive effects of stigma on the service provider/service user relationship. Services that promote a sense of shared identity between user and provider or at least a respect for differing identities should help to foster treatment engagement.

However, the study has some limitations. First, a comprehensive understanding of the role played by wider networks suggests the need to collect data from these sources on their perspective of their role in the recovery process. Second, our data reflect retrospective accounts of group experiences, rather than investigating group dynamics in situ. Exploration of the latter could be particularly important to determine exactly how a group manages violation of group norms and ensures that the group remains recovery-oriented. Third, we are unable to precisely state how representative our sample is of the population of people experiencing Diabulimia, given the dearth of statistics for this demographic as a whole. While our sample was female, the online group described in this study is also used by males with Diabulimia. Future research should consider the male experience of living with Diabulimia as well as the prevalence of the disorder among males with Type 1 diabetes. Finally, the use of online recruitment and discussion is a strength in that it engaged participants in the topic of interest using the same means of communication, allowing a level and means of interaction that was directly comparable to their familiar interactions. However, this means of recruitment also created a bias in recruiting people who were existing and ongoing members of the community, who were therefore more likely to report positive experiences. There may have been individuals who suffered through accessing the group but who would not have remained present in order to respond to the advert, and these voices need consideration if possible through other means.

5. Conclusions

To conclude, we believe that this study represents an important addition to the social identity and recovery literature. Our findings illustrate the importance of ensuring groups that potentially play a key role in recovery (and positive long-term health outcomes) should be formally incorporated into the treatment process. This requires clinical interventions to address the "relational dimension" of eating disorders rather than solely focusing on eradicating disordered behaviours (Leonidas & dos Santos, 2014, p. 926).

Contributors

Authors 1, 2 and 3 designed the study and development of data collection materials. Author 1 collected the data, conducted literature searches, and provided summaries of previous research studies. Authors 1, 2 and 4 conducted and refined the qualitative analysis. All authors contributed to and have approved the final manuscript.

Conflict of interest

Author 3 is the former Director and current Research and Training Manager for the support organisation that assisted with participant recruitment and hosted the secure chat room where the online focus groups were conducted.

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