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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] Although we acknowledge that the term does not currently hold academic clinical validity – and that diagnostic labelling of human distress is a criticised process within fields of clinical psychology - we will continue to use the term Diabulimia in this article in recognition of the importance of this identity to our participants; we have continued the capitalisation of the term throughout to maintain the salience of our decision in this regard throughout the text.

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