The role of social and family support in the management of eating disorders

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Abstract

This paper aims to consider the role of informal social support in contributing to the welfare of people with eating disorders (EDs). Anorexia nervosa usually emerges between the ages of 16 and 17 years for females and at 12 years for males, followed by other common forms of EDs, such as bulimia nervosa and binge eating disorder. Families can play a key role in the outcome of an ED by recognising the problem and accessing early support. Unfortunately, the provision of services does not match the current need. Carers have been involved in co-designing and co-delivering information and support that can fill some service gaps. This involves learning how to manage the traps that are easily triggered and lead to unhelpful interactions driven by expressed emotion, such as overprotection, accommodating the ED behaviours by ignoring and/or using hostile confrontation and criticism. Families provide a great amount of practical support and are important partners during treatment. They can prevent the individual from becoming isolated and trapped within the ED identity.

Keywords: eating disorders, families, expressed emotion, early support, treatment

Introduction

Eating disorders (EDs) are serious conditions that negatively impact both the person with the disorder and their family members. Clinical guidelines emphasise the importance of involving and supporting family members in the care of their loved one (1, 2). Family members are impacted in many ways, including financial strain, social isolation, physical health (3) and emotional and psychological stress (3, 4). By addressing these challenges faced by family members, we can improve both their wellbeing and the treatment outcomes for their loved one (3, 4). Families often shoulder guilt and distress as they assume that they have contributed to the illness. As in most forms of illness, there may be a genetic element; however, the aetiology is not fully known and probably involves several interacting factors, possibly activated by puberty.

In Figure 1, we outline how three broad factors, including those related to the illness itself, the societal response to the illness or the parental/carer response to the illness can impact the functioning and wellbeing of carers and interfere with their ability to provide effective care and support. In this paper, we consider the level of difficulties that carers face, respect the key roles they provide and discuss ways in which health professionals can work productively with carers.

Illness factors

First, there is often a large mismatch between what close others recognise as problematic and the experiences of the individual. There are a variety of ways in which the ED may become valued for the individual. For example, living by the rules of the ED facilitates a focus on the goal of being "good enough", which is a key maxim for those at risk of developing an ED. EDs flourish alongside temperamental traits of anxiety, social comparison, sensitivity to reward and/or punishment, perfectionism and compulsivity or impulsivity. This alignment between values, personality features and the ED leads to ambivalence and resistance to the need to change. In contrast, the disruption to core features of family functioning,

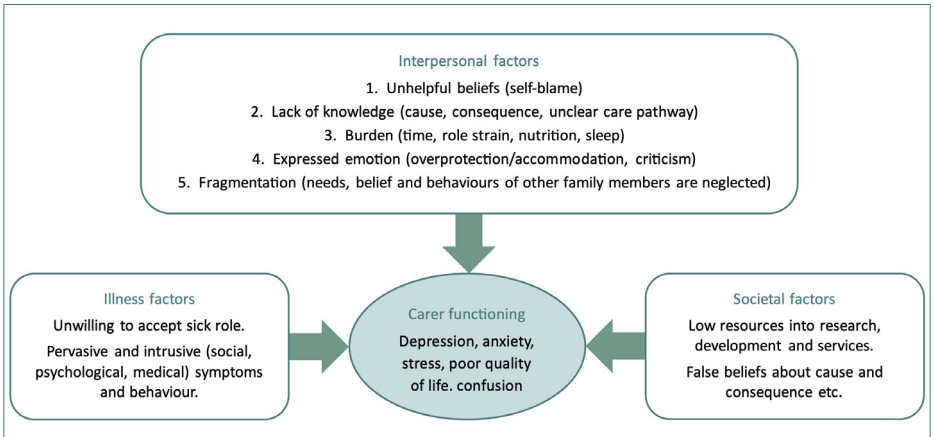

Figure 1. Factors that affect carer function

such as the provision of nutrition and a healthy environment, has a large impact on the family and the wider social network. This disparity between the stages of change of the individual and the family makes planning for change difficult. There is good evidence to suggest that the demands of the ED on the family unit, coupled with the constant worrying and unpredictability of the illness, bring multi-layered changes reflected by a "new normal", where life becomes centred around the ED (5).

Societal factors

Society and the media have contributed to the causes of EDs by fostering idealised and unrealistic body image standards and the opportunity for social comparison by normalising symptoms that may entrap the individual. Previous studies have explored the role of social media on body dissatisfaction and negative body image (6). However, there is a lack of evidence about individual differences and how social media, body images and pro-ED societal influences affect distinctively heterogeneous and under-represented groups.

Recent research has discredited harmful established stereotypes that have shaped public understanding of and research on EDs for decades (7). This research highlighted that many aspects of disadvantage increase the risk of developing an ED, including socioeconomic disadvantage, food insecurity and weight stigma, challenging the view that EDs only affect those who are affluent. The myth that EDs only afflict privileged, White, middle-class females may have contributed to the paucity of resources that have been allocated to increase knowledge about the causes and consequences of EDs and what constitutes an effective care pathway for these problems. However, carers and individuals themselves have been diligent in bringing to the attention of the government the deficiency in resources allocated to EDs (8). There is now an ombudsman overseeing this area and more attention and resources have been given to research, training and services.

Family factors

Recognition and access to care

In the absence of reliable evidence and understanding, many carers jump to the conclusion that they are responsible for the development of the ED. The consequent guilt and distress add to the burden arising from the high levels of practical support that carers provide (9, 10).

Parental responsibility for causing the illness is one of the many myths associated with EDs which can hinder recovery. One of the truths associated with an ED is that carers can facilitate early intervention by recognising the early signs and taking steps to access help, which can lead to an improved outcome. Carers, including family members, teachers, coaches and those in primary care, have a key role in early recognition and access to care.

Nevertheless, the first step is fraught with difficulties because of the ambivalence and secrecy about the illness. Also, accessing the correct form of help can be difficult. Often, the signs and symptoms of an ED are dismissed as a teenage "phase" or conceptualised as part of a physical problem. A multicentre European study found that, on average, two intermediary health professionals and a period of over two years elapsed before specialised services were accessed (11). Indeed, a systematic review reported that the average duration of untreated EDs was 29.9 months for anorexia nervosa (AN), whereas perhaps because the symptoms and signs of binge-spectrum disorders are less visible, the delays in accessing treatment were longer, 53.0 months for bulimia nervosa (BN) and 67.4 months for binge eating disorder (BED) (12). A recent systematic review concluded that patients' shame, guilt and stigma, coupled with a lack of knowledge among health professionals, were the main barriers to seeking early help (13).

The diverse nature of EDs and the uncertainty about how they are best supported, combined with the exhaustion that arises from the high burden of care, impact different family members in a variety of ways. This complexity makes it challenging to develop a coherent and collaborative approach. For example, as discussed above, some family members blame themselves, possibly because a thread of EDs or other forms of mental illness exists within their family of origin. Others may be bewildered by how the illness defies the common-sense understanding that eating is essential to sustain health. Thus, the emotional reactions of the family can oscillate between a tendency towards overprotection and/or accommodation towards the behaviours, through to irritation, criticism and hostility. These common reactions occur both within and across individuals and both accommodation and criticism can have adverse impacts on the treatment outcome (14).

A meta-synthesis of the qualitative literature relating to the lived experience of caring (mainly from a parental perspective) for a range of EDs (for example, AN, BN or EDs not otherwise specified) found nine core themes (15). Amongst the themes were changes in their behaviour, for example, adapting to the illness by accommodating and enabling symptoms and tolerating and ignoring behaviours. Carer guilt was prominent across and within themes. Overall, caring for people with an ED placed a significant strain on interpersonal and family relationships with conflict, particularly around mealtimes.

The idea of "overprotection" and accommodation is complicated because it varies across cultures and changes as people grow. Different ways of measuring these behaviours can mean slightly different things. For example, parents might try to ease their child's fear of eating by giving lots of reassurance, preparing special foods and following spe-

cific mealtime routines (16). However, these "safety" behaviours can interfere with treatments meant to help the child overcome their eating fears (17, 18). They can also make ED behaviours take over family life, especially if the child has traits of autism or obsessive-compulsive disorder. To address this, families might need to make gradual, reasonable changes to reduce these behaviours.

A network analysis examining the connections between carers and the individual with the ED found that depression and accommodation impacted the outcome of the illness (19). These variations in emotional reactions can easily lead to fragmentation within the family. Time and attention for other family members need to be ring-fenced away from the huge burden of care absorbed by the ED. The heavy burden of care usually falls on mothers, which means that it is easy to overlook the needs and opinions held by other family members, such as fathers and siblings.

Fathers

Many of the studies that consider the parental burden and reaction to the development of an ED mainly examine the impact on the primary caregiver, who is usually the mother. However, the experience of both parents attending a skills-sharing intervention (SUCCEAT) was obtained from two clinics in Austria (n = 92) (20). Fathers had lower baseline levels of general distress, emotional overinvolvement and burden (for example, only 15% had >4 hours of contact compared to 46% of mothers). Both parents had similar levels of adherence and engagement with the skills-sharing workshops (fathers, 5.9/8 sessions and mothers, 6.5/8 sessions) and the majority reported satisfaction with the workshop and additional materials. Following the intervention, caregiver skills were increased and the ED burden and emotional overinvolvement were decreased. This highlights the important role that fathers can play by counterbalancing the tendency for mothers to become overly emotionally involved and protective. The inclusion of fathers can reduce the tendency for the family to use polarised approaches and become fragmented, which may lead to better outcomes.

Siblings

The sibling relationship varies according to age, gender, culture, stage of development and living arrangements. The small amount of research from siblings' perspectives suggests that the challenges they face are like those experienced by their parents (21). Siblings experience significant distress related to the ED symptoms and the physical state of their sibling (22), accounting for difficult and divergent emotions (23). The ED may build on the tendency for comparison and competition between siblings and increase family fragmentation. For example, this may lead to the size of a meal or the intensity of exercise being calibrated in competitive behaviours between siblings. On the other hand, siblings may help sustain peer relationships and protect against isolation. However, there needs to be a greater consideration of the impact that EDs have on siblings, who have unique needs that differ from those of other family members, such as parents (24). Yet, siblings often feel overlooked by healthcare services and have limited resources and support, with one study finding that the majority of experiences reported by siblings did not meet the published guidance for supporting carers (24).

A systematic review of the qualitative, quantitative and mixed-methods literature on siblings' experiences of having a brother or sister with an ED found that EDs have negative inter- and intrapersonal impacts on siblings, including fragmentation in family relationships, parentification and competition and jealousy (25). This research underscores the importance of considering the broader family context in the treatment of EDs and providing comprehensive support to all family members.

Peers

Individuals with EDs highlight the importance of relationships with significant others, such as friends and peers, in the recovery process. One of the key tasks of adolescent development is to seek group affiliation and develop a clear identity (26). However, EDs directly or indirectly limit social interactions. Also, secondary effects on social cognition can impact the quality of intimate relationships (27), contributing to loneliness and alienation, which are core experiences of the illness (28, 29). This social disruption can allow the ED identity to become more firmly embedded. On the other hand, those individuals who can share their thoughts, feelings and fears with close others, including siblings and family members, have better outcomes (30).

However, peers can also play a role in the development and maintenance of EDs and poor-quality relationships with peers are linked to greater ED symptoms (31). This is also relevant in inpatient settings, where peer relationships are often complex. While these relationships can reduce feelings of isolation and help normalise and validate individuals' experiences, they can also have harmful effects when individuals engage in psychological and behavioural comparisons.

Some individuals described this as a contagion effect, where they become more aware of the detrimental behaviours of others and are more likely to adopt them (32). The role of peers in the context of EDs is complex and multifaceted, so it should be considered on the basis of individual cases and what works best for the individual with the ED.

Partners and spouses

There is evidence to suggest that adults with EDs have similar chances of forming romantic relationships as their healthy peers. Yet, there is very limited knowledge about the experiences of partners/spouses caring for their loved ones. Partners of individuals with EDs have reported on the impact of caring responsibilities and the changes in psychosocial functioning related to the illness (5). Partners often describe that they feel isolated and lonely in the process of treatment due to the high level of care associated with the illness. They often experience rejection as a result of the primacy associated with the ED. Perceived stigma encourages secretive behaviours and a lack of sharing with close or extended social networks, which further increases the burden on partners.

The involvement of the family in treatment

One of the core principles of family-based treatment (FBT) is that the approach is agnostic about aetiology, focusing not on the causes of the illness but rather on engaging the family to provoke behaviour change (33). However, uncertainty about causal factors is both frustrating and debilitating for family members, who tend to blame themselves (34). The focus of FBT on particular aspects of recovery, such as refeeding, can be confusing to parents as they seemingly ignore the psychological symptoms of EDs; as such, it is imperative to have effective communication and sharing of appropriate information between the family and professionals (5). Thus, people with lived experience, such as patients and carers, have linked with professionals to produce materials that guide a collaborative approach. Charities such as Beat, FEAST, Bodywhys and First Steps have set up support groups. The New Maudsley Carers website offers access for both clinicians and families to the worksheets, videos and podcasts around the New Maudsley Carer Skills Workshops, and the Charlie Waller Trust is now one of the most active providers of carer skills workshops. Individuals have written books that share basic information (35) or specific skills, such as motivational interviewing (36) and the Maudsley Model of Collaborative Care (37).

The involvement of family members in clinician-led treatments

Family members play a critical role in the recovery process of EDs and a recent meta-analysis found that family-based interventions are effective for adolescents with EDs, leading to better recovery rates and reduced chronicity, compared to other interventions (38). A recent umbrella review concluded that treatments involving family members showed the most benefit for patients with AN (39). These highlight that strong family support systems and a supportive family environment are associated with positive treatment outcomes. By providing emotional support, participating in therapy and being involved in treatment planning, family members can significantly contribute to the recovery process.

A systematic review and meta-synthesis of 25 studies highlights the role of clinicians in acknowledging parental challenges, which can facilitate the process of recovery for adolescent AN patients by building stronger therapeutic relationships (40). For example, expressed emotion and psychological distress in carers have been identified as risk factors for relapse. Promoting collaboration between parents/carers and health professionals can improve outcomes and empower young people, carers and clinicians. Parents are encouraged to have high levels of involvement in meal support in the form of family therapy for younger patients. This is less often the case for adults unless there is a high level of risk which needs to be carefully managed. The Medical Emergencies in Eating Disorders guidelines offer materials that can be shared with carers to manage risk across the life span (41).

FBT views the family as a resource for the recovery of their loved one with an ED (42) and is considered best practice for the treatment of AN in children and adolescents by the National Institute for Health and Care Excellence (NICE) guidelines (2). FBT tasks parents with meal management, whereas siblings are tasked with emotional support.

Family skills-sharing

Carers, including siblings, fathers and partners, are invited, either together or occasionally separately, to skills training workshops which may be linked to services of independent charities, such as FEAST, Beat and the Charlie Waller Trust, among others. Figure 2 demonstrates the types of support available for EDs. These are a form of task-sharing and provide supporters with information and skills which have been found to reduce their caregiving burden and distress; they also show patient benefits, such as improving mood and reducing ED symptoms (16, 43). In a UK-wide multicentre study, we found that providing supporters of adult inpatients with AN access to the elements of the New Maudsley Approach within the Experienced Carers Helping Others (ECHO) study not only reduced carer burden but also impacted on the need for further support, in that it reduced the length of admission and the relapse rate (44, 45). Also, carers of adolescents with AN given access to these materials found caregiving less burdensome and it reduced service use (46). The materials have been translated into German and found to reduce carers' distress and improve caregiving skills in face-to-face and virtual workshops (47). Fathers engage well and actively share emotional reactions and skills in all-male groups (20).

Multifamily approaches

A variety of multifamily approaches in which several families (including patients) attend workshops designed to support change have been introduced. These were initially developed in adolescents and a randomised controlled trial was undertaken (48). A recent intervention, ECHOMANTRA, which included a form of the multifamily approach, found

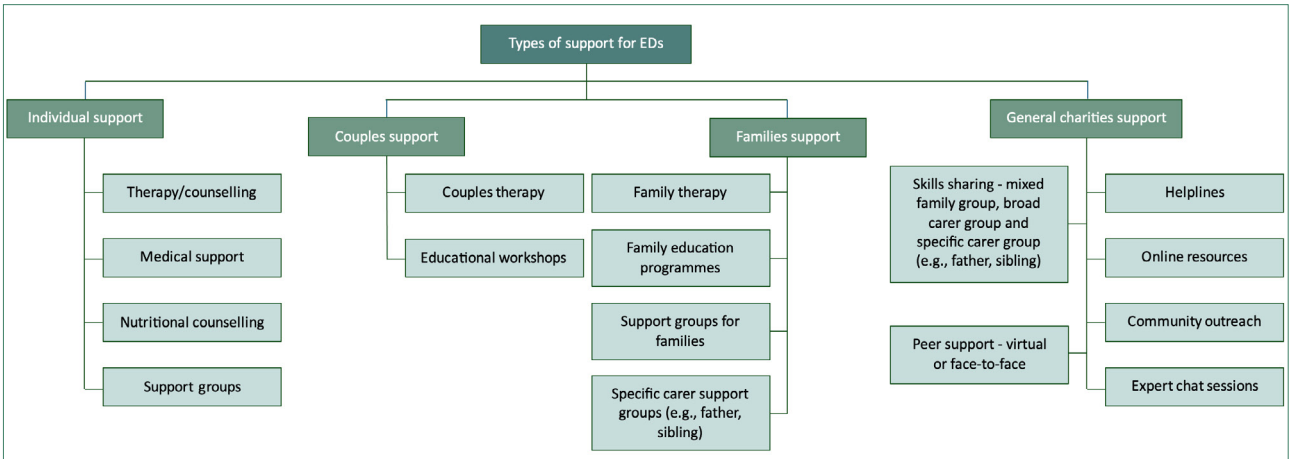

Figure 2. Types of support for eating disorders

that this element of the approach was highly rated by participants (17). This approach can include targeted support for siblings, partners and fathers or peer-delivered support for siblings (5).

Conclusion

Families or close others often play a key role in noticing and taking the steps needed to access early help for an ED, which can be a difficult step because the individual themselves does not recognise that there is a problem. The involvement of families or key elements of the social network participating in various ways to provide support is of particular relevance for people whose ED-related behaviours threaten their health or development. Families provide a large amount of invaluable unpaid care and frequently they are the first to recognise the initial ED symptoms. Therefore, increasing support and information channels for this group throughout all stages of the ED journey can positively impact treatment outcomes (10). People with lived experience reflect that isolation is a core part of the illness (28) and this is something that carers can target within their role. The development of a well-functioning adult identity benefits from support both within and outside the family and so a collaborative approach to care is needed.

Declaration of interest

The authors declare that they have no conflicts of interest.

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