

Seeing with your eyes wide shut: a comprehensive study of the effects on family members who live with someone with an eating disorder.

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Abstract:

Background: The purpose of this study is to highlight the little support that is there for families and carers of someone suffering with an eating disorder. Previous studies blame families for their role in the development of eating disorders. Awareness and support is needed to highlight the impact on family members and their carers. This will alleviate the stigma that is still prevalent to this day.

Aim: The aim of this study is to investigate what family supports are available and the impact to the family members and their carers of someone suffering with an eating disorder. The data will be collated through a series of semi-structured interviews.

Method: Recent empirical and theoretical evidence around the family's emotional and practical experiences of caring for someone with an eating disorder were examined. Participants were interviewed. They shared their experiences on how their lives were altered through stress and emotional upheaval caused not only by the disease but the stigma that is associated with this illness.

The following themes were discussed: (i) the association between family functioning and the development of an eating disorder, (ii) the impact on the lives of family members, (iii) the lack of information available to caregivers, (iv) the high level of carers' distress and the stigma associated with the illness, (v) sibling relationships.

Results: Most recent results indicate and support the view that families and their carers become isolated and depressed as a result of living with someone with an eating disorder. As the illness monopolises and manipulates family structures families find that family members need to reorganise their lives in order to survive the full blow of eating disorder behaviours.

Conclusion: Professionals need to address the needs of the family as a whole by implementing a more holistic therapeutic approach to their needs.

Chapter 1

Introduction

Kate Moss stated in November (2009) that “*Nothing tastes as good as thin feels*”. The prevalence of eating disorders in today’s society is enormous and appears to be growing year on year, particularly with the growth of the Internet. Added to this is the constant media coverage where the super-thin, size zero models are on our screens and in our magazines and newspapers on a daily basis. The quest to be thin is supported by the food industry who are constantly imposing new diets and super-slim foods on us. Thus, individuals who suffer from eating disorders, not only suffer their own miseries, but their suffering also can impact on their families.

The aim of this study is to investigate what family supports are available and the impact to the family members of someone suffering with an eating disorder

Although the effects of the eating disorder are apparent and physically noticeable in the individual, the psychological effect and impact of the illness may go unnoticed and untreated for the other family members. This is the kernel of this study.

The 6 participants selected for interview are all related in some way to a person who has had an eating disorder and have first hand knowledge of the effects of living with someone with an eating disorder on the family.

Face to face / semi-structured interviews were conducted with each of the participants.

The data collected was coded for themes which were analysed and correlated and used throughout the study.

Library resources have shown an abundance of material for the sufferer of an eating disorder but few included a section for the parents and siblings of the patient and the support they need. This shows that more research on this topic is favourable.

The literature sourced to-date show that family distress is evident in families where one of its members has an eating disorder. Research does not focus on the distress and disruption of family members but rather on the sufferer. Research is required into the area of recovery, to investigate how to locate the sources of stress in the sufferer's family and how to help them in a healthy way.

Chapter 2

Literature Review

By the end of the 1970's, the eating disorders known as Anorexia Nervosa (AN) and Bulimia Nervosa (BN) were receiving world attention and were to be considered both mystifying as they were frightening (Killian, 1994). As little is known of the contributing factors to these diseases, more research is needed to establish the source of these disorders and to their prevention. (Button and Warren, 2001).

Since then medical, psychological and family therapy research on AN and BN has exploded, with most of the attention devoted to their etiology. In particular, attention is focused on the association between family functioning and the development of an eating disorder. The prevalence of eating disorders, their insidious onset in the adolescent years and the role family factors play in their occurrence, maintenance and successful treatment make a thorough understanding of both AN and BN important for family therapists and other medical health practitioners. (Killian, 1994).

Whitney and Eisler, (2005) pointed to the mounting evidence directed at the impact on the lives of family members who live with someone with an eating disorder.

Although each person found their experience of the disease to be different, there was a common theme that emerged. Namely they all felt a sense of loss of control in one or more areas of their lives, from difficulties within relationships to a loss of self-esteem.

The most unhelpful experience being the overemphasis on weight during medical treatment although they recognised that help was needed. The most helpful was psychotherapy/counselling and the support of family and friends.

As the care givers' lives revolve around the sufferer, they strive to accommodate the seriousness of this potentially life threatening illness. Carers often experience high levels of emotional stress as their lives revolve around the eating disorder, and family lives become monopolised by the illness.

Kyriacou, Treasure and Schmidt, (2008) research showed the lack of information available to caregivers also, showing how their psychological needs were being neglected. When the family members sought help and support from the health services they found that it was not accessible to them, causing the family further stress and anxiety. In some cases the families and carers believed they were being blamed for the illness. The health services did not include the family and carers in the treatment plan which only added to their feelings of inadequacy and isolation.

This research also highlighted the poor social support for family members and the total lack of understanding shown towards the carers. The little support that is there is found to be totally inadequate, which may be due to the lack of understanding shown towards the sufferer, their family and friends. The results of this and other studies make it abundantly clear that due to the lack of understanding shown towards carers, their feelings of isolation and frustration grow and in some cases these feelings are associated with depression and high levels of anxiety. (Kyriacou, Treasure and Schmidt, 2008).

Similar findings are shown in Whitney, Haigh, Weinman and Treasure, (2007) study and showed where limited support systems are in place, they are without doubt inadequate.

However, their study also highlighted the high level of carers' distress caused not only by the dependency of the individual with the eating disorder but also the stigma associated with the illness.

The stigma associated with this illness can only contribute to the families suffering. Many families feel isolated and alone. The carers' isolation and frustration is magnified as the patient's physical needs become more dependant on the carer, as the eating disorder becomes chronic.

Kyriacou, Treasure and Schmidt, (2008) discussed how carers face the inappropriateness involved in caring for the physical needs of adult children, as their needs go unmet and their quality of life diminishes.

The carers believe that it is their role to just 'fix the problems' as they arise but they fail to realise that their caregivers' role is more demanding and stressful than someone caring for an individual with other psychiatric illnesses (Brown and Geller, 2006).

Due to the way the family members respond to the illness, they may inadvertently play a role in maintaining the problem through their efforts to help (Eisler, 2005).

A study carried out by Brown and Geller, (2006) examined how female students anticipated how they would approach a family member or friend with an eating disorder and what kind of support they felt would be helpful. The result showed that high levels of unhelpful approaches were used. This result confirmed how family members and carers experienced the lack of social support that is available. It is possible that family members and friends react emotionally, through frustration, distress, anger or/and anxiety to such a degree that they found difficulty in expressing themselves in the way they wanted.

These results were based upon previous research in clinical settings, whereby caregivers expressed their preference to a collaborative approach to treatment but indicated that directive approaches were also likely to happen in practice.

Dominy, Johnson and Koch, (2000) results related to previous research carried out and the significance of the parent-child relationship in the development of eating disorders, showing there to be less parental affection and acceptance. These results confirmed these families to be disorganised, more conflictual, nonnurturing, controlling and they show less affection than those families without an individual with an eating disorder.

Polivy and Herman (2002) described how patients believed that living in their family home was similar to a clinical environment where there was little or no communication, a lack of parental caring and very little expected of them. His findings also showed that those who report physical or sexual abuse are at an increased risk of developing an eating disorder.

It was stated by Polivy and Herman (2002) that BN patients reported greater parental intrusiveness, namely invasion of their privacy, they were jealous of any attention shown towards them and in some cases parental seductiveness. BN patients perceived a level of negative competitiveness between their parents and themselves.

Killian, (1994) used Winnicott's script to explain how the "concept of the mother-child 'holding environment' and the idea that persons develop ego deficits when the care their mother provided was insufficiently nurturant, empathetic and 'good'. Failures in the holding environment tend to be transmitted intergenerationally and involve deficits in nurturance, tension regulation, empathy, and affirmation of separate identities" (Winnicott, p. 316).

Blessing, (2007) argues that sibling relationships are the missing piece of the eating disorder puzzle. She argues that without an adequately developed place for these relationships within our theories, an important level of understanding has been missed. If sibling relationships are not attended to in the transference/countertransference, an essential level of understanding is overlooked. Therefore the impact on the psyche remains untouched. Blessing, (2007) noted the assumption made by Freud, (1909 and 1918) as how sibling relationships were principally displacements from parental relationships and primarily hostile in nature, although he did acknowledge that they had some impact on mental life. Also, the study stated that Klein, (1932) made room for siblings in her theories, although she did not give them a defined role within the internal world. The author also addressed the difficulties her patients had and made links to the emergence of the eating disorder within the context of family life where extreme projective and introjective identifications are the governing style of communication. The author also goes on to say 'that the forcefulness of these practices points to a predominance of paranoid-schizoid states of mind' (Blessing, p.37). She noted the degree of splitting implied in this position may add to the understanding why achieving ambivalence is so difficult for AN and BN patients.

Whitney, et al (2005) illustrated through their study that as the sufferer demands more time of the parents, siblings may find they are ignored and do not receive the amount of support they need. Parents may feel guilty that they are ignoring the other family members. Paradoxically, the patient may also have feelings of guilt around the attention

they are receiving and experience the extra attention as intrusive (Perkins, Winn, Murray, Murphy and Schmidt, 2004).

Jones, Harris and Leung, (2005) highlighted the studies examining the recovery process from the patient's perspective, and how they were closely related to cognitive factors, such as self-acceptance, self-esteem and self-determination. Jones, Harris and Leung, (2005) directed their attentions to Young's schema-focused theory, developed in 1994, and suggested that the need to address maladaptive core beliefs about the self, others and the world is necessary to treating chronic patients. These core beliefs refer to self-defeating beliefs which develop as a result of dysfunctional interactions with significant others in childhood.

Young showed how these dysfunctional interactions are processed and how they manifest themselves in later life through our thoughts and feelings and how in turn this affects our future relationships.

Cooper, et al. (2006) conducted two studies on how to measure the thoughts and behaviours when assessing eating disorder patients. The first of these studies looked at the eating disorder-related thoughts and the second study assessed the wide range of eating disorder-related behaviours.

To assist with their study they used questionnaires but their findings proved to be limited. The questionnaires proved to be unsatisfactory as the questions were devised by therapists and not directly by patients. They claimed this to be common practice in this field, which raises the issue that important topics to patients may have been missed.

Sepulveda, et al. (2008) together with Rhodes, Brown and Madden, (2009) drew attention to the guidelines of The National Institute for Clinical Excellence (NICE) (2004) and their recommendation that patients (in particular AN patients) be subject to early release and cared for by their families, the families stated they lacked the necessary skills and resources and found the task extremely stressful. The workshops focused on giving information and problem-solving skills for coping with the specific difficulties that these illnesses may bring. Sepulveda, et al. (2008) noted that the participants gained skills and knowledge of what is required of them and benefited from meeting others who understood and shared similar situations thus alleviating some of their stress.

Sepulveda et al. (2008 and 2009) examined the impact of the Maudsley eating disorder collaborative care skills workshops offered to family members. Parents were encouraged to take an authoritative stance, by working together in the home setting, having gained the necessary skills, they should now be in a position to stand up to the full range of AN behaviours.

To explain this further, the siblings were recruited and give their emotional support to the patient; the parents are then in a position through this positive support to re-feed their child to eventual recovery. Responsibility is handed back to the patient when a healthy weight has been established.

The Maudsley model is unique in the history of family therapy and AN by giving the necessary support to families and to patients. This model also follows up on the treatment plan and its outcome after five years. Through this model, all family members are valued and are an integral part of the healing process.

Marinilli Pinto, Guarda, Heinberg and DiClemente, (2006) followed up a large cohort of patients suffering with both AN and BN after a seven year period. They discovered that only a modest percentage of patients with AN achieve full recovery and those with BN have a higher success rate.

However, Herzog, Dorer and Keel, (1999) showed that the majority of patients suffer some kind of relapse after a 6 year period of remission. Keel and Mitchell, (1997) noted that relapse may be caused by the lack of motivation which in turn may be related to the treatment process and its outcome. This adds to the distress and anguish experienced by family members, followed by the disruption to family life again.

Highet, Thompson and King, (2005) lay emphasis on the carer's experience and the feelings of not being able to stand the situation any longer and how they would not be in the position to invite people to the house yet again. As well, there are the financial costs of the illness, adding to the carer's emotional stress and the feelings of isolation. The most distressing aspect was the fear of the long term dependency on them from the patient.

Sharfran and Robinson, (2004) research showed associations between thought-shape fusion and the psychopathology of eating disorders. They based this research on clinical experience and the evidence that cognitive distortion exists in this population and may be directed to the over evaluation of their eating, shape and weight.

They indicated that cognitive distortions occur if the thinking of the sufferer is consistent, non-veridical and skewed and its contribution to the maintenance of the disorder.

Schwartz, (N.D.) stated how Minuchin's family therapy is extremely beneficial in the treatment of eating disorders and was encouraged by its success rates.

Minuchin and his team applied structural family-therapy to families whose child was suffering from a psychosomatic illness, (for example, asthma, ulcers and anorexia nervosa). Their findings indicated that families frequently demonstrated the same four characteristics – rigidity, lack of conflict resolution, enmeshment and over protectiveness. Their findings were compared to anorexic families and found that they too possess these same four characteristics.

Family therapists have the ability to track the interactional sequences that occur in families. Johnson and Waldo, (1998) also stated that these interactional sequences generally form patterns that are characterised by a homeostatic process, mostly under stress. Whether the style is a repetition or a reaction to historical events and relationships, each family member has a part to play (for example, parents bring their own family legacies into the relationship and pass on their differentiation levels to their own children).

To explain this further, Ringer and McKinsey Crittenden, (2007) believe that unresolved traumas carried by the mothers affected their behaviour, especially in inexplicable moments when the mother became unavailable to their daughters just when they, the daughters, thought they were being invited to approach. The author believes there are two kinds of distortion in progress. One of the distortions is where the spousal dyad is so troubled that the child is used as a means to stabilise the marriage and the other is where

the child's physical needs are adhered to but her psychological needs are ignored, due to the spouses' preoccupation with each other.

The study carried out by Colohan and Robinson, (2002) argues that eating disorders with early onset and short duration respond well to conjoint family therapy and separated family therapy, whereby the family members are seen separately from the patient. The patient is seen by themselves. This form of treatment is also suited to young patients with BN.

Perkins, et al. (2005) study indicated that family therapy is well established for AN patients but not so for BN patients. They showed through their study that BN patients' family background may make family involvement less acceptable to them, as their families tend to be more dysfunctional than those with other eating disorders.

The authors of this study also noted that BN patients are more secretive about their bulimic behaviours due to related feelings of guilt and shame. Also, BN patients tend to be older and therefore spend less time with their parents.

Tasca, Balfour, Ritchie and Bissada, (2007) together with Hilbert and Tuschen-Caffier, (2005) proved how well BN patients respond to Group Cognitive Behavioural Therapy (GCBT). Participants benefited from common goals, agreed on tasks and on the method of treatment, resulting in a sense of belonging and ownership that have all the characteristics of a cohesive group, (Yalom, 2005).

A study carried out by Cockell, Zaitsoff and Geller, (2004) mentioned that residential treatment is beneficial for those suffering with eating disorders, in particular those with AN. It involves emotional, financial and time commitments from the clients, staff and

also the health care system. Clients have made substantial social, psychological and nutritional changes on discharge. However, when the intensive support is no longer available, it is common for the patient to return to their previous patterns.

In conclusion, although family therapy appears to be well established, the findings still show there is a need for further research. Kog, Vandereycken and Vertommen, (1985) showed there is an avenue where established forms of family therapy should be revisited and re-examined. These findings can only benefit families by supporting both the carers and the patients, and by tailoring a more supportive form of therapy to suit their needs. Raymond, Friedlander, Heatherington, Ellis and Sargent, (1993) also argues this point stating that further research in structural family therapy is required to test whether it would be beneficial to observe family conversations in the therapist's absence as the treatment progresses. By monitoring the family's conversations it would allow researchers to establish whether they are receiving the support they so desperately need. The study carried out by Vandereycken, (1987) criticises clinicians' choice of family therapy as he argues that these principles are based on personal beliefs rather than on solid research. He argues that therapy should be integrated using a multidimensional approach which is led by a positive and constructive attitude towards the family, incorporating a pragmatic but flexible scientist-practitioner spirit.

Chapter 3

Methodology

Research Question:

The aim of this study was to investigate what family supports are available, if any, and the impact on the family members who have lived with someone suffering from an eating disorder. The kernel of this study looks at the psychological effect and impact of this illness on family members.

Semi-structured Interviews:

The method used for this study was conducted by using semi-structured interviews.

The questions were designed by the researcher and were divided into 3 sections covering 3 different aspects of living with someone with an eating disorder. (Appendix A)

Ethical consideration: Prior to running the interviews, the list of questions were sent to the author's supervisor for approval.

The first section explored the thoughts, feelings and emotions of each family member interviewed. The purpose was to determine their reaction, if any, towards their relative's illness on an emotional level.

The aim of the second section was to explore the impact of living and/or caring for someone with an eating disorder. This section assisted the author in determining the actual impact on the family member towards the person with the eating disorder.

Whether they talked about their experience to anyone and if they did discuss it, did they feel they were being supported? Did talking help to make sense of what it is like to live with someone with an eating disorder?

The final section determined whether they were aware of any support systems available to them and to other family members and if so, did they avail of them. If this was not the case, what was their rationale.

The aim of the third section was to determine whether the family members felt supported throughout this experience or was there a feeling of loneliness and isolation.

Throughout the semi-structured interviews 5 were taped and themes gathered. In the case of the sixth interview the interview was conducted by telephone and the data was transcribed.

Participants:

Six participants took part in this research and they all shared one similarity in that they are all closely related to someone who suffered from an eating disorder. Each of the participants was chosen specifically for this reason.

The family members partaking consisted of a mother, brother and sister, two cousins and a sister-in-law, none of whom were related.

The author sourced the participants from different geographical areas of the country, including Dublin, Cork and Wexford.

Procedure:

A pilot interview was carried out in order to test the questions - any comments and recommendations were factored in to the final set of questions.

The author contacted, by telephone, each of the participants and outlined the purpose and procedure of the interview. The participants were informed that the information provided by them was to be used solely for the purpose of the study. It was envisaged that each interview would last approximately one hour. Each interview was treated in a confidential manner and each participant was given total anonymity. Participants had been informed that they had the right to withdraw at any stage during the process, especially if the participants felt anyway uncomfortable discussing their experiences, became distressed or had any other concerns around the interview. Participants had been informed that they could see the final report. (Appendix B)

The participants were also given the contact details for services who dealt specifically with the treatment of eating disorders, where they could access further information or/and supports. (Appendix C)

The author contacted each participant again and arranged a suitable date, time and venue in the case of the participants from Dublin and Wexford to conduct the semi-structured interview. In the case of the participant residing in Cork, a suitable date and time to telephone was arranged.

A contact telephone number for the author was given to each of the participants.

Data Analysis: The data was qualitative and transcripts were coded for themes.

The author gathered a list of themes that emerged from the semi-structured interviews.

These described and organised the possible observations and the aspects of the

phenomenon. The author interpreted the themes and the information in a way that contributed to the development of the research (Boyatzis, p. 5-9). To ensure the validity of the transcripts, another researcher also coded for themes.

Chapter 4

Results

Of the 6 participants contacted to take part in the semi-structured interviews, 5 participated. The remaining participant was noncontactable. The author did not pursue her, having left several messages on her mobile telephone. As part of the initial conversation, participants had been informed that they had the right to withdraw at any stage during the process, especially if the participants felt anyway uncomfortable discussing their experiences, became distressed or had any other concerns regarding the interview.

The interview consisted of 13 questions in total which were divided into 3 sections covering 3 different aspects of living with someone with an eating disorder.

The first section explored the thoughts, feelings and emotions of the participant, the second section covered the impact of living and/or caring for someone with an eating disorder and finally the third section was to determine whether the family members felt supported throughout the entire experience.

The participants that took part in the interviews were all related to someone who had an eating disorder. Of the participants 1 was related through marriage, 1 was an aunt, 1 a cousin, 1 a brother and lastly 1 a sister. None of the participants were related to each other. The participants were from different parts of the country.

When the participants were asked what feelings they experienced when they first heard about their relative's illness, 1 participant felt relief "that the physical evidence was there to be seen and everyone knew that there was a problem". The remaining participants had different emotions; 1 participant felt very confused as she did not know what was happening to her sibling, 1 participant felt extremely angry, 1 participant was saddened by it and the final participant does not remember much about the whole episode.

When the participants were asked if they felt they could have done more to help the relative, 2 of the participants said they felt guilty that they should have done more to help, 1 replied that she did not feel she could have done more but "as the illness continued she was left to manage her physical needs as my mother refused to do it – so I did plenty to help her". Of the 2 remaining participants, 1 felt very helpless as she did not understand what was happening and the last participant felt there was nothing that he could have done to help her.

The last question in this section asked the participants who did they turn to for support and was it helpful to them. 2 participants spoke to family members only as the family members preferred to keep 'this problem' within the family circle.

Of the last 3 participants, 1 participant spoke to no one about it and relied on 'their inner strength' to get them through the illness as she was "afraid to talk about what was really going on" and the other 2 participants kept it to themselves as they felt nobody would understand what they had to say.

The first question in the second section asked the participants did the illness have an impact on the family members and they all agreed that it did. 1 participant said "it left a

dent and I am able to pinpoint a number of vulnerabilities which were projected over a period of time through family relationships”. Another participant felt that her cousin was a huge part of her life and that after her death the family was never the same again and never will be. 1 participant said “the atmosphere in the house was like a stick of dynamite, an explosion ready to happen at any time”. 1 participant felt that it made no difference at all and lastly 1 participant said “Yes, nobody talked to anyone in the family – we didn’t get on”.

Of all the participants, 5 replies were similar when asked if they felt they talked about the impact on family members sufficiently, they answered “No”. 1 participant expanded on this by saying “I just wanted to be left alone, I was just too angry”. 1 participant experienced comfort when talking to her own mother. 1 participant had no reply to the question and of the last 2 participants, 1 participant said that it was kept within the family and the other participant said “we were told to talk to no one outside the house but then we didn’t talk to anyone in the house either”.

The sixth question was how this support manifested itself. 5 of the participants had varied answers; 1 participant said that her parents were too guarded of her niece, 2 participants said they were strong people and totally reliant on themselves to get through this and life goes on, 1 of the participants got great comfort from her mother who was “very good” and the last participant had no reply to the question.

When asked whether the complexities of the illness impacted on the family system, 3 of the participants said there were always arguments and rows in the house. 1 of these participants also said her niece was very manipulative and controlled the family and her grand mother was made feel responsible for it all. 1 participant said that their parents took the blame as the entire family were very confused about the whole thing. The final respondent said “that she (the patient) died within 6 months of my mother dying; it was all too much for the family. She (the patient) could not cope with this and her father hanging himself”.

What were the effects of family members was the next question put to the participants. 1 participant said everyone went their own way. 1 participant felt that as nobody knew what was happening, their parents were blamed for what was happening and he felt this was unfair. Another participant felt that there was not enough communication between family members that they were all too annoyed and had their own opinions of what was happening and this caused rows between them all. 1 participant believed they all went their own ways as that was the only way they could cope with family life. The last participant feels that it has left the situation very guarded as her niece still manipulates everyone and the atmosphere is very strained and she feels disconnected from it all.

The final set of questions concerned the support systems for family members. The first question asked the participants what support systems they would have needed throughout the illness. 1 participant did not know but the other 5 participants felt there was no support of any kind. 1 participant felt that support financially would have helped towards

alleviating some of the stress in the house along with marriage counselling for her parents. 1 participant was offered 'a chat' by a therapist but as she lived quite a distance away this did not happen, her own mother had 1 therapy session by default and she feels that she was treated very badly throughout the entire episode. 1 participant said "that as family members were not babies they could get on with their own lives". The comments that the final participant gave were: "Well there was none – the doctor in Beaumont told her mother to take her home and give her a bowl of muesli and not to waste his time".

When the question was asked by the author if the participants were aware of any support systems 1 participant was unsure and the remaining 5 participants said that they were not informed of any support systems by the professional bodies and were not aware of any support.

The participants were asked if they felt counselling would have helped them, 1 participant would have liked it and is still considering it, 1 participant is still 'just too angry and upset', another participant is attending counselling for a number of years but she had to seek this herself. Only for geographical difficulties 1 participant feels that group therapy would have been very beneficial. Even though 1 participant was not directly related to the family she feels that the family would have benefited from group therapy, they would have realised that they were not alone in coping with the stresses of living with an eating disorder and may have alleviated some of the family conflict that has continued to this day and the last participant is too angry to consider it even if it had been offered to her.

The last question asked if the participants had learnt anything from this experience. 1 participant remembers only the rows in the house. 1 participant felt that it was not her blood relative so feels detached somewhat from the experience. 1 participant feels there has been a process of self-reflection and has learnt through this experience a lot about herself. 1 participant feels she is still grieving and very angry that nobody, in her opinion, tried to save her cousin from an early death. The final participant's viewpoint is that her "family is still split. We try to meet up now and again but family occasions are too stressful. Too much has happened. I tend not to meet the family and that suits fine".

Chapter 5

Discussion

To strengthen the awareness of the supports needed by those living with individuals suffering from eating disorders, further studies are required to evaluate the impact it has on them.

Even though it is distressing for the patient, it is also a frightening experience for other members of the family. The family members may have feelings of helplessness, confusion and anger regarding the impact of the illness on them as an individual and to the family structure. The overt functioning of the family environment changes due to the onset of the illness. Feelings of lack of control for themselves and the family are apparent as the family system appears to focus on the sufferer. The impact of the illness on others can often be ignored to their detriment. Family member can find they are helpless. These feelings manifest themselves through a lack of control in their day to day living.

The anger and confusion they experience may be directed towards the sufferer, seeing them as controlling the entire household and those who live in it. They may not understand why the person can not shake themselves out of this state and eat! –therefore allowing life to return to some state of normality.

Compassion and understanding from the professional bodies and society in general, the families and patients alike would not only understand the difficulties incorporated with

this illness but offer the support that they need in order to survive and thrive as individuals without the stigma that is involved.

Dallos and Denford (2008) conducted a study in the United Kingdom and explored the experiences of four families who each had a young family member suffering from an eating disorder. Their findings suggest that the common factor to each family were conflictual relationships and communicational difficulties.

It is paramount, therefore, for the family as a unit to know that professional help is available to them and to be open to the process. It is only through the therapeutic process that each member of the family will not only gain insight into this illness but will have the benefit of learning from each other, providing them with the support and the encouragement that is needed. This in time will alleviate their sense of isolation and open a line of communication between each family member and add to their social interactions.

Parents and siblings alike will be enabled to live their own lives as fully as possible and to be seen for whom they are, giving them the empowerment to separate themselves from the illness.

Each family member often finds themselves overwhelmed by their caring role of the patient, especially at meal times. Added to this caring role are the burdens and the difficulties of understanding the illness.

When one of the participants was asked to recall what feelings she experienced when she was told of the diagnosis of her family member, she said it was “relief” she also

commented “that the physical evidence was there to be seen and everyone knew that there was a problem”.

Everyone knew “there was a problem” nothing had been done before this – why was this so?

The remaining participants had varied feelings and emotions, such as confusion, anger and sadness regarding the diagnosis. Had the symptoms not been visible prior to the diagnosis and “to be seen by...everyone?” The question still remains – why do family members not act on what was so clearly obvious as “everyone knew that there was a problem”.

The evidence indicates that these emotions are common reactions of family members, who experience varied emotions, ranging from confusion to sadness and anger. They do not understand what is happening to the patient. Family members noted being “very very angry” - that nothing had been done before this. A feeling of great sadness was experienced by another participant; it was beyond her comprehension that this happened to someone so intelligent.

The second question as to whether they could have done any more to help received a mixed response. One interviewee said “as the illness continued I was left to manage her physical need as my mother refused to do it – so I did plenty to help her”. A comment expressed by some of the participants described how “very helpless” they felt, while another felt “there was nothing that he could have done”. The remaining participants felt “guilty” and they felt they should have done more.

Another question enquired if they turned to anyone for support and whether that was helpful to them. A number of the interviewees answered that they had only spoken to the

immediate family as they had been told to keep “the problem” within the family circle. One of the participants said she was “afraid to talk about what really is going on in the house as nobody would understand”. The remainder of the participants seemed to rely on “their inner strength” to get them through this experience.

All the participants agreed that the illness had an impact on the family members but one of the participants said “it left a dent and I am able to pinpoint a number of vulnerabilities which were projected over a period of time through family relationships”.

After the death of one patient, her cousin expressed extreme sadness when she related “how the family was never the same again and never will be as she was such a huge part of all our lives”.

A comment expressed by another participant was “ the atmosphere in the house was like a stick of dynamite, an explosion ready to happen at any time” explaining the effect the illness had on family members while another said “ yes, nobody talked to anyone in the family – we didn’t get on”. The author’s understanding is there was such disharmony within the family as a direct result of the illness.

When the participants were asked if they had talked sufficiently to family members about the impact of the illness they all categorically said “No” except for one. The remaining participant said “I just wanted to be left alone, I was just too angry”. On reflection the interviewee added to her comment by saying “we were told to talk to no one outside the house but then we didn’t talk to any one in the house either”.

Regarding the question of support, the participants were asked how it manifested itself. Some of the participants looked internally for support as they felt they were “strong

people”. Another participant received ample support from her mother while another participant replied that the family was too guarded of her niece which implied that the family were closed to outside intervention.

When asked if the complexities of the illness impacted on the family systems, several of the participants said there were always rows and arguments in the house. In the case of some of the participants, they felt it was unfair that the blame was placed firmly not only on the parents, but in one case the grand mother for what had happened to the patient.

The remaining participant believed that her niece was very manipulative and controlled the entire family making life in the house increasingly difficult.

What were the effects on family members was the next question put to the participants.

There was not enough communication between family members, that they all were all too annoyed and had their own opinions of what was happening thus causing rows between them all was one reply. A comment expressed by some of the participants was that the family members went their own ways in order to survive family life, that nobody knew what was happening and their parents were blamed for the situation. Finally, one participant believed that due to her niece’s illness “it has left the situation very guarded....the atmosphere is very strained and she feels disconnected from it all”.

When the family members were asked about the support systems they have would needed throughout, all but one of the participants felt there was no support of any kind offered another participant believed that financial help would alleviated some of the stress from the household and counselling for her parents would have been useful. 1 participant was unsure.

Of the participants 1 said she was “offered a chat” by a therapist but due to geographical constraints this was totally unworkable. Her mother received 1 therapy session by default the participant believed her mother was treated badly throughout the entire episode.

Another interviewee believed that “the family members were not babies and they could get on with their own lives”. When asked about support one participant said of the doctor in charge in the hospital “.....take her home and give her a bowl of muesli and not to waste his time!”

When the question was asked by the author if the participants were aware of any support systems, 1 participant was unsure while the remaining 5 participants said that they were not informed of any support systems by the professional bodies and were therefore unaware of any support.

The participants were asked whether they felt personal counselling, group therapy and/or family therapy would have been beneficial. 1 of the participants believed that group therapy would have helped them to realise that they were not alone in coping with the stresses that living with an eating disorder brings and may have alleviated some of the family conflict that has continued to the present day. Another participant is “too angry” to this day to even consider any kind of therapy. Another participant initiated counselling herself and has been attending regularly to help her work through her experience, while another participant is considering it and would have attended counselling had they know about it at the time.

What have they learnt from the experience if at all was the last and final question put to the participants. One of the participants can only remember the constant rowing in the house and another believes that as they are not a direct blood relative they feel detached

from the situation. For another participant “it has been a process of self-reflection and I have learnt quite a bit about myself”.

One interviewee’s viewpoint is “the family is still split. We try to meet up now and again but family occasions are too stressful. Too much has happened. I tend not to meet the family and that suits fine!”

Whitney and Eisler (2005) pointed to the mounting evidence directed at the impact on the lives of family members. Each family member found their experience to be different but there was a common theme that emerged which was they all felt a loss of control in one or more areas of their lives, ranging from difficulties within relationships to a loss of self-esteem. The most helpful experience for them all was the support of family and friends and attending regular psychotherapy and counselling sessions.

Kyriacou, Treasure and Schmidt, (2008) found that the psychological needs of carers were being neglected. Family members who sought help and support from the health services were often turned away and in some cases blamed for the illness itself. This attitude, the authors believed, was both unhelpful to both the family and the sufferer. Their research also highlighted the poor social support for family members and their feelings of isolation were heightened adding to their stress and anxiety.

Similar findings are shown in Whitney and Eisler, (2007) which stated that where support was available to family members and their carers it was totally inadequate and added to this was the stigma attached to the illness which increased the levels of stress and anxiety of their carers and families.

In some cases, Kyriacou, Treasure and Schmidt, (2008) stated that as the feelings of isolation and frustration grew there was an association with depression and high levels of anxiety.

Dominy, Johnson and Koch, (2000) viewed previous research in this field and their results showed that families with an eating disorder are disorganised, more conflictual, nonnurturing, controlling and show less affection than those families without an individual with an eating disorder.

Sepulveda, et al. (2008 and 2009) encouraged the use of the Maudsley model when treating eating disorders as it is unique in the history of family therapy by giving the sufferer and their family the necessary support they need. This model values the importance of a family working together towards recovery and values the family as an integral part of the healing process.

When the sufferer is proving to be controlling and manipulative, the families are offered collaborative care skill workshops where they are encouraged to take an authoritative stance by working together in the home setting. Having gained the necessary skills, they are in a better position to stand up to the full range of eating disorder behaviours.

This model is exclusive in that it follows up on the sufferer's recovery after a 6 year period where relapse may occur.

There is a belief that some kind of relapse may occur after a period of remission. This may be due to a lack of motivation which may be related to the previous treatment process and its outcome. Hight, Thompson and King, (2005) also found that this again adds to the stress and anxiety for the family, who will have to face the financial

constraints as before. The family found the most distressing fear was the fear of the long term dependency on them from the patient.

Having re-evaluated the scripts, the use of semi-structured interviews was valuable as the author was able to determine the feelings of the participants. To witness the feelings of guilt, anger and confusion that is still with the participants gave the author a truer sense of what they are still experiencing. In some cases, the participants' experiences are as long ago as forty years and as recent as 8 years but they are still in a position to recall their life changing experiences as if they have only occurred. All the participants would have gained more from this experience had the implication of living with someone with an eating disorder been explained to them by the professionals bodies. This not only would have led them to a better understanding of their own feelings and attitudes to the illness but also a fuller understanding of the sufferer and what their experiences of the illness was like from their perspective.

A therapeutic approach to the illness would have been extremely beneficial in all cases excluding one. This approach needs to include personal therapy, group therapy and family therapy.

The data gathered proved overall to show similar findings in regards to their feelings, emotions and thoughts when living and coping with someone with an eating disorder.

The study would have benefited from a second interview with each of the participants in the author's opinion as this would have given the participants the opportunity to reflect and to absorb the questions as they were posed.

Each of the participants was very responsive to the questions and found the experience quite reflective. The author had furnished each of the participants with a list of agencies they could contact in the future if the need arose. A number of the participants found this to be supportive as they had never been offered a list of help lines previously.

Interviews were held face to face which the author believes to be successful. However, due to geographical constraints one of the interviews was conducted over the telephone. The author feels it was the least successful of the interviews as it was difficult to judge the reaction of the participant. Due to the nature of the illness being discussed the author believed the interviewee to be somewhat guarded in the responses to the questions. This is in comparison with the face-to-face interviews where the author was in a position to monitor the reactions of the interviewees and proceed at their pace. The author deems this method of interviewing as a more constructive method due to the highly emotive nature of the topic being discussed.

The studies thus far indicate that there is an ongoing need for further research in this area. Apart from the Maudsley model, whose service is based in London, there seems to be a gap in treatment that incorporates both the family members and the patient. This model is unique as it follows on from the initial recovery phase to the inevitable relapse period, approximately 6 years hence, and lends its support again to families and patients.

The author believes that there is a greater need for programmes such as this, to be more family member orientated that can offer them the support they greatly need, thus enabling them to cope with the difficulties that living with an eating disorder brings.

Further studies are needed to highlight the effects of the stigma that is attached to eating disorders. The outcome related to stigma is still in prevalence today and adds to the high level of anxiety and stress which it causes to family members.

One of the participants only proves this point by saying they were “saddened that this (the illness) could happen to someone so intelligent”. This illness is still perceived to be within the lower classes but studies have shown that eating disorders have no social boundaries.

The doctor who told the mother of the patient “to take her home and give her a bowl of muesli and not to waste his (the doctor’s) time” is quite shocking, that as recently as 8 years ago an attitude such as this along with the lack of understanding surrounding this illness is still prevalent.

The participant, who gave negative responses to the interview throughout, found difficulty in recalling the first reaction to the diagnosis, internalised the whole experience. The author feels that this person would benefit from a therapeutic intervention. The participant has become split and is disassociated from this episode in their life and found this to be the only way in which they could deal with the trauma that was inevitable. Had this participant been given the knowledge, the understanding and the opportunity of counselling during the time it was so desperately needed, it would have alleviated some of the stress and anxiety caused.

When a family member develops an eating disorder, it is time to listen as eating is only one of the underlying concerns of this illness.

Chapter 6

Conclusion

The research supporting this study verify that families who live with someone suffering from an eating disorder lack the support and care that they desperately need to assist them in coping on daily basis. In most cases the support offered by professional bodies is inadequate for the family members as it is centred towards the needs of the patient. It is evident from the research that the support structures required to manage this illness by all members of the family system need to be in place to ensure a full recovery thereby avoiding relapse. A holistic approach would help to alleviate a lot of the issues that present to the family as a whole. Through the use of personal therapy, group therapy and in particular family therapy individuals are encouraged through learning new coping skills to take an authoritative stance. By working together in the home setting, having gained the necessary skills, they should now be in a position to stand up to the full range of eating disorder behaviours. This will empower the family members to open the lines of communication within the family structure by regaining their self-esteem and confidence. It is evident from the semi-structured interviews that families with an eating disorder are closed to communication. The results from the interviews have shown this to be so, in the case of one participant the initial diagnosis was forty years ago and the effects are still prominent today.

In conclusion, the Maudsley model offers the families and the patient an all inclusive therapeutic programme. This therapeutic programme is all encompassing as it requires

the involvement of all relevant family members and caregivers. Responsibility is handed back to the patient when a healthy weight has been established.

The Maudsley model, based in London, is unique in the history of family therapy by giving the necessary support to families and to patients. This model also follows up on the treatment plan and its outcome after 5 years. Through this model, all family members are valued and are an integral part of the healing process.

The author found through her research a similar model in the Marino Therapy Centre where therapy is offered to both families and patients. The programme also offers an outpatient programme for 1 year duration. While this programme and other support systems are serving a need for the populous in the author's opinion it is unfortunately not offering the Maudsley model in its entirety.

It is imperative that to treat an individual with an eating disorder family involvement is crucial to their recovery and to promote, develop and facilitate autonomy and independence.

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Appendices

Appendix A

Semi- Structured Interview:

Section 1 – Emotional Level:

1. In Recalling your first reaction to the diagnosis of your family member with an eating disorder – what feelings did you experience?
2. Did you feel there was anything you could have done to help your relative?
3. Who was the first person you turned to for support and how helpful for you was that?

Section 2 – Impact on family members:

4. Did living with someone with an eating disorder change your life?
5. How did that impact on you?
6. Did you feel that you talked about the impact sufficiently to others?
7. If so, how did this support manifest itself?
8. How did the complexities of the illness impact on the family system?
9. What were the effects on family members?

Section 3 - Support:

10. What support would you and your family have needed throughout the illness?
11. Were you aware of any support systems?
12. Would counselling have helped e.g. personal counselling, group therapy and/or family therapy?
13. What have you learnt from this experience if anything?

Appendix B

To the participant

I am a 4th year student studying Counselling and Psychotherapy through Dublin Business School. As this is my final year one of the requirements is to complete a dissertation. My chosen topic for this study is to gain a greater understanding and insight of the effects and the impact on family members living with someone with an eating disorder.

As part of this study I am interviewing family members who have been directly affected by living with someone who has had an eating disorder.

I have gained approval from the Ethics Committee and my supervisor, Ms. Siobain O'Donnell to conduct this interview.

It is envisaged that the interview will take no longer than one hour to complete and all participants will be treated with total anonymity. All information given will be treated in a confidential manner and is for use of the author for this study only. In due course all interviews will be destroyed. A copy of which will be given to you if you require it.

If you wish future support or information on eating disorders a list of contact numbers are attached.

Please sign below giving permission for this interview and a copy of it will be forwarded to you on request.

I wish to thank you for your time and your contribution to this study.

Participant

Appendix C

Support Contacts:

- Bodywhys, Dublin - (01) 2834963
- info@bodywhys.ie
- Bodywhys, Cork. - (021) 879678
- info@bodywhys.ie
- Eating Disorder Resource Centre of Ireland, Cork. - info@eatingdisorder.ie
- Marino Therapy Centre, Dublin - (01) 8333126
- www.eatingdisorderselfhelp.com
- St. Patrick's University Hospital, Dublin – (01) 2493333
- info@stpatsmail.com
- St. John of God Hospital, Dublin - (01) 2771400
- www.sjoghosp.ie
- Rutland Centre, Dublin - (01) 4946444
- info@rutlandcentre.i

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