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Caring for an Adolescent with Anorexia Nervosa: Parent's Views and Experiences

Abstract

There is a distinct lack of studies that explores the views and opinions of parents in relation to people diagnosed with an eating disorder. **This** study specifically investigated the subjective experiences of parents who were caring for an adolescent with anorexia nervosa **in Ireland**. A qualitative descriptive approach was used to elicit the unique views and experiences of seven mothers and three fathers. The **findings** showed that parents recognised the significant impact that the illness was having on all facets of family life. Despite the negative impact of the illness, parents remained hopeful that the adolescent would recover. In terms of current mental health nursing practice, this study demonstrates the importance of viewing parents as an integral resource and involving parents in care planning and treatment approaches.

Keywords: adolescents, anorexia nervosa, parents, caregiving

Introduction

It has become increasingly apparent that caring for an individual with mental health difficulties can have a negative impact on the psychosocial wellbeing of the carer (Cohn, 2005; Whitney et al., 2005; Kyriacou, Treasure & Schmidt, 2008; McCauliffe, O'Connor & Meagher, 2014). Research exploring care-giving distress remains limited, although some studies do exist that investigate the burden associated with caring for individuals with an eating disorder (Treasure et al. 2001; Hight, Thompson & King, 2005; Sepulveda, Whitney, Hankins & Treasure, 2008; Coomber & King, 2012). The caregiver role has been associated with a broad range of issues including dependency, a sense of loss, a negative impact on family functioning including leisure and financial burden (Szmukler et al., 1996, Santonastaso, Saccon & Favaro, 1997; Ma, 2011). In a recent study, some parents identified objective burden including disruption to life, and subjective burden related to the emotional costs of care-giving and attitudes towards providing care (Goddard, McDonald & Treasure, 2011). Moreover, parents providing care to adolescents with anorexia nervosa may experience further challenges that relate to a lack of information, stigma, difficulties accessing services, negative staff attitudes and a lack of psychosocial supports (Treasure et al., 2001; Haigh & Treasure, 2003; Whitney et al., 2005; Hillege, Beale & McMaster, 2006; Stewart, Keel & Schiavo, 2006; Gisladdottir & Svavarsdottir, 2011). Recent intervention studies incorporated family centred care approaches including education and support which significantly reduced negative aspects of caregiving commonly associated with anorexia nervosa (Carlton & Pyle, 2007; Honey et al., 2007; Kyriacou, Easter & Tchanturia, 2009). Additionally, collaborative care skills workshops enabled carer's to address distress and improve interpersonal difficulties (Goddard, MacDonald & Treasure, 2011). The literature suggests that nursing staff are in a position to engage and support parents in the care and

treatment process (Turrell, Davis, Graham & Weiss, 2005) and provide multidisciplinary educational support programmes (Carlton & Pyle, 2007).

Global statistics have shown that prevalence rates in the US, which were previously estimated at 0.3% (Bulik *et al.*, 2005), have risen and more recently been estimated at approximately 0.5% in adolescent girls (Rosen, 2012). In Western countries, the prevalence of anorexia nervosa among young females is currently estimated as 0.2–1% (Zanetti, 2013). Lifetime prevalence studies in US and Canada indicated rates of 0.5-0.6% with up to 1% being reported in the Netherlands (Preti *et al.*, 2009). From an Irish perspective, official Government statistics report that up to 200,000 people are affected by eating disorders with approximately 400 new cases each year (Department of Health and Children, 2006). One study revealed that 1.2% of girls may be at risk of developing anorexia nervosa (McNichols, 2007). In terms of mental health services, available statistics show that eating disorders represent 18% of all inpatient child and adolescent admissions (Health Research Board, 2008). Despite these figures, there is a distinct lack of studies that investigate the experiences of parents in relation to an adolescent with anorexia nervosa.

Materials and Methods

Aim of this study

The aim of the current study was to investigate the subjective experiences of parents in caring for an adolescent diagnosed with anorexia nervosa.

Design

A qualitative descriptive approach was **utilized** to address the aim of this study. Data were collected through semi-structured interviews conducted with ten parents to explore their experiences of caring for an adolescent with anorexia nervosa.

Recruitment and sampling

Parents of an adolescent with anorexia nervosa were recruited from an outpatient clinic in Ireland. The participants included both mothers (n=7) and fathers (n=3) from both rural and urban communities. An identified gatekeeper distributed information packs to parents who met the study inclusion criteria. Parents were eligible to participate if the adolescent had received a diagnosis of anorexia nervosa and were outpatients at the time of recruitment.

Ethical considerations

Approval to carry out the study was granted by the University Ethics Committee and the relevant Hospital Ethics Board. **Information packs were provided to both parents and adolescents detailing the purpose of the study. Informed consent was obtained from the parents while informed assent was obtained from the adolescents. Both parties were given the opportunity to discuss any questions they may have had prior to signing consent forms.**

Interviews were conducted individually in a private space in the clinic whereby the interviewer could gauge any discomfort, offer support, and answer any concerns. Participants consented to be audio recorded and were assured that they could stop the interview at any point. Anonymity was assured. All data was stored securely in accordance with the Data Protection (Amendment) Act 2003 (Government of Ireland, 2003).

Data analysis

The computer software package NVivo 9 was used in the data analysis (QSR International, 2010). The interview data were transcribed verbatim. A coding guide was developed that was used to analyse the transcripts for new concepts or emergent themes. The data were further examined for meaning and similar themes combined. This constant comparative process continued until major **thematic** categories were formulated (Lincoln & Guba, 1985). **Coded transcripts and the coding framework were reviewed by an experienced**

researcher which added to the dependability of the findings of the study. NVivo enables transparency by maintaining a clear audit trail to dispel such concerns. All processes and stages of coding were tracked to demonstrate rigour and to enhance the validity and reliability of the research.

Results

Four key themes emerged from the data including: the family environment, psychosocial impact on parents, experience of services and future hopes and aspirations.

The family environment

Some participants disclosed that all aspects of family life remained affected by anorexia nervosa in the family home. For one person, the tense environment was particularly challenging:

The atmosphere in the house was horrendous, you know because it takes over, actually the whole house really, because you trying to get her to eat and she's sitting there in tears and its horrendous and it's the worst thing ever and its happening under your nose and you know its dreadful. (Participant 3)

Another parent spoke of the emotional impact of being informed about their child's condition:

Well it turned all of us into turmoil I suppose really would be the initial stage of shock. We found it very hard. (Participant 8)

While all of the participants agreed that the illness had initially 'taken over,' this feeling reduced as the adolescent began to recover from the illness. Communication within

the family became problematic and parents observed an increase in arguments within the family home both with the spouse and with other children. They commented that disagreements usually stemmed from differences of opinion about how the young person should 'be managed' or supervised. One person was perhaps being perceived as giving the adolescent too much 'freedom' thereby undermining the other parent. While some parents viewed this role as more time consuming than others, it was evident that, for the most part, mothers undertook this role as they were traditionally at home with the adolescent.

Furthermore, the issue of stigma was reported to have had a huge impact on both the adolescent and for parents. Some parents felt that they were acting in the young person's best interest by not disclosing the illness as they felt that this may be poorly understood or accepted by others. By 'concealing' the illness from younger siblings, some parents felt that they would be protecting them from undue anxiety and distress. Others parents chose to acknowledge the young person's request for privacy but some wondered about how these behaviours may lead to increased feelings of loneliness and social isolation. All parents expressed guilt at not having identified the signs earlier and sought appropriate help and support. Parents attributed the lack of awareness or perhaps missing the early signs due to having no knowledge of **the early signs and symptoms of the condition**.

Psychosocial impact on parents

The data revealed that many aspects of the participant's lives were being affected as a direct result of the condition including social, financial, personal and parenting styles. One person expressed her frustration at having to try to cope with the financial burden she endured:

It is a lot of money. It is like a second mortgage. Luckily I have money there at the moment and I have enough to tide me over. (Participant 1)

Further emotional frustration was evident in the interviews. It emerged that family meals outside the home became restricted to locations where the adolescent would feel comfortable. Others acknowledged that they missed this social outing with the family, as did the other siblings. One participant spoke about the negative consequences around preparing food at home:

I used to love to cook...I couldn't be bothered now. You know because food has become a battleground (Participant 8)

Participants commented that 'regardless of the cost of care' or the personal sacrifices they had to make, the adolescent's care was 'always the priority'. Parents emphasised that although the adolescent may have been aware of the cost of care, this was never openly discussed with them. Parents also commented on how they became sensitive to not discussing diets around the adolescent. Parents also reflected on their own dietary habits in the past and how this may have impacted on the adolescent. A number of parents, who had dieted in the past, felt 'somewhat responsible' for their adolescent's food concerns. Furthermore, parents described various concerns for adolescents including the emotional impact and increased anxiety related to guilt and blame. Some parents acknowledged concerns for the future and particularly issues around being well and remaining well. As one person articulated:

I am constantly worrying; she is always on our mind, even on good days.

(Participant 1)

Several parents expressed concern for their child's progress, both in terms of what they were missing from a developmental perspective in the present, and for what they stood to lose in the future. Parents disclosed that coping with the consequences of the condition

often resulted in them feeling ‘emotionally drained.’ One person recognised the negative effects upon her own self-esteem:

Oh yeah dreadful, you feel like such a failure...you know my little girl and how did I miss it? You really feel like you’ve, I felt like I failed her you know. (Participant 3)

The emotions related to guilt and blame emerged as fundamental concerns for parents and consideration was given to the contributing factors. In terms of the attribution of blame, some parents continued to believe that they were responsible for causing the illness:

I suppose at the beginning you feel guilty...what why has this happened and what have I done or why and you blame yourself. (Participant 7)

Experience of services

This category captured the positive and some of less favourable parental experiences of primary care services. All of the parents in the study commented positively on the quality of the service they had received. Some attributed this to ‘not being judged’ and that professionals in the service actively supported the family through the illness. Some parents felt they needed more information about the illness from service providers. Most participants had negative experiences with General Practitioners (GP’s) with one person describing a dismissive reaction:

I went to her doctor who was an old doctor, an old man, and he dismissed her. He totally dismissed her she went and insisted on going in herself ...and then we went in to talk to him and we were saying she seems to have a problem with her eating and he just totally dismissed her. (Participant 10)

Participants commented that most GP’s remained unaware of the services and treatment options available for adolescents with anorexia nervosa. This often led to feelings

of frustration and anger in parents. In terms of early responses or interventions, some parents felt that there were severe delays in finding appropriate help for the adolescent. To compound the issue, one participant was also concerned about negative staff attitudes and poor communication:

I won't use the word that I was irrelevant but I was. If there was a bit more talking with me then.....(Participant 2)

One participant commented that at times assumptions are made that parents know more than they actually do about the illness. A significant number of parents felt that a support group would be highly beneficial in terms of peer support available in their own respective localities. Some parents described feeling isolated within their caring role and implied the need for greater consideration to be given to the future development of supportive networks or groups both at service and national level. Participants also called for better service provision outside cities and in rural settings. In the same vein, parents wanted to have more professional lead information session such as one to one sessions with the therapist or a multi-disciplinary team member in terms of discussing the prognosis for the adolescent.

Future hopes and aspirations

Despite all the challenging aspects of care-giving that was reported, parents also articulated that they were able to 'recognise positive aspects to the illness.' A fundamental part of the recovery process is hope, and this was considered crucial to one of the participants:

I hope for her that she has gained back a lot of her own self-esteem and feeling better about herself and stronger and I'm hoping she won't relapse and that she will, you know, go from strength to strength. (Participant 7)

Parents frequently commented on the inherent strengths and resilience within the adolescent and how they had seen the adolescent grow and develop through the recovery experience:

She has matured a huge amount even though she's been sick. She has matured and now she wants to get better (Participant 10)

Additionally, all participants perceived that communication patterns within the family had improved having gone through this experience.

Discussion

There is a global public health concern about anorexia nervosa and this is reflected in current government mental health policy documents (Department of Health and Children, 2006; Australian Government 2008; Department of Health 2014). Despite the apparent importance of the issues, no Irish studies exist that examines parental experiences and responses to the condition. Participants in the current study gave vivid accounts of concerns in family life that included: atmosphere at home, communication issues, the time consuming nature of the condition, taking over the home, avoiding meals out and increased vigilance towards the adolescent.

The study findings indicate that parents who spent more time at home reported higher significant disturbances than those who worked outside of the home. Study participant's experiences also varied, depending on the duration of the illness, and before accessing mental health services and these findings concur with other studies (Gowers & North, 1999; Tierney, 2005). Participants noted an increase in arguments with their spouse over differences of opinion in terms of the management of the adolescents' eating patterns. This disharmony was also reported to have negatively impacted on both the atmosphere in the home and the marital relationship. These findings are similar to those contained in other studies (Dimitropoulos, Carter, Schacter & Blake-Woodside, 2008; Latzer, Lavee & Gal, 2009; Ma, 2011).

Interestingly, the results of the present study indicate that Irish parents experience similar levels of stress and impact on family functioning when compared with British or French families (Emanuelli et al. 2003; Cook-Darzens, Doyen, Falissard & Mouren, 2005). Parents spoke of strategies they had developed in order to maintain ‘normality’ in the home and minimise the impact on siblings (Karwautz et al., 2003; Honey, Clarke, Halse, Kohn & Madden, 2006).

The issue of stigma in mental health has been widely recognised in the literature (Jones, 1996; McMaster, 2004). The current study found that parents caring for an adolescent with anorexia nervosa had similar experiences. Parents mentioned ‘hiding the illness’ in order to protect the adolescent or siblings, and also to protect the parents from the common misconception that parents were to blame for the illness (Stewart et al., 2006; Mond, Robertson-Smith & Vetterre, 2006; Crisfulli, Thompson-Brenner, Franko, Eddy & Herzog, 2010; Wingfield, Kelly, Serdar, Shivy & Mazzeo, 2011). The parents highlighted the positive experiences they had felt in terms of their current care setting.

Many parents in the study commented on the quality and high standard of care they had received by their current service providers. Parents often sought additional information about the illness and wanted to feel more included and informed about treatment strategies and to develop skills to deal with the illness on a day-to-day basis (Honey et al., 2007). The present study signifies the importance of clinicians involving parents in the treatment of anorexia nervosa and has shown, with the support of the literature, that inclusion, skills based training and education will reduce carer distress and may improve experiences of care (Kyriacou, Easter & Tchanturia, 2009; Goddard, MacDonald & Treasure, 2011). Such interventions have shown to improve communication within the family, empower parents in their caring role and build on problem solving skills (Sepulveda et al., 2012). Existing studies have shown correlations between positive attitudes towards parents and improved treatment

outcomes (Halvorsen & Heyerdahl, 2007; Roots, Rowlands & Gowers, 2009). The key findings of the current study demonstrate the positive parental response to adolescents during and throughout the illness. Interestingly, no previous research to date has identified positive aspects experienced by parents of a child with anorexia nervosa.

The concept of recovery was undoubtedly of significant importance to parents who frequently commented on the strength and determination of the adolescent to ‘get well’ and remain well. Additionally, parents observed that communication patterns within the family had improved and identified themselves as important supports and resources to adolescents. These findings compare favourably with existing studies (Sherkey- Orgnero, 1999; Cohn, 2005). Furthermore, the findings demonstrated that no aspect of the family remained unaffected. Participants detailed the distressing perceptions of anorexia nervosa and the ‘devastating’ effects it had on the family unit. While many of the participants described negative encounters publicly and with healthcare professionals, they also highlighted the positive outcomes of their experiences including hopes for the future. Despite the negative experiences, parents demonstrated resilience and a commitment to help the adolescent in whichever way possible to recover. Parents also showed great strength and determination in terms of the strategies they employed to cope with the illness and illustrated how as parents and as a family they adapted to meet the needs of the adolescent.

Implications for mental health nursing practice

The results of study attest that parents urgently need additional support and knowledge related to managing and coping with the person’s eating disorder. Mental health nurses working in this specialist area are ideally placed to provide such support to parents. Nurses possess both the knowledge and skills required to deliver psycho-educational training and support to parents, at either group or on an individual basis. As such, skills based training sessions

should contain education about the condition, problem solving skills, enhancing interpersonal and communication skills and building positive relationships within the family. This increase in psychosocial supports may significantly reduce parental distress, instil confidence and further empower parents to assist their adolescent towards their recovery goals. The development of such supports within mental health services at both inpatient and outpatient settings would significantly improve the care giving role and experiences of parents (Sepulveda et al, 2012).

Moreover, some mental health nurses in ‘non-specialist’ areas may need additional skills training in order to effectively deliver parental supports in the clinical setting. We would strongly support nurses undertaking further education in specialist eating disorder training, psychosocial intervention courses, and group facilitation training where necessary. In terms of nursing practice developments, future policy makers should consider the need for the expansion and development of services specifically tailored to meet the needs of adolescent living with anorexia nervosa and their parents.

Limitations and conclusion

The current study offers an account of the unique opinions and experiences of parents of adolescents with a diagnosis of anorexia nervosa. However, it is acknowledged that due to the small sample size, while this is a true representation of the experiences of this sample, it may not be the experience of all parents in similar situations. Future research should examine the effectiveness of psychosocial and psycho-educational interventions with families caring for an adolescent with anorexia nervosa and available supports to siblings.

Mental health services in Ireland are in transition with policy directives supporting the provision of services in the community. However, challenges remain for all practitioners in primary care in relation to people with eating disorders and their families.

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