



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



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ABSTRACT

There is a distinct lack of studies that explore 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.

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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; Kyriacou, Treasure, & Schmidt, 2008; McCauliffe, O'Connor, & Meagher, 2014; Whitney et al., 2005). 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 (Coomber & King, 2012; Highet, Thompson, & King, 2005; Sepulveda, Whitney, Hankins, & Treasure, 2008; Treasure et al., 2001).

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 (Ma, 2011; Santonastaso, Saccon, & Favaro, 1997; Szmukler et al., 1996). 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 (Macdonald, Murray, Goddard, & 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 (Gísladóttir & Svavarsdóttir, 2011; Haigh & Treasure, 2003; Hillege, Beale, & McMaster, 2006; Stewart, Keel, & Schiavo, 2006; Treasure et al., 2001; Whitney et al., 2005). 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, MacDon-ald, & 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, Reba, Siega-Riz, & Reichborn-Kjennerud, 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 & 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.

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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:

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