ABSTRACT

Anorexia nervosa can be a chronic, life-threatening illness associated with poor outcomes and considerable stress to the carer. Research on caregiving in mental illness and in anorexia nervosa has found that the relationship between the carer and healthcare professionals can impact on patient outcomes and on caregiver stress. However, there remains a paucity of research which examines carers' experiences of the carer-professional relationship in the domain of anorexia. Therefore the aim of this study was to explore the experiences of parents of adult children with anorexia nervosa in relation to their interactions with healthcare services and professionals. In particular, the study was concerned with how parents made sense of their experiences. Semi-structured interviews and interpretative phenomenological analysis (Smith, 1996) were used with five parents to generate themes. The analysis revealed that parents experienced a struggle to secure help for their child and felt excluded from their child's treatment. Parents appeared to make sense of their experiences in relation to their perceived role as parents and responded to their experiences in ways that reaffirmed their parental role. The latter finding is discussed in relation to a small body of literature on caregiving which highlights that perceptions of parental role are central to understanding how parents make sense of their caregiving experiences. The finding that parents report being excluded from the treatment is discussed in relation to literature on caregiving in mental illness which has consistently found that carers experience exclusion from the treatment process. Experiences of exclusion are discussed with reference to UK policy on caring for an individual with a mental illness. The present study contributes to knowledge and understanding of the experience of caregiving in anorexia nervosa.

INTRODUCTION

I went, as the saying goes, to hell and back, and to hell and back, and to hell and back.
(Wendy, mother of a son with anorexia)

Anorexia nervosa (hereafter anorexia) typically starts in late adolescence (Hoek, 2006) and there is a tendency to favour outpatient care (National Institute for Clinical Excellence [NICE] guidelines, National Collaborating Centre for Mental Health [NCCMH], 2004). These features result in a situation where families, and parents in particular, are likely to be the main caregivers. Unsurprisingly, given that anorexia can be a chronic, relapsing disorder with high levels of psychiatric co-morbidity (Steinhausen, 2002) and mortality (Nielsen, 2001), this role has been found to be burdensome and distressing (Treasure, Murphy, Szmukler, Todd, Gavan, and Joyce, 2001; Haigh and Treasure, 2003). In particular, carers' experiences of accessing and working with treatment services have been found to contribute to caregiver burden (Haigh and Treasure, 2003). Despite these findings, there is a paucity of research which examines parents' experiences of interactions with healthcare services and professionals in anorexia. Those qualitative studies which have investigated carer-professional interactions in anorexia (McMaster, Beale, Hillege, and Nagy, 2004; Highet, Thompson, and King, 2005; Tierney, 2005) have focussed on carers' experiences of exclusion; the present study extends this research by considering how parents' make sense of their experiences.

Anorexia

The diagnostic criteria for anorexia in the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* (*DSM-IV*; American Psychiatric Association [APA], 1994) include a refusal to maintain body weight at or above a minimum expected for age and height; an intense fear of gaining weight or becoming fat, although underweight; a disturbance in the perception of body weight or shape, or their undue impact on self-evaluation, or a denial of the seriousness of the current low body weight; and, in postmenarchal females, amenorrhea.

A review of epidemiological studies from the United States and Western Europe reported that the average prevalence rate for anorexia in young females based on *DSM-IV* criteria was 0.3% (Hoek and van Hoeken, 2003). In the UK, the age and gender

adjusted incidence of anorexia diagnosed in primary care in 2000 was reported at 4.7 per 100,000 population [95% CI: 3.6-5.8] (Currin, Schmidt, Treasure, and Jick, 2005). However, the incidence rate varied dramatically according to age and gender with a relative risk of females to males of 12:1 and the highest incidence, 34.6 per 100,000 population [95% CI: 22.0-47.1], reported for females aged 10-19 years (Currin et al., 2005). This finding corresponds with other epidemiological evidence that eating disorders emerge in late adolescence (van Hoeken, Seidell, and Hoek, 2005; Hoek, 2006). The incidence rates reported are likely to be a gross underestimation of incidence of anorexia in the community, particularly as people with anorexia tend to conceal their illness and avoid professional help (Hoek, 2006). Additionally, many cases of anorexia go undetected in primary care (NICE guidelines, NCCMH, 2004).

Research on the course and mortality associated with anorexia emphasises the seriousness of the illness. A review of 119 studies published in the English and German literature reported that at long-term follow up just over 40% of patients showed full recovery from the illness and approximately 20% developed a chronic course of the disorder (Steinhausen, 2002). In addition, psychiatric co-morbidity was common and was associated with poor outcomes (Steinhausen, 2002). Anorexia is frequently reported to have the highest mortality rate of all psychiatric illnesses (Hoek, 2006). A meta-analysis estimated the standardised mortality rate for anorexia in studies with 6-12 years follow up to be 9.6 [95% CI: 7.8-11.5], about three times higher than any other psychiatric illness, illustrating the seriousness of the problem (Nielsen, 2001). These figures are based on patients in tertiary care who represent the severe end of the clinical spectrum; lower mortality rates could be expected for sufferers from the general population. Death most commonly results from eating disorder complications or suicide (Hoek, 2006).

In terms of treatment, the NICE guidelines (NCCMH, 2004) recommend that, where possible, anorexia should be managed on an outpatient basis. Inpatient care, consisting of psychological treatment and refeeding, should be considered only if there is a significant deterioration in the patient. These recommendations, which result in much of the care taking place within the home setting, are in line with the move towards care in the community in mental illness in the UK which has resulted in an increased role for informal carers in mental illness (Lloyd and Carson, 2005).

Family-based Interventions and Patient Outcomes

A growing body of research suggests that, in the domain of mental illness, family involvement in aspects of the treatment process can improve outcomes for the patient (Feeley and Gottlieb, 2000; Stanbridge and Burbach, 2007). In the domain of eating disorders, there is increasing evidence that family-based interventions are an effective treatment, although the evidence is stronger for adolescent patients than for adult patients, who are the focus of this study (Eisler, le Grange, and Asen, 2005). For patients of all age groups, there is strong evidence to suggest that family factors, such as levels of expressed emotion, affect both adherence to treatment and outcomes, and are modifiable by family-based interventions (Eisler et al., 2005; Treasure, Sepulveda, Whitaker, Todd, Lopez, and Whitney, 2007) which has led researchers to suggest that, in anorexia, family involvement in treatment is preferable (Treasure et al., 2007).

Findings of improved outcomes associated with family involvement in treatment, together with the recognition of the increased role for informal carers as a result of the move towards care in the community (Lloyd and Carson, 2005), have impacted on both theories of mental illness and mental health policy in the UK. In particular, there has been a shift in perspective from a deficit model, in which the family have been considered to be a contributing factor in the disorder, to a strengths model, which considers the family to be a resource in the treatment process (Feeley and Gottlieb, 2000). This has resulted in policy which increasingly advocates working in partnership with families and family-based interventions (Stanbridge and Burbach, 2007). In terms of anorexia, the NICE guidelines (NCCMH, 2004) recommend family-based interventions for adolescent patients. The best practice for adult patients is less clear although the guidelines emphasise the need for effective communication with families and carers. Given the impact of carer-professional interactions on patient outcomes and given the national context (in terms of recommendations and guidelines), it is important to examine carers interactions with healthcare staff.

Literature on Caregiving in Mental Illness

It is important to investigate carer-professional interactions not only because they affect patient outcomes but because they impact on carer stress. The term 'carer' has been defined both narrowly with reference to the amount and kind of care provided and more broadly with the terms 'carer' and 'family' used interchangeably (Stanbridge and

Burbach, 2007). The present study draws on a broad definition such as that proposed in a recent Department of Health/Rethink leaflet: 'someone who provides or intends to provide practical and emotional support to someone with a mental health problem' (DoH/Rethink, 2006). While there is a growing body of literature on caregiving in mental illness, there is a paucity of research on caregiving in anorexia (Baronet, 1999; Schulze and Rössler, 2005).

The literature on caregiving in mental illness focuses on caregiver burden which refers to the (adverse) consequences of activities associated with providing care to a relative or friend whether these costs are observable and tangible (objective burden) or self-perceived psychological distress (subjective burden; Hunt, 2003). Research has consistently reported a negative impact of caregiver burden on the physical and psychological well-being of the carer (Schulze and Rössler, 2005). Further, caregiver burden has been associated with a number of variables including professional support (Baronet, 1999; Schulze and Rössler, 2005). The latter finding highlights the importance of research which focuses on carers' needs in relation to accessing and working with healthcare services and staff.

The little research on caregiving in anorexia similarly focuses on caregiver burden and indicates that caregiving is associated with significant burden and distress and that accessing and working with healthcare services and professionals contributes to the burden. In what appears to be the first study on caregiver burden in anorexia, Treasure et al. (2001) found that carers (mainly parents) of adults with anorexia reported high levels of difficulties related to the caregiving role, as evidenced by high scores on most subscales of the Experience of Caregiving Inventory (ECI; Szmukler, Burgess, Herrman, Benson, Colusa, and Bloch, 1996) which is widely used as a measure of caregiver burden in mental illness. Compared with carers of individuals with schizophrenia, the carers in the anorexia group reported higher levels of psychological distress as measured by the 28-Item General Health Questionnaire (GHQ-28; Goldberg and Williams, 1988). These findings suggest that caring for someone with anorexia is at least as burdensome as caring for someone with schizophrenia. Haigh and Treasure (2003) similarly found high levels of reported difficulties on the ECI subscales in caregiving in anorexia. Taken together, the findings from these studies emphasise the importance of investigating the experiences of carers in anorexia.

Moreover, Treasure et al. (2001) and Haigh and Treasure (2003) found that carers reported the greatest number of difficulties for the 'problems with services' subscale of the ECI. The latter study also reported that carers experienced high levels of unmet needs in relation to obtaining support from health professionals and information about treatment, as measured by the Carer's Needs Assessment Measure (CaNAM), which was developed and piloted as part of the study, and suggested that these factors contributed to caregiver burden. These findings highlight the importance of research which investigates carers' experiences of healthcare services and staff in anorexia.

In the domain of mental illness, there is a growing body of research, mainly quantitative and questionnaire-based, which specifically focuses on carers' experiences of the healthcare services and staff. A consistent finding is that families feel excluded from their relative's care particularly in terms of decision making and treatment planning. This contributes to the burden of caregiving (Jubb and Shanley, 2002; Lelliott, Beevor, Hogman, Hyslop, Lathlean, and Ward, 2003; Stanbridge and Burbach, 2007).

Although this research contributes to our understanding of carers' experiences of staff and services, there is a small body of qualitative research which is critical of the caregiving literature and its focus on burden particularly because it decontextualises the caregiving experience. This literature suggests that experiences of caregiving must be understood within the context of the relationship of the carer to the patient (Milliken 2001; Young, Dixon-Woods, Findlay, and Heney, 2002; Harden, 2005). In particular, Milliken (2001); Young et al. (2002); and Harden (2005) focus on parent caregivers and suggest that parents make sense of their experiences of healthcare services and staff in terms of narratives of parenting. Given the paucity of research on carer-professional relationships in anorexia, there is a role for qualitative research which focuses on a detailed investigation of carers' experiences. In particular, given the findings by Milliken (2001); Young et al. (2002); and Harden (2005) that parents make sense of their experiences of caregiving in terms of parental identity, there is a role for research which uses a methodology which can explore how parents of children with anorexia make sense of their experiences.

There are only three known qualitative studies which consider carers'/parents' experiences of anorexia in relation to the treatment services or healthcare professionals.

An Australian study by McMaster et al. (2004) examined the experiences of parents of children/adult children with an eating disorder (not specified) in relation to their involvement with healthcare professionals. It was found that, for the majority of parents, finding help was challenging and stressful and required parental resourcefulness. During treatment, parents reported feeling excluded which was linked to a perceived culture of 'mother blaming' (p70). In general, the parents reported negative interactions with healthcare professionals.

The second study, by Highet et al. (2005), was also based in Australia. Focus groups and in-depth interviews were conducted with parents, partners and friends of adolescents or adults with an eating disorder (both anorexia and bulimia nervosa). The analysis included a substantial section on accessing treatment and interactions with staff. It was found that the reported distress of caring for someone with an eating disorder was compounded further by difficulty accessing treatment and perceptions of exclusion from information on the illness, treatment options, progress and care management. The carers perceived that healthcare staff lacked an understanding of the burden of caregiving. These findings mirror those of McMaster et al. (2004).

However, in both studies, it is unclear how the themes were arrived at and analysed as the method sections of the studies lack detail and make no reference to the particular qualitative methodological paradigm in which the researchers were working (e.g. interpretative phenomenological analysis). In addition, both these studies were based in Australia. The experiences of parents in the UK might be expected to be very different particularly since, as mentioned, current mental health policy in this country is informed by a model which recognises the family as a resource and proposes a partnership model of the relationship between families and healthcare professionals. Thus it is particularly interesting to consider the experiences of parents in the UK, given the national context.

A single, qualitative UK-based study has examined parents' experiences of the treatment of adolescent anorexia. Similarly to the two Australian studies, Tierney (2005) reported that parents experienced lack of provision for the illness, as well as lack of validation of the seriousness of their child's condition which together resulted in a situation where they had to use their own skills to find help. Subsequently parents

reported feeling isolated from the treatment process and denied information. These factors contributed to feelings of parental disempowerment.

While Tierney (2005) examined the experiences of parents of adolescents with anorexia, the present study focuses on experiences of parents of adult children with anorexia. There are likely to be some differences in the experiences of parents of adults with anorexia since, as mentioned, in the UK the NICE guidelines (NCCMH, 2004) recommend different levels of family involvement for adolescent or adult patients. In addition, all three studies in this area focus on the carers' experiences; the present study employs a methodology which facilitates the analysis not only of the experiences themselves but how the parents make sense of those experiences.

Qualitative Method

Given the paucity of research on this topic, a qualitative approach was adopted. This is appropriate as qualitative research focuses on investigating the lived experiences of participants and the meanings they give to them which was also the focus of the present study (Willig, 2001). Semi-structured interviews were used which are engaged with exploring the everyday lived world of participants and how they make sense of it (Kvale, 1996). The semi-structured interview is democratic and flexible: the researcher has an area of interest and questions relating to this but there is a wish to enter the psychological world of the participant. Thus the schedule is used flexibly within the interview and the interviewer is free to follow up novel avenues that were not predicted and to be guided by the interests and concerns of the respondent. The participant shares closely in the direction that the interview takes. Given these features of the semi-structured interview, they are considered a good way to generate rich data on respondents' experiences and the meanings they give to them, which is particularly important when researching an under-researched area (Smith, 1995).

The method of analysis used was interpretative phenomenological analysis (IPA; Smith, 1996). IPA can be described as phenomenological in that it is interested in exploring the life-world of the participant and particularly how the participant makes sense of, or gives meaning to, her lived experiences (Smith, 2004). The aim is for the researcher to gain an 'insider's perspective' (Conrad, 1987 in Smith, 2004, p40). At the same time, IPA recognises the interpretative role of the researcher and accepts that the analytic

account is always jointly produced by the participant and the researcher. Smith (2004) describes this as a 'double hermeneutic' (p40) in which the researcher tries to make sense of the participant who is trying to make sense of their personal and social world.

Because IPA is an exploratory tool which is able to reveal unanticipated phenomena and produce rich, participant-centred accounts, it is particularly suitable for under-researched topics (Shaw, 2001). Smith (2004) suggests that IPA allows for both empathic and critical readings, however, he emphasises that IPA is grounded in a hermeneutics of empathy and meaning-recollection. Arguably an attitude of empathy and a desire to remain faithful to the voices of the participants is appropriate for an under-researched area in which the assumption is that the participants are the experts. IPA has been particularly prominent in health psychology in part because its realist assumptions (that language taps underlying cognitions) mean that it can usefully dialogue with research which takes place within a social cognition paradigm, again suggesting that it is an appropriate choice for the present study (Smith, Flowers, and Osborn, 1997). IPA is particularly suitable for this study because of its focus on the meanings respondents attach to their mental and social world (Smith, 2004).

Research Question

The present study sought to explore the experiences of parents of adult children with anorexia nervosa in relation to their interactions with healthcare services and professionals.

METHOD

Ethics

Approval was sought and gained both from the Clinical Governance Committee of the hospital from which participants were recruited and from the Ethics Committee at the Institute of Psychological Sciences, University of Leeds. The hospital also requested Criminal Records Bureau (CRB) clearance. For a copy of the proposal for the hospital, Clinical Governance Committee approval letter, ethics form showing local ethical approval and CRB clearance documentation, please see Appendices 1-4. Written consent was obtained from each participant before commencing the interview. Signed consent forms were passed on to the chair of the local Ethics Committee in a sealed

envelope to protect the anonymity of the participant. For further detail of the ethical considerations relating to this project, please refer to the ethics form, Appendix 3.

Researcher

As the researcher conducting this study, I am a female undergraduate psychology student. I do not have firsthand experience of the eating disorder and I was not known to any interviewees prior to collecting data. However, I made contact with the hospital through a family member (my father) who is currently a consultant psychiatrist at the hospital. Steps were taken to reduce the possibility of this biasing the data collected. Respondents were assured that they, and any persons or establishments to which they referred, would remain anonymous and that what they said was confidential. In particular, prior to commencing the interview, respondents were reminded that the staff at the hospital would not have access to the data and that the patient's treatment would not be affected in any way by what was said in the interview. Confidentiality has been strictly maintained. In addition, respondents were reminded that they could choose not to answer questions relating to the current hospital if they preferred (all the patients had received treatment from other hospitals prior to the current one). No parent declined to answer a question, however, as questions about the current hospital were reserved until later in the interview, they were often not the focus of the interview.

In terms of the analysis, to reduce the possibility of bias, it was ensured that, at each stage, emerging themes were grounded in the data. This was important given my relationship with the consultant and given that it was not possible to suspend the literature search until after the analysis had been completed as knowledge of relevant research was necessary in order to develop the project idea. These factors could have affected my interpretation of the data. This will be discussed in more detail in the analysis section.

Pilot Interview

A pilot interview was conducted in order to evaluate the suitability of the proposed interview schedule to the research topic. The data collected in this interview was not included in the final analysis.

Participant

The participant was the mother of a 20-year-old female inpatient receiving treatment for anorexia on the adult eating disorder programme at the private mental health hospital in the West Midlands where the participants were recruited. At the time of interview, the patient had been receiving treatment for the eating disorder for a total of approximately two years including two previous National Health Service (NHS) admissions and three weeks in the current hospital. The participant was aged 47 years and was White British. She was recruited by the consultant psychiatrist in charge of the patient's care. The consultant approached her to take part in the study and gave her the participant information sheet (Appendix 5).

Pilot interview schedule

Before the interview, an interview schedule was developed. First, as Smith (1995) recommends, a topic guide of relevant areas to be covered was developed. These included:

- experiences of interactions and relationships with healthcare staff throughout the treatment process;
- how the participant feels about and responds to the interactions;
- how the participant sees their role or identity in relation to staff; and
- how relationships with staff impact on coping.

The interview opened with four questions about the relation of the respondent to the patient, and their role in the care ('What is your relationship to the patient?'; 'Does she normally live with you?'; 'Is there anyone else in the household?'; 'Are you the main carer?'). These questions were included because they established useful background information and were considered straightforward questions designed to put the participant at ease and to establish rapport at the start of the interview (Smith, 1995). The following question concerned when the respondent had first become aware that the patient had an eating disorder ('Could you tell me about when you first thought that your child might have an eating disorder?'). This question aimed to orient the participant towards the topic and facilitate recollection of experiences which may for some participants have taken place several years ago.

The first substantive area (interactions and relationships with the staff) was covered in six questions each of which tapped a different stage of treatment: initial contact with healthcare staff; initial contact with specialist services; subsequent experiences of healthcare staff; experiences of staff when daughter was admitted as an inpatient; and experiences of staff in current hospital. The aim was to encourage the respondent to think through the stages of the treatment and their interactions with the staff at each stage in order to facilitate recollection of particular instances and occasions and avoid generalised responses (Kvale, 1996). This is important as IPA is primarily concerned with lived experience and the meanings we give to it (Smith, 2004). The questions were formulated using a broadly narrative style ('Can you tell me about…') in order to encourage the participant to tell their own story in their own words with minimum intervention from the interviewer, in keeping with the participant-centred approach associated with phenomenological interviewing (Smith, Flowers, and Osborn, 1997). To further encourage the participant to ground their responses in their own lived experiences, the prompt 'Can you describe a particular instance/occasion' was used. As the stages of treatment are likely to be different for each patient, it was anticipated that the sequence assumed in these questions would not apply in all cases and that the questions would change in the interview. More generally, the interview schedule guided rather than dictated the interview (Smith, 1995).

There were no specific questions relating to how the participant felt about or responded to the interactions he or she described (the second substantive area). Instead these areas were covered in the prompts to each question ('How did that make you feel?'; 'How did you respond to that?'). The rationale for this was, again, to ensure that responses were linked to a particular instance to avoid generalisations (Kvale, 1996).

There was a single question relating to the topic role/identity ('How do you see your role in relation to the healthcare staff?') and two questions relating to coping (Is it important to you to have good relations with the healthcare staff?'; 'Do your relationships with the healthcare staff affect how you cope?'). These questions were included as research suggests that interactions with healthcare staff can impact on the stress of carers (Baronet, 1999; Schulze and Rössler, 2005). This study aimed to tap the processes relating to role or coping which might contribute to this. Following Smith (1995), these questions were reserved until later in the interview as they were broad

questions requiring participants to draw upon their overall experiences and demanding in depth reflection and thus were considered fairly difficult to respond to. Finally, in keeping with the democracy of the semi-structured interview, at the end of the interview, the participant was asked if they had anything to add.

The semi-structured interview attempts to tap the psychological world of the participant, therefore leading questions which prioritise the interviewer's meaning frame were avoided and all questions were open-ended to facilitate maximum opportunity to respond with minimum prompting (Smith, 1995). For a copy of the pilot interview schedule, please refer to Appendix 6.

Interview process

Signed consent was obtained before the interview and the participant was reminded of her right to withdraw and to choose not to answer a question. She was given an information sheet indicating sources of advice and support which was considered necessary given the sensitive nature of the topic. For sample consent form and information sheet, please see Appendices 7-8. The participant was interviewed in a private room at the hospital at a time convenient to her. The interview was audio-taped with the participant's consent. The interview lasted approximately 90 minutes.

Reflection on pilot interview

The questions on the interview schedule elicited lengthy responses without use of prompts. In addition, the participant's responses often took a narrative form suggesting reflection and recollection. Despite the fact that the issue was not explicitly addressed in the interview schedule, the participant's responses included an insistence on the difficulty of finding help or getting access to the relevant healthcare professionals. Even when help was found, the respondent described very limited contact with the staff. These responses prompted me to consider my own preconceptions about the focus of the research question. My initial conceptualisation of 'interactions' focussed mainly on actual meetings and discrete instances; the pilot interview suggested that for relatives the *lack* of access to or contact with staff is as important as what takes place during interactions. Thus there was justification for including a question on relatives' experiences of trying to access help for the illness. The question: 'Could you tell me

about your experiences of trying to find help for your daughter?' was included in subsequent interviews.

More generally, on playback of the recording, I became aware that I had on occasion interrupted the participant to ask a question which resulted in a loss of valuable material. This reminded me of the importance of being disciplined in the interview and not asking the next question until the interaction has been handed back (Smith and Osborn, 2003).

The Main Study

    Participants

Purposive sampling of participants for whom the research question was relevant, as recommended by Smith and Osborn (2003), resulted in a broadly homogenous sample of participants who were all relatives of adult patients receiving inpatient treatment for anorexia at a single private mental health hospital in the West Midlands at the time of interviewing. Nine interviews were conducted in total, five of which were included in the final analysis. The small sample size is appropriate for the idiographic approach taken by IPA which proceeds by detailed case-by-case analysis (Smith and Osborn, 2003).

Four of the nine participants were partners of patients. The data from these interviews were not included in the final analysis because different themes emerged from these interviews compared with interviews with parents. While it would be useful to compare the experiences of parents and partners and the meanings they give to them, this was not the purpose of the present study.

Five of the participants were parents of patients: three fathers and two mothers were interviewed. Their mean age was 47 years (range: 37-65 years). Regarding ethnicity, all the parents were White British. All of the parents stated that the patient lived with them when not receiving inpatient care and all but one of the parents identified themselves as the patient's main carer. Participants were recruited by the consultant psychiatrist. The consultant approached them to take part in the study and gave them the participant information sheet (Appendix 5).

Regarding the patients, all were receiving treatment on the adult eating disorder programme at the hospital at the time of the interview. All but one were female. They had a mean age of 22 years (range: 18-37 years). Total duration of treatment varied between patients, with a mean duration of three years (range: 1.5-10 years). All had at least one previous admission in either an NHS or private hospital. All had received outpatient care prior to the current admission. The mean duration of treatment at the current hospital was four weeks (range: 2-10 weeks).

Interview schedule

For development and rationale, please refer to the pilot interview section. For a copy of the final schedule, please refer to Appendix 9.

Interview process and transcription

Signed consent was obtained before each interview and participants were reminded of their right to withdraw and to choose not to answer a question (Appendix 7). The information sheet indicating sources of advice and support was made available (Appendix 8). The participants were interviewed individually in a private room at the hospital at a time convenient to them. The interviews were audio-taped with the participants' consent and transcribed verbatim. Transcription conventions used were those cited in Smith (1991). The verbal elements of the spoken discourse were transcribed as well as the fairly gross features of corrections, pauses, laughter and crying as these details can inform the meaning/nuance of the content. More detailed transcription is considered unnecessary as IPA is interested in broad content themes (O'Connell and Kowal, 1995). For transcription conventions, please see Appendix 10. To protect the anonymity of the participants, pseudonyms were used and other identifying information such as names and places omitted. The interviews lasted between 40 and 90 minutes and the resulting transcripts were between 3,471 and 12,556 words.

Analytic procedures

The analytic procedures for IPA outlined by Smith and Osborn (2003) were used as a guide. An ideographic approach was taken in which each transcript was examined in detail before moving on to the next transcript. First the transcript was read several times in order to become familiar with the account. This is important as Smith and Osborn

(2003) suggest that a sustained engagement with the text is necessary from the outset in order to capture the content and complexity of participant meanings which are central to IPA. Comments were annotated in the margin. These comments were generally descriptive including attempts to paraphrase or summarise the text.

On re-reading the transcript, these descriptive codes were transformed into more abstract, analytical, higher level themes which were documented in the other margin. An attempt was made to invoke psychological terminology. For example, in Tony's transcript, the low level theme 'staff not prepared to talk to Tony' became 'exclusion'. At the same time there was an attempt to ensure that the emerging themes captured the essence of what was found in the text. Smith (2004) emphasises the importance of grounding readings in the specifics of the data as IPA aims to prioritise the meaning-frame of the participant.

The next stage was to look for connections between themes. Similar themes were clustered together and arranged into possible hierarchies such that some themes subsumed others and became superordinate themes. For example 'concerns not taken seriously' and 'lack of control over treatment' were subsumed by the single category, 'barriers to getting help'. Again these emerging themes were checked against the transcript to ensure that they worked for the source material. Smith and Osborne (2003) suggest that this close interaction with the text allows the researcher to draw on her own interpretative resources while remaining grounded in the meanings of the participant. This approach is in keeping with the notion of the 'double hermeneutic' (Smith, 2004, p40) which underpins IPA.

The process outlined above resulted in the production of a master list of themes. Instances from the transcript were noted for each theme using in vivo terms and line numbers. The entire process was repeated for each transcript and a master list for each transcript was produced. These were consolidated to produce a final master list. This was an iterative process: I returned to transcripts which had already been analysed in light of themes which emerged from later transcripts. Themes were modified, re-clustered, and became more nuanced as the analysis proceeded. Several common themes emerged and these are presented in the present paper. For a copy of a transcript, in-depth analysis of that transcript, master list of themes, as well as a photograph of the

analytic procedure (as I did much of it by hand rather than on a computer), please refer to Appendices 11-14.

ANALYSIS

Two core themes emerged which were expressed by all parents, albeit in various forms: 'disempowerment' and 'negotiating the parental role'. The two themes are interlinked: the respondents described themselves as disempowered in ways that compromised their ability to fulfil their role as parents; these experiences prompted a renegotiation of their parental role. For reasons of clarity, I will discuss the themes separately however the analysis is sensitive to the links between them.

Disempowerment

This theme comprises parents' experiences of lack of control over the treatment their son or daughter receives, and perceptions that they have been denied the support necessary to perform their role as parents adequately. Two subordinate themes speak to this core theme: 'barriers to getting help' and 'exclusion'.

Barriers to getting help

Parents articulated two major barriers to getting help: lack of provision for the illness and dismissal of their concerns by healthcare professionals. These barriers were associated with parents' fears that their child might die without treatment. Further, the analysis suggests that barriers to getting help contributed to parents' feelings of disempowerment particularly in relation to their parental role.

All the parents interviewed described a struggle to secure help for their child relating to inadequate provision for the illness:

> There isn't the help out there [   ]. Our own health centre hasn't actually got anybody based there who can actually deal with eating disorders. (Wendy, lines 201-204)

Further, this lack of provision was associated with a risk of death:

> There is and there still will be people actually dying of anorexia and what goes through my mind is 'is it because they had the same problem as what I did? Can't they find the help anywhere? Is it not possible for them to have anybody else to turn to?' (Steve, 184-187)

Similarly, other parents described waiting for treatment while their child's health deteriorated:

> She was at home, very ill and you just felt in limbo because, you know, she's supposed to be in hospital getting care and not still losing weight at quite a rapid rate then, and it's like at what point is, you know, she's, you're telling me four weeks ago she's, she's critical, she needs to go in now. (Sally, 199-202)

The reference to being 'in limbo' suggests that Sally is waiting for something to happen that is outside of her control, indicating a lack of agency. Further, Sally's enforced inactivity while her daughter continues to lose weight is likely to be disempowering. In particular, her daughter's continuing deterioration contrasts with Sally's expectations about the care she should be receiving: 'she's supposed to be in hospital getting care'. While this is a reference to the shortcomings of the service provision which does not fulfil Sally's expectations, perhaps it also suggests a conflict between Sally's understanding that when a child is ill they should receive care and her own inability to secure care.

The conflict between wanting to provide care and needing to rely on inadequate services is in evident other parental narratives. Parents described their role in terms of wanting to help their child:

> All you wanted to do was help. (Tony, 776-777)

> As a parent, you'd do anything. (Edward, 115)

This contrasts with the reality of provision for anorexia:

> There's nowhere I could get any help from. (Edward, 113)

> It wasn't until she eventually took another overdose in January that there's a reaction from [doctor's] side. (Edward, 151-153)

Here Edward describes how he had to wait until his daughter's health reached a crisis point before any action was taken. Again, a situation where parents perceive that they are not in control of securing the care their child needs is likely to be disempowering particularly in terms of parental role which is associated with helping and perhaps with action: 'you'd *do* anything' (Edward, 115).

In addition to their experiences of inadequate service provision, parents suggested that they struggled to get help for their child because their concerns were ignored by healthcare professionals. One father indicated that he was pleased with the response he received from his general practitioner (GP) regarding his daughter's condition:

> He did everything that we wanted him to do in relation to referrals or seeking extra help. (Steve, 47-48)

However, all the other parents reported difficulties accessing help for their child because their concerns were not taken seriously in the first instance.

In response to a question about her experiences of her GP, one mother said:

> It really wasn't very good. It was, you know, 'you must try to eat a little bit more' and y- they didn't seem to bother a great deal. (Sally, 47-48)

Another mother's description of the healthcare professionals suggested that they were a physical barrier to getting help:

> I felt personally as though I was banging my head up a wall. I was going to professionals for help and I just wasn't getting the help. (Wendy, 95-96)

The metaphor Wendy draws on to express her frustration at having her concerns dismissed is particularly appropriate here because it suggests that the staff are a 'wall' blocking Wendy's path to getting treatment for her son. This also indicates a lack of agency: Wendy's efforts do not translate into action. This reading is supported by Wendy's insistence throughout her narrative on how luck, rather than her own actions, played a large part in getting treatment:

> As luck happened, they did take [son] as an inpatient. (Wendy, 35-36)

A situation in which parents' concerns are ignored, their efforts lead to failure and they must rely on factors outside of their control to get help is likely to be disempowering.

A similar experience of disempowerment as a result of having his concerns dismissed was evident in a father's description of his interaction with his GP:

> I said 'well hang on. Well what about her eating?' I said 'you can see she's virtually skin and bone. What are you going to do? What do you suggest and so on like? I need help'. [   ] She says 'so she's obviously digesting something and, you know, that's obviously adequate for the way she is like' and I couldn't believe it and I was really hurt. (Tony, 193-199)

Again there is a conflict between parents' need for action (Tony wants to know what the doctor will 'do' or what she 'suggest[s]') and the perceived inactivity from the GP. The lack of validation of parents' concerns results in a situation where parents no longer know how to secure help for their child as they start to reassess their understanding of the role of healthcare professionals as individuals they can trust to provide care and translate parental concerns into action:

> And it just got worse and worse and nobody would help me at the end of the day. I didn't know where to go or where to turn. I knew the doctors were pointless. (Tony, 237-239)

While Wendy talked about luck, Tony repeatedly talked about chance. Each interaction with the healthcare staff was regarded as the (last) chance for his daughter to get help. For example, when Tony described taking his daughter to the accident and emergency department after she collapsed, he said:

> When I got down to the hospital [   ] I said 'come on [daughter]' I said. 'I'm going to get you in here like', telling her 'this is our chance now' to, you know, we can get her sorted out once and for all if she agrees, like, you know. (Tony, 258-261)

The connection between not being taken seriously and needing to rely on chance suggests a pattern of hope followed by disappointment which is likely to be disempowering: Tony tries to seize each chance or opportunity but is unable to as on each occasion his concerns are dismissed and he must wait for the next chance to come along. This is reminiscent of Sally's description of being 'in limbo' waiting for someone else to take the action which is perceived as critical to her daughter's survival.

Parents' perceptions that their concerns are not taken seriously must be understood against a backdrop of parents' perceptions of anorexia as a life-threatening illness:

> And he was practically living a death because that's all he was. He was just dying in front of me and that just, well I kept, like I say, I asked for help. I was banging my head up walls and just shouting and screaming and people just didn't want to know. (Wendy, 139-140)

This quote captures what it means for a parent to have their concerns dismissed and calls for help ignored in the context of anorexia. Wendy's increasing desperation is clear and contrasts with healthcare staff 'who didn't want to know'. Again the conflict between the parental role of caregiving and watching a child dying and being powerless to intervene is likely to be disempowering. Indeed, Wendy's 'shouting and screaming' appears to have no effect.

Another parent's narrative related the experience of caring for a dying child to his own role as a parent. Tony compared his daughter with his father who died of cancer:

> When I was thirteen my father died of cancer but prior to that he just got thinner and thinner and thinner and he was, he was half the man he was before sort of thing and I remember seeing him in hospital and they'd only put a 'jama top on him which was hardly covering him and so on and he wanted to use the toilet because he was bed ridden if you like [   ] I had to assist him, me and my brother and, but all I saw then was the fact that he was so thin and you knew, well he wasn't going to make it sort of thing at the end of the day and so I think that's the attachment here with [daughter] like. Whereas he didn't make it but [daughter] is so I think that's difficult to let go as well. So that, I think that's what it is a lot of it. (Tony, 685-695)

This quote makes explicit the very real fear Tony has that his daughter might die. This instance also speaks to the second core theme of negotiating the parental role. Firstly, in

this story, Tony is a son, not a father, however, he takes a fatherly role, helping his father to go to the toilet. This is the hands-on role that Tony wishes to take in his daughter's treatment: he describes wanting to 'spoon-feed' (375) her in order to get some sustenance into her. Secondly, while there was no hope of recovery in his father's case, in his daughter's case, there is. While there was no possibility for control over his father's illness, there is over his daughter's. We could understand Tony's statement 'I think that's the attachment here with [daughter]' as referring to the fear of her dying as his father did, however, the distinction Tony draws between his daughter and his father: 'whereas he didn't make it but [daughter] is' suggests that the attachment is also because of Tony's perception of the possibility that his daughter could recover if some control were gained over the illness. Perhaps, then, Tony's struggle to 'let go' is both related to a fear of death and a reluctance to relinquish his role as carer.

In sum, parents experienced a struggle to secure help for their child because of lack of provision and dismissal of their concerns. Parents made sense of these experiences in the context of their perceptions of anorexia as a life-threatening illness. Parents' experiences were disempowering in part because they hindered parents' abilities to provide care for their child which they perceived as central to their role.

Exclusion

All parents described at least one positive experience of their interactions with healthcare professionals during treatment:

> He's an excellent man [specialist nurse]. Absolutely wonderful [   ] I could ring him at any time and speak to him. (Sally, 172-177)

However, one of the most pervasive themes to emerge from the narratives was 'exclusion'. Parents described being excluded from treatment decisions and progress meetings, and being refused information. This theme is linked in the narratives both implicitly and explicitly to a denial of the parental role.

In reference to the treatment, a mother explained that:

> It was all like done behind closed doors. (Sally, 140)

This suggests that parents are locked out of the treatment. Other parents recounted being excluded from meetings:

> I attended one meeting in all the time that she was there. All the other times if I'd phone up asking to speak to someone, I'd never get a response. (Steve, 56-57)

The elusive nature of the staff expressed in the quote above was a common theme. In response to a question about contact with the staff, one father said:

> I kept asking sort of thing but a lot of it was the fact that obviously it was dismissed, the right people weren't there and so on like, you know. (Tony, 341-342)

Additionally, parents experienced informational exclusion which they sometimes related to issues of confidentiality:

> Ye- well he wouldn't tell us anything, he, which is fair enough, it's all private. (Tony, 135)

These experiences of exclusion impact on parents' perceptions of their role and their ability to fulfil their role. One father described being denied a say in the treatment his child received at an accident and emergency department (A & E). He began the narrative by saying that the doctor 'wouldn't talk to [him]' (302) and instead asked the patient herself if she would agree to eat because otherwise he will not give her a place on the ward. Later in the interview Tony went back to the story:

> I started the story about the drip because the nurse was really surprised at it and that upset me it did. I would have thought they'd put one in but after that, they actually asked her whether she wished to have one in and I thought well it shouldn't have been her decision, they should have done it [   ] because I, as I say, I would have thought they would have done it which would have relieved my mind then that she was getting something in her, as I say. So she refused it, she said 'I', she agreed to do it by mouth and they accepted it. That was it. They accepted it. I actually said 'well I would have signed any documentation if you want to make her have it. You know, take the onus off you'. (Tony, 533-542)

This description suggests that Tony is struggling to negotiate the complex issue of control and who should have control over his daughter's treatment. Tony thinks that the decision to have a drip put in should not be made by his daughter. His evident disappointment and disbelief at the staff accepting her refusal of the drip is clear when he repeats 'they accepted it. That was it. They accepted it' and he repeats that he thought the staff should have simply put the drip in. This suggests that Tony wants the staff to take control of the situation by exerting their authority. However, the final lines of this extract suggest that Tony also wants to be consulted and his authority and role as a father acknowledged. Tony struggles with his exclusion and the power it confers on his daughter for making her own treatment decisions.

Other parents were more explicit about the impact of being excluded on their ability to perform their role as parents. One mother described being denied access to her son's progress meetings:

> If they had a ward round, which was once a week basically to discuss the progress and to see where they went from there, I wasn't allowed to sit in [   ]. If I asked how he was doing and how things were going, it was 'can't discuss it'. (Wendy, 161-166)

Later Wendy suggested that this exclusion impacts on her ability to care for her son:

> Also I as- did ask to go into the meeting and they said 'no. You're not allowed'. So what am I supposed to do if I've got a problem while at home? (Wendy, 311-313)

Wendy wants to do all she can for her son but feels that her power to do this is no longer under her control because she is excluded from the meetings which might provide valuable information on how to adequately care for her son when he is not in hospital. In other words, by excluding Wendy from meetings and by denying her information, the staff make it difficult for Wendy to perform what she perceives to be her maternal role. Wendy captured this in a vivid image:

> Because if you don't know what's happening, you know, you might as well just put a person in a padded room and just leave them there and just throw them meals basically. (Wendy, 503-505)

This image suggests that enforced ignorance (resulting from exclusion) results in Wendy being able to give her son only the crudest form of care.

Other parents similarly suggested that they needed information of a practical nature to be able to provide their child with adequate care:

> I still wasn't sure as to the dos and don'ts, questions to be asked, where to go, what she can eat, what she can't eat. (Steve, 58-60)

The above quotes suggest that parents made sense of the exclusion they experienced in terms of its impact on their ability to perform their role as carers. Indeed a striking feature of the interviews was parents' failure to mention their own needs which were subordinated to the perceived needs of their child.

One parent articulated the disempowerment associated with informational exclusion. He described how the GP initially refused to confide in him and tell him what was wrong with his daughter. In response to a prompt about how he felt about that situation, Edward said:

> Very annoyed because at times I think that patient confidentiality can go too far, especially when a third party is supposed to pick up the pieces (.) and that I think goes a long way in a lot of areas (.). You don't know where you stand. You don't know what's going on. You're kept in the dark [   ]. How am I supposed to react if I don't know what's going on? Or what's expected of me and parties that can also be involved. So I was kept totally in the dark like a mushroom. (Edward, 27-40)

In this quote Edward describes a sense of total ignorance: he is 'in the dark'. For Edward, this ignorance relates to a sense of confusion over what his role should be: he does not know where he stands, what is expected of him, or how to react. By denying him information, the staff have stripped Edward of his agency. This is evident when he describes himself as 'kept totally in the dark like a mushroom' which suggests a lack of control. Further this informational exclusion conflicts with Edward's perceptions of himself as the person who must 'pick up the pieces'. Again this suggests that parents make sense of the exclusion they experience in terms of the impact it has on their ability to fulfil their perceived parental responsibility of caring for their child. In response to a question about what these experiences were like for him, Edward said:

> It was like being ostracised. The, the, I'd only see a couple of the staff as I went in to visit and that was it and they wouldn't speak with you because patient confidentiality, once again, banging your head against a brick wall. (Edward, 80-82)

The sense of exclusion and frustration is clear. Once again the staff are seen as a brick wall encountered by the parents. This is suggestive here of a wall of silence but elsewhere, as we have seen, is indicative of pathways to action which have been blocked.

Other parents place their perceptions of being excluded and denied support in the context of their experiences of anorexia as an ongoing illness in which most of the care takes place at home. One mother described how she felt about her interactions with the healthcare staff:

> Alienated (.). You know, it was 'we'll have her well enough. She'll come home and she'll be ok. She won't need care when she comes home' and to me that, that was the total opposite. (Sally, 143-145)

The quote suggests that care does not stop when her daughter is discharged from the hospital; she will not 'recover'. In contrast, the illness and the care continue at home. However, the integral role of the parents in their child's care does not appear to be acknowledged by the staff.

The nature of anorexia as experienced by these parents, results in a situation in which parents must take over from the hospital when their child is discharged. When asked how he sees his role, Edward responded:

> The way I look at it and that is that, when she's not in hospital, I am doing the work of the hospital [   ] they know what she can eat and drink, medication, right? I don't. I'm kept in the dark so when she comes out, there's nothing stopping her doing what she wants to do, right? (Edward, 195-199)

Again, anorexia is conceptualised as an ongoing illness which continues outside the boundary of the hospital. Edward begins by defining his role. He sees himself as doing the 'work of the hospital'. This suggests that he, like the hospital, is integral to his daughter's care but the ability to fulfil this role is being denied him: he lacks the tools to carry out his 'work' because he is denied access to the information that could support him in his role.

One parent summarised the sense of exclusion engendered by lack of support from the staff:

> There was none of *caring for the carer.* You was just the mother, you know, 'step aside. It's not your job now. Let us deal with it' (Wendy, 287-288)

This quote explicitly links lack of support and a feeling of exclusion to a denial of the maternal role by the staff. It is evident that the parents interviewed in many ways perceived that they had to 'step aside' and relinquish their role as carers and parents. The line 'it's not your job now' captures the sense in which parents felt stripped of their responsibility and role.

In sum, exclusion can lead to a sense of disempowerment particularly in terms of parental role. Exclusion can be understood as particularly pernicious in the context of parents' experiences of the chronic and recurrent nature of the illness and the demands it makes on them.

'Negotiating the Parental Role'

In light of experiences of disempowerment particularly in relation to parental role, all the parents interviewed expressed a struggle to come to terms with what their role might be or an attempt to reposition themselves as central to their child's care. Parents' negotiation of their parental role took various forms but was a universal theme of the interviews and often framed how parents made sense of their experiences.

The central and pervasive nature of this theme was clear in an interview with a father. At the opening of each interview the respondents were asked if they were the main carer. This was intended to be a background question to establish parents' perceived level of involvement in the treatment: some parents, for a variety of reasons, might be minimally involved in the patient's care. Most parents responded simply by affirming

that they were the main carer. Steve's response was more complex and revealed a preoccupation with role:

> She is her main carer [   ]. We are her parents. And trying to resolve the conflicts between those two, if you like, has exercised us quite a lot recently [   ] I think we see our role (.), this is the difficulty. It hasn't been like this before [crying]. I'd like a drink if you could get me one please [tape stopped]. (Steve, 9-17)

Steve struggles to define what his role might be and expresses a conflict between the role of parent and carer. What is most interesting about this instance is that Steve very early in the interview has introduced the issue of parental role which for him is clearly a distressing topic. Later in the interview Steve again raised the issue of parental role:

> This is where the conflict as to what we should do arises and we de- have always I think decided that we are her parents not her doctor and to maintain the, as normal a relationship and to be there for her, has, has always been important [crying]. (Steve, 146-148)

This interview highlighted that, for parents, the issue of what their role should be was central to their understanding of their experiences of having a child with anorexia and to making sense of their interactions with the healthcare staff. While Steve appears here to reject the role of carer, later he negotiates his role in other ways, as will be discussed shortly. In general, some parents negotiated their role by defining themselves as their child's main caregiver, others by identifying themselves as an essential component in a reciprocal relationship with the staff. These categories were not mutually exclusive.

'Parents as main caregiver'

As presented in the previous section, parents experience anorexia as a chronic, relapsing disorder requiring ongoing caregiving within the setting of the home. In light of this, it is perhaps not surprising that some of the parents forged a role for themselves by describing themselves as the main source of care and even as experts on the illness or on their child.

One father described himself as 'doing the work of the hospital' (Edward, 207-208) when his daughter was at home suggesting that he is as integral to her treatment as the healthcare professionals. Other parents also identified themselves as full-time carers when the patient was at home:

> I mean, the two weeks before [son] was admitted, he needed twenty-four hour a day care which was hard, very hard. (Wendy, 62-64)

This intense, round the clock, care would normally be associated with a younger child emphasising the integral role of parents in the care of their child. Similarly another father described wanting to be physically involved in his daughter's care:

> Even if I had to spoon-feed her, I wanted to be there at dinner time. (Tony, 375-376)

Again the image is suggestive of a relationship with a younger child who is dependent on her father's care. Thus we see that, faced with exclusion and disempowerment, parents write themselves back into the picture by describing themselves as the main carers who are integral to their child's daily lives.

Often parents perceived themselves as a permanent source of care while staff were transient:

> There were loads of bank nurses so you never got a regular, you did have a named nurse but very often they weren't there either, you know. It's just such a turnaround all the time. (Sally, 40-42)

Similarly, parents described themselves as the people who must 'pick up the pieces' (Edward, 30) when treatment was unsuccessful or not available. Indeed, parents identified themselves as the person to whom the patient turned when distressed:

> Many a time [son] has picked up the phone and he's been in hysterics on the phone to me 'mum, I can't stop here no longer'. (Wendy, 120-122)

> I was just so worried, so worried for her and she was constantly on the phone upset. (Sally, 83-84)

These incidents suggest that parents have an integral role both when their child is at home and in hospital.

Some parents' narratives demonstrated that they perceived themselves as having expertise to offer in their child's care. One mother recounted an instance when her son was discharged from hospital against her wishes to then relapse within six weeks. She concluded by saying:

> No my op- my, my point of view wasn't listened to. I wasn't a professional. I didn't know what I was talking about [   ]. (Wendy, 270-271)

This quote suggests that Wendy is bitter that her judgement was ignored by the healthcare staff. Wendy's experience of the illness was not validated by the staff because she is not a 'professional'; perhaps Wendy is suggesting that she is in a sense a professional. This interpretation is supported by the following quote:

> I've seen it from both ends I have [   ] and all in the space of less than twelve months. It's no wonder I've learnt so much. [   ] I could write a book. (Wendy, 518-523)

Here, in the face of exclusion and denial of her role, Wendy negotiates her role as an expert on her son's illness. Thus exclusion can result in disempowerment but it can also encourage renegotiation of the parental role in which parents begin to define themselves as the experts.

Other parents also defined the family as the experts:

> I mean my dad's quite involved with the, like[daughter's] care and that and even my dad turned around and said 'I think I know more about anorexia' [   ] even my dad turned round and said to them 'what actually is your job because personally I think I know more about the disease than what you do'. (Sally, 99-105)

The implication here is that families have more knowledge about anorexia than the professionals (perhaps because of staff incompetence implicit in the quote). This claim seems to be at odds with the suggestion in the previous section that parents rely on the staff to support them in their role as carers particularly in terms of informational support. This contradiction can, in part, be resolved if we take into account that parents are describing different points in what for many has been a lengthy treatment process; some parents suggested that they forged a role for themselves as experts by educating themselves over time:

> I was threw in at the deep-end. I knew nothing. What I know now is what I've learnt over the past six, eight, ten weeks and that's actually by reading books. (Wendy, 218-220)

However, it is also important to accept that parents are responding to their experiences of disempowerment in ways that place power on them and that this may result in contradictory ways of articulating and understanding their experiences.

While other parents did not necessarily define themselves as experts on anorexia, their narratives suggested that, as parents, they were in a unique position to provide key information which might help in the patient's treatment if they were involved:

> Because at the end of the day anorexia, they're not always truthful so I was being asked, was obviously my chance to kind of say 'yeah I know what she said and that's her view but this is mine' so I think actually, by making sure that I was included in the conversation, got a better picture of what was really going on, rather than just [daughter's] idea of what was going on. (Sally, 272-277)

The quote suggests that parents' input into their child's care has to be understood in the context of anorexia as an illness in which the patient is not always willing or able to communicate honestly with healthcare professionals in order to provide information about their behaviour and condition. In the light of this concern, it is unsurprising that parents negotiated their role as individuals who could keep the healthcare staff informed

of the real situation. This suggests a desire to support the staff ultimately to benefit the child. On this occasion, Sally's expertise was acknowledged by the professional staff, however, as is clear from the foregoing analysis, often this is not the case.

Other parents also demonstrated a desire to support the staff in the recovery process driven by a fear that their child was deceiving the staff or concealing information from them. Tony described how he told his daughter's counsellor her true story:

> I spoke to him, rang him up and explained, to give him the tools, if you like [   ]. So, ringing up to make the appointment, I spoke to him and I said 'look I know it's all confidentiality and so on' I said 'but I really feel I ought to tell you the way she is because you might not be aware of it'. I said 'what she's doing at present' [   ]. So I explained all the various things [   ]. This is why I asked him or told him the story, but I genuinely, the idea was to give him the tools to work with that he could make her better or help her along the way. (Tony, 67-101)

Here Tony describes how he informed the counsellor of the situation because he 'might not be aware of it'. Twice Tony repeats that he contacted the counsellor to 'give him the tools' to work with to help his daughter recover. In this way, Tony articulates a need to be recognised as a useful resource in his daughter's recovery. The metaphor he draws on of providing the tools which can be picked up and used by the counsellor suggests a desire to work together towards the same goal to 'make her better or help her along the way'. In this way, Tony tries to negotiate an active role for himself in a situation in which he feels disempowered. In fact, on this occasion, Tony's expertise is rejected.

To summarise, parents identified themselves as integral to their child's treatment in a variety of ways: they provide a permanent source of caregiving; they have expertise and knowledge about the illness; and they are a valuable source of information on their child. In these ways, parents negotiate a role for themselves within a disempowering situation.

'Desire for reciprocal relationship with staff'

Although parents negotiated a role for themselves as experts and as sources of information, it is clear from earlier sections of the analysis that parents also perceived that they were unable to perform their role adequately because of lack of support (particularly informational support) from healthcare professionals. Some parents managed the possible conflict between the desire for their expertise to be recognised and the need to rely on professional staff for their support and knowledge by identifying themselves as an integral part of a reciprocal relationship with healthcare professionals.

Both parties were perceived as vital to the care of the patient and as working towards the same goals. Some parents suggested that, at times, they had achieved this relationship; for other parents it remained an ideal.

One parent described his ideal relationship with the staff:

> I hope it would be one of sort of mutual support [   ] I hope that we're sort of, without over-egging the pudding, supporting the messages that they're, and the strategies that they're trying to deal with [daughter] [   ] but likewise they are then supporting us as parents when [daughter] comes out [   ] so yeah, I think it's a two way thing. (Steve, 149-159)

This quote suggests that Steve perceives his role as continuing the work of the staff and extending it outside of the hospital. He describes a reciprocal relationship with the healthcare professionals: parents reinforce the work of the staff; staff support the parents. It was clear from the earlier theme 'exclusion' that parents often did not achieve this relationship with the staff. Again it is necessary to acknowledge the possible contradiction between parents' experiences of exclusion and their descriptions of mutually supportive relationships with the staff. It was evident from the narratives that often these positive relationships were associated either with a particular member of staff or a particular hospital (most of the patients had been treated at more than one hospital) and that often they were associated with later in the treatment perhaps suggesting that, in response to exclusion, parents had forged a role for themselves within a reciprocal relationship.

It is clear, that when parents feel included in the treatment process, this is a positive experience:

> We had meetings as well [   ]. We were involved. He would outline what he was trying to do and what he was asking [daughter] to do so that we were sort of well, not, wouldn't say compliant, but could support the work he was doing and yeah, very pleased really. (Sally, 227-256)

Sally first suggests that the meetings allowed her to 'compl[y]' with the staff but quickly corrects this to 'support' the staff. In this way, Sally rapidly renegotiates her role from a passive one to a more active one where she too is involved in the 'work' and where staff and parents are equals. Being able to have this active role is evidently a positive experience for Sally. It is interesting that despite perceptions of exclusion, parents do not reject the staff but want to support them (and be supported/involved). This is evident in other parental narratives:

> We would never have rejected so as to speak anything that was said or advice given or whatever, I mean, we were in the receive mode, we wanted to learn. (Edward, 229-231)

It is possible to understand the desire to support the staff in the face of exclusion in the light of parental perceptions that a mutually supportive relationship will be of most benefit to their child which, for parents, is the main concern:

> I think it's important we have good relations, or the relationship is, is, is mutually sort of symbiotic because I think it's, again it's down to where [daughter] is. If she thought it was daggers drawn I think that would influence her psyche and her recovery. I think she, I think she sees, she sees that we are collaborating or trying our best to collaborate with the hospital and the hospital are trying their best to collaborate with us and that the, it's a holistic approach to her recovery as opposed to well 'it's going to, you're going to be made better there and then you're going to come out'. She can, she can see that it's, she knows that it, that, that, in terms of anorexia, that's not going to happen. There is, the recovery is going to be largely based around her own ability to manage the illness while she's in here but also while she's out, out of, when she comes out [   ] she's coming to the realisation that she's going to need some structure and she's going to need the support of us as parents and that, that level of collaboration between hospital and home is going to be vital to her in coming through this and leading a normal life and moving on so yeah I think the friendship is important or, you know, mu- or, as I said, sort of a symbiotic relationship is very important. (Steve, 189-206)

Here Steve explicitly suggests that a good relationship must be maintained between staff and parents for the sake of his daughter's well-being and recovery. Again, a reciprocal relationship is described as the ideal: a relationship in which both parents and staff benefit from the support they give each other (a 'symbiotic relationship'). Steve suggests that ultimately it is the child who benefits from this 'holistic approach'. Here by 'holistic', Steve seems to be suggesting continuity between his daughter's treatment in hospital and her ongoing care at home again in the context of anorexia as an illness which is not cured but must be 'manage[d]' in the long-term. Clearly this requires communication between staff and parents, or 'collaboration' as Steve describes it evoking a sense of working together but also perhaps the idea that in different circumstances the staff could be perceived as the enemy with 'daggers drawn' hinting at parents' more negative experiences. In this way, Steve articulates a role for parents which is as 'vital' as the role of the staff.

Other parents similarly suggested that a reciprocal relationship with the staff benefits the patient:

> You can, if you pick up on something that you don't think is right with [daughter] that they might not have noticed, she might not have said that to them, so, and it's not like telling tales, it's all, at the end of the day, if you can work together, it's all in the benefit of, of [daughter]. It's, it is sort of a team approach isn't it so that you all know what's going on and then, like I said before, when that comes back to us well we can actually support [daughter] and reinforce what the staff are, what the staff are doing. (Sally, 300-306)

Here Sally suggests that she can provide the staff with information that they do not have access to again suggesting that she has a key role in her daughter's recovery. Although

there is a hint of guilt ('telling tales'), Sally emphasises that her actions are for the good of her daughter. Again we see that parents suggest that with informational support from the staff, parents can reinforce the work of the staff which ultimately results in positive outcomes for the patient. Sally describes it as a 'team approach'. The notion of a team evokes a sense of in groups and out groups, here Sally firmly places herself within the in group (she is an essential part of the team) thus negotiating a role for herself.

In sum, it seems that parents were unable to accept the disempowerment they experienced and negotiated roles for themselves in the care. In particular, parents forged a role for themselves by describing themselves as an integral part of a care team providing care to their child. Further, parents' negotiations of their role revealed a commitment to putting the needs of their child before their own.

DISCUSSION

The present study sought to explore the experiences of parents of adult children with anorexia nervosa in relation to their interactions with healthcare services and professionals. Interpretative phenomenological analysis of the interview data revealed two core themes: 'disempowerment' and 'negotiating the parental role'. Experiences of difficulty getting help (both because of lack of provision for the illness and because their concerns were ignored by healthcare professionals) and experiences of being excluded from the treatment and from information contributed to the parents' feelings of disempowerment. These experiences were disempowering because they hindered parents' ability to fulfil their parental role of giving care to their sick child. In response to their experiences, parents renegotiated their parental role in ways that repositioned themselves as the main caregiver or as an integral part of a team involved in their child's care.

The three existing studies on carers' experiences of healthcare services and staff in anorexia (McMaster et al., 2004; Highet et al., 2005; Tierney, 2005) reported similar findings to the present study in terms of carers' experiences of difficulty getting help for their child, exclusion from the treatment process and denial of information. As only the study by Tierney (2005) was based in the UK and it examined the experiences of parents of *adolescent* children, the present study contributes to research in this area by

reporting comparable findings for parents of *adult* children in the UK. This is particularly important given that the guidelines on the involvement of carers in the treatment of anorexia in the UK differ for adolescent and adult patients (NICE; NCCMH, 2004) so it was not self-evident that parents of children of different ages would report similar experiences.

Additionally, the present study extends the findings of the three existing studies by identifying that parents make sense of (and respond to) their experiences in terms of their perceived parental role. The previous studies only minimally considered how carers made sense of their experiences: McMaster et al. (2004) reported that parents associated their experiences of exclusion with a culture of 'mother blaming' but they did not discuss this finding in terms of parents' perceptions of their role or challenges to it. Tierney (2005) reported that parents' experiences made them feel disempowered; however, this disempowerment was not described in terms of parental identity or role. The present findings, then, are a significant contribution to current knowledge of how parents make sense of and respond to their experiences of healthcare services and staff in anorexia.

The remainder of the discussion will focus on two aspects of the present findings: firstly it will discuss the finding that the respondents made sense of their experiences in relation to their perceived role as parents. This finding demands discussion as it was an unexpected but pervasive theme which prompted the decision to change the focus of this research from all relatives to only parents of individuals with anorexia, as mentioned in the method section. Secondly, it will discuss parents' experiences of being excluded. This was not only a pervasive theme in the analysis, but is also commonly reported in the literature on caregiving in mental illness so is a particularly interesting theme.

Parental Identity/Role and Caregiving
The centrality of parental role in the present analysis was not anticipated, but it was found to mediate parents' experiences of their difficulties getting help and of feeling excluded during the treatment process as well as their responses to these experiences. As mentioned in the introduction, although the context of caregiving (e.g. who is doing the caregiving) has been largely ignored in the literature, there is a small body of

research which focuses on parents and suggests that perceptions of parental identity or role impact on caregiving experiences (Young et al., 2002; Harden, 2005; Milliken, 2001).

Young et al. (2002) used a qualitative methodology to explore the experiences of mothers caring for a child with cancer. Although the mothers reported more positive experiences of their interactions with healthcare staff compared to the parents in the present study, they reported that lack of communication with healthcare professionals and inadequate information provision was upsetting because it hindered their ability to monitor and maintain their child's health and engendered perceptions that they had failed as protectors of their child. The authors suggested that these findings indicated that protecting the health of one's child was perceived as central to mothers' role and informed the meanings they gave to their experiences. Although Young et al. (2002) focused on mothers of young and adolescent children while the present study interviewed both mothers and fathers of adult children, the present study similarly found that parents' experiences of having their concerns ignored and being denied useful information resulted in feelings of disempowerment particularly because parents felt unable to secure or provide help for their child. This suggests that protecting the health of one's child also contributes to parental identities in the present study and mediates how parents make sense of their experiences of their interactions with healthcare services and staff.

More generally, the parents in the present study appeared to perceive their role as one of caregiving. This role was hindered by exclusion and lack of information. Harden (2005) examined parents' experiences of having a child with schizophrenia and similarly found that parents' narratives were structured around a key concern: the ways in their perceived ability to care for their child was inhibited by lack of knowledge and experience of mental illness and by their negative relationships with the staff including inadequate information provision. Harden (2005) suggested that, by constructing their narratives in this way, parents presented themselves as concerned with fulfilling their responsibility to give care to their child. Although the present study uses more realist terminology in keeping with IPA, it similarly suggests that parents' perceptions of their role as caregiver influences the meanings they give to their experiences and, in particular, that negative experiences are understood in terms of parents' in/ability to

give care to their child rather than in terms of the respondents' own needs (e.g. a need for reassurance).

Harden's (2005) notion of the responsible parent is a particularly useful approach to what is perhaps a surprising finding in the present study: despite their negative experiences, parents in the present study were unwilling to reject the help of the healthcare professionals and instead described a desire to forge reciprocal relationships with them which would ultimately benefit the patient. The notion that parents perceive themselves as responsible agents whose role is to care for their child and put their needs first (Harden, 2002) can facilitate an understanding of this finding: if parents perceive themselves in this way, it is unsurprising that they subordinated their own needs to the perceived needs of their child.

Milliken (2001) similarly found that parents of adult children with schizophrenia responded to their negative experiences of healthcare staff in ways that reaffirmed their role as parents. More generally, Milliken (2001) reported that, for parents, caring for a child with schizophrenia was a process of continually redefining their identity in response to their experiences. The present analysis similarly suggests that caring for a child with anorexia demands a renegotiation of parental identity.

The foregoing discussion suggests that, in anorexia, as well as in other areas of chronic (mental) illness, parents make sense of and respond to their experiences in the context of their identities as parents. One implication of this finding is that research on caregiving might usefully consider the context of caregiving, in particular the relationship of the carer to the patient (e.g. parent-child), which appears to impact on how carers make sense of their experiences. More generally, it suggests that it is important to examine the meanings that carers give to their caregiving experiences. An approach which attends to these factors could facilitate a more detailed understanding of how experiences such as exclusion and inadequate information contribute to caregiver burden.

As mentioned in the introduction, a questionnaire-based study by Haigh and Treasure (2003) found that carers of individuals with anorexia reported high levels of unmet needs in relation to support and information about treatment and that these contributed

to caregiver burden. The present study, and those studies which have considered the meanings that parents give to their experiences, provide a way to connect lack of support and information to burden by suggesting that lack of support and information may not be burdensome per se but because they impact on carers' abilities to perform their caring role. This is perhaps particularly pernicious if the carers are also parents (which is often the case in anorexia, as mentioned in the introduction) because parents may regard caregiving as an important part of their role or identity. Although further research would be necessary to investigate the proposed connection between perceived inability to fulfil one's caring role and burden, some support comes from a study by Lelliott et al. (2003) which developed and piloted the carers' version of the Carers' and Users' Expectations of Services questionnaire (CUES-C) to assess the needs of carers of adults with severe mental illnesses. Lelliott et al. (2003) found that carers were more likely to state that they needed help with their role as a carer than with their own personal needs. This was despite the fact that they rated lowest levels of satisfaction with their situation in relation to their own lives. This study suggests that carers' perceptions that they are unable to fulfil their caring role contribute to their burden. However, the study did not assess whether this finding particularly applies to parents as opposed to partners or other carers.

Exclusion

Thus far I have focused on the finding that perceptions of parental role are central to understanding how parents make sense of their caregiving experiences and I have indicated how this finding integrates with and contributes to existing research on caregiving. However, given the paucity of research on carer-professional relationships in anorexia, particularly in the UK, the finding that parents experience exclusion and inadequate information is in itself an important finding which demands discussion. Reports of exclusion and inadequate information are in line with both quantitative and qualitative research in the domain of mental illnesses (Jubb and Shanley, 2002; Lelliott et al. 2003; Stanbridge and Burbach, 2007) and in the domain of anorexia (Haigh and Treasure, 2003; McMaster et al., 2004; Highet et al., 2005; Tierney, 2005), as outlined in the introduction. The finding of carers' perceptions of being excluded in the present study is not only interesting because it is the first time it has been reported for parents of adult children with anorexia in the UK but also because of the current national context in terms of policies and guidelines.

As mentioned in the introduction, current policy in the UK in the domain of mental illness advocates working in partnership with families (Stanbridge and Burbach, 2007). In particular, Standard 6 of the *National Service Framework for Mental Health*: *Caring for Carers* (Department of Health [DoH], 1999) requires that carers have their needs assessed and, where possible, addressed. This policy was in part a response to increasing recognition of the vital role of informal carers (mainly families) in the care of the mentally ill as a result of the move towards care in the community (Lloyd and Carson, 2005). More recent policy is yet more explicit about the need to recognise the role of carers and to forge partnerships between families and professionals: the *Mental Health Policy Implementation Guide* (DoH, 2002) states that 'Families and carers should be involved in the Care Programme Approach as much as possible' (p13). In terms of eating disorders, while the NICE guidelines (NCCMH, 2004) only recommend family-based interventions for children and adolescents, they state that for patients of all ages there must be effective communication with carers. Further, there is an emphasis on information provision which applies to carers of patients of any age. In particular, the guidelines emphasise that carers should be provided with enough information to allow them to provide care effectively.

Against this background of policy and guidelines in mental illness and anorexia, the present findings are perhaps surprising and disappointing. When considered alongside the remarkably similar findings in other areas of mental illness (Jubb and Shanley, 2002; Lelliott et al. 2003; Stanbridge and Burbach, 2007) and the few studies which focus on anorexia (Haigh and Treasure, 2003; McMaster et al., 2004; Highet et al., 2005; Tierney, 2005), the present findings of experiences of exclusion and inadequate information provision, suggest that the approaches recommended in policy and guidelines are not always routinely adopted. One implication of this finding is that there is a need to examine how policies are implemented.

In an attempt to understand the gap between policy and routine practice, Stanbridge and Burbach (2007) examined the ways in which policies regarding carers in mental illness have been implemented. The authors indicated that policies have often resulted in the implementation of new services for carers which are separate from mainstream mental health services. They suggested that, perhaps paradoxically, this approach can contribute to carers' experiences of exclusion because it can result in a situation in

which existing mental health staff become less involved with families because they feel that this is the responsibility of the new carers' service. Stanbridge and Burbach (2007) argue that to encourage staff to work in partnership with families, there is a need to develop family-focused services *within* mainstream services. This would involve training existing professionals in specific skills for working with families. The findings of the present study suggest that, in the domain of anorexia, guidelines for best practice are not always implemented at the level of the carer-professionals relationship and that there is a need for staff training to work within a partnership model.

Other studies have attempted to explain the gap between policy and practice in the domain of mental illness by highlighting the possible conflict between the partnership model and the legal obligation for healthcare professionals to maintain patient confidentiality. Wynaden and Orb (2005) argue that patient confidentiality issues often inhibit the family's involvement in treatment on an ongoing basis. They suggest that there is confusion around patient confidentiality and that healthcare professionals require education on how to apply patient confidentiality to clinical practice. In particular, they recommend that patient confidentiality should be negotiated with the family who must be recognised as integral to the care of the patient. The NICE guidelines (NCCMH, 2004) emphasise that patient confidentiality is not an excuse for denying families information which paradoxically indicates a possible conflict between an inclusive model of care and the requirements of confidentiality. However, the guidelines provide no guidance on how to manage this conflict. Without guidance for healthcare professionals on ways to maintain patient confidentiality while including the family, it is unsurprising that many carers continue to experience exclusion, despite family-inclusive policy. The requirement of patient confidentiality can help to explain the reported exclusion of parents by healthcare professionals in the present study. Indeed, the present analysis reported that participants often associated their experiences of exclusion with issues of confidentiality.

Trying to make sense of the exclusion parents experienced is an important area of investigation given that, as outlined in the introduction, there is increasing evidence in the literature that involving families in the treatment can not only relieve caregiver burden (Haigh and Treasure, 2003) but also improve outcomes for the patient (Treasure et al., 2007). Given that anorexia is a chronic and life-threatening illness associated with

poor outcomes for the patient (Steinhausen, 2002; Nielsen, 2001) and a significant burden of care for the family (Treasure et al., 2001; Haigh and Treasure, 2003), the present findings of exclusion and denial of information are particularly pernicious.

Evaluation of Study

The findings of the present study should be considered in the context of its methodological limitations. The present analysis rests on a particular sample. The respondents were all White British and their children were currently receiving care from a private hospital. Although all of the patients had prior experience of NHS treatment which informed much of the data, it would be useful to interview parents of children currently receiving care within the NHS, as this might impact upon experiences and ways of making sense of them. Further, it may be that features of the respondents' experiences of the NHS, the severity of their child's illness, or their own characteristics may have prompted these particular parents (or their child) to seek private treatment. Additionally, parents from different ethnic backgrounds might have different experiences from those reported in the present study. While a strength of this study was that both mothers and fathers of children with anorexia were included, only a small number of each participated. This precluded the possibility of comparing the experiences of mothers and fathers although research on caregiving suggests that mothers may play a more prominent role in caregiving (Twigg and Atkin, 1994).

Elliott, Fischer, and Rennie (1999) suggest that one of the criteria for quality in qualitative research is to carry out 'credibility checks' (p222) of the analysis. This can involve checking interpretations with original informants or various forms of triangulation including investigator or method triangulation. While it was not possible to carry out these credibility checks in the context of a student project, the recurrent patterning of responses from different participants indicated the trustworthiness of the findings (Tindall, 1994). Further, the analysis was grounded in examples at each stage and the methods used are detailed and transparent so that readers are able to judge the fit between the data and the analysis (Elliott et al., 1999).

Reflexive analysis

Qualitative research in general (Tindall, 1994) and IPA in particular (Smith, 2004) recognise the contribution of the researcher in the research process including the

analysis. As the researcher, I was committed to the project from the outset and this contributed to the final project in several ways. In terms of the interviews, the respondents appeared to be engaged with the task of articulating their experiences fully and accurately: they often corrected their accounts, took time responding and attempted to recall the specifics of their experiences and their feelings. They appeared to be emotionally engaged with the topic, with some participants becoming upset during the interview. These features suggested that the respondents took the research seriously and wanted to contribute to it which may have been a response to my commitment and enthusiasm. It also suggested that the topic was one that is important to parents themselves and that they wished to have their experiences heard. I was acutely aware of the sensitive nature of the topic and my main concern in the interviews was to ensure the well-being of the participants. This included pausing the recording at points and checking if respondents were happy to continue the interview. Perhaps my sensitive approach allowed respondents to discuss distressing experiences and emotions fairly openly.

On the other hand, my commitment to the project may also have resulted in my following up avenues in the interviews which I considered to be interesting. Undoubtedly my own interests, as well as those of the participant, at times influenced the direction of the interview. Having said that, I was conscious of this and, particularly as I became more experienced at interviewing, I was able to allow the participants to lead the interview and to accept that all the data was valuable, even if it didn't appear to be directly relevant to the topic.

In terms of the analysis, as mentioned, I ensured that my analysis was systematic and grounded in the data. This disciplined approach in fact led to the emergence of an unexpected theme 'negotiating the parental role' which shifted the focus of the project from relatives to parents. I was able to be flexible and accept this theme although it meant the loss of some valuable data from the interviews with partners.

Future Research

There are several ways in which future research could expand on the findings of this study. One particularly interesting avenue, given the emergence of the theme of negotiating the parental role, would be to compare the experiences of parents and other

relatives such as partners. Additionally, literature on caregiving suggests that mothers often take a more prominent role in caregiving than fathers (Twigg and Atkin, 1994), therefore it would be useful to compare the experience of mothers and fathers.

Conclusion

The present study contributes to knowledge and understanding of the experience of caregiving in the domain of anorexia. Recently there has been a surge of literature which examines the experience of caregiving in mental illness. This is partly in response to changes in mental health policy including the shift towards care in the community which has increased the role of informal carers. Given this context, the present study is a timely contribution to research in this area. When considered alongside other research which has reported similar findings of caregiver exclusion, the present findings also point to potential policy implications particularly in relation to the implementation of mental health policy and staff training which aims to forge partnerships between carers and healthcare professionals.

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