

**Adolescents' Experiences of their In-patient
Treatment for Anorexia Nervosa**

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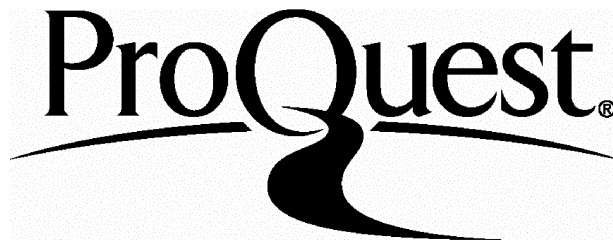
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ABSTRACT

This study aimed to explore how young people experience their in-patient treatment for anorexia nervosa. Semi-structured interviews were conducted with nineteen participants, recruited from two in-patient, adolescent eating disorder units. The interviews were audiotaped and transcribed verbatim. Participants also completed some brief questionnaires which measured their stage of change and readiness to change, and their perceptions of ward atmosphere, satisfaction with, and overall helpfulness of, the unit.

The interviews yielded rich qualitative data, which was analysed using Interpretative Phenomenological Analysis. Five themes were identified from the analysis: (1) What is this illness that I have?, (2) Do I want to get well?, (3) Being with others: support versus distress, (4) Being an individual versus just another anorectic, and (5) Collaborating in treatment versus being treated. Conflict, both internal and external, was at the core of all of the themes. The results are discussed in terms of the existing literature and theoretical perspectives, particularly the transtheoretical model of stages of change. The methodology of this study and the research and clinical implications are also discussed.

ACKNOWLEDGEMENTS

I would like to thank the consultants, nurses, therapists and research assistants in the adolescent eating disorder units, for all their help in setting up this study and with recruitment and room bookings. I was always made to feel welcome on the units and the continued interest and support of the staff was greatly appreciated.

The young people who participated in this study gave up a great deal of their time to share their experiences and ideas with me. Their continued interest in the research was a huge encouragement. Thank you to you all. I hope that I have managed to portray your views consistently and fairly.

To Nancy Pistrang, my supervisor, thank you. I could not have done this without your unfailing support, encouragement and thoughtful discussion.

Finally, no thesis is written without some degree of angst on the part of the author!
Cassius and Simon – thank you for giving me so much help and support throughout.

CHAPTER 1 ~ INTRODUCTION

OVERVIEW

A notoriously difficult illness to treat, anorexia nervosa is a chronic illness with a high mortality rate (Beaumont, Russell, Touyz, 1993). Following their initial treatment, many patients, both adults and adolescents, relapse and require numerous hospital admissions. Extended hospital stays cause significant disruption to the lives of children, adolescents and their families as patients are removed from the family home, their friends and school, which can delay social and academic development. The physical consequences of anorexia are severe and can be fatal, especially for young people, and psychological disorders such as depression and obsessive compulsive symptoms are frequently co-morbid (Lask & Bryant-Waugh, 1995).

What makes this illness so difficult to treat? What is it that young people find helpful or unhelpful in treatment? It is important to ask anorectic patients how they experience their illness and its treatment: their responses could give us important clues as to what treatments might, or might not, help. It is certainly the case that such lines of research have been severely neglected. Such an oversight seems extraordinary in the light of health care professionals struggling to treat and help people with this illness. We must not underestimate the importance, for both clinicians and patients, of understanding how young people experience this illness and their treatment.

This chapter will begin by outlining the key features of, and diagnostic criteria for, anorexia, its epidemiology, aetiology, prognosis and general outcome. The literature on anorexia in children and adolescents will then be reviewed, with a focus on in-patient treatment and its efficacy. Following this, a synopsis of the literature on the transtheoretical model of stages of change will be offered and its application to eating disorders considered. Such literature as has been published on the views of anorectics on their illness comes next and, finally, the aims and rationale of the current study will be presented.

ANOREXIA NERVOSA

Clinical features of anorexia nervosa

Anorexia nervosa (AN) is a severe mental illness with an unpredictable course and treatment outcome (e.g. Katz, 1985; Rathner, 1992; Russell, 1992) that typically begins in mid to late adolescence between the ages of 14 – 18 years (DSM-IV-TR, 2000). It is characterised by determined attempts to lose weight, or to avoid weight gain, which can be achieved through food avoidance / starvation, self-induced vomiting, laxative abuse, excessive exercise or, as is more common, a combination of two or more of these (Bryant-Waugh, 2000). Individuals with AN display a morbid fear of becoming fat and a desire to maintain a sub-optimal weight. They also exhibit a significant disturbance in the perception of the shape or size of their body and post-menarchal females lose their periods, becoming amenorrhic (DSM-IV-TR, 2000). The symptom that most frequently

brings AN to the attention of the medical profession is dramatic or life-threatening weight loss and emaciation. The diagnostic criteria for AN, as in DSM-IV-TR (2000) are:

1. Refusal to maintain body weight at or above 85% of weight for height and age, or a failure to make expected weight gain during a period of growth, leading to body weight of less than 85% of weight for height.
2. Intense fear of gaining weight or becoming fat, even though underweight.
3. Disturbance in perception of body shape or weight, undue influence of body weight or shape on self-evaluation, or denial of the seriousness of the current low weight.
4. In post-menarchal females, amenorrhoea for at least three consecutive menstrual cycles.

Two subtypes of AN are also specified: a) Restricting type which is characterised purely by limiting the amount of food consumed being an absence of purging methods, and b) Binge-Eating / Purging type, where the individual with AN regularly engages in binge-eating or purging, using self-induced vomiting, laxatives, diuretics or enemas (DSM-IV-TR).

In pre-pubertal, or early onset AN, the child may fail to make expected weight gains, as opposed to direct weight loss (DSM-IV-TR, 2000). Obviously in pre-pubertal onset AN amenorrhoea will be primary, not secondary. Irwin (1981) has commented on the “refusal to maintain hydration” often being present in children with AN, leading to a dangerous

state of dehydration. The other features of early onset AN are very similar to those of later onset, with abnormal cognitions regarding weight and shape and a morbid preoccupation with weight, shape, food and / or eating (Bryant-Waugh, 2000).

Further features often associated with AN in both children and adults include obsessive-compulsive symptoms, perfectionism, poor self-image and marked mood disturbance with co-morbid depression being common (Bryant-Waugh & Lask, 1995). Low self-esteem is a characteristic of eating disorder patients, that differentiates them from those who show concerns about their weight and normal controls (Williams, Power, Millar, Freeman, 1993). The physical characteristics of AN are emaciation, poor circulation leading to circulatory failure, a slow, weak pulse, low blood pressure, cold hands and feet, discoloured skin, insomnia, constipation and abdominal pain, and lanugo (a fine, downy hair) all over the body (Bryant-Waugh & Lask, 1995). These features are directly related to self-starvation.

There are numerous potential physical consequences of AN that cause medical complications which can be both disabling and life-long. Resultant conditions include anaemia and low white cell count leading to a failure in bone marrow and osteoporosis, circulatory and renal failure, resulting from laxative abuse or vomiting and abnormalities in plasma electrolytes, liver damage and severe protein deficiency and infertility (Todd & Treasure, 1997).

Epidemiology

Ascertaining the prevalence rates of AN has been difficult as notable discrepancies have arisen in reported estimates (Crisp, Palmer, & Kalucy, 1976; Szmukler, 1985; Rastam, Gilberg, & Garton, 1989). The type of data source and the number of data sources consulted will have an effect on the overall reported prevalence for any disorder (Doyle & Bryant-Waugh, 2000). For instance, Hoek (1993) conducted a review of epidemiological studies of eating disorders. He reported that approximately 370 cases of AN in females could be found in the community per 1,000,000 of the population in any one year. However, if the focus was on psychiatric in-patients then only 30 female cases would be found in the same population. He therefore concluded that a tenfold reduction of the rates of AN is seen when the focus is shifted from the community, where many sufferers may not be in treatment, to psychiatric in-patients.

It has also been suggested that a large number of individuals suffer from some, but not all of the symptoms of AN, and so do not meet the criteria for a diagnosis. Compounding this is the fact that diagnostic criteria have changed and developed over the past 20-30 years (Doyle and Bryant Waugh, 2000). Button and Whitehouse (1981) posited that about 5% of all teenage girls following puberty, develop “sub-clinical” AN, which by definition, never requires psychiatric attention. Clearly it is not possible to gather data on such cases if they do not present to professionals. The prevalence estimates of AN must therefore be taken as rough estimates only.

In a review of prevalence studies of AN, Hoek (1993) reported an incidence of 0.2% in state school and 0.8% in private schools. Johnson-Sabine, Wild, Patton, Mann, and Wakeling (1988) used the same measure as did Hoek (1993) and found no cases of AN in their study of school girls between the ages of 14 and 16 years. This demonstrates the extent to which prevalence studies are likely only to be estimates. Joergensen's (1992) study of the incidence of eating disorders in Denmark is interesting as the author included female patients registered within both psychiatric and non-psychiatric services, as well as in-patients and out-patients. Joergensen found the occurrence of eating disorders using these populations to be 9.2 cases per 100,000 in 10-14 year olds and 11.9 cases in the 15-19 year old age group.

Using strict diagnostic criteria and summarising the two-stage surveys, in which a population is initially screened with a self-report measure, following which high scoring subjects are selected for second stage evaluation, Hoek (1991) reported an average prevalence rate of 0.16% of females aged between 15 and 29 in primary care and of 0.28% of young females generally. Similarly Hoek's (1991) general practitioner continuous registration study in Holland found 6.3 cases per 100,000, whilst Lucas, Beard, O'Fallon, et al. (1991) found a rate of 14.2 per year in Rochester Minnesota, for the period of 1980-1984. As has been shown, incidence rates vary widely and despite a considerable amount of research in to the incidence and prevalence of AN, there remains very little certain information.

Aetiology

Eating disorders have never been explained adequately by single aetiologies – they require a more complex, multifaceted understanding of their origins (Andersen, Bowers, & Evans, 1997; Lask, 2000). Given the phenomenological complexity of AN, contemporary aetiological theory has tended to invoke a multi-dimensional, biopsychosocial causality (Garfinkel & Garner, 1982; Strober, 1991). In general, such theories propose that AN implicates: a “collision” between genetic and biological factors such as heritable influences on temperament, impulse controls and mood; social pressures that promote body-consciousness, and a cultural desire to emulate thinness; psychological tendencies; personality factors, including perfectionism, hypersensitivity to social approval and autonomy disturbances; and developmental process conducive to self-image or adjustment difficulties (Steiger & Israel, 1999; Lask, 2000).

It is important to note that AN does not suddenly occur at a particular moment. Rather, eating disorders in general, and AN specifically, develop over time, with some causative factors being in place from birth, others emerging in early life and yet others later (Lask, 2000). It is therefore necessary to differentiate between predisposing factors without which the disorder is unlikely to occur, precipitating factors which trigger the condition and prolonging factors which serve to maintain the illness once it has emerged.

Research into the genetics of AN has found the incidence of AN in first degree relatives of those with AN to be up to eight times greater than the highest reported incidence figure

in population surveys (Crisp et al., 1976). Similarly, the concordance for AN in monozygotic (identical) twins is around ten times greater than for dizygotic (non-identical) twins (Holland, Sicotte, & Treasure, 1988; Scott, 1986; Treasure and Holland, 1990). Although there has been research into the biological components of AN it has not been possible to date to differentiate between primary and secondary abnormalities, although there is thought to be enough evidence to indicate that primary biological factors do exist (Lask, 2000).

The literature on AN has many references to personality traits in AN, especially those dealing with the unusual sensitivities and extremes of personality seeming to underpin AN (e.g. Fosson, Knibbs, Bryant-Waugh, & Lask, 1987; Srinivasagan, Kaye, Plotnikov, Greeno, Weltzin, & Rao, 1995; Strober, 1995). Another commonly associated feature of anorectics is that of low self-esteem (Button, Sonuga, Barke, Davies, & Thompson, 1996; Lilienfeld et al., 1998), with almost all children with AN seeming to have a very poor self image. Such a perception may be reinforced by the perfectionist traits that are common. None of the attempted psychological explanations for the pathogenesis of AN have received any empirical support (Lask, 2000). However, the most influential work has been that of Bruch (1974) who suggested that the refusal to eat and a fear of fatness have their roots in early mother-child interactions, which persist through childhood and can have a profound effect on the developing personality. From a psychoanalytic perspective, as is Bruch's, disturbed eating can have a vast range of symbolic meanings (which will not be explored here) such as expressing rage and hatred, a sense of omnipotence and a rejection of parents.

Finally, no model for explaining the aetiology of AN is complete without providing an answer as to why AN occurs predominantly in females in Western, developed society. It is well recognised that the cultural pressure on women to be thin is a predisposing factor for AN (e.g. Fallon, Katzman & Willie, 1994). Indeed, being thin has almost become synonymous with being good in today's society. Hill, Oliver and Rogers (1982) found that even 6-9 year olds have concerns about their weight and shape. The cultural analysis of eating disorders is re-enforced by the finding of Bryant-Waugh and Lask (1991), for example, that whereas immigrants to Western societies do not develop eating disorders, their daughters are as likely to as those of the indigenous population. Although the multifactorial model of the aetiology of AN seems the only plausible and credible model, with so many different elements and factors being likely to contribute to the aetiology of AN, the picture is a complex one, with cause and effect at times becoming confused.

Prognosis and Outcome

Long-term prognosis and the outcome of AN are both difficult to predict. AN is known to be associated with a chronic course and high mortality (Beaumont, et al., 1993). Zipfel, Lowe, Reas, Deter and Herzog (2000) conducted a 21 year follow up study that investigated outcome and predictors of outcome. Of their sample of 84 women (mean age 41.9 yrs) who had had AN and a first admission 21 years previously, 50.6% had made a full recovery, 10.4% still met diagnostic criteria for AN (the majority of whom had binge / purge subtype) and 15.6% had died from causes related to AN. Zipfel et al. identified the predictors of poor outcome as being a long illness duration before the first admission,

a low body mass index (BMI) and inadequate weight gain during the first hospitalisation and severe psychological or social problems. Interestingly, those with binge/purge subtype seemed to have a higher risk of a poor outcome. Age at onset was not clearly associated with increased risk for a chronic course. These results demonstrate the importance of early intervention and dealing with psychological and social factors during hospitalisation as well as weight restoration.

In his meta-analysis of 42 published studies, Sullivan (1995) found the aggregate estimated mortality rate for patients with AN to be 0.56% per year or 5.6% per decade (178 deaths over 3,006 individuals with AN). In the 38 studies where cause of death was reported, 54% was due to complications of an eating disorder, 27% suicide and 19% unknown causes. This is more than 12 times higher than the annual death rate (due to all causes) for females aged 15-24 years in the general population, more than 200 times greater than the suicide rate in the general population (Rogot, Sorlie, Johnson, Schmitt, 1992) and more than twice that of a national study group of female psychiatric in-patients aged 10-39 years (Zilber, Schufman, & Lerner, 1989). These disturbing figures illustrate the pressing need to find new and more effective treatment interventions for those with AN.

It has been repeatedly hypothesised that adolescent AN has a better prognosis and outcome than does later onset (Fichter & Quadflieg, 1995). However, many factors such as heterogeneous groups of subjects with regard to age at onset, the small number of

outcome studies based on only adolescent patients and methodological shortcomings have hampered a thorough test of this.

The most recent and up-to-date follow-up study of adolescent eating disorders is that of Steinhausen, Boyadjieva, Grigoriu-Serbanescu, Seidel and Winkler Metzke (2000), which attempted to amend these difficulties and test the above hypothesis. The authors carried out an international study including Western and Eastern European clinical and research centres. 138 patients with adolescent onset AN were followed-up after a mean of 5 years since the initial admission and, for the first time, a systematic assessment of treatment efforts was conducted. On average patients had spent 25% of the total follow-up period in either in or out-patient treatment. Half of the sample required a second admission and 50% of those required a third admission. This illustrates clearly the relapsing nature of AN and implies that a more concerted effort to understand what patients find helpful in treatment is necessary. It was also found that psychosocial functioning was more adversely affected, with sexual behaviour in particular being frequently impaired. However culture may have biased findings on psychosocial functioning and within culture studies need to be conducted.

The main clinical implication of Steinhausen et al.'s research is that the outcome of adolescent eating disorders is relatively similar across cultures with regard to the main features. Patients spend a considerable proportion of their lifetime in treatment but, as was found in earlier studies (e.g. Steinhausen, Rauss-Mason, & Seidel, 1991), a younger age at onset carried better prognosis. However, when considering the long list of potential

clinical features of AN, it has been shown that very few have a significant predictive value. In contrast, the preliminary data indicates that the inclusion of other or co-existing psychiatric disorders implies less favourable outcome. Giving a prognosis for an individual patient is thus problematic.

Steinhausen et al. (1991) reviewed four decades of outcome research on AN, from 1950-1990, to determine whether the course of AN has changed. No evidence that typical age at onset during adolescence or early adulthood has changed was found, although studies of early onset AN are very rare. A comparison of treatment effects was impossible due to the many different treatment regimes used in the studies. Thus the efficacy of specific treatments for long-term outcome could not be evaluated. Methodological shortcomings in many studies and the use of different diagnostic and outcome measures precluded the use of standardised meta-analysis. However, these authors did identify a number of prognostic factors. Earlier age of onset was associated with a better outcome. Good parent-child relationships were linked with good outcome (Bryant-Waugh et al., 1988, Burns & Crisp, 1984, Morgan, Purgold, & Welbourne, 1983). Specifically unfavourable prognostic factors included vomiting (Nussbaum, Shenker, Baird, & Saravay, 1985) purging and bulimia, (Zipfel et al., 2000; Martin, 1985; Scholberg, Norring, Holmaren, & Rosmark, 1989), and extreme weight loss and chronicity (Burns & Crisp, 1984).

Despite the usefulness of such outcome studies in indicating further areas for research and avenues for improving treatment, many studies have been wrought with methodological problems (Schoemaker, 1997). The exclusion of patients who recovered

after their first admission or treatment period will have led to negative patient selection - only those who remained ill will have been included in many of the follow-up studies. Chronic patients are often under-represented as they are often older than 18 at their first admission, and thus admitted to adult centres, so not included in the research. Similarly, Hsu (1992, p.125) states that “methodological robust outcome studies for the eating disorders are rare”. He attributes such shortcomings to a failure to meet a number of methodological requirements including: defined diagnostic criteria; adequate duration of follow-up; adequate outcome criteria; and clear data presentation (Hsu, 1992). In addition, there are no randomised trials, so there may be potentially confounding variables (Shaw & Garfinkel, 1990; Steinhausen & Glanville, 1983c). Denial, co-morbidity, negative selection, treatment failures and chronicity are inextricably interwoven. Nonetheless, these outcome studies do exemplify the severity and chronicity of AN and they beg for more methodologically sound research to be conducted.

In summary, the research on the prognosis for AN illustrates how difficult and complex an illness it is. Predictors of good and poor outcome have been identified (e.g. Zipfel et al., 2000), but few have a significant predictive value (Steinhausen et al., 1991) and most remain unsubstantiated. Multiple admissions are common (Steinhausen et al., 2000) and the mortality rate has been found to be much higher than the annual death rate in the general population for females aged 15-24 (Sullivan, 1995), the suicide rate in the general population (Rogot et al., 1992) and a national study group of female psychiatric in-patients aged 10-39 years (Zilber et al., 1989). Most studies of the prognosis and outcome of AN are wrought with methodological difficulties (e.g. Schoemaker, 1997; Hsu, 1992)

which, at the very least, cast grave doubt on many of the findings to date. It seems imperative that systematic research into these areas is carried out urgently, as until more reliable data is available on prognostic factors for the course and outcome of AN, there is little hope of an improvement in the understanding, consequent treatment and mortality rates for this chronic, complex and disturbing illness.

Treatments

The treatment of AN traditionally relied on in-patient care, with the primary priority being weight restoration – a process that usually takes about fourteen weeks (LeGrange, 1999). Following discharge, patients were, and in many cases still are, managed with supportive psychotherapy and regular weight monitoring. Despite these endeavours, and as mentioned above, many patients relapse with a significant number requiring readmission (e.g. Steinhausen et al., 2000; McKenzie & Joyce, 1992).

In the past decade the number of psychotherapeutic options available in treating eating disorders expanded greatly (Garner & Needleman, 1997). The trend has been for clinical formulations to reflect a particular orientation to the treatment of eating disorders. However, at the same time, there seems to have been an opposite movement in the general field of psychotherapy towards eclecticism and integration of different therapeutic approaches (Garfield, 1994, Garfield & Bergin, 1994). The notion of applying different treatments to different eating disorder patients is not new and has formed the basis for multidimensional approaches to psychotherapy. The more recent trend,

however, is in stepped care, decision tree or integration models which rely on set rules for the delivery of the various treatment options (e.g. Agras, 1993; Fairburn, Marcus, & Wilson, 1993; Tiller, Schmidt, & Treasure, 1993). Although they will not be discussed, these treatment delivery systems share the value of non-allegiance to a single theoretical orientation. Patients usually receive either one, or a mixture, of family therapy, individual therapy, either cognitive behavioural or psychodynamic, group therapy, out-patient treatment or hospitalisation.

Integration is a concept which has been used in different ways to denote combination of two or more forms of psychotherapy (Garfield, 1994). Although integration overlaps with eclecticism, it is generally agreed that integration tends to signify the combination of two or more theoretical orientations, whereas eclecticism connotes the selection of techniques and procedures regardless of theoretical orientations (Garfield 1994). This section will discuss only those treatments used with, and treatment outcome for, early onset AN that are relevant to this research.

Although psychotherapy is generally considered crucial in treatment (APA, 1993), few controlled studies investigating its efficacy have been conducted. Those studies that have been carried out show that involving the family in treatment of adolescents with AN has proved to be beneficial for young clients with an illness of short duration (Le Grange, 1999). It is now the initial treatment choice for AN patients aged under 18 years (Dare & Eisler, 1997; Russell, Szmukler, Dare, & Eisler, 1987). The most influential study is Russell's et al.'s (1987) randomly controlled trial of individual versus family therapy.

They found that in those adolescents with AN, whose onset of illness was before the age of 19 years and with an illness duration of less than 3 years, family therapy was clearly superior to individual therapy. These benefits proved to be enduring at 5 year follow-up (Eisler, Dare, Russell, Szmukler, LeGrange, & Dodge, 1997). Similar findings were obtained by Dare, Eisler, Russell, and Szmukler (1990) and Robin, Siegel, Koepeke, Moye, and Tice (1994). In reviewing these findings, it has been concluded that family therapy, which supports the parents in taking control of their child's eating, is an effective intervention which, in the majority of cases of short duration, enables recovery without admission to hospital (LeGrange, 1999; Dare & Eisler, 1997). These findings unequivocally support the use of family therapy in all adolescents with AN, even if it is used in conjunction with other therapies, such as individual or cognitive behavioural therapy. But what happens when therapy on an out-patient basis fails?

In-patient treatment

One of the dilemmas in AN is whether to choose in-patient or out-patient treatment. When out-patient treatment of children and adolescents with AN is either obviously failing, or when medical and physical complications occur, admission to hospital may become necessary. There are two different types of hospitalisation. First is that aimed at treating physical complications in the event of a medical emergency. This does not require a commitment by the patient to recover from their anorexia. The second form of admission is that intended as a critical step in the recovery process, aimed at addressing both the physical and the psychological aspects of the disorder. Considerable effort is

required to enlist the patient's genuine commitment to participate in every stage of the treatment process (Garner & Needleman, 1997). Garner and Needleman believe that psychotherapy can achieve only modest goals, given the limits imposed by dietary chaos or chronic starvation.

Much of the literature on specialist adolescent in-patient eating disorder units is prescriptive in outlining what constitutes the most effective and helpful environment for young people with eating disorders, as opposed to reporting research findings on the topic. I will outline these principles before discussing the more general research findings on the second type of hospitalisation outlined above.

There is unanimous acceptance of the need for a multidisciplinary approach to the treatment of eating disorders in childhood and adolescence, as the disorders are complex and of multifactorial aetiology. Whatever the type of in-patient setting and treatment offered, the approach should recognise this, and consequently intervene at a variety of levels in the child's life (Honig & Sharman, 2000). Many young people will go to great lengths to avoid weight gain and will deny that they are ill (Honig & Sharman, 2000; Lask & Bryant-Waugh, 1997).

Honig and Sharman propose milieu therapy as a helpful in-patient setting. This is the provision of a therapeutic environment in a clinical setting which aims to build on an individual child's strengths and encourages the child to examine her own behaviour, recognise and name upsetting feelings and find alternative ways of expressing these

(Crouch, 1998). Such therapy is an essential part of any in-patient treatment for eating disorders (Honig & Sharman, 2000; Lask & Bryant-Waugh, 1997).

In the early stages of treatment it is essential that the medical team take charge of food and fluid intake (Honig & Sharman, 2000). Electrolyte imbalance and dehydration need to be treated immediately to maintain life. A target weight must be established and, with anorectic patients, some kind of re-feeding is always necessary. If, however, the young person is dangerously malnourished or dehydrated and refusing to eat or drink, artificial re-feeding, usually via a naso-gastric tube may be necessary. Mealtime management is always difficult on eating disorder units and it is important to find the balance between being firm, vigilant and consistent, but at the same time, understanding, empathic and flexible. This is particularly the case as children with AN are frequently skilled at concealing their techniques for avoiding weight gain (Lask & Bryant-Waugh, 1997). Hiding food, exercising, vomiting and laxative abuse are all common.

One final, fundamental part of in-patient treatment of AN, is maintaining the involvement of the parents. It is vital that the parental feelings of guilt and blame are lowered and that family problem solving is enhanced (LeGrange, Eisler, Dare, & Hodes, 1992). It is important to remember that the parents hold the ultimate responsibility for their child and so family work must occur outside of the family therapy session in the form of family meals, both on the unit and at home, with frequent telephone liaison and family involvement at every stage of treatment.

Research on hospitalisation for AN and its outcome

There is little empirical evidence on the comparative efficacy of different treatments for eating disorders and few outcome studies have been conducted. In addition, as treatment programmes differ, one is frequently not comparing like with like. Those studies that have been conducted, however, raise significant concerns about in-patient treatment for AN. Garfinkel, Garner, and Goldbloom (1987) suggest there is little empirical data to help determine the best treatment regime or setting for AN. In-patient care is intrusive in the sense that it removes the sufferer from her normal environment, as well as being intensive and expensive. Morgan's et al.'s (1983) prospective study suggested that earlier intervention and long-term continuity of out-patient care may be important components for effective treatment. These authors suggest that putting more effort into prevention, reduction of waiting-list time together with more continuity of out-patient care and more support in the community, such as half-way houses, may reduce hospitalisation time and chance of chronic illness.

Despite the short-term effectiveness of in-patient treatment, there is the view that this treatment is ultimately disadvantageous, and that it leads to a poorer long-term outcome than does out-patient treatment (e.g. Gowers, Weetman, Shore, Hossain, & Elvins, 2000; Morgan et al., 1983). During admission, patients are taken away from their families, peers, friends and school. Morgan et al. (1983) state that in-patient treatment can "involve considerable disruption in the patient's management: it may represent counterproductive retreat from the confrontation with certain life difficulties and signify confirmation of the

sick role in the eyes of relatives who then dissociate themselves from active participation in therapy”.

Walford and McCune (1991) followed up 15 children who developed AN aged 13 or under. They found that as long as weight loss is not life-threatening, children with AN may be adequately managed without admission. Russell et al, (1987) postulated that the superiority of family therapy over individual therapy in younger anorectic patients might in part have been related to its ability to help parents overcome their sense of failure and regain control over their child’s eating. Prolonged hospital admissions may have the opposite effect on parents, demoralising and deskilling them and thereby contributing to the poor prognosis noted in those with longer admissions.

McKenzie and Joyce (1992) examined the length of stay of 100 patients with AN in New Zealand over a 5 year period after their first admission. They found relapse rates to be high following admission, with 48% of patients being readmitted on more than one occasion. Patients younger than 16 years were more likely to be readmitted and the cumulative length of stay in hospital was exceeded only by patients with schizophrenia or organic disorders. This is a shocking finding and it is therefore essential to look at how length of admission can be reduced and thereby at what works in terms of treatment. Similarly, Gowers et al. (2000) found that those participants who had been hospitalised for AN had a significantly worse outcome than those who were never admitted. Indeed, Gowers et al. suggested that admission seemed to be the major predictor of poor outcome.

In addition, Nozoe et al. (1995) studied the clinical features of AN and assessed factors influencing the duration of 55 patients who had all completed in-patient treatment. They found longer hospitalisation correlated with older age at onset; poor social adaptation; and longer duration of illness prior to admission. Frequent previous admissions or hospital treatment for AN or other somatic disorders after onset indicated that previous treatment had been unsuccessful. Previous treatment failure has also been reported by Halmi and Larson (1977) to have the greatest influence on prognosis.

So what about admission seems to be at worst, detrimental, and at best, simply not helpful? It may be, as discussed above, a removal of the young person from their family and thus disruption to their home and social lives and education. Possibly the adoption of the sick role could have a deleterious effect. It may be that the atmosphere or environment of the ward can impact greatly on patient's engagement with treatment or, it may be that if patients are not yet ready to get well, no amount of in-patient treatment will quicken the process of long-term recovery.

STAGES OF CHANGE

As has been discussed, the literature on the prognosis, treatment and outcome of AN shows nothing conclusive which can help with understanding why this illness is so difficult to treat, has a chronic course, poor prognosis and high mortality rate. One way of trying to integrate some of the above findings, and increase our understanding of AN and recovery from it might be by using the transtheoretical model of stages of change

(DiClemente & Prochaska, 1982; Prochaska & DiClemente, 1983; Prochaska, DiClemente, Velicer, Ginpil, & Norcross, 1985). Although this model was initially developed to help with understanding the process of smoking cessation, its application has now broadened to many problem and addictive behaviours, and very recently it has been considered in relation to recovery from AN and bulimia nervosa (Ward, Troop, Todd, & Treasure, 1996). It may be an important variable in helping us to determine what treatment works for whom and when.

This model of change offers an integrative perspective on the structure of intentional change (Prochaska, DiClemente & Norcross, 1992). Retrospective, cross-sectional and longitudinal studies of how people quit smoking alone, found evidence that individuals modifying their addictive behaviour move through a series of 5 stages of change (DiClemente & Prochaska, 1982; Prochaska & DiClemente, 1983; Prochaska et al., 1985). These stages were precontemplation, contemplation, preparation, action and maintenance.

The five stages will be briefly outlined. When in the precontemplation stage, individuals cannot see that they have a problem, let alone recognise or consider a potential solution. They have no intention of altering their behaviour in the foreseeable future. Contemplation signifies “knowing where you want to go but not quite ready yet” (Prochaska, DiClemente & Norcross, 1992). People are aware that a problem exists and are seriously thinking about overcoming it, but have not yet made the commitment to take action. In preparation, people seriously consider changing their behaviour in the near

future, but have not yet begun to act. Action is the most visible stage and the stage in which people receive the greatest external recognition. It involves individuals modifying their behaviour, experiences, or environment in order to overcome their problems and it requires considerable commitment of time and energy. Finally, maintenance consists of work to prevent relapse and consolidate the gains attained during action. Although it appears static to the outside world, it is a continuation of, not an abstinence from, change.

In one of the few studies on stages of change in eating disorders, Ward et al. (1996) used questionnaire measures to examine stage and process of change in 35 in-patients with AN. They found that self-re-evaluation was the most frequent process endorsed to achieve change, followed by helping relationships and consciousness raising, all of which are cognitive / affective processes. Least used were the behavioural strategies of reinforcement management and stimulus control. The transtheoretical model predictions were largely fulfilled in this study. Precontemplators used the fewest cognitive processes of change (Prochaska & DiClemente, 1983). Consciousness raising and self-re-evaluation were used by patients in the contemplation and action groups. Maintenance was not used as all participants were in-patients and thus the category was inapplicable.

Such awareness of stage and process of change lends itself to a motivational model of therapy (Miller & Rollnick, 1991; Rollnick, Heather, Gold, & Hall, 1992) in which it is essential to match the treatment given to an individual's stage of change. This model implies that different resistances are important at different stages, suggesting that therapist style may need to be flexible in order to enhance motivation. Ward et al. (1996)

add that relapse is common in all eating disorders and the model sees change as a cycle, with relapse as an integral part. Earlier work is not negated by relapse, rather the cycle continues more rapidly subsequent times around. Such a view seems relevant and extremely helpful in understanding and working with eating disorders. The authors believe that cognitive and affective processes of change need to be continued beyond normal weight in order to minimise the number of cycles through which patients go.

There are, however, limitations to the transtheoretical model for eating disorders. There was a difference between the clinical impression that staff had of patients and the stage of change at which patients were on the questionnaires. The majority of patients seemed to be in action, whereas the clinical impression was one of more ambivalence. This raises the question of how accurately a patient can be assigned to a single stage, especially for more complicated problems such as AN.

In contrast, McConnaughey, DiClemente, Prochaska, and Velicer (1989) supported the idea of it being possible to be simultaneously engaged in behaviours and attitudes of more than one stage, which would validate the ambivalence and difference in staff and patient ratings of stages of change found by Ward et al. (1996). Women with AN are notoriously ambivalent about treatment and can deteriorate into entrenched battles over food and weight, especially in an in-patient setting. Unsuccessful outcomes are often attributed to poor motivation on the patient's part, citing, for example personality factors, or secondary gains. However, it may be more helpful to understand unsuccessful outcomes in terms of a recycling through the stages of change, and the transtheoretical

model does suggest a way of thinking about helping this very ambivalent group to instigate and maintain change.

THE VIEWS OF ANORECTICS ON THEIR ILLNESS

The views of those with anorexia about both their illness and treatment have been severely neglected. Only two systematic research studies in this area exist (Lemberg & May, 1991; LeGrange & Gelman, 1998). Autobiographical accounts, dealing with the author's experience of the illness, their treatment and recovery, constitute the only other published material. Such material is seminal to our understanding of this complex illness. Those trying to develop and enhance treatments for AN would be likely to develop more appropriate, thoughtful and person-centred approaches if they could understand the experience for patients of their illness.

Research findings

To date, only two studies have explored what adolescents with eating disorders find helpful and unhelpful about their treatment (Lemberg & May, 1991; LeGrange & Gelman, 1998), and both are wrought with methodological problems.

Lemberg and May (1991) evaluated what 28 anorectic and bulimic patients found helpful and unhelpful about a new, in-patient, twelve bed eating disorder unit, for those aged 15

and above. Their assessment tool was a 52 item forced response questionnaire, administered anonymously upon discharge, which measured satisfaction with: admission and intake assessment, environmental conditions, unit expectations and rules, therapeutic interventions, and discharge and after-care preparation. Overall the results were positive, with the treatments being perceived to be the most helpful including individual therapy, group therapy, one-to-one meetings with a primary nurse, especially when this involved supportive talks, exercise training and nutritional counselling. Not surprisingly, didactic groups were positively viewed as they addressed patients' conscious concerns as well as being within a psychologically 'safe' structured format which allowed for the exploration of the more threatening underlying dynamics. Least helpful therapies were found to include family education, occupational and art therapies, and the evening lecture.

One significant problem with this study is that there was only a 50% response rate which may have skewed the results in a positive direction, in terms of a response bias of only those who were content with the unit having responded. Also, satisfaction measures do not allow for detailed exploration of what it was about a particular therapy or intervention that was helpful and nor do they always indicate what the patient needs from a therapeutic perspective. Descriptions of the different therapies and activities were not included and so it is difficult to know exactly what constituted each item, and it is not known whether anorectic and bulimic patients underwent the same or different therapies.

LeGrange and Gelman (1998) conducted a qualitative study exploring what patients found "helpful as well as harmful" about the out-patient treatment that they had finished,

on average 13 months earlier. Twenty one participants were interviewed, 10 of whom were anorectic. The 7 anorectics who were aged between 14 and 18 years and were still living at home received family therapy, and the remaining 3 received cognitive behaviour therapy. The mean treatment duration was 7 months. Areas explored were recovery, helpful / harmful aspects of therapy, whether the treatment effects had lasted over time, termination, whether causes of the illness were adequately dealt with, and whether they would recommend this treatment to friends.

In both the cognitive behaviour therapy and family therapy groups the majority of participants found the supportive and understanding environment helpful, although this was more evident in family therapy than in cognitive behaviour therapy. Similarly, psycho-education was seen as helpful by both groups, though by a larger percentage of those receiving family therapy. Nearly half of all participants felt that a significant oversight of either model was the exploration / addressing of the causes of their AN. Personal problems were mentioned by both groups as being seen as secondary to eating, an approach which was viewed as not helpful. Although behavioural strategies were identified as helpful, a significant number of participants found them unhelpful, especially those with more severe illnesses. It may be that severely ill patients need different or amended interventions.

As with Lemberg's and May's (1991) study, the mixture of the two main eating disorders and the small sample sizes make the findings difficult to evaluate. This is particularly the case for cognitive behaviour therapy for AN as only 3 participants were in this group –

the other 11 patients in this group had bulimia, which is a different illness requiring different treatment. A significant shortcoming of this study was its reliance on participants' accurate recall and interpretation of their internal world (as it had been at the time of treatment) for information about their treatment. As indicated by the authors, hindsight was likely to have altered the perceptions that patients held of their illness and treatment. In addition, for the younger anorectics, it may have been difficult to verbalise their memories of what their internal world state had been at the time of their AN.

Despite the significant shortcomings of these studies, they do offer some insight into a vital area in which there is a dearth of research, in spite of the continually expressed doubts by researchers about effects of treatment on recovery (e.g. Steinhausen et al., 2000). Furthermore, the protracted and relapsing / remitting course of AN means that recovery continues to be uncertain for many patients (Wilson, 1996; Windauer, Lennerts, Talbot, Touyz, & Beaumont, 1993).

Personal accounts

The themes discussed, and quotations used in this section, are taken from Shelley's (1997) compilation of written, autobiographical accounts of individuals' experiences of AN and their treatment for it. Although it is difficult to summarise the diverse experiences that emerge from personal accounts of AN, a few overarching themes do seem to emerge. The notion of being ready for treatment, or recovery, comes through in many personal accounts. Kirsty (p.127), for example, talks about the lengths to which an

anorectic will go to “get people off their back”. She then says “if an anorexic does not want help, it is impossible to force it on them. It isn’t until an anorexic wants to get better that anyone can do anything”. Similarly, Elaine (p.124) believes that “sufferers need to live out their anorexia until they reach the point where they no longer want to have it”. These quotations suggest that the transtheoretical model of change may, with further research, prove to be a useful framework for understanding and treating anorexia.

The intensity with which AN can feel all-consuming and can take over sufferers’ lives, and the degree to which anorectics can feel allied to their illness is another thread running through personal accounts. “Control that is so controlled it’s out of control” comments Lisa (p.133). Victoria (p.69) speaks of the stealthy way in which she felt anorexia took control of her: “It crept up on me silently and relentlessly, eventually becoming the driving force behind my whole existence”. Cherry (p.87), graphically states how essential her AN has become to her: “I have spent 28 years of my life consumed by an obsession with food so strong that I would rather commit suicide than allow anyone to control my eating”. Linked to this is the pervasive theme of anorexia as a friend. “I would compare putting anorexia behind me to losing my best friend” (Kirsty, p. 125). In such instances, the potential feelings of cruelty, loss and grief if this friend seems to be being taken must be worked with in therapy. Otherwise it appears to be impossible to help individuals who see their anorexia in this way to get well.

Such potent personal accounts of the grip in which AN holds its sufferers, and the importance that it holds in their lives, can be used to enhance professionals’

understanding of the illness and inform the direction that therapy ought usefully take. For example, the accounts suggest that it might be particularly important for therapy to focus on helping patients to disentangle the self from the anorexia, and then to work through what it would then mean to lose the anorexia. In this way, patients' perspectives of their treatment could inform therapeutic process and provide greater understanding of recovery. The importance of patients' perspectives has been demonstrated in other areas, such as dementia research. A brief summary of this, and its implications for research in to AN, is presented below.

THE ANALOGY WITH DEMENTIA

Research into dementia has traditionally been based on the premise that dementia is of an organic origin and therefore not amenable to psychological explanation or intervention (Kitwood, 1997). It has been predominantly biomedical in nature and has focused on the neuropathology of dementia. It is only over the last decade that this view of dementia has been challenged by an increasing interest in, and understanding of, the importance of the person (Kitwood & Bredin, 1992) and the subjective experience of dementia.

Perhaps the greatest shortcoming of the biomedical approach to dementia was the tendency to attribute the experiences of those with dementia exclusively to a disease process (Lyman, 1989). The individual was given the status of an object and a disease entity, instead of someone who could add to our understanding of dementia (Cotrell &

Schulz, 1993). Consequently, the immense variability in presentation and course of the dementias were overlooked, as were the personal and psychosocial needs of those with dementia. Similarly, the general behaviour and so called 'problem behaviours' of those with dementia have been taken out of the wider social context in which people live (Bender & Cheston, 1997). These behaviours are viewed as 'difficult' and as part of the dementing process, instead of being seen as interpersonal communications which are meaningful (Kitwood, 1993, Cotrell & Shulz, 1993). Consequently, psychological and psychosocial interventions that could maximise the quality of life of the sufferer have been neglected, as medication has been seen as the only treatment option.

Over the last decade there has been a paradigm shift in dementia research (e.g. Moyes & Christie, 1998), which involved a transition from sufferers being what Lyman, (1989) called "hidden victims", because their experience of the disease was ignored, to their being the essence and focus of research, treatment and care planning. Recent research has shown that discovering and acknowledging the individual in dementia is vital in gaining an understanding of the illness (Cotrell and Shulz, 1993), and that the central issue is 'personhood' (Kitwood and Bredin, 1992). The previous, narrow approach excluded an invaluable avenue of investigation based on the assumption that the individual is an "expert on their own life" (Stalker, 1999). This recent realisation has led, through talking to sufferers about their experiences of their illness and care, to the development of new and adapted therapies which have at their core, the belief in the essential nature of the subjectivity and uniqueness of individuals. Their aim, therefore, is to maximise the

‘interpersonal process’ where, by accessing the rich emotional life of dementia sufferers, meaningful interactions can occur (Kitwood, 1993).

Although a very different illness, the analogy of dementia with AN can teach us important lessons about researching, understanding and treating AN. Unlike in dementia, psychological intervention in anorexia is a first line treatment. However, the dearth of research into the subjective experience of anorexia illustrates the view of all anorectics being, in essence, the same, without individual characteristics – just a manifestation of a disease. Autobiographical accounts of the illness support the perception of those with AN not being cared for as individuals whilst in hospital. In her account of her hospitalisation for AN, for example, Fiona (in Shelley, 1997, p.22) states that “the aim of treatment seemed to be a case of fattening me up and sending me home”. This is similar to simply medicating an individual with dementia, so as to remove some of their ‘symptoms’.

The very nature of in-patient treatment for AN means removing the child or adolescent from the wider social context in which they live. As with dementia, difficult behaviours and observed resistances to treatment are often attributed to “the manipulative” or difficult “patient” (Honig & Sharman, 2000). AN is a secretive and often a deceitful illness. Whilst it is undeniable that anorectic patients can manipulate their families, friends, medical and nursing teams (Lask & Bryant-Waugh, 1997), it is often the case that resistance is the patient’s attempt to communicate a very real concern or unhappiness, especially at the beginning of their admission, where they are in an environment and surrounded by people entirely other to that to which they are used. In

such instances it is at best neglectful, and at worst negligent, to ignore such communications by putting them down to the manipulative or difficult patient.

As with dementia, listening to patients with AN talk about their experiences of the illness and of treatment is bound to increase our understanding, and guide us towards new avenues for research and treatment of this troublesome, complex and disturbing condition. It is surprising too that in today's NHS culture of 'evidence based practice', evidence showing the benefits of treatments for AN is so sparse when it should be vital, both in terms of providing the most cost-effective treatments, but also ethically, in really thinking and examining what treatments anorectic patients find most helpful.

RATIONALE AND AIMS OF THE PRESENT STUDY

The literature on AN shows how debilitating, dangerous and potentially fatal an illness it is (e.g. Bryant Waugh & Lask, 1995; Todd & Treasure, 1997). The origins of AN are complex and multi-causal (Andersen et al., 1997; Lask, 2000). The long-term prognosis and outcome of AN seem to be poor, with many patients frequently relapsing and requiring multiple hospital admissions (Steinhausen et al., 2000; Zipfel et al., 2000). Although the existing research is wrought with methodological difficulties (Shoemaker, 1997; Hsu, 1992; Shaw & Garfinkel, 1990; Steinhausen & Glanville, 1983c), the severity and chronicity of the illness can not be underestimated. Despite ever increasing research into AN itself and treatments for it, such studies show that the outcome is not improving.

One of the dilemmas in treating AN is whether or not to admit patients for intensive, in-patient treatment. This dilemma is intensified with children and adolescents, as, in admitting young people, one removes them from their family, school, friends and environment, usually for a period of some months.

There seems to be little empirical data to suggest that in-patient treatment for this group is best (Garfinkel et al., 1987; Morgan et al., 1983). Such treatment has been found to be effective in the short term as it restores patients' weight, thereby removing the imminent physical danger in which they were in prior to admission. However, some researchers have concluded that hospitalisations ultimately lead to a poorer long-term outcome than does out-patient treatment (Gowers et al., 2000; Nozoe et al., 1995; McKenzie & Joyce, 1992; Walford & McCune, 1991; Morgan et al., 1983).

The transtheoretical model of stages of change (DiClemente & Prochaska, 1982; Prochaska & DiClemente, 1983; Prochaska et al., 1985) offers one way of trying to integrate the literature and understand the inconclusive outcome data. This model suggests that patients have to be ready for change if treatment is to work. Unless they are either at the 'preparation' or 'action' stage, change is unlikely to occur. The implication of this is that if patients are in the stages of 'precontemplation' or 'contemplation', it is important to work on their stage of change rather than purely trying to change their behaviours. The link between eating disorders and stage of change is only just beginning to be explored. Ward et al.'s (1996) study offers promising results and gives indications of some of the cognitive processes used by patients to achieve change in the different

stages. Such a model seems highly relevant to AN and it offers both an understanding of why relapse is so common and admissions so frequently unsuccessful in the long-term.

Research exploring how those with AN perceive and understand their illness has been largely neglected. The new, person centred research in dementia (Kitwood, 1993, 1997; Cotrell & Schulz, 1993) illustrates the importance of listening to patients' accounts of their illness and current life, in giving us an understanding of the illness, which can then be used to guide research and clinical practice. The same would undoubtedly be true of young people with AN. The absence of qualitative, phenomenological research in eating disorders is seen by Hepworth (1994), as "being a weakness in developing theory and clinical practice" (p.179).

The present study aims to explore the views of adolescents on in-patient, specialist eating disorder units about their treatment. A 'discovery-oriented', phenomenological approach has been taken because its focus is upon an individual's experience of their world, and the diversity and variability of individual experiences (Willig, 2001). In accordance with this, this study aims to obtain an in-depth view of individuals' experiences of their anorexia and life on an in-patient eating disorder unit. It is hoped that these findings will contribute to our understanding of what it is like for young people with AN to be hospitalised for extended time periods. In turn this might inform future treatment plans, and potentially move both treatment and research towards a more patient centred focus, as has so successfully occurred in the field of dementia.

RESEARCH QUESTIONS

Preliminary Questions

The two preliminary research questions are intended to set the context for the main research question. They will be addressed using quantitative measures.

1. How do young people with AN perceive their stage of, and readiness for, change?
2. How do they perceive the eating disorder unit, in terms of ward atmosphere, satisfaction with, and overall helpfulness of, the unit?

Main Research Question

This research question will be addressed using a qualitative approach.

How do young people with AN experience their treatment on in-patient, specialist eating disorder units?

CHAPTER 2 ~ METHOD

OVERVIEW

Semi-structured interviews were conducted with 19 adolescents receiving in-patient treatment for anorexia nervosa. Interpretative Phenomenological Analysis (IPA) was used to analyse the data. This chapter has five main sections. The first will describe the setting in which the research took place, the second, ethical considerations, the third, participants, the fourth, measures used and the fifth, analysis of the qualitative data.

THE SETTING

As the patient turn over on adolescent eating disorder units is small and each eating disorder unit has on average 10 beds, there were two units from which participants were recruited. Both units were regional NHS units, but both took out of area referrals. To ensure confidentiality they shall be referred to as Unit 1 and Unit 2. Further, in accordance with the conditions upon which permission for this study was given, no comparisons between the units will be drawn.

Adolescent eating disorder units in general are more like therapeutic communities than hospitals, with the unit generally becoming the patient's home for a minimum of three months, but more often about six months. Typically they have around ten beds each and

are self-contained. Adolescents eligible for admission to in-patient eating disorder units are usually aged between twelve and eighteen, have lost a large amount of weight and are seriously emaciated, often showing the physical complications of starvation, although admission criteria vary between units. AN is the most common reason for admission, but patients with severe bulimia and pervasive refusal are also sometimes admitted. Although weight restoration is a major treatment goal, individual and family therapy is viewed as an essential component, in order to help the adolescent and their family understand why the anorexia developed and to think about relapse prevention.

The basic components of the treatment offered by the two units were similar, but the units had a different ethos thus emphasising different treatment components. Both units have a school and so patients attend school, with breaks for meals / snacks and which can be interrupted for therapy. On both of the units daily exercise was included and patients had individual cognitive therapy weekly, and family therapy at least fortnightly. Unit 2 offered art therapy which was optional, and Unit 1 included compulsory motivation enhancement therapy. One difference in the treatment regimes of the two units was in the slightly different meal regimes: for example on Unit 1, patients ate three meals a day. On Unit 2, patients ate three meals and three snacks each day. In addition Unit 1 used naso-gastric feeding as a means of re-feeding patients less often than did Unit 2.

Information about the ethos of the two units was gathered from discussions with the respective consultant psychiatrists and nursing teams, and the ethos differed more significantly than did the treatment regimes. Unit 1's ethos was collaborative and patients

were involved in decisions about their treatment, for example as to by how many calories their diet plan increased each week. Despite the collaboration between staff and patients, no debate was permitted about whether patients completed meals, and naturally the ultimate treatment decisions lay with the medical and nursing team. From admission, patients were involved in a strong programme of rehabilitation, which included liaison with their schools, frequent contact with their friends and regular family meals. The maximum length of stay allowed was 6 months, and if this meant that re-admission would be required at a later date, then discharge nonetheless occurred. The rationale for this was to try to prevent patients from viewing and choosing the unit as their home, and thereby becoming 'stuck', avoiding discharge (consciously or otherwise) for long time periods.

The culture of Unit 2 was a less collaborative and less lenient one than Unit 1 and patients were less autonomous. Rehabilitation began at a later stage on Unit 2, as patients were not allowed to go home, even for one day until they had reached a certain weight for height. There was no maximum length of stay on Unit 2, and, indeed, many patients had been there for around 9 months.

ETHICAL CONSIDERATIONS

Ethical approval for this study was granted by two local ethics committees (see Appendix 1).

Minimising the potential distress of participants was of paramount importance in designing this study. In terms of recruitment, the preferences and protocols of each unit was followed, so as to cause the least amount of confusion and disruption to the young people. In addition, parents were not contacted until after consent had been gained from the patients themselves. This was so that there could be a discussion with participants about their parents having to give consent, and any problems with this raised, and also in an attempt to remove potential pressure from parents for their child to participate and 'help others with anorexia'.

It was decided that individual interviews with participants instead of focus group discussions would both maximise the opportunity for participants to speak freely about their experiences and minimise the possibility for them to feel pressured into talking by other patients. It was also hoped that this would help participants to feel that what was discussed was wholly confidential.

PARTICIPANTS

Inclusion Criteria

The study included 19 adolescents aged between 12 and 17 years old who had been diagnosed by their consultant psychiatrist as having primary anorexia nervosa. Although boys do get AN and are sometimes admitted for in-patient treatment, it is still a rare occurrence (there was only one male on one of the units and none on the other during the

course of the study). Thus for the purposes of this study only female adolescents with AN were included.

All participants had to be current in-patients on one of the two adolescent eating disorder units from which participants were recruited. However, one participant was interviewed twelve days after she was discharged as she and her family had decided that they wished to celebrate immediately following her discharge meeting, which was the original time of our interview. One other participant was classified as a 'day patient' which meant that she lived close enough to the unit to sleep at home. This was all that she did at home, as she ate every meal on the unit, arriving at 7.45 a.m. and going home at 8.00 p.m., an hour after the end of dinner and her treatment regime was exactly the same as the other patients on this unit. She was therefore included in the study.

Recruitment Procedures

Participants at the two units were approached differently due to differences in existing research procedures at the units. Unit 2 carried out much research and so had research assistants whose job it was to recruit participants for any research done at the unit. In contrast, Unit 1 did little research, and so I recruited all of the participants from Unit 1. For both units, however, consent was obtained from the participants before parents were contacted. This was due to the ethical reasons mentioned above, and to minimise potential confusion that could be caused by parents giving consent, but their children not wishing to be interviewed.

Unit 1: Having initially spoken to the consultant psychiatrist and clinical nurse specialist about the project, I visited the unit to attend a meeting with the patients. The meeting had been set up by the clinical nurse specialist for my visit, as she advised that the patients had formed a cohesive group and would therefore be best approached as a group. At the meeting with the patients I explained the study, answered any questions that were raised, gave potential participants information sheets (see Appendix 2) and discussed each point in the information sheet. Participants were assured of the confidentiality of the interviews and of their anonymity. Consent (see Appendix 2 for consent form) was obtained from five patients who were, at that time, willing to be interviewed. The information sheet contained my telephone number, and participants were told that they could contact me at any time. After this initial meeting further recruitment was done on an individual basis whenever I was at the unit interviewing participants.

Having obtained consent from participants, I then obtained the contact details of the parents of the patients who had agreed to participate, from the medical or nursing notes. All participants were informed that their parents would be contacted and their consent obtained prior to the interview, and all were agreeable. A letter explaining the study, a parent information sheet and a parental consent form (see Appendix 2) was then sent to parents, along with a stamped addressed envelope in which they could return the consent form. Both the letter and the information sheet contained my telephone number so that parents were able to ask any questions that they might have. If parents returned the consent form within one week they were not contacted by telephone. If they had not contacted me, or returned the consent form within one week, then they were contacted to

enquire whether they had received the study information and whether they had any questions.

Unit 2: As mentioned above, Unit 2 had research assistants who knew patients well and who therefore discussed the research with them and obtained their consent. This was done on an individual basis and in close collaboration with me. Again, once participants' consent had been obtained parents were contacted in the same way as with Unit 1.

Characteristics of the Sample

Nineteen female patients with AN agreed to participate in the study. In Unit 1, eighteen patients were approached, ten agreed to participate and eight declined. It is not known how many patients in Unit 2 declined to participate because the initial recruitment, as described above, was conducted by the unit's research assistants. The age range of the sample was 12 to 17 years, with a mean age of 15.4 years. Only two participants, however were younger than 14. Seventeen participants (89%) were white British, 1 (5%) was white Irish and 1 (5%) was British but of Afro-Caribbean origin. The mean illness duration was 23 months (SD 12.4 months) from the onset of anorexia, with a range of 10 to 60 months. Only one patient's anorexia had lasted for more than 36 months; excluding her, the mean illness duration was 21 months (SD 8.9 months). One (5%) participant was under a section and the rest (95%) were informal patients. 4 (21%) participants had had no previous admissions, 6 (32%) had had one admission to a paediatric ward of a general hospital, 7 (37%) had had more than one previous admission to an eating disorder, or

paediatric unit. Participants had a range of other problems including co-morbid depression, obsessive compulsive symptoms, deliberate self-harm and suicidal ideation. 8 (42%) were taking anti-depressant medication, 2 of whom (10.5%) were also taking other psychotropic medications. Additional data on participants' perceptions of the ward atmosphere and participants' stages of change will be presented in the results chapter.

RESEARCHER'S PERSPECTIVE

It is good practice in qualitative research for the researcher to state their personal biases that might have an influence on that research (Elliott, Fischer & Rennie, 1999). The idea for this research arose from my previous clinical and research work in eating disorders generally, and on an adolescent in-patient eating disorder units in particular. I was struck by how 'stuck' were many patients who had had multiple admissions to different eating disorder units, over a period of years, and did not seem to make progress or recover. Informal conversations with patients suggested that they felt that they were there to be re-fed, 'fattened up and then sent home', which was not seen as helpful. Similarly, patients frequently said that the treatment was not working and that their views were invalidated because it was the 'anorexia speaking' and not a thoughtful, healthy individual. Thus I began to believe that in-patient treatment for AN might be detrimental and wondered how patients experienced their admissions and how they thought that their treatment could be improved. My theoretical orientation was influenced by my current work in the

Adolescent department of the Tavistock Clinic, London. As such, the theoretical models that guide my thinking have been predominantly psychodynamic and systemic.

MEASURES

Procedure

Each interview was arranged in conjunction with the nursing team on the units so as to cause minimal disruption to participants' routines and inconvenience to the staff. All interviews took place in the unit and lasted for between fifty minutes and one and a half hours. No interviews lasted for longer than an hour and a half and I reassured people that they could stop or have a break at any time. At the beginning of the interview participants were reassured of the confidentiality of the interviews and of their anonymity, in that all interviews and questionnaires were given a patient code, and that all names would be removed from the interview transcript. At the end of each interview, participants were asked to complete three brief questionnaires which took between five and fifteen minutes to finish. Finally, participants were given an opportunity to talk about how the interview had felt and ask any questions that they might have. If they no longer had the study information sheet, I gave them my telephone number should they wish to ask questions or discuss the interview in the future. In practice no participants did telephone me following the interview.

After each interview I systematically read through the participant's medical notes to obtain some demographic data such as their age, diagnosis, onset and duration of illness,

family background and other relevant information, for example whether they self-harmed and were on medication. Never were the notes read prior to the interview. This was to minimise the number of pre-conceptions with which I conducted and could influence the interview, and to prevent my becoming side-tracked by potentially irrelevant information obtained whilst reading the participants' notes. It was also hoped that if I knew very little about each participant, participants would be more forthcoming with their experiences of their treatment, as the participant would feel that they had a 'clean slate'. Finally after analysing all of the interviews, I sent participants and their parents a short summary of the study's conclusions.

Semi-structured Interviews

A semi-structured interview schedule was designed specifically for this study (see Appendix 3). It served as a guide which allowed exploration of new areas that emerged during the course of the interview. Interviews lasted for between 50 and 90 minutes and all were tape-recorded.

The interview focused on the experiences of in-patient treatment of the individual with anorexia and the style was one of 'directed conversation' (Pidgeon & Henwood, 1996). Thus the format was to pose open questions which facilitated disclosure and thought and did not request specific answers. For example, the first question, once a rapport was established with the participant, was: "What do you find helpful and unhelpful about your treatment here?" However, as highlighted by Pidgeon and Henwood, there is a need to

balance the researcher's desire not to limit and constrain the participant's responses and the need for the interview to remain focused on the research topic. In this study, therefore, follow-up questions and prompts were used to re-focus participants if it seemed that participants' answers had drifted too far from the research area. Similarly, care was taken to follow participants and only return to topics on the interview schedule if they had not been covered towards the end of the interview.

The interview schedule contained nine sections which were covered, in a flexible order and varying degrees of detail, in each interview.

1. Getting to Know the Patient. The main purpose of this section was to establish a rapport with the participant and to help them feel as relaxed as possible. The section began with a brief statement about the aims of the study, confidentiality and anonymity before asking participants about why they were on the unit and what it was like for them to be there.
2. Treatment. The aim of this section was to explore what participants found helpful and unhelpful about their treatment and ways in which they felt it could be improved.
3. Being with Others in the Same Situation. This explored what how participants felt about being with other anorectics, who were in a similar position to themselves and what were the pros and cons.
4. Being away from Home, School, Family and Friends. This part considered patients' experiences of, and thoughts about, being away from their 'normal, outside' life and whether they found it helpful to their treatment or not.

5. Relationships with Staff. This section aimed to discover whether participants believed that their treatment was affected by their relationships with staff, and if so, in what ways.
6. Trust and Responsibility. This explored how patients viewed the amount of trust and responsibility that they were given and how they felt this affected their treatment.
7. Other Questions. This section was primarily a prompting section, referred to only if therapy had not arisen in previous discussion. It aimed to consider the role that the different therapies played in the patients' treatment and their thoughts about this.
8. The Anorexia. The purpose of this part of the interview was to discuss the participants' experience of the anorexia itself. What was it like for them to have AN? What were the possible benefits, and what would be their ideal treatment plan?
9. Closing the Interview. This was just an opportunity for participants to clarify any points raised during the interview, ask any questions, and for the researcher to thank participants for their participation.

Questionnaires

Three self-report measures were administered and used for descriptive purposes, to add to the information gathered in the interview about how participants perceived the unit, and their readiness to recover and change.

The Ward Atmosphere Scale (WAS: Moos, 1996)

Participants completed the short form of the WAS (see Appendix 4), which is a self-report measure, designed for both staff and patients, that assesses respondents' perceptions of the ward atmosphere. The full scale consists of 100 descriptive statements pertaining to the atmosphere on the ward, against which respondents are asked to mark 'true' or 'false'. The items make up 10 subscales - Involvement, Support, Spontaneity, Autonomy, Practical Orientation, Personal Problem Orientation, Anger and Aggression, Order and Organisation, Program Clarity and Staff Control - with 10 items per subscale. The short form of the WAS consists of the first 40 items of the full scale. This means that each of the 10 subscales has 4 instead of 10 items. It was used in this study for the sake of brevity and because it was being used for descriptive purposes only.

Moos (1996) reports good reliability for the WAS, based on data obtained from 160 American psychiatric wards and 36 British wards. Test-retest reliabilities over one week for the 10 subscales were "adequate", with values ranging from .68 to .83; test-retest reliabilities over longer time periods remained stable at around .70. The short form yielded profiles that were extremely similar to those obtained with the full scale, demonstrating that it too has good reliability. The internal consistencies of the subscales have also been found to fall in the "acceptable range", ranging from moderate (e.g. Support, .65 and Spontaneity, .55) to substantial (e.g. Involvement, .78 and Anger and aggression, .76).

The WAS has been shown to have good validity (Moos, 1996). Although Moos does not discuss the validity of the short form, he does state that it is very similar to that of the full scale measure.

Stage of and Readiness to Change (Jordan, 2001)

This self-report measure (see Appendix 4) assesses which stage of change participants are at, and how ready they are to change specific dieting behaviours. It is quick to complete and easy to use. The first question on this questionnaire is a discrete single-item measure, based on the transtheoretical model of change (DiClemente & Prochaska, 1982; Prochaska & DiClemente, 1983). It ascertains at which of 5 stages of change – precontemplation, contemplation, preparation, action or maintenance – participants view themselves in relation to their anorexia and respondents tick the statement that best describes themselves. The Maintenance (fifth) stage was removed from this question as all participants were still in in-patient, intensive treatment and so none would be maintaining a change in eating behaviour that had already lasted for more than 6 months. The measure has a correlation of $r = .58$ with the EAT-26 (Garner & Garfinkel, 1979; Garner, Olmstead, Bohr & Garfinkel, 1982) suggesting adequate validity (Jordan, 2001).

The second part of the questionnaire (Jordan, 2001), is also drawn from the transtheoretical model of change (DiClemente & Prochaska, 1982; Prochaska & DiClemente, 1983). It is an eight-item scale that measures participants' readiness to change specific behaviours and attitudes associated with anorexia nervosa, such as 'trying

to be thinner' and 'dwelling on the calorie content of foods I eat'. Items are based on those used in the EAT-26 (Garner et al., 1982) and participants are asked to indicate their readiness to change on a five-point Likert scale, ranging from "not at all ready to change" (1), to "no longer or never was a problem"(5). Jordan reported that the eight-item scale has high internal consistency (Cronbach's alpha = .89).

Satisfaction with the Unit (Larsen et al., 1979).

This questionnaire (see Appendix 4) consisted of four out of the eight items of the Client Satisfaction Questionnaire (CSQ-8: Larsen, Attkisson, Hargreaves & Nguyen, 1979). The CSQ was developed to assess how satisfied clients of health services are with the service that they received. Participants are asked to indicate their satisfaction on a 4-point scale, ranging, for example, from "None of my needs are met" (1) to "Almost all of my needs are met" (4). Larsen et al. report that the four items used in this study have been aggregated into a scale with a coefficient alpha of .76.

Overall Helpfulness

A final question (question 5 on the 'Satisfaction with the unit' questionnaire: see Appendix 4) was adapted from Elliott's and Wexler's (1994) Session Impacts Scale. It is a single item, global measure of helpfulness and participants are asked to rate on a scale of 1 (extremely unhelpful) to 9 (extremely helpful) how helpful overall they found the unit.

ANALYSIS OF QUALITATIVE DATA

All interviews were transcribed verbatim, and any details that might identify either the unit, participants or staff were excluded to ensure confidentiality (see Appendix 5 for an excerpt of an interview transcript). Transcripts were then analysed using Interpretative Phenomenological Analysis (IPA; Smith, Jarman & Osborn, 1999).

Rationale for using IPA

IPA was designed specifically as a psychological research method. It is a phenomenological approach and is thus interested in the world as experienced by individuals within particular contexts and at particular times as opposed to being interested in discovering objective truths. Unlike Grounded Theory, IPA is not attempting to develop comprehensive theories about the phenomena under investigation, from participants' accounts of their experiences. Instead it is concerned with gaining understanding and insight into the nature and essence of individual experiences and it is participants' accounts that become the phenomenon with which the researcher engages. In addition, IPA is still a relatively new and developing research approach and it is not associated with debates and controversies that now surround Grounded Theory (Willig, 2001). It is therefore a method that invites the researcher to explore the data freely and with creativity.

IPA aims to explore in detail the participant's view and beliefs about the subject being discussed. It is "concerned with an individual's personal perception or account of an object or event as opposed to an attempt to produce an objective statement of the subject or event itself" (Smith et al., 1999, p. 218). A dual approach to the analysis is implied in the term 'interpretative phenomenological'. Smith (1995) describes this as being represented by an attempt to understand participants' psychological, internal worlds from the examination of their overt communication, as well as the researcher's own interpretations of the text that can clarify less 'transparent' meaning. Thus the approach is both phenomenological and interpretative respectively. IPA recognises the complications caused by this dependency and acknowledges that although an individual's thoughts are not transparent, the analytic process hopes to be able to comment upon that individual's thinking.

Stages of analysis

Several stages are involved in the process of 'looking for themes' in the data (Smith et al., 1999). First, the researcher reads the transcripts several times and notes their meanings and associations. Secondly, these notes are distilled into tentative theme titles which capture the essential meanings. Thirdly, these titles are further refined with reference to the original transcript and quotations illustrating each theme title are noted. Fourthly, the themes are hierarchically ordered into themes and sub-themes before finally, quotes from the transcripts are added to illustrate the overall themes. Once this has been done for one transcript, the theme titles can be used to analyse further

transcripts, which again can be refined or added to as necessary. Lastly a cross-case analysis is conducted in which individual cases are integrated in the identification of themes that reflect the experiences of the sample as a whole.

Credibility Checks

A credibility check of the themes resulting from the analysis was undertaken by a second researcher experienced in IPA. This researcher read over two thirds of the transcripts independently, following which she and I discussed the ideas and potential themes before arriving at a consensus about the main themes and sub-themes. Following the cross-sample analysis I produced a tentative organisation of the themes and sub-themes and then discussed them with the second researcher. The initial organisation was then modified and examined once more by the second researcher, who looked at the extent to which they most accurately represented the data. Following discussion, a final set of themes and sub-themes was agreed upon.

CHAPTER 3 ~ RESULTS

This chapter has two sections. The first sets the context for the second, and addresses the preliminary research questions: how participants perceived their stage of change and readiness to change, and how they perceived the unit in terms of ward atmosphere, overall helpfulness of, and satisfaction with, the unit. The second section discusses participants' experiences of being on an in-patient eating disorder unit and their treatment.

SETTING THE CONTEXT

Perceptions of the Unit – Ward atmosphere, satisfaction and helpfulness

Table 1 shows participants' scores on the Ward Atmosphere Scale (Moos, 1996), which measures patients' views of the ward environment. Data from a normative sample of 160 American, adult psychiatric in-patients are also presented for comparison. No normative data was available for adolescent in-patients.

Table 1: Ward Atmosphere Scale (Moos, 1996) Means and standard deviations for patient participants and the normative sample

| Sub-Scale | Participants (n = 19) | | Normative Sample (n = 160) | | t |
|---------------------------------|--------------------------|------|-------------------------------|------|----------|
| | Mean | SD | Mean | SD | |
| Involvement | 2.16 | 1.17 | 2.18 | 0.61 | 0.00 |
| Support | 2.32 | 1.38 | 2.04 | 0.54 | 0.9 |
| Spontaneity | 1.63 | 1.16 | 1.9 | 0.57 | 1.04 |
| Autonomy | 1.63 | 1.16 | 2.53 | 0.51 | 3.46 *** |
| Practical Orientation | 2.42 | 1.43 | 2.49 | 0.49 | 0.2 |
| Personal Problem Orientation | 1.47 | 1.07 | 1.97 | 0.61 | 2.08 * |
| Anger and Aggression | 3 | 1.05 | 2.28 | 0.59 | 3 ** |
| Order and Organisation | 1.47 | 0.96 | 2.49 | 0.59 | 4.64 *** |
| Programme Clarity | 2.21 | 1.36 | 2.16 | 0.54 | 0.16 |
| Staff Control | 2.47 | 0.84 | 2.14 | 0.61 | 1.65 |

* $p < .05$, ** $p < .01$, *** $p < .001$

On all of the subscales, possible scores range from 1 to 4, where higher scores indicate greater endorsement of that scale and lower scores are indicative of lower endorsement.

Overall, participants viewed the ward environment as being relatively high on involvement, support, practical orientation, programme clarity and staff control. Anger and aggression, personal problem orientation and order and organisation were perceived as being relatively low on the units.

The scores of this sample and the normative sample are similar on 6 of the subscales, but significantly different on Autonomy, Personal Problem Orientation, Anger and Aggression and Order and Organisation.

The satisfaction with the unit was rated on a 4-point scale, ranging from 1, “None of my needs are met” to 4, “Almost all of my needs are met” (Larsen et al., 1979). The mean score for the sample was 2.38 (S.D. = 0.8, range 1.25 to 4). As can be seen in table 3, 9 participants had a mean score of 2 or less, showing average or less than average satisfaction with the unit, and 10 had a score of greater than 2, indicating better than average satisfaction with the unit.

The overall helpfulness of the unit was rated on a 10 point Likert scale ranging from 1, “not at all helpful” to 10 “extremely helpful” (Elliott & Wexler, 1994). The mean score for the sample was 5 (S.D. = 2.73, range, 1 to 8). As can be seen in table 3, there was a bimodal distribution – 11 participants found the unit helpful (scores of 6 and above), 7 found it unhelpful (scores of 1 to 4) and one related it as neutral.

Stage of change and readiness to change

Table 2 shows how many participants were at each of the four stages of change (Jordan, 2001). In this study the fifth stage of maintenance was omitted because by definition, if participants were still on an in-patient unit they were not yet maintaining their change.

Table 2: Participants' stage of change.

| Stage of change | Number of participants |
|----------------------|------------------------|
| 1 (Precontemplation) | 3 |
| 2 (Contemplation) | 6 |
| 3 (Preparation) | 1 |
| 4 (Action) | 9 |

Almost half (47%) of the sample related themselves as being in the action stage: positively making changes to their behaviour in order to get well. About a third (32%) were in the contemplation stage: thinking about change, but not yet ready to act. Three (16%) participants were in precontemplation: not yet thinking about recovering from AN.

Readiness to change across 8 attitudes and behaviours associated with AN, was rated on a five-point Likert scale, ranging from 1, "not at all ready to change" to 5, "no longer or never was a problem". The mean readiness to change for the sample was 2.77 (S.D. = 1.2, range 1 to 4). As shown in table 3, 7 participants were not thinking about change (scores of 1 and 2) and 12 were thinking about, or actively trying to change (scores of 2 to 4).

Table 3 describes the sample as a whole. The age, illness history, stage of and readiness to change scores and overall helpfulness rating for each participant are presented.

Table 3: Participant (P) information: demographic and questionnaire data

| P | Age | Total Illness Duration | No. of previous admissions | Length of time on unit | SoC | RtC | CSQ-8 score | Overall Helpfulness rating |
|----|-----|------------------------|----------------------------|------------------------|-----|-----|-------------|----------------------------|
| 1 | 17 | 36 months | 1 | 6 weeks | 1 | 1 | 2.5 | 7 |
| 2 | 17 | 36 months | 4 | 9 weeks | 2 | 1.9 | 2 | 5 |
| 3 | 16 | 18 months | 0 | 14 weeks | 2 | 2.9 | 2 | 6 |
| 4 | 12 | 12 months | 1 | 5 weeks | 4 | 4 | 3 | 7 |
| 5 | 15 | 12 months | 0 | 5 weeks | 2 | 2.9 | 3 | 7 |
| *6 | 15 | 21 months | 1 | 12 weeks | 3 | 1.5 | 1.5 | 1 |
| 7 | 14 | 15 months | 0 | 12 weeks | 4 | 3.4 | 2.75 | 8 |
| 8 | 17 | 12 months | 1 | 11½ weeks | 4 | 3.8 | 3.25 | 8 |
| 9 | 16 | 20 months | 0 | 7 weeks | 2 | 1.9 | 3.25 | 8 |
| 10 | 17 | 12 months | 0 | 5½ weeks | 4 | 4.5 | 4 | 8 |
| 11 | 17 | 32 months | 1 | 14 weeks | 4 | 3.6 | 2.75 | 6 |
| 12 | 15 | 18 months | 1 | 20 weeks | 4 | 4 | 3 | 7 |
| 13 | 17 | 27 months | 3 | 9½ weeks | 1 | 1 | 1.25 | 1 |
| 14 | 13 | 17 months | 0 | 18½ weeks | 4 | 2.4 | 1.5 | 2 |
| 15 | 14 | 10 months | 1 | 8½ weeks | 4 | 4.1 | 3 | 7 |
| 16 | 14 | 24 months | 0 | 3 weeks | 1 | 1.1 | 1.75 | 2 |
| 17 | 14 | 36 months | 1 | 17 weeks | 2 | 3.9 | 1.5 | 2 |
| 18 | 16 | 60 months | 3 | 6 weeks | 2 | 1.5 | 1.75 | 3 |
| 19 | 16 | 22 months | 3 | 11 weeks | 4 | 3.3 | 1.5 | 1 |

* On a section

SoC: Stage of change

RtC: Readiness to change

CSQ-8: Satisfaction with the unit

PARTICIPANT ACCOUNTS

Analysis of the transcripts of participants' accounts yielded a number of themes and sub-themes (see Table 4). These themes are not mutually exclusive: inevitably there is some overlap. In all themes participants experienced much conflict, both internally and externally. Themes 3, 4 and 5 reflect the conflicts experienced by participants.

Table 4: Overview of Themes and Sub-themes

| Themes | Sub-Themes |
|---|--|
| 1. What is this illness that I have? | It's my friend It's my enemy The murderous monster The battle that is Anorexia |
| 2. Do I want to get well? | |
| 3. Being with others: support vs. distress | Understanding and support Comparisons and competition Becoming "illier" Fear and upset caused by others |
| 4. Being an individual vs. just another anorectic | Weight restoration vs. psychological help Support and flexibility vs. rigid enforcement of rules Feeling cared for vs. feeling neglected |
| 5. Collaborating in treatment vs. being treated | Feeling helped by structure vs. feeling punished by restrictions Can I use freedom and responsibility or will I abuse it? Wanting to comply vs. wanting to rebel |

Two distinct themes arose in the qualitative data which seemed essential to understanding participants' experiences of the unit and their treatment. These are themes 1 and 2 in the above table - how participants saw their anorexia and their stage of change.

Excerpts from the transcripts that are used in this section have, in some instances been edited for concision and brevity. Where editing has occurred, three dots "...” represents this. Where dialogue is presented, "I" refers to Interviewer and "P" to participant. Where the interviewer has interjected in the participant's speech, this is indicated by text in italics and square brackets [xxx]. The source of each quotation is indicated by the participant number.

What is this illness that I have?

All participants spoke about their illness and how they saw and felt about it. There was great variation in participants' perceptions. Some viewed their AN as a friend which gave them confidence, safety and security, whereas others felt it was a depriving, murderous, suffocating enemy. For some participants, their AN was their identity and thus without it they said that they would be lost. One thing, however, that was unanimously felt, was that the AN was addictive illness which snowballed and deteriorated very fast. The majority of participants experienced much conflict about their illness, saying that it was both good and bad, helpful and deleterious simultaneously.

It's my friend

Many participants described their anorexia as being their friend. It was experienced as being a shield to hide behind, an escape, a coping mechanism and something which removed responsibility and instead gave confidence, security, power and safety.

“Sometimes I think it’s sort of my friend and if I didn’t have it I’d just be totally on my own.” (16)

The sense of protection that the AN gave some participants is illustrated in the next two excerpts. The participant speaking in the second excerpt acknowledges how stifling her AN can be but still feels that it is safer and preferable to being in the ‘real world’.

“I think for me it numbs a lot of my emotions, it protects me from feeling all the that [*Right*] and it kind of when I’m losing weight is when I’m happy.” (1)

“I guess having anorexia was like having a bit of a shield [*Mmm, mmm*] um and although you often like suffocate in a closed box it’s better than being out in the real world, sometimes.” (3)

For some, their anorexia was a way in which they could not be noticed and disappear, literally, but without being responsible as they would if they actively committed suicide.

“I say that I probably was pretty suicidal [*Right*] and I developed anorexia and it was the idea of diminishing but not being responsible for it [*Right*] I didn’t like the idea of doing anything and feeling selfish for doing that ‘cause it would’ve hurt my family who I’m really close to and you know everyone else being affected whereas the idea of just disappearing slowly...” (3)

“I wanted my weight to keep going down and down because I wanted to like

disappear [*Uh-huh*] and when you've got like loads of food in you and get you fatter and fatter you're just noticeable so much." (17)

Some participants felt that their anorexia was their whole identity. It made them who they were.

"It's the hardest illness I've ever, ever been through but it's the one I like the most (laughs) because it's... to me it's like this anorexia is like me as a person and I'm just the outside bit of it I suppose." (1)

"I need it and without it I don't know what I'd be..."; "...but because I can't find any bit of me inside me then I don't really know what it's like to have me. I can't really tell the difference." (17)

"Um. Sometimes it feels like it's me, that's just the way I am." (19)

"It just feels it's my life...It just doesn't feel in my control, really" (6)

For the following participant, the AN is not her identity, but it is what she feels is her achievement that distinguishes her from others. To take it away from her then, by treating her, can be seen as removing what she sees as the one thing that makes her unique.

"...it's something that I achieved...I've you know something that I've achieved and no one else has done it and they said you know, but we just want to get you normal, but I don't want to be normal..." (16)

It's my enemy

For many, anorexia was an enemy. It was seen as suffocating, frightening, selfish, addictive, isolating and depriving.

“I see it as my enemy completely [*Really?*] It just took so much away from me.” (8)

“I see anorexia as an enemy and I really hate it. Because when I started off it wasn’t about, it was just that I wanted to be a bit thinner, and I do feel like it’s taking over my life and making it really crap [*Mmm*] Then I can’t kind of get it out of my head.” (2)

One participant described how people changed from being likeable to being “bitches” when in the throes of anorexia. The overpowering, trapping nature of AN is further echoed in the following excerpts.

“They’re such lovely people [the other girls], but when it comes to the anorexia, they’re just bitches. They’re horrible. It just takes them over.” (8)

“I mean I think anorexia’s a very selfish illness...because you’re very wrapped up in yourself and you know your main focus is just on you losing weight and you don’t take other people in to consideration much.” (6)

One participant described her anorexia as being “...the biggest mistake of my life, I never meant for this to happen” (19). For others it was a depriving and punishing illness.

I “...*what it’s like for you actually having anorexia?*”

P “(pause) Gutting.”

I “*Gutting? Can you say a bit more?*”

P “You feel as though you’re being, I feel as though I’m being punished for something I did or something. I don’t understand why out of, I mean I would never ever wish it upon anybody, but I don’t understand why out of a million different people in the street it strikes who it strikes. [*Right. Mm-hm*] And you feel you know you’ve, you just feel that it takes so much time more than anything. I mean I’m never going to be 15 for a summer ever again and this is how I’m spending it. And it’s time lost, I’m never going to get it back.” (5)

The murderous monster

Many participants perceived their AN as being a separate entity, almost like a person or being inside them that was not them. For some it was a monster. For others just a power, an “It” or a “He”, in their heads. On the whole this entity was frightening; however for a minority of participants it was purely another part of them – the bad part, which was relatively benign, despite its overpowering nature. The most vivid and frightening image, of what this participant previously called a monster, is shown in the following excerpt.

“It’s like a monster...like this big thing with claws wrapped around you. But it’s really trapped around your heart, the claws are trapped around your heart and it’s still inside your head but it’s got claws which reach down to your heart and start squeezing your heart and start squeezing your head and, and like the nails digging into your throat and it’s like you can’t get out and you can’t breathe because you’re trapped there and however hard you scream no one can hear you and you know you’re going to die and you know it’s going to be really painful. You just can’t do anything about it.” (17)

If this is the experience of anorexia, it is not surprising then, that as this participant said,

“It’s hard, it’s just like you want someone to put you to sleep so you can get rid of all the pain.” (17)

Another participant described a less terrifying image of anorexia as a separate, yet still overpowering, entity.

“It’s horrible. ‘Cause you don’t know it’s doing it, other people can see it. [Right] And it’s like, but it was taking over and my mum was like “X this ain’t you talking to me, it’s the gremlin inside you” sort of thing, the anorexia [The gremlin?] Yeah. She used to say it’s the other thing inside that’s talking ‘cause you would never be like this, sort of thing. So it does control you and you don’t, even though I didn’t see it, looking back now after being in here I have seen that it did control my life and that’s how I ended up in here sort of thing so...” (10)

The battle that is anorexia

Having a constant conflict and internal battle was described by all participants. That their anorexia was both a friend and an enemy, good and bad and thus incomprehensible was felt by all. Some talked about this in terms of themselves being split in two with one good and one bad part, whereas another reported there always being a “counter argument for everything” and others referred to feeling continually confused. The excerpts below illustrate this range of descriptions.

“That is how I see myself. One part is my enemy and one part is my friend.”
(5)

“...It’s sometimes, it’s, like having schizophrenia. Um, because you’ve got, you’ve got like two, two things in your head, you know. One is like, you know, ‘Oh I’d like to eat that’ and the other is saying ‘you can’t eat that’. And it’s like battling it out in your head and most of the time the anorexia wins.” (4)

“I have like two completely contradicting opinions” (9)

“Um, but they [the bad bits and the good bits] just contradict each other all the time and I don’t know what to do. [*Uh-huh*] And when I do something good the bad bit feels guilty and when I do something bad the good bit gets angry.” (17)

With such internal conflict being rife it is not surprising that being ready to have treatment and recover from anorexia was seen as being seminal to recovery itself.

Do I want to get well?

The key to recovery was unanimously thought to be a desire and a readiness to get well. Without this, participants said that recovery was almost impossible, as the power of the anorexia was such that the determination and resilience required to combat it was too great. Others were conflicted about whether or not they were ready to recover and were evaluating the pros and cons of remaining anorectic or getting well, and others still had no desire to get well. This was particularly the case for the one participant who was on a section. Some participants were tired of having anorexia. They had had enough and wanted to return to a 'normal' teenage life with school and their friends. For many, the main motivation for recovery was for their families and, for a minority, loathing the unit was the impetus. Many participants believed that it was only they who could help themselves as recovery would only succeed when it was for themselves and not others. In other words, their stage of, and readiness to, change was critical.

The following excerpts illustrate the centrality of wanting to get well. The second and third excerpts are taken from participants who were not yet ready to recover.

“...to me the whole illness is about, is about actually wanting to get better.”
(3)

“...it's quite hard at the moment 'cause I'm not ready to get better and I don't want to get better so, that's a bit hard, 'cause I have to want to do it and at the moment I'm not ready so I have to wait 'till I am ready, but I'm not at the moment, so I don't think they are going to be able to help me.” (6)

- I* "...So if we're thinking about treatment, in terms of what would work for you..."
- P* "... it would have to be the right, I'm really sick, I never want this any more and I'd do anything I can not to have it." (2)

For many, however, there was much confusion and conflict about whether or not they wanted to recover and this was not a clear cut decision at all. A feeling clearly voiced by this participant was resonated by many:

"It's like, well, I want to get out of here but I don't really want to put the weight on... You have doubts all the time [*Mmm*] and you're just like 'I don't want to be this weight, so does that mean I don't want to get better?' and you become quite confused sometimes." (7)

The following account reflects the confusion and sense of a 'no win' situation felt by many about wanting to recover. She also, however, refers to not wanting to disappoint her family, thus at least partially wishing to get well, or at least wishing that more of her wanted to get well for them.

- P* "I don't want to have anorexia but at the same time I want to be thin and that's really strange."
- I* "*Right. So that sounds like a bit of a battle.*"
- P* "Yeah. And I can't win really, like if I eat I feel guilty, if I don't eat I feel guilty 'cause I'm disappointing my family, and people, so I just can't really win, it's like a losing battle." (16)

The subsequent participants show the determination and the importance of being ready to change necessary for recover successfully.

“I’m determined that when I go home I won’t stop eating or ever go down this road again, ever...I just don’t want to, I don’t want to be like this anymore.” (15)

“...But in my assessment they said ‘how do you feel?’ and I go ‘to be honest I just want to come in now, you know I’m just sick of it.’” (7)

Participants believed that they had to help themselves but the importance of agreeing with the treatment regime in working on their recovery was also raised.

“If I don’t agree with the help I’m getting then...it’s just like I can’t really help myself ‘cause I don’t feel OK and I don’t think it’s helping me [*Sure*] and I can’t really help myself [*Sure*] if you know what I mean. And everyone says it’s down to me, but I don’t agree with this place, so it doesn’t make me feel better to try and help myself.” (13)

Families often seemed vital in providing support and impetus for their child’s or sibling’s recovery.

“And to see my parents’ faces every single time they had to come in and visit me, it just made me think ‘God, I can’t do this anymore’... And I mean, my family was, they’re very important to me and in a way it was sort of like blackmail like you know, if you don’t sort of put on weight and stuff, then you know, we’re gonna like sort of not talk to you in a way. You know, not, not being horrible, but my dad was like that, you know.” (8)

Friends, normality and having a life ahead was, for many, another impetus for change:

“I thought ‘Hang on a minute’. Something clicked you know, you shouldn’t be in here. You’ve got the rest of your life ahead of you.” (10)

“I mean that’s always what I’ve always sort of craved for, the whole normal thing...Just going out and socialising and discovering things, shopping...And now I realise that the life outside of the anorexia and outside the [unit] is way better. And that’s what I mean, you know, going out all the time with my friends and things, and it’s just wonderful.” (8)

EXPERIENCES OF IN-PATIENT TREATMENT

Being with others: Support vs. distress

All participants discussed being with other patients who had AN, and the impact that this had on their experience of treatment on an in-patient eating disorder unit. As with many of the themes and sub-themes, participants simultaneously held both positive and negative views about being with others. Whilst the support, friendship and sharing of experiences were found to be highly positive, much distress and emotional disturbance was felt to be caused by competition with other patients and hearing and seeing others in a distressed state. For example watching fellow patients struggle whilst being fed via a naso-gastric tube and seeing the results of deliberate self-harm was felt by participants to cause fear, upset and at times to hinder their own recovery. Many participants commented on the powerful nature of the patient group as a whole, with the group dynamics and atmosphere of the unit changing with admissions and discharges. Thus some participants described how the group unified them and was an extremely helpful aspect of their treatment whilst others spoke of the converse.

Understanding and support

All patients reported experiencing understanding and support from fellow anorectic patients, though to varying degrees. For some it was the emotional support and sharing of experiences that was felt to be beneficial and for others it was the non-verbal or practical support that was helpful. Most participants found that the freedom with which they could

discuss their anorexia was an enormous relief as was realising that they were not alone and that others too knew what they were going through and were experiencing the same illness and similar feelings. They felt that they could finally be understood without having to struggle to put into words what they were feeling, and they no longer felt that what they were feeling was odd or abnormal.

“The good points is there’s finally someone, people that actually know what I’m going through who are the same.” (16)

“So I think it’s good to talk about how you’re feeling, because other people probably feel the same, so you don’t have to struggle to describe your feelings to people that don’t understand, because they understand. I mean ‘cause sometimes things can be difficult to explain, but they sort of know automatically, so you don’t have to struggle to find the words to describe it.” (6)

“It’s, it’s nice. Um, it is good, you know, you can see that other people are experiencing and have experienced what you’ve been through, and you’re not on your own... I don’t know, you, it’s, it’s good because you know, we can all talk to each other, and try and help each other out, because we understand each other, and um, you know, it’s not like if you say the word calorie, you know, you’re weird like it would be at home, kind of thing.” (4)

The relief felt by not needing to explain their feelings to each other was expressed by many. Some participants said that prior to their admission they felt that their anorexia had been a taboo subject. The contrast between negative experiences at school prior to admission and the difference in feeling understood on the unit was also reported.

“... you can talk to them (patients) so much easier than what you can when you’re out of here. Do you know what I mean, you can talk about anorexia just as you can talk about Coronation Street... Whereas at home, that issue would be totally avoided and I would not even talk about it.” (10)

- P “I was labelled as a freak really.”
- I “*You were labelled as a freak. [Yeah] So that must have been pretty tough? [Yeah] ... And what did that make you feel, being labelled a freak?*”
- P “Um really feel out of place and weird and stupid and everything bad that I wasn’t like everyone else and normal and natural.”
- I “*Mmm. And so did coming in here help with that at all?*”
- P “Um... yeah I suppose it did because everyone knows what you’re going through, or the patients do. It’s not so hard.” (17)

In addition to just gaining understanding, participants reported how beneficial it was to be given advice and pointers on how to manage the more difficult times in the unit. In the following accounts the first participant speaks of feeling helped by others’ sharing how they managed difficult situations. The second participant talks of difficulties that she has experienced with friends and how sharing stories with others lessens or relieves the upset and tension that she would have felt had she been alone.

“Um well if you’re upset, or you’re just quiet, or you’re subdued then um you, someone will come over and say ‘do you want to talk?’ and then you talk and they might share their experience with you, or if they’ve experienced that then they’ll tell you, maybe give you pointers of how to cope with it.” (7)

“Um I think it’s helpful here because lots of people have the same kind of experience with their own friends... it’s like we can laugh about it and it isn’t so serious, even though if I was like by myself I might get a bit upset over it.” (9)

Many participants spoke of support around specific issues such as the distress frequently caused at the table and when weighed. Non-verbal, physical responses were also felt to be extremely supportive.

“If you come out of the weigh room and you are upset or distressed, they will come over and give you a hug and you know they’ve been there before.” (5)

“... she finished her dinner before me obviously, because she was... she was quicker, she sat with me and said ‘Do you want me to sit here with you?’ and you know ‘until you finished?’ and she did. And that really helped, whereas someone else might have just got down [from the table].” (9)

Getting motivation from other patients who were further on in their treatment is something which the majority of participants reported. Although some participants said they were not ready to recover, they still found being with others who were positive about their treatment and close to discharge motivating and encouraging, in that it showed them how different life without the anorexia could be, and on what they were missing out.

P “... I know I’m not a good influence, but I like to talk to the people who, who are really positive here, because it kind of helps me [*Mmm*] to be able to talk to them.”

I “*What do you get, what’s so helpful about being able to talk to the positive people?*”

P “Because they’re not in here worrying about... if they’re going to be, not competing to be a certain weight or something when they get out, and not... they kind of just making me realise more about my social life and [*Mmm*] about what I should be doing and my age now and other things.” (2)

“... what helped me Get out from that whole smudging and things, was seeing someone who had passed that stage and who was now you know, really motivated. [Names another patient] watching her eat and you know, how she finished so quickly. I was like ‘gosh, I wish I could do that’. [*Right*] And it motivated me a lot more to think ‘God, you know, I don’t have to do this. I don’t have to look at everyone else. Just concentrate on [other patient]. So I always, you know, if they put me on the other table, I’d swap it round, so that I was sitting next to her. and you know it would, you know, just take my mind off things.” (8)

Comparisons and competition

Despite the positive and helpful aspects of being with other patients with AN, all participants described concomitant difficulties. Comparing themselves with others is something that all participants reported, whether or not they were doing well. Most said that seeing other patients being admitted made them envious of their thinness, and triggered more negative thinking, but a few participants said that they never wanted to look like new admissions again and so to see them was a motivating factor.

The majority of participants spoke of competition, either implicit or explicit. Never was this competition thought to be helpful, as it was always surrounding who could be the thinnest or do the most exercise.

“Because a lot of people come in here and it’s sort of like who’s the best anorexic type of thing.” (8)

“On walks and stuff it’s quite, you know, one person jumps on the side on the kerb or I might jump up on the kerb twice ‘cause they only did it once. Do you know, it’s silly things you probably wouldn’t even pick up on but then you realise sub-consciously that you’re doing it.” (5)

Comparing themselves with others was something that almost all participants raised, and such comparisons were often seen as extremely stressful, especially when they were with much less well patients.

“But when new people come in, I mean, it’s hard in a way, because they’re so, they look so ill and underweight and in a way that makes you feel bigger, when you see how thin they are.” (6)

“...the new admissions generally are very, very ill, um and often very, very underweight so it’s like makes everyone else further along the treatment feel really fat so it’s stressful to deal with so...” (1)

One participant described how comparing oneself with others on the unit increased the implicit competition, and how she tried to avoid becoming caught up in it:

“You’re always looking round at people and especially when you’re all in the same situation. Although people have different sized diets and things, if you’re having the same amount of sandwiches and someone is getting away with more, it’s playing on your mind. You’re thinking god, I should do that, I should do that. That’s why I don’t sit at the table anymore, so that I don’t have to see it, so that it doesn’t play on my mind.” (8)

Many participants described the internal conflict caused by comparing themselves to other, much thinner patients on the unit. Although they did not want to get to that stage again, they still compared themselves to, and were affected by, such patients.

“Um...um it is quite tough really, especially when you’re near your end of your admission, and there’s new people, you’re not, you don’t envy being that skinny ‘cause you know that they’re ill, and you, and you know sometimes I comment to myself ‘they look really ill, I wouldn’t want to look that skinny’, but they just make you feel really fat and horrible.” (7)

Becoming “iller”

It was not purely that participants found that they engaged, sometimes actively and sometimes by default, or implicitly, in comparisons and competition with others. Some participants felt that being with others had positively detrimental effects. As one participant put it, she was “becoming iller” (11) on the unit.

“Sometimes I, I find I feel that sometimes coming here I get more anorexic, kind of more anorexic feelings because I s’pose I wasn’t feeling so competitive when I’m out of here, you know, I’m not with [*Mmm*] you know I’m not trying to...but here I do feel a bit kind of...you know I’m competing against other girls.” (2)

“...I didn’t really know what tube feeding was, didn’t know about self-harm, um, about pacing to stop your weight going up, you know, walking around, exercise. I soon cottoned on.” (11)

One participant talked about another patient being the trigger for her to begin self-harming. She had become friends with a patient who self-harmed, and felt herself to be a less likeable person, who therefore deserved to self-harm. This shows how much more complex are the dynamics on the units than just those of competition.

“...it broke my heart because I liked her so much I didn’t know how she could do that to herself and I just thought I like her so much better than I like myself so what am I saying by not doing it to myself?” (3)

Some participants spoke of learning bad eating behaviours which they perceived as being detrimental to their recovery. It was not until they ate with their families that they realised that these habits were not normal.

“Things like smearing jam and marmalade and things on toast. Bad habits that when everyone’s doing it, you almost feel like it’s normal...And then when you get home, on leave for a little while and you’re with your family again, they’re like what are you doing?” (9)

I “They open up their sandwiches and squish them all over the plate?”

P “Yeah, all the butter and things like that. [*Right*] And you know, I started to do it and things and when I first, I had my first family circle with my dad and you know, I didn’t know anything, anything else apart

from squishing my sandwiches around you know, the plate, because that's what anorexics do, you know. And I thought um, so I like started to break up my sandwiches and he said you know, 'stop it! It's really peeing me off and stuff.' And I got really upset and you know. But I can now say with confidence that I never ate like that, you know, until I came in here. And so that was a bad thing..." (8)

The following participant relates how important it is to remember to focus on her treatment and not become engaged in others' problems and treatment.

"But the one thing I've learnt from coming in here, that you have to concentrate on yourself and your own treatment and not others. And not get caught up in their you know, um, issues and things like that, 'cause that's for them to deal with really. I doubt that they're as concerned about mine, my you know, problems and things as I am about theirs." (8)

Fear and Upset caused by others

Some patients related feeling frightened and disturbed by the distressed behaviours of other patients. Some even feared for their personal safety.

P "Sometimes it's kind of disturbing as well when people have to have injections to calm them down"

I "*They have injections?*"

P "You hear them shouting, or when they're tubed they scream and they shout...and then they bang doors and you're sleeping right next door at night"..

I "*...And what does it make you feel when you hear all those things?*"

P It's kind of um really upsetting [*Mmm. Yeah*] When you hear um...and people cut themselves as well and things like that." (14)

“...But once I was in the corridor and this girl was kicking and screaming and had like 6 people with her...and I just, I was so frightened ‘cause I thought she was going to lash out at me or something and I was like so scared.” (16)

This participant talks about how abnormal an atmosphere distressed patients create, the distress that she experiences and the effect that hearing the screaming has on her.

“It’s ‘cause like they say that you know they try and make it as normal an atmosphere as possible, but having people kicking, screaming, being tube fed and things like that is just not normal at all [*No*] and it’s all the time and it’s driving me insane”... “Yeah, it’s well it’s like every time I hear it now it’s just getting, it just goes straight to my head and I just sort of like end up like in floods of tears. I just can’t take the screaming any more”... (15)

The degree of distress and desperation experienced by this patient caused her to want to abscond and leave the unit.

“... the last couple of times there’s just all the screaming and stuff I just feel like running away.” (15)

Distress was also caused by the strain put on friendships, when participants felt used, frustrated and burdened by others. The following participant describes how she had gone to comfort and help a fellow patient who was distressed during a meal. The patient asked her to distract the staff so that she could hide food. This participant describes how this ruined their friendship as she could no longer trust this patient.

I “And how does that kind of affect how you are with her?”

P “Um...um, it sort of makes me question, you know, is she actually doing this because she wants to do it or because of our friendship or because she’s getting more exercise out of coming over and talking to me [*Right*] or all type of things like that. And it’s really upsetting to

thing God, is that person actually wanting to talk to me or just, you know, wanting to come over here and stand up for even longer and everything.” (8)

Finally many participants reported feeling that they had to rely on one another for support too much, causing them to feel responsible for, and to take on, others' problems, which they found detrimental to their recovery.

“...it is really, really difficult when you kind of hear other people's struggles and you've got your own struggles as well and it's just, you can just feel a bit crushed down by it sometimes and helpless that you can't do anything to help...and it's just a huge responsibility.” (3)

“...There is a very, very strong patient group...we've been so close and if we have a problem we support each other to either get help or to work through the problem, and I think it has become a problem at times when we've taken on other patients' problems to the extreme where it could be life-threatening.” (1)

Participants, however, did feel conflicted about offering each other support: despite finding it difficult and upsetting, at times they also found it gave them a sense of being helpful and needed which increased their self-esteem.

I And what effect did that have on you when other people relied on you?”

P It made me feel really good and in a bizarre way it helped, um, because it increased my self-worth. Um, um and then also I felt this, again it's a two-sided coin as well, as at the same time I'd feel really, again like the time I said where something 'cause I was able to help with them and I was able to share experience and um the idea that that would prevent them from doing anything else felt really, really good, um, at the same time they'd leave the room then I'd be left with an awful lot of um thoughts that would be detrimental to me.” (3)

Being an individual vs. just another anorectic

A key dimension along which participants described their experiences was whether they were individuals with different and unique needs and variations of an illness or whether instead, they were just another anorectic coming through the unit on the “conveyor belt” of anorectics. Did participants feel that they were understood, supported and encouraged as individuals or were they treated in a rigid, inflexible and thoughtless fashion? Those participants who believed that the unit’s main aim was to ‘fatten them up’ and restore their weight felt that the whole point of their illness was being missed. Therapy was to all, almost more important than was weight restoration and indeed, therapy and psychological treatment is about the individual. Those participants who felt cared for were the ones who were more likely to experience themselves as being treated as a unique person who was cared about, unlike those who felt like just another anorectic and thus felt neglected. The following excerpts illustrate both sides of this.

P “I think sometimes the staff are helpful when they kind of like talk to you and stuff...If you’re upset they like talk to you and try to comfort you”

I “...*What is it about that that you like?*”

P “...It seems as though they kind of care a bit more. That, that you’re not just a patient, you’re like somebody they kind of care about a bit and want to make happier” (12)

P “I just find it difficult because I find she [the nurse] treats me a bit like a phrase book”

I “*What do you mean by that?*”

P “Yes I suppose that’s very difficult. How can we support you with this?’ And you just think...please don’t treat me as though you’ve asked this question to a million other pieces of meat...’Cause a lot of

people say, you know, they do feel like a number passing through a conveyor belt. They stack you up and they put you out and, you know, they bring more in and they stack them up and put them out.” (5)

One participant, in summing up the difference between staff that she felt were good and those who were bad, commented that good staff “normally see the person behind the anorexia” (5). In contrast, an ethos or attitude that all patients are anorectic, and thus have the same illness and should be treated in exactly the same way, was perceived as unhelpful.

“it’s just like everything’s anorexic and everything you do’s anorexic. If you like stand up that’s exercising, if you sit in a certain position that’s exercising, everything you do is just classed as like anorexic...Everyone always says you can’t trust an anorexic.” (13)

Participants felt that it was extremely important to be recognised as individuals: although they shared a common illness, they felt that their anorexia was nonetheless different for each of them. This was put succinctly by one participant:

“We’re not all the same. It’s a different illness for each of us and we do suffer from it in different ways. [*Yeah*] So like we’re not all a textbook...we would have it in common that we would be diagnosed with anorexia, but we might not have all that much else.” (5)

Weight restoration vs. psychological help

Many participants experienced the units as being too focused on their weight and restoring it to a healthy level at the expense of their psychological health. This, they believed, missed the point of their illness and was detrimental and ineffective, especially

in terms of their long term recovery and health.

“I just wish they would have helped me with the fact that I needed help with calming myself down, rather than just increasing my diet which made me panic.” (13)

“It just feels like the physical perspective is, a little too...out of perspective in comparison to the mental, because to me the mental problems are what have cause physical problems [*Sure, sure*] and it doesn't seem to be working that way in terms of recovery.” (3)

The importance of therapy and understanding their anorexia and other feelings is something that participants emphasised consistently. All participants who received motivation enhancement therapy reported finding it particularly helpful. Much as some found therapy, and particularly family therapy, very difficult and painful, almost all thought that therapy and that which they received was essential and invaluable, but that there was not enough.

“And that [cognitive therapy] has been extremely helpful and that's where I feel that people need it on a more day to day basis you know it doesn't have to be as deep and as long as, as those sessions but, you just, you can't switch on and off.” (3)

“All these little groups and things I don't really seem, feel that they help very much...The only things that's helpful is the counselling really.” (16)

I “In what ways are they [the therapies] helpful?”

P “you can be feeling something but not know how to say it and they go ‘I bet you're feeling like this’...before you could be confused at why you're feeling like it, like this. And they sort of help to explain it a lot easier, and it...It sort of gives you encouragement to move on as well ‘cause like you could get to a point where you're stuck and you think, ‘I can't, you know, move on from here’. And then you go to talk to

someone about it, like you come in here, talk to him and it's like, you come out and you're like 'oh that makes sense now. I can sort of move on from here.'" (10)

However, it is not just in terms of the therapies that participants felt that psychological help and understanding was so essential. It was in relation to how staff treated them in general, during the day, evening, meals and activities.

"It's not helpful when I have people shouting at me if I'm upset or something just to sit down or something. They don't even bother to come up to me and say 'are you o.k.' as soon as I walk in the room if I'm upset 'oh just sit down'. It's just like 'oh thank you. You're supposed to be the people trying to help me and all you care about is that I've got to like put as much weight as you want me to put on.'" (13)

"I can try to a certain extent, but nothing I seem to do seems to, you know, do me any favours or no one seems to recognise it, you know, that I'm doing o.k." (15)

This previous participant speaks about what, to many, would seem obvious and natural: that people need encouragement and praise when they have done well, and not only punishment, or attention, when they are struggling.

Support and flexibility vs. rigid enforcement of rules

Many participants spoke about how rigid and inflexible the staff and the units could be. They felt this was understandable for meals, exercising and other anorectic behaviours, but not outside of these times, for example, during activities or free time. The common consequence of participants feeling that staff were rigid was as this participant reported.

Being encouraged made her want to try, whereas a more forceful and less supportive approach provoked her in to rebelling.

“When they’re more encouraging and supportive it makes me want to try harder and when they’re more forceful it makes me always want to pull against and try harder at doing the wrong things.” (9)

This participant describes how when she and another patient were having a play fight, they were told off for exercising, which she felt showed a lack of balance in staff’s responses to behaviour and thus denied her any space to behave as a normal teenager.

“it’s like yesterday we, I whacked [another patient] around the head with a pillow and she whacked me back and we immediately got told we were exercising, don’t exercise.” (15)

Linked with the inflexibility of the units is the issue of freedom. A few participants felt that the units were reasonably flexible and that they did get, if not enough, then at least some freedom albeit within certain boundaries. In addition, participants at a later stage of change and closer to discharge discussed the reciprocal relationship between trust, freedom and responsibility: if they showed staff that they could be trusted they were given more trust and responsibility.

“So the more I compromised with them, the bonuses I got. So as my weight increased, I could do more...and I mean now, I’m pretty much, you know, they sort of leave me to do what I want, in a way, ‘cause of my age as well. *[Mmm]* So, they can trust me a lot more” (8)

“I know that some people get privileges faster than others and some people say ‘but I’ve been in longer than you’, you know, ‘you shouldn’t be doing breakfast’... but then it’s ‘cause they kind of don’t stick to their programme

and stuff so they're messing around a bit which is why it takes longer." (7)

The majority of participants, however, felt that they had little, if any freedom both on and away from the unit. This frequently led to them feeling frustrated and desperate for some space, privacy and free time.

I "And how would that [having more freedom] help...?"

P "Just less stressed out about things. If, and you're going to be here you've just got to have some time to yourself. It just gets you more stressed out...Just when you can't do a normal teenage thing like sitting outside, sunbathing without having someone with you. It's just really frustrating. You can't do something normal 'cause of all the restrictions I think that if they're trying to get us back to normality they should let us do more teenage things." (19)

It seems that for participants the issue about freedom is also about having some normality in their lives and being allowed to behave as normal teenagers, something to which the participant recalling the pillow fight referred.

Many participants thought that there were too many rules and restrictions on the units. They understood the necessity for some, but felt that often restrictions and rigid rules were applied, removing what individuality the programmes contained. Blanket rules were also experienced as being uncaring, pointless and unhelpful to treatment.

"They just don't take any consideration in how you're feeling [*Right*] All they concentrate on is the rules and regulations and don't think about you."
(13)

“I just find it hard to stick to rules when I can’t see the point for them...I think, like, instead of having blanket rules, I think rules should be applied to certain individuals. *[Right]* That would make more sense to me.” (6)

Although some participants reported feeling that their treatment was appropriate, well balanced and helpful, none felt that it was individualised enough.

Feeling cared for vs. feeling neglected

About one third of participants reported noticing that unless they were in obvious distress, and showing it to what seemed an extreme degree, they received little if any attention. These participants related how distressing and neglectful it felt not to be given attention.

“It’s just upsetting if you see that you’re just left if someone else is like (began to cry) screaming and shouting...If you’re struggling more, if you scream and shout and stuff it seems that you’re struggling more, so that’s why you get more attention. Whereas if you don’t say anything everyone just thinks you’re o.k. and leaves you” (13)

“I think I just wish I could speak to someone *[Mmm]* but I just can’t *[Mmm]* ‘cause they always, they only focus on the people who scream or who are just I don’t know what” (16)

In addition some participants found that they felt neglected by their family, as well as by the unit. This was because in placing them in the units for treatment, it seemed to them as if their families no longer cared for them, even though at times they knew that this was not true.

“It’s just like I feel my parents don’t care anymore. They just put me in here and all that happens now is that we have arguments and everything, whereas when I was at home we did have arguments about food, but that was it...All I ever wanted was like my mum to look after me. And that’s all I feel I want now.” (13)

“‘Cause even though I know that they haven’t given up I just keep on telling myself that they have. Because it feels like they have in a way ‘cause they’ve given me here, well taken me here, so I just feel like if they’ve given up then I’ll also give up...because even though I don’t want to punish them I do because, because they’ve punished me by putting me here.” (16)

These excerpts contain a sense of dejection, rejection and desolation. For participant 16, this seems almost magnified by the internal conflict that she feels about whether or not her family do still care for and love her and whether they have tried to help her or punish her by admitting her to the unit. Instead of feeling motivated to recover, she wants to punish her family. She continues to relate how let down she feels.

“I feel let down that my parents have sent me here, I feel let down that...about that, I feel let down about having to eat, I just feel let down about everything really.” (16)

In stark contrast to this, some participants reported feeling well cared for. The following excerpts describe how available staff were: if patients needed to talk to them for support and advice, the response was extremely fast which participants found made them feel supported and cared for.

“Just having the confidence to go up to them [staff] or liking them enough to go up to them and ask them you know, ‘can I have a few words with you please’...and the good thing is that they nearly always make time to do that.” (7)

“[Names staff member] was very, very helpful...and...said that I’d do well...and you know he’d often um, um, reassured me that things were going to be o.k. And he just, you know, if I was ever worried about my family therapy, he’d come and talk to me about it and things, so it’s very, really helpful.” (8)

Participants for whom the staff and unit had become their home and family, found discharge difficult and upsetting.

“Cause it does feel like home because it’s a really friendly environment and you know, it really, all the staff, I mean I get on with most of the staff so they do kind of become like a family in a way so it’s hard to say goodbye to them” (1)

“I don’t know whether I’ll miss it. I think I will, the friendships that I’ve built up with people, um what with the staff as well, not just the patients” (8)

Collaborating in treatment vs. being treated

Participants talked about ‘being treated’ as opposed to collaborating with their treatment and owning it in some way, however small. Those participants who felt that they were being treated seemed less positive about their admission and felt that they were ‘being done to’, whereas those who felt it was a collaborative endeavour and were ready to collaborate, seemed more motivated and ready for recovery. They also reported feeling heard, understood and helped and seemed in less conflict with the unit and staff.

“I kind of felt like I was being heard and I actually had a part in this and wasn’t just a balloon being pumped up.” (3)

“I think the staff here want, generally want to help you. You know they want to work with you instead of against you...if you do go to them with a problem then they will actually come out, generally, take it on board and say you know this is how we’re going to try and deal with it...and it has helped, it’s taken quite a while but it’s helped.” (1)

This participant relates how the more collaborative ethos in this unit made her consider what she wanted from her life more than did the less collaborative ethos of her last unit.

“I suppose this place gives you a chance to think to yourself do you wanna spend your whole life going in and out, or do you just kind of wanna, kind of put on the weight or just get on with life...I mean it, it does make me think. It does make me realise that they’re just trying to help really, whereas at [other unit] I just thought everything is a punishment and they’re just being evil.” (2)

Some participants, however, did echo this participant’s sentiments about her previous unit, in that they found the units were not collaborative and thus their locus of control, with regards to their treatment, was external.

“They can do whatever they want to me in here...If I don’t agree with the help I’m getting then...it’s just like I can’t really help myself ‘cause I don’t feel o.k. and I don’t think it’s helping me.” (13)

“I don’t really mind when they [staff] give me ideas, but I don’t really like them ordering me around you know.” (14)

“It’s less confrontational isn’t it? Working together rather than against. *[Right, right]* It just feels like they’re against you most of the time.” (18)

The next excerpt shows how this participant feels that the consultant holds all of the control over her treatment and makes all of the decisions, without her input. She has only

met him once and so she feels that his input is unfounded and either incorrect or invalid.

“I don’t see how they can make decisions when they don’t even know me [Right] But [consultant] I’ve spoken to him once on my um induction day, and since then I haven’t even spoken to him, so I don’t see how he can make decisions if he doesn’t know me” (16)

Participants felt it was essential that they had some input into, or at least understanding of, their treatment, whether or not they wanted to recover. Without this, their experiences were of a punitive environment in which things were being done to them without their consent.

Feeling helped by structure vs. feeling punished by restrictions

There was much variation in participants’ perceptions of the restrictions and structure that was imposed in the units. For some, it felt punitive, intrusive and at times abusive, whereas for others, these were helpful in giving the day a structure and stability, and keeping them mindful of their treatment goals and distracted from their preoccupation with food.

“I think, sometimes it’s reassuring because you know what’s going to happen, you know [Right] especially around meal times. You know that breakfast is going to be 8 o’clock and you’re not sat there worrying like when it’s going to be.” (9)

“I needed the structure of a day here, which I couldn’t always get somewhere else... You do need to be occupied so they do try and organise a programme for you. So that’s helpful, definitely.” (5)

The one concern raised by participants who found the structure helpful was that they could become too dependent on it and then struggle with being flexible at other times, both when things did not go as planned in the unit, or following discharge. For example, one participant considered it important that she had learnt to create her own structure when her day otherwise did not have one:

“I’ve learnt to deal with the structure a lot better now, because in the real world, there isn’t always structure and you have to create it for yourself.” (8)

Many participants however experienced the restrictions as being punitive. The image conjured up by one participant is one of confinement, almost like being imprisoned for having done wrong:

“Like they kept me in my room, they, ‘cause I had a problem with walking around and stuff and I was at quite a low weight when I came in but they kept me in my room for really, really long, just, I was like confined to my room. Like I had my birthday here and I was only allowed out for like half an hour...I did have a problem with walking around, but actually preventing me from doing anything frustrated me more and I panicked and things.” (13)

“It’s a place for hell... You just feel like it’s the worst place in the world and you’re stuck in here and you can’t get out, you can’t do anything and you’re being ordered around, it’s horrible.” (17)

Some participants felt exposed, intruded upon and in need of some privacy. The first excerpt is from a participant who was extremely unwell. Despite realising the need for herself to be closely supervised she still found that even her telephone conversations with her parents were listened to by staff.

“You don’t get any privacy for yourself and there’s not been one moment of the whole entire...4 months here, that I’ve been on my own...I know that probably isn’t safe but um having 2 levellers (staff doing continuous one-to-one observation) is horrible because they listen in on, to your conversations with your parents and stuff like that” (17)

“There’s too many staff...I don’t think you get enough space...it just winds me up...some of the staff like when you’re say having a shower or something and like they know you’re in there and, and they keep checking. The door’s open about that much (shows small gap with fingers). But then there’s other people that totally unnecessarily have it open that much just so they can have a good glare.” (18)

This previous excerpt refers to the literal, physical exposure that she feels on the unit. Some participants felt that there was also emotional exposure as well, usually within the therapy.

“She tries to dig out the underlying things that I don’t like talking about. [right] And she makes me try and speak about them. (17)

Can I use freedom and responsibility or will I abuse it?

A more common conflict for participants was that of wanting to be given more freedom and responsibility but being worried about their capacity to use it well. A minority wanted it so as to abuse it. Participants were cogently aware that they would either be unable to use what freedom they were given, or that they wanted the freedom so as to abuse it.

“I think at the moment freedom is a very dangerous thing for me, ‘cause I don’t know how much damage, I mean people say at the moment you are your worst enemy...half of me would say if I was really honest with myself...you know, I can’t really control myself and the other half would say I’m fine. Just let me go.” (5)

I “What would make it unhelpful to be given a choice?”

P “Because you wouldn’t, because if you were given a choice then you would always make the wrong decisions, so you wouldn’t get any better...like not to eat and to do whatever you wanted.” (12)

“This is not the right reason for going for out-patient but out-patient treatment for me because I don’t want to, the fact that they’re not there to watch me and whether I eat or not.” (1)

Wanting to comply vs. wanting to rebel

Participants described feeling that they either wanted to comply with treatment or to rebel against it. Those who found the unit collaborative and rewarding of improvement more often wanted to comply and those who found it punishing and dictatorial often described feeling rebellious. Some participants felt guilty about complying with their treatment, even though it had been their choice. A minority of participants expressed confusion about which they wanted to do and so spoke of wanting to comply at the same time as wanting to rebel.

The following two participants describe how with their choice to comply with their treatment came increased responsibility, freedom and independence, which both wanted.

“I don’t do it, [deceive staff and rebel] you know, it’s tempting to join in and it’s not normal, and you’re trying to get back to normal when you’re

surrounded by kind of not normal things, and, and that is all you see, it kind of becomes that looks like what is normal.” (4)

“The more I compromised with them the more bonuses I got. So, as my weight increased, I could do more...I mean now, I’m pretty much, you know, they sort of leave me to do what I want in a way...I love to be independent and it is a great bonus, you know, being able to do things for yourself.” (8)

One participant talked of the guilt that she and others felt when she did comply with the programme and take some responsibility for her recovery.

“You get quite a lot [of trust and responsibility] when you’re...allowed to do your meals and prepare them. And sometimes you feel guilty for doing it...and they feel so awful and guilty and you know they’re practically crying, you know, ‘cause they’ve asked for it [food]. And I know I’ve done that and it just feels horrible to ask for it!” (7)

The following excerpts illustrate how volatile a relationship some participants had with complying with, and rebelling against, their programmes.

“Some days I just think, just do everything that’s required...But then other days I’m just battling against this place...like one week I’ll start hiding food.” (2)

“I was pretty set up for recovery and things just went completely wrong and I just went no I don’t want to recover, but even though the staff are aware of this I’m still really grateful to the staff ‘cause they’re letting me go, they’re letting me go home and they’re letting me get on with it, whereas other units would not allow me to discharge.” (1)

Many participants spoke about the extent to which they were conflicted about wanting to comply with, and rebel against the programme.

“I have been exercising and things, even though I know I shouldn’t be and if I’m caught I know I’m going to go back on level 1 but it’s all a game...but a part of me wants to get caught and to realise, people to realise that I’m doing it and I want them to stop me, but then again I feel, then again I don’t want to get caught so it’s another losing battle.” (16)

Summary of experiences of treatment

Participants expressed a diverse and varied range of views on their in-patient treatment for AN. All of the themes and sub-themes can be seen as being on a continuum with positive and helpful experiences of treatment at one end and more negative, unhelpful experiences at the other. Participants frequently held conflicting views simultaneously. For example, being with other anorectic patients was experienced as extremely supportive but also troubling, upsetting and at times detrimental. Being on the unit was often felt to be helpful, yet simultaneously being away from home was experienced as unhelpful.

All participants spoke about losses that they sustained due to being on the unit. Included were a loss of normality and a teenage lifestyle, home, family, friends, school and academic level and ability; they also experienced a loss of their anorexia and all that accompanied it. All participants believed that greater integration in their treatment would have been beneficial to their long-term recovery. This included integration of home and the unit, and a better balance between restrictions, flexibility and freedom, weight restoration and therapies, and patient input in to treatment and staff control.

CHAPTER 4 ~ DISCUSSION

OVERVIEW

The findings of this study will be discussed in relation to the research questions and the existing literature. Methodological issues addressing strengths and limitations of the study will be explored and potential areas for future research suggested. Finally the clinical implications of this research, and possible areas for improving practice will be considered.

STUDY FINDINGS

This study aimed to explore how young people experience their in-patient treatment for anorexia nervosa. Interviews with 19 participants yielded rich qualitative data, which were analysed using interpretative phenomenological analysis. Conflict, both internal and external, was at the core of all of the themes. Participants described their anorexia as being primarily either a friend or an enemy, but for most it was both. All felt that wanting to get well was the key to their recovery, but they were confused as to whether or not they were ready. Being on a unit with other anorectic patients had many pros and cons. The understanding and support that others could give was highly valued, but significant distress was also caused by other patients' behaviour. Many participants felt that they were treated as 'just another anorectic', which at times left them feeling neglected. Again,

however, there were times when they felt cared for as an individual. Whether or not participants did, and wanted to, collaborate in their treatment was another conflict that was discussed.

Participants' perceptions of their Anorexia

The majority of participants felt that their anorexia was an entity separate from themselves. Most were ready to consider life without it, but a few were not even ready to contemplate, or actively did not want, such change. To some their anorexia was just a 'him' or an 'it'. To others it was a much more sinister presence and felt to be a murderous monster. For most the presence was unwelcome and felt to be an intrusion which they were struggling to expel. For a minority, the anorexia seemed to be their identity and thus talking about 'getting well' meant losing their identity. However participants viewed their anorexia, almost all were conflicted about whether they were ready to change and recover. On the one hand, they wanted to be well and out of hospital, but on the other, they wanted to keep some of their anorexia, if only in the form of slimness. The quantitative, questionnaire data and the qualitative, interview data presented a consistent picture about participants' readiness to change. The stages of change literature and theoretical framework (DiClemente & Prochaska, 1982; Prochaska & DiClemente, 1983; Prochaska et al., 1985) will be returned to later in this section, as it is a way of integrating all of the results.

Whether the anorexia was a friend or an enemy, participants felt confused, conflicted and as if they were fighting a constant battle, in every area of their life. This sense of perennial conflict seemed to be due to the relentless influence and power of their anorexia. In many ways the anorexia was a friend who gave them confidence, security and protection from the real world. On the other hand, it robbed them of their normal teenage life, deprived them of their family, friends and ability to enjoy themselves. The power, however, which the anorexia had over them was immense. Even for those who saw their anorexia as a stealthy, murderous monster, maintaining it was preferable to letting it go. For almost all participants, the list of good points was much shorter than that of bad points. Such views are consistent with the anecdotal accounts reviewed earlier (Shelley, 1997). So why is anorexia so difficult to relinquish?

At this point, it is pertinent to consider what participants felt their anorexia gave them. Many said it made them feel safe, protected, shielded and secure. It absolved them of responsibility and gave them confidence and power. It was an achievement, “a year’s hard work” and something that differentiated them from others and gave them individuality and an identity.

In light of the way in which participants saw their illness, it is perhaps unsurprising that they did not want to give it up. Nor is it surprising that participants had been on the unit for many weeks, nor that many had had, and were likely to have, multiple admissions. In many ways to take away something perceived as being so positive would seem extraordinary.

Participants' experiences of their treatment

Participants' accounts of their experience of in-patient treatment were characterised by conflict. As one participant said, "there's always a counter argument for everything", which seemed to lead to frequent, if not constant internal, and at times external, conflict about all aspects of participants' illness and treatment.

Support and understanding

Many of the themes that emerged can be encompassed under this heading. Into this comes being with others, participants' perceptions of the unit's ethos, its helpfulness and their general experiences of treatment. It links with being treated as an individual and not just another anorectic. In addition, almost all participants wished for more therapy to explore why they had developed AN. This echoes LeGrange's and Gelman's (1998) research, in which 43% of all of their participants felt that a significant oversight of both cognitive behaviour therapy and family therapy was an exploration of the causes of their AN.

Being with others: support vs. distress

The majority of participants were conflicted about being with other anorectic patients. They felt less alone than they had prior to admission as they realised that other people also had anorexia and they found that they received support from others going through

similar experiences to themselves. Patients on the units understood one another - the highs and lows which all reported, the internal and external conflicts and the general issues around staff and families - which many had not previously experienced. This was all felt to be beneficial.

Consistent with the anecdotal accounts discussed earlier (Shelley, 1997), there were also felt to be many disadvantages to being with other anorectics. Implicit and explicit competition and comparisons between patients were engaged in frequently. Participants felt disturbed and distressed by seeing other patients who were very unwell commonly exhibiting serious behaviours such as cutting their wrists and other forms of self-harm. Some perceived that they received less care and attention from staff than did extremely distressed patients. This, participants believed, was because they were more self-contained and thus seemed to be less unwell or upset, which led to their feeling angry and resentful. Participants felt that they learnt more tricks and became more adept at deceiving staff with respect to hiding food and exercising, and some felt that they were thereby deteriorating instead of improving.

Such conflicting data makes it difficult to evaluate whether it is beneficial or detrimental for young people with anorexia to be with others with the same illness. It may be, as suggested by one participant, that the very unwell patients should be separated from those who are less disturbed. However, if this were to happen, those who were very unwell would not have the opportunity to gain motivation from those closer to discharge, which many reported finding extremely helpful. Will those at a later stage of change maintain

more resilience and strength in the face of patients who are hiding food, exercising and self-harming, or will they relapse? Will patients who are not ready to change gain motivation, support and encouragement from those at a later stage of change? It is a very difficult balance to strike.

Being an individual vs. just another anorectic

Whether participants felt that they were just another anorectic, or an individual seems vital. For those who felt that they were just another anorectic, their admission felt ill considered and at times punitive. 'Another on the conveyor belt' was how one participant described her experience of treatment. Many participants felt that the aim of their treatment was to restore them to a healthy weight. Treatment manuals recommend helping 'children' to examine their behaviour, recognise and name upsetting feelings and find alternative ways of expressing these (Crouch, 1998) and psychotherapy is accepted to be crucial in treatment for anorexia (APA, 1993; Dare & Eisler, 1997; LeGrange, 1999; Russell et al., 1987). However, participants felt that psychological intervention was believed to be secondary to weight restoration, which they thought was the wrong way round.

Inflexible staff and the application of inflexible rules was considered unhelpful and participants believed that their treatment would be more beneficial if treatment programmes were further individualised. Individual differences in presentation were thought to be ignored as were participants' views on their illness and treatment.

Participants experienced being told by a professional that what they were feeling was 'their anorexia talking' as patronising, demeaning and provocative. In sum, participants reported that such experiences reduced their desire to get well and further entrenched their anorexia.

Collaborating in treatment vs. being treated

Closely linked to support, understanding and individuality is whether or not participants felt that they collaborated in their treatment, which appears to be extremely important to their experiences of treatment. Those who felt that they were just 'being treated' felt disengaged, punished and deprived, as opposed to those who felt helped and supported by the structure of the unit and the supervision. The need to place restrictions on patients with anorexia is unanimously accepted (Honig & Sharman, 2000; Lask & Bryant-Waugh, 1997), as is the knowledge that patients frequently try to avoid weight gain and are thus prone to conceal their techniques for doing so (Lask & Bryant-Waugh, 1997). Although all participants wanted more privacy and space, it was those who reported having no input into their treatment who felt intruded upon, exposed, vulnerable and thus desperate for space and privacy.

Two related conflicts emerged in this area. Some participants spoke of wanting to comply with their treatment and get well, whilst at the same time wanting to rebel against it. This seems in part, to be connected to their stage of change but it was also linked to how involved in, and engaged with, their treatment they felt. Some found that on admission

their motivation to recover was high, but that feeling ignored and punished immensely reduced this, which in turn seemed to lead them to rebel against their treatment. For those participants who experienced collaboration with the staff, the conflict was more surrounding whether they would use or abuse the increased responsibility that they desired. Interestingly, as is proposed in the literature on treating anorexia (Honig & Sharman, 2000; Garfield, 1994; Garfield & Bergin 1994), all participants discussed wanting more balance and integration with the opposing elements of treatment discussed above.

INTEGRATING THE FINDINGS

The data presents a highly complex picture of both anorexia itself and how young people with anorexia experience their treatment. It is characterised by perennial conflicts and dilemmas, in which every element of the illness and its treatment has pros and cons. As mentioned earlier, a helpful theoretical framework in which to place such data is that of the transtheoretical model of stages of change (DiClemente & Prochaska, 1982; Prochaska & DiClemente, 1983; Prochaska et al., 1985).

The transtheoretical model of stages of change offers an integrative perspective on the structure of intentional change (Prochaska et al., 1992). Initially developed to help with understanding the process of smoking cessation, its application has now been broadened to many problem behaviours. The model proposes that in modifying such behaviours,

individuals move through 5 stages of change – precontemplation, contemplation, preparation, action and maintenance.

For the 3 participants (16%) who were in the stage of precontemplation - not yet ready to begin considering change - treatment often was felt to be punitive. It seems unsurprising that those participants who saw their anorexia as a friend were not ready to get well. The anorexia still gave them too much. Even for those participants who saw anorexia as their enemy, it still had something redeeming, if only its familiarity, which made it difficult to reject completely. In these cases it may be the fear of the unknown that maintains the anorexia, or at least the conflict about leaving it behind.

For those 9 participants (47%) who were in the stage of action and were therefore actively engaged in modifying their behaviours in order to overcome anorexia, the treatment programme was not necessarily liked, but it was mainly experienced as helpful. It seemed that for those at a later stage of change, being helped to lose their anorexia was at times difficult, but it gave them hope for their future and motivation to live a full and enjoyable life. The contrary appeared to be the case for those in the stage of precontemplation: not even contemplating change. For these participants trying to remove their anorexia felt like robbing them of their identity, their friend and ally and the one thing that made them feel safe.

Just over one third of participants (37%) were in the contemplation or preparation stage. Contemplation signifies “knowing where you want to go but not quite ready yet”

(Prochaska, DiClemente & Norcross, 1992). Indeed, many participants in this study, including those who were in the action stage, spoke of wanting to be well and out of hospital, but not yet being ready to give up their anorexia. The implication of this is that working with patients' conflict about recovering and the pros and the cons of their anorexia is crucial to their recovery. Their motivation to get well also seems key to helping patients to let go of their illness and all that comes with it (Miller & Rollnick, 1991; Rollnick et al., 1992), as until the desire to get well outweighs their need to maintain their anorexia, they are unlikely to get well or engage in the work that accompanies recovering (DiClemente & Prochaska, 1982; Prochaska & DiClemente, 1983; Prochaska et al., 1985).

As with Ward's et al.'s (1996) study, one difficulty of understanding these results in terms of the stages of change is that some participants seemed to either border on, or be in, two stages of change at once, for example precontemplation and contemplation, or preparation and action. However, McConaughy et al. (1989) supported the idea that patients may be simultaneously engaged in behaviours and attitudes of more than one stage. This could help to explain some of the dilemmas and conflicts raised by all of the participants in so many areas of their treatment.

One of the advantages of understanding recovery from anorexia within this framework is that the model sees change as a cycle, with relapse as an integral part. Earlier work is not negated by relapse, rather the cycle continues more rapidly subsequent times round (Ward et al., 1996). This understanding of relapse in anorexia is likely to help minimise

patients' sense of guilt and blame, which many participants in this study reported, for having failed to recover.

Considering the data in terms of a stages of change framework seems to be a helpful context in which to understand participants' entire experience of being on an in-patient eating disorder unit. It was not that participants were ready, or not ready, to relinquish their anorexia and get well. They reported struggling and feeling conflicted across the whole spectrum of their experience of treatment. No participants appeared to be definitively engaged in only one stage of change. Their desire to get well oscillated, which seems to mirror their experience of treatment. Participants' perceptions of the units and their treatment also fluctuated and they were often conflicted about what help they wanted, and whether the help that they did receive was positive. How participants made sense of their experiences of treatment, their ability to use treatment and the influences of their readiness to change on their perceptions of their treatment is also given a context in this framework.

METHODOLOGICAL ISSUES

The strengths and limitations of this study will be considered in terms of sampling issues, the interview and quality of the data, and broader issues in qualitative methodology.

The sample

Participants in this research spanned the range of illness severity, from being sectioned to being ready for discharge when almost maintaining change, as well as the complete age range for admission. The heterogeneity of the sample made it possible to explore a diversity of experiences of treatment. Very few patients declined to participate and those who did were identified by staff as patients who either did not talk openly or freely, or those who always refused to participate in research. No male participants were interviewed and so it is not possible to relate the findings to young men with anorexia. The units from which participants were recruited were also heterogeneous. Although the units had many similarities, as discussed earlier, no treatment programme for anorexia is the same (e.g. Steinhausen et al., 1991; Hsu, 1992) and thus participants' experiences of treatment were more varied than they might have been had only one unit been used. Nonetheless the emergent themes were common across the sample.

The heterogeneity of the sample and the consequent variation in treatment experiences was at times confusing and it reduced the similarity of participants' presentations. A homogenous sample would have been more likely to present a clearer picture of patients'

experiences on an in-patient eating disorder unit. However, data yielded from a more homogeneous sample would be less generalisable than that of a heterogeneous sample such as this. It is probable, therefore, that themes and experiences explored in this study are representative of the views of patients with anorexia who are on in-patient eating disorder units, as opposed to a select group. If this is the case the study's findings are likely to be relevant to the wider population of adolescents with anorexia.

In order to gain an in-depth understanding of a phenomenon, qualitative research investigates a small number of cases. This study followed the recommendations of Hill, Thompson and Nut Williams (1997) that qualitative studies should draw on a sample of about 8 to 15 participants. The notion of 'saturation' is also important in qualitative research (Willig, 2001): when the phenomenon under investigation seems exhausted, and the same themes repeatedly emerge, data collection can stop. In this study, saturation had occurred long before the final interview, when I was getting a consistently conflicted picture of participants' experiences of their in-patient treatment for anorexia. It is possible that I could have stopped collecting data at about interview fourteen or fifteen.

The interview and quality of data

A number of factors need to be considered when evaluating the interviews and the data obtained. These include: whether participants felt able to talk openly, their ability to be self-reflective, and the adequacy of the interview schedule. Each of these is discussed in turn.

Participants appeared to be very engaged in the research process and they seemed to want the opportunity to talk about their experience of treatment. There was a good response rate during the recruitment phase, and the majority of participants seemed very comfortable throughout the interview, despite being audiotaped. They appeared to be speaking openly and did not seem to be responding to any demand characteristics, such as my being an outsider. In fact, this seemed to enable many participants to speak openly as many of them said that they felt that they could not have spoken to me had I been feeding back to staff about individuals. Most participants talked at length during the interview; my impression was that many had not been listened to before. This led to some difficulties in knowing how closely to stick to the interview schedule and it also meant that an interview lasting an hour was often insufficient. In addition, due to meals, snacks, therapies and other such demands, interviews were sometimes prematurely curtailed. Unfortunately, because of the treatment programmes and the initial organisation of this study, it was not possible to return and conduct a second interview with participants, which I would hope to do if I were to carry out this study again.

Conducting research with participants who are currently experiencing psychological and emotional distress can be problematic in terms of the reliability and validity of the data provided. It was interesting that this was a concern to some parents of the participants in this study, who believed that their daughters were so encompassed by their anorexia that their reports of their treatment would be invalid. However, this study was based on a phenomenological, 'relativist' theoretical position, which places importance on the

realities constructed by individuals in relation to their environment, rather than on one verifiable reality (Barker, Pistrang & Elliott, 1994).

Certainly, anorectic patients can be manipulative when trying to avoid weight gain, and their anorexia is exceptionally powerful in influencing how they think and conduct their daily life (Lask & Bryant-Waugh, 1997). However, in conducting the interviews, I had the sense that participants were extremely aware of the powerful influence and control over them of their anorexia. They were also acutely sensitive to the dilemmas and conflicts that it provoked as well as the numerous detrimental consequences. In addition, participants were very good at critical self-appraisal. For example, some admitted to wanting more freedom so as to abuse it. They seemed cogently self-aware.

Finally, the quality of the interview schedule needs to be considered. The interview schedule was used only as an aide memoire. Despite using it in such a flexible fashion, it remained under constant review, and was updated three times during the interviews. It was extremely useful in reminding me to ask participants about areas that had not naturally arisen previously in the interview and, as such a guide, it appeared to work well. Had I been aware of the relevance of stages of change to participants I would have added a section to the interview schedule that further explored this, instead of just following participants' leads. Similarly, the nature of the research prevented the exploration of links between variables such as family background and history, illness duration, stage of change, self-harm, anorexia and experiences of treatment.

Qualitative methodology

The evaluation of qualitative methodology has been addressed by a number of researchers (Stiles, 1993; Smith, 1996; Elliott, Fischer & Rennie, 1999). Elliott et al. (1999) devised a set of 'evolving' guidelines for reviewing qualitative research in clinical psychology, with the aims of legitimising qualitative research and encouraging better 'quality control'. These guidelines will be used to consider the present study.

Owning one's perspective

Elliott et al. (1999) state the importance of qualitative researchers "specifying their theoretical orientations and personal anticipations as known in advance and as they become apparent during the research" (p. 228). The section 'Researcher's Perspective', in this study, presents these. I anticipated that the majority of participants would report primarily negative experiences of treatment and I was careful in interviews to facilitate participants' thinking around the more helpful aspects of their admission. I was also aware that participants might worry that our conversations during the interviews would be reported to staff, especially as they were of a younger age group. Thus, I was explicit about confidentiality and the fact that unless they said anything that made me worried about their safety or that of others, none of our discussion would be relayed to staff.

As discussed by Elliott et al., my perspectives did alter during the course of the study with the emergent data. I was surprised by the number of participants who felt positive

about their treatment. In being reflexive – considering the impact of the data on myself – my preconceptions about in-patient adolescent eating disorder units became less negative and I tried harder in the interviews to think about which of the beneficial or more detrimental aspects of their treatment participants did not raise. It also helped me to consider with participants alternative explanations for their experiences and thoughtfully to explore what they might find preferable. It may also be that my predominantly psychoanalytic and systemic orientations precluded my consideration of a more social constructionist approach which could have focused on issues of power and gender inequalities that might expose new ways of helpfully understanding participants' experiences of treatment.

Situating the sample

It is important for readers to be able to judge the range of people and situations to which the research findings may be relevant. Demographic data are helpful in contextualising participants' thoughts and experiences. In this study, information on participants' age, illness duration, length of current admission, number of previous admissions and stage of change was presented at the beginning of the results. The ward atmosphere scale was also used to give a description of the ward environment. It may have been helpful to provide some data on participants' backgrounds and histories but I thought that the vast quantity of such data would be overwhelming and confuse, instead of aid, readers.

Grounding in examples

That the researcher's ideas are supported by quotations and examples in the text is important in enabling the reader to understand how the researcher has arrived at their interpretations, especially with an interpretative phenomenological approach. This also helps the reader to arrive at their own interpretations of the data. In the current study all themes discussed are accompanied by examples from interview transcripts.

Providing credibility checks

A number of possible credibility check are suggested by Elliott et al. (1999). In this study an additional 'analytic auditor', with extensive experience in qualitative research, read interview transcripts and discussed tentative themes and sub-themes with me. This process did seem to be adequate, although gaining respondent validation by checking participants' views of the initial themes would have enhanced the credibility of the analysis. In addition, the qualitative and quantitative findings appeared to converge, which further adds to the credibility of the findings.

Coherence

Elliott et al. recommend that the understanding of the data forms an integrated and coherent narrative for the phenomenon under investigation, whilst also preserving some individual differences. The aim of this study was for the experiences and stories of

participants to be amalgamated and condensed into an organised narrative of what it is like to be an adolescent being treated for anorexia on a specialist in-patient eating disorder unit. The picture that emerged was characterised by difference and conflict. However, due partly to data overload and partly to the process of condensing the data, some differences in accounts have been lost. Hopefully coherence has been achieved without losing important differences.

Accomplishing general versus specific research tasks

This study had a specific research task: the exploration of anorectic patients' experiences of in-patient treatment for this illness. Elliott et al. (1999) propose that when the research task is specific the study must be systematic and comprehensive and address the limitations of extending the findings to other instances. This has been discussed in the earlier section entitled "The sample".

Resonating with readers

Finally, Elliott et al. assert that the completed manuscript should 'resonate' with readers so that they are able to clarify and expand their appreciation and understanding of the topic. It is up to readers to judge whether this has been achieved.

SUGGESTIONS FOR FURTHER RESEARCH

A number of potentially beneficial qualitative and quantitative research avenues arise from this study. The following discussion is divided into three research areas. The importance of involving patients in research should not be underestimated and thus the first area is further research exploring patients' experiences of anorexia and its treatment. Second is research into stages of change and, third, outcome research with a focus on the comparative outcomes of different in-patient units, both specialist eating disorder and general adolescent units.

Experiences of anorexia and its treatment

Replicating this study would be useful in ascertaining whether the experiences of this sample were shared by other young people on in-patient eating disorder units. Are the conflicts raised by the participants in this study unique or shared by other anorectic patients on in-patient units? It seems likely that at least some of these findings will be shared, as two units with a diverse range of patients were used for recruitment and there was much variation in the views expressed. Just as important is to explore how anorectic patients who are treated on general in-patient adolescent units experience their treatment. Do they share the views of those on specialist units? Are their experiences of their illness and treatment as characterised by conflict as this sample? If there are differences, then it would be interesting to investigate further in which areas differences arise and why.

More focused, qualitative research exploring how young people with anorexia view their illness would also be beneficial. Unfortunately this question occurred at the end of the interview in the present study and little time was generally available for its discussion. The depth of data that did emerge is indicative of just how fruitful such a project would be. As suggested by Serpell, Treasure, Teasdale and Sullivan (1999), thinking with anorectic patients about the pros and cons of their anorexia is an essential component in both research and treatment: until we understand what the illness gives young people we can not work with them to replace such benefits by less dangerous means.

Stages of change

Participants in this study believed that until they were ready to get well, no treatment would be of benefit. This seems an important future research area. Is stage of change actually relevant in anorexia, or is patients' stage of change less important than is indicated by the minimal research to date (Ward et al., 1996; Geller, Cockell & Drab, 2001; Geller, 2002)? Is stage of change predictive of outcome, recovery or dropout? The literature on stage of change and bulimia nervosa presents mixed results (Wolk & Devlin, 2001; Treasure, Katzman, Schmidt, Troop, Todd & DeSilva, 1999; Levy, 1997). Would the same be true of anorexia? Do adolescents with anorexia differ from adults with the illness and what would be the potential implications for treatment? Are anorectic patients, as suggested by McConaughy et al. (1989) and Ward et al. (1996), frequently engaged in the thought processes and behaviours of more than one stage? If so, how can we help them to move on through the stages, to action and ultimately maintenance? It might also

be useful to assess whether staff share patients' perceptions of their stages of change. Ward et al.'s (1996) study found not, but investigating this further might yield potentially fruitful avenues for future treatment.

Outcome research

As was discussed in Chapter One, research into the outcome of anorexia, and particularly early onset anorexia, is strewn with methodological difficulties (e.g. Hsu, 1992; Steinhausen et al., 1991, 2000). One of the main difficulties is that all treatment programmes differ and like is therefore not compared to like. It seems essential that methodologically sound outcome studies are conducted, in order to increase understanding of what does and does not work in treating anorexia nervosa, and especially early onset anorexia. Even a comparison of similar units with similar patients and programmes would increase our current knowledge.

Bearing in mind the complex portrayal of the advantages and disadvantages of being with others with anorexia, given by participants in this study, it would seem important to explore the outcome of adolescents with anorexia who are treated on general, as opposed to specialist units. Perhaps this would also aid our understanding of what patients find helpful and unhelpful and what factors emerge as objectively beneficial, or not, in treating adolescent anorexia.

CLINICAL IMPLICATIONS OF THIS STUDY

Perhaps the most striking finding of this study is the amount of conflict that participants experienced in all areas, to a greater or lesser extent. In all domains of their life, and particularly in relation to their anorexia, participants reported feeling confused and conflicted. These conflicts suggest a number of ways in which clinicians and services might enhance or reconsider treatment programmes.

Psychotherapies

It seems trite to state the importance of psychotherapies in treating anorexia. However, the degree to which participants reported feeling confused seems indicative of their needing a substantial amount of psychological help. As was discussed above, almost all participants felt that their psychological difficulties were secondary to weight restoration and many specifically said they wanted more individual (psychodynamic or cognitive behavioural) therapy, some wanting it as frequently as four or five times weekly. It may be that reducing the number of group activities to make time for more individual work would create more time for individual therapy. It may also be that a daily session with either their key-worker or a member of staff with whom patients got on well, would give participants space to talk through some of the difficulties and conflicts that they are experiencing, which in turn might reduce the need for formal therapy. In the light of their difficulties, such a request seems reasonable.

It also seemed to be very important to participants that they were not 'separated' from their anorexia and told, 'that's your anorexia speaking'. Many found that this kind of response allied them closer to their anorexia and pushed them further from wanting to recover, which is ultimately detrimental. It seems that an understanding of the importance of their anorexia should not be underestimated by staff and therapists. This ties in with considering the pros and cons of the anorexia in therapy (Serpell et al., 1999).

Those participants who received motivation enhancement therapy reported its helpfulness specifically, which has also been supported in the literature (Miller & Rollnick, 1991; Rollnick et al., 1992). Those participants who did not get this therapy spoke about wanting encouragement and help in moving forward with regards to their eating behaviours and thinking. It therefore seems likely, especially in regards to the potential benefits discussed above of working with patients' stages of change, that all anorectic patients could benefit from motivational enhancement therapy.

Working with patients' stages of change

There has already been much discussion about the importance of patients' stage of change. Participants felt that no treatment would help them recover unless they were ready. In fact some went as far as to say that until such a time all treatment was pointless. This implies the importance of matching treatment aims and programmes to patients' stage of change. For example, it might be more beneficial in the long-term, to admit those patients who are in precontemplation primarily for weight restoration and to minimise the

physical complications of anorexia, than to treat them with the same programme as is used for patients in the action stage. This might seem counter-intuitive when considering the danger of AN, but, as suggested by Miller and Rollnick (1991) and Rollnick et al. (1992), such awareness of stage and process of change lends itself to a motivational model of therapy in which it is essential to match the treatment given to an individual's stage of change. This model implies that different resistances are important at different stages, suggesting that therapist style may need to be flexible in order to enhance motivation.

Being with other anorectic patients

Being with other anorectic patients gave participants much needed support and understanding whilst simultaneously causing them great distress. It is difficult to know what might alleviate such a mixed situation. Whether patients would find it easier to be on a general adolescent unit, catering to those with a variety of difficulties cannot be known in advance. It may be that without having the opportunity to engage in competition and comparisons with other anorectic patients, recovery would be easier. On the other hand it might be that patients would feel a lack of support and a feeling of aloneness and stigma. Indicative of this is that most participants reported feeling greatly relieved and helped by realising that they were not alone in having anorexia. One potential middle path might be to do as one participant suggested and separate those who are very unwell from those who are closer to recovery. However, as discussed above, this

would remove the chance for those at an early stage of change to gain motivation from others at later stages.

Integration of treatment

Balance and integration of aspects of the treatment programme was something to which all participants referred. They said that they wished to start having home leave early in their treatment programme so that it could be slowly increased throughout their admission. Several reported having been on the units for many weeks before going home. For patients who live a long distance from the unit, having brief periods of home leave is difficult. However, it does seem likely that to begin an integrated programme of rehabilitation from as early in patients' admissions as possible would be beneficial. It might help with their motivation for recovery and would be likely to prevent the loss of friendships at home and at school that so many participants reported.

This links to Nozoe's et al.'s (1995) finding that longer admissions were correlated with poorer social adaptation. Similarly, the superiority of family therapy over individual therapy (Dare and Eisler, 1997; LeGrange, 1999; Russel et al., 1987) in younger anorectic patients may in part have been related to its ability to help parents overcome their sense of failure and regain control over their child's eating. Allowing patients home from an early stage in admission might enable parents to maintain some control over their child's eating, which would hopefully reduce the potential for parents to feel a sense of failure and lessen the anxiety when patients finally return home.

The need for flexibility and to balance restrictions with freedom is another important clinical implication of this study, which ties in with many of the themes discussed. It became apparent during the course of the interviews that many participants felt desperate for some space and privacy. They did not deny the necessity of having restrictions imposed upon them around eating and exercising behaviours, but it did seem that such restrictions were perceived as being punitive when they were not balanced with some flexibility and space. It seems likely that to give patients some freedom, which could be increased or decreased depending on whether it was used or abused, would be a useful premise from which to start.

It is also important that patients feel that they have some enjoyable times whilst on the unit. Participants in this study reported that without experiencing fun and enjoyment, the whole admission felt punitive and even detrimental. No participant rejected the idea that hard work was necessary, but they also felt that having some normality, which included going outside the unit and doing “normal teenage things” like shopping and cinema trips, once ready was vital. For treatment to be helpful and hopefully even successful, it is essential that it does not feel punitive throughout, as this is likely to further entrench the anorexia.

CONCLUSION

An unresearched, but important area – how young people experience their in-patient treatment for anorexia nervosa – was explored in this study. Such outcome data as we have for anorexia is demoralising, in that the mortality and relapse rates for this illness remain high. A new approach to researching treatment, particularly for early onset anorexia, seems necessary. In failing to ask patients about their views and experiences of treatment, researchers have neglected an invaluable source of information both about anorexia and its treatment.

The data in this study yielded a number of themes, all of which were characterised by conflict. It appears that the experience of in-patient treatment for anorexia is a difficult one. A patient's stage of change, upon admission to a unit and at different intervals throughout treatment, seems to be important: matching treatment to patients' stage of change might provide innovative treatment regimes with better outcomes than are currently available. It seems imperative in any treatment programme that patients feel understood and helped instead of blamed for their illness. It is hoped that an increased understanding of patients' experiences of treatment will give rise to some new research avenues and treatment approaches.

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Appendix 1

Letters granting ethical approval

CAMBRIDGE LOCAL RESEARCH ETHICS COMMITTEE **NHS**

Box 148 Addenbrooke's NHS Trust Hills Road Cambridge CB2 2QQ

Miss Anna M Colton
Sub-department of Clinical Health Psychology
University College London
Gower Street
LONDON
WC1E 6BT

26 April 2001

Dear Miss Colton

How young people with eating disorders view their treatment.

Ethics Reference: LREC 01/085

Documents Reviewed:

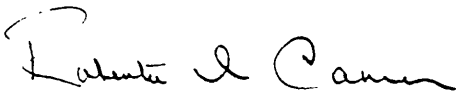
Patient Information Sheet for Subjects
Consent Form for Subjects
Letter to Subjects
Patient Information Sheet for Parents/Guardians
Consent Form for Parents/Guardians
Questionnaire The Atmosphere of the Unit
Questionnaire Satisfaction with the Unit
Protocol
Questionnaire Readiness to Change

Thank you for your letter of 27 March 2001, clarifying the points raised by the Local Research Ethics Committee. This was received by the Committee at its meeting on 20 April 2001, and I am pleased to inform you that this project was approved. This approval is for three years from the date of this letter.

The Committee operates in accordance with ICH Good Clinical Practice Guidelines and have studied and approved, where applicable, the completed Cambridge Local Research Ethics Committee application form and have reviewed the above listed documents.

Furthermore, whilst I am sure that every effort is already made to preserve the confidentiality of any patient information used in this study, could you please ensure that the team of investigators are aware that everyone who has access to patient information appreciates the importance of maintaining the confidentiality, particularly in respect of the use of computers and the statutory regulations laid down in the Data Protection Act 1998.

Yours sincerely



Mrs R L Cannon
Deputy Chairman
Local Research Ethics Committee

East Berkshire Research Ethics Committee

John Lister Postgraduate Medical Centre, Wexham Park Hospital, Slough,
Berkshire SL2 4HL

15th June 2001

Anna Colton
Sub-Dept of Clinical Health Psychology
University College London
Gower Street
London
WC1E 6BT

Dear Ms Colton,

**Re: East Berkshire Research Ethics Committee Application No: 2283
Adolescent patient's views of treatment for eating disorders**

Thank you for sending the amended Patient Information Sheet with the typographical errors corrected that the Committee had requested from the previous month's meeting, your letter dated 23rd May 2001.

The Committee received and approved the paperwork at the meeting held on Thursday 14th June 2001, you now have full ethical approval and may proceed with this project.

The Committee wishes to be kept informed of the progress of this study. When you produce your report, please let me have a copy. I wish you every success, and if you have any queries regarding the above please let me know.

Yours sincerely



Vicki Gedge
Ethics Administrator

Chairman: Dr. A Macaulay
Telephone: (01753) 634670

Administrator: Miss Vicki Gedge
Telephone: (01753) 634364
Fax: (01753) 634189
Email: vicki.gedge@hwph-tr.nhs.uk

Appendix 2

Participant information sheet and consent form

Letter sent to parents

Parent information sheet and consent form

Research Project : How young people with eating disorders view their treatment

INFORMATION SHEET FOR PARTICIPANTS

You are invited to participate in the above research study. This study aims to explore what young people on in-patient eating disorder units find helpful and unhelpful about their treatment and the unit.

What will I have to do?

If you participate in this study you will be asked about your experiences of being a patient on an in-patient, adolescent eating disorder unit. You will have an interview with the researcher, which will last for approximately one hour. Topics that will be covered during the interview will include: what aspects of your treatment you find helpful and unhelpful for your recovery, what it is like for you to be away from your school, family and friends, what it is like being with other people in the same situation and what ideas you might have for improving your treatment. At the end of the interview you will be asked to complete 3 brief questionnaires which asks about: your view of the unit, and its atmosphere, how happy you are with the unit and questions related to whether you want to recover. The questionnaire will take about 20 minutes to complete. The interview will be tape recorded. All interviews and questionnaires will be anonymous – you won't have to give your name, and all information given will be treated confidentially. All audiotapes will be destroyed at the end of the study.

Do I have to participate?

You do not have to take part in this study if either you, or your parents do not want to. If you agree to participate, you can withdraw at any time without having to give a reason. Your treatment is not affected if you do not participate in the study, or if you withdraw from the study.

A copy of the summary report of the project will be sent to each unit and available to everyone who has participated. The results of the study may also be written up for publication in a scientific journal. Written reports about the project will not contain any identifying information about participants.

All proposals for research with people are reviewed by an ethics committee before they can proceed. This proposal was reviewed by Cambridge Ethics Committee.

| |
|---|
| If you would like to contact Anna Colton, the researcher for any reason, she can be reached at: Sub-Department of Clinical Health Psychology, University College London, Gower Street, London, WC1E 6BT. Telephone: 07779-148-761 (Anna Colton) |
|---|

I look forward to hearing from you. Thank you very much for taking the time to read this.

Research Project : How young people with eating disorders view their treatment

Anna Colton BSc
Nancy Pistrang, Ph.D.
Sub-Department of Clinical Health Psychology
University College London
Gower Street
London WC1E 6BT
(020) 7380 7896/7

Consent Form for Participants

Confidential

Circle the right answer

- | | | |
|--|-----|----|
| Have you read the information sheet about this study? | YES | NO |
| Have you had an opportunity to ask questions and discuss this study? | YES | NO |
| Have you received good enough answers to all of your questions? | YES | NO |
| Have you been given enough information about this study? | YES | NO |
| Do you understand that you can withdraw from this study | | |
| * at any time | YES | NO |
| * without giving a reason for withdrawing | YES | NO |
| * without it affecting your treatment | YES | NO |
| Do you agree to take part in this study? | YES | NO |

Signed.....Date.....

Name in Block Letters.....

Researcher.....

Research Project : How young people with eating disorders view their treatment

Anna Colton BSc.
Sub-Department of Clinical Health Psychology
University College London
Gower Street
London WC1E 6BT
07779 148-761

Dear

I am working with X unit. I am currently doing my Doctorate in Clinical Psychology at University College London, and my research is exploring what young people on specialist, adolescent in-patient eating disorder units find helpful and unhelpful about their treatment. Very little research has investigated the views of adolescents with eating disorders. We hope that the current project will help us to better understand factors that aid or hinder recovery from eating disorders, so that better services can be planned and developed for young people.

I am writing to you to ask for your consent for your child to participate in this research (I will also be asking your child for consent). Enclosed are an information sheet which outlines the study and what participation involves, and a consent form. If you are happy for your child to participate, please sign the consent form and return it to me in the stamped addressed envelope. I shall telephone you within the next week to discuss the study and answer any questions that you may have. However, please do not hesitate to contact me if you wish to discuss the research. I can be contacted at the above address and telephone number.

Thank you very much for your time and consideration.

Yours faithfully

Anna Colton

Research Project : How young people with eating disorders view their treatment

INFORMATION SHEET FOR PARENT(S) / LEGAL GUARDIAN(S)

Your child is being invited to participate in the above research study. This study aims to explore what is that young people on specialist in-patient eating disorder units find helpful and unhelpful about their treatment and the unit.

What will my child have to do?

If your child participates in this study she will be asked about her experiences of being a patient on an in-patient, adolescent eating disorder unit. The study will involve an interview with the researcher, which will last for approximately one hour. Topics that will be covered during the interview will include: what aspects of her treatment your child finds helpful and unhelpful in aiding her recovery, what it is like for her to be away from their school, family and friends, what it is like being with other young people in the same situation and what ideas she has for improving her treatment. At the end of the interview your child will be asked to complete 3 brief questionnaires which ask about: her perceptions of the unit, and its atmosphere, how happy she is with the unit and questions related to her motivation to recover from her illness. The questionnaires will take about 20 minutes to complete. The interview will be tape recorded. All interviews and questionnaires will be anonymous and all information given will be treated confidentially. All audiotapes will be destroyed at the end of the study.

Does my child have to participate?

Your child does not have to take part in this study if either you, or they, do not want to. If you and your child agree to participate, she can withdraw at any time without having to give a reason. Your child's treatment is not affected if she does not participate in the study, or if she withdraws from the study.

A copy of the summary report of the project will be sent to each unit and available to everyone who has participated. The results of the study may also be written up for publication in a scientific journal. Written reports about the project will not contain any identifying information about participants.

All proposals for research with people are reviewed by an ethics committee before they can proceed. This proposal was reviewed by Cambridge Ethics Committee.

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| If you would like to contact Anna Colton, the researcher for any reason, she can be reached at: Sub-Department of Clinical Health Psychology, University College London, Gower Street, London, WC1E 6BT. Telephone: 07779-148-761 (Anna Colton) |
|---|

I look forward to hearing from you. Thank you very much for taking the time to read this.

Research Project : How young people with eating disorders view their treatment

Anna Colton BSc
Nancy Pistrang, Ph.D.
Sub-Department of Clinical Health Psychology
University College London
Gower Street
London WC1E 6BT
(020) 7380 7896/7

Consent Form for Parent(s) / Legal Guardian(s)

Confidential

Delete as necessary

- | | | |
|--|-----|----|
| Have you read the information sheet about this study? | YES | NO |
| Have you had an opportunity to ask questions and discuss this study? | YES | NO |
| Have you received satisfactory answers to all of your questions? | YES | NO |
| Have you been given enough information about this study? | YES | NO |
| Do you understand that your child can withdraw from this study | | |
| * at any time | YES | NO |
| * without giving a reason for withdrawing | YES | NO |
| * without it affecting their treatment? | YES | NO |
| Do you agree to your child participating in this study? | YES | NO |

Signed.....Date.....

Name in Block Letters.....

Researcher.....

Appendix 3

Interview Schedule

INTERVIEW SCHEDULE

BEFORE TAPE IS TURNED ON

Introduction about interview & questionnaires

Mention taping

CONFIDENTIALITY

TURN TAPE ON!

Getting to know the patient

- Can you tell me a bit about why you're here?
- What's it like here?
- How long have you been an in-patient here?
- Is it what you expected?
- Can you tell me what a typical day is like?
- Do you get much free time?

Treatment

- What do you find helpful and unhelpful about your treatment here?
- In what ways would you improve it?
- How do you feel about the amount of freedom that you have on the unit?
- What is it like to have decisions about what you eat taken by the doctors and nurses?

Do you think that this is helpful or unhelpful?

Being with others in the same situation

- What is it like being with others in the same position as you?
- Some people say that there is a lot of competition between patients on EDU's.
What do you think about this?
- In what ways do you get support from, or give support to other patients?
- What happens when you disagree with other patients about their or your treatment or behaviour?

Being away from home, school, family, friends

- What's it like being away from home?
- How do you feel about missing school?
- Are your school and teachers supportive of you?
- Do you think that your being in hospital has made any difference to your family and friends?
- Do your family treat you differently now that you are here?
- How do your friends treat you now that you're an in-patient?
Is this different from before you came into hospital / were ill?
- Do you think that being away from home and school is helpful or not?
- Can you sum up what you miss because of being in hospital

Relationships with staff

- Do you have a keyworker, named nurse / staff member to whom you are allocated?
How do you get on with them?
- Are there any other members of staff with whom you get on very well?

What do they do that is different from other people?

- Is your treatment affected by your relationship with staff?

In what ways?

Trust & Responsibility

- How do you feel about the amount of trust that staff give you / have in you?
- If you were in the staffs' shoes, what would you do?
- How do you feel about the amount of responsibility you have for your own recovery / treatment.

Other questions

- We've been talking a lot about food, but I'd like to know about the other things that happen here. (You don't spend all day eating!)
- I assume you have therapy. Can you tell me a bit about it?
What's it like?
What do you get from it?
- What is it like?
- What does it feel like?
- What do you get from it?

The Anorexia

- We've talked a lot about your treatment and what it's like for you being here, but can you tell me what it feels like for you to have AN?
- Can you tell me a bit about it?
- Did you receive any treatment before coming here?
- Can you tell me about it – what it consisted of and what it was like?
what did you find helpful and unhelpful about it?

- *Lots of people say that there are many benefits of having anorexia, and that the illness is a friend to them. What do you think about that?*
- If you had all the resources and money that you wanted, with which you could devise the ideal treatment plan, what would it be?

Closing the Interview

- Thank you very much for participating in the study. How has the interview felt for you?
- Do you have any questions that you want to ask?
- What have you got planned for the rest of the day?

TURN TAPE OFF

Do Questionnaires

Appendix 4

The Questionnaires: The Ward Atmosphere Scale

Stage of, and readiness to, change

CSQ-8 and overall helpfulness

Research Project: How young people with eating disorders view their treatment

The Atmosphere of the Unit

The following statements are about in-patient units. We would like to know which statements you think are true and which you think are not.

If you think that the statement is true, or mostly true of your unit, circle *T* (true). If you think that the statement is false, or mostly false of your unit, then circle *F* (false).

(Circle One)

- | | | |
|--|----------|----------|
| 1. <i>Patients put a lot of energy into what they do around here.</i> | <i>T</i> | <i>F</i> |
| 2. <i>doctors have very little time to encourage patients</i> | <i>T</i> | <i>F</i> |
| 3. <i>Patients tend to hide their feelings from one another</i> | <i>T</i> | <i>F</i> |
| 4. <i>The staff act on patient suggestions</i> | <i>T</i> | <i>F</i> |
| 5. <i>New treatment approaches are often tried on this unit</i> | <i>T</i> | <i>F</i> |
| 6. <i>Patients hardly ever discuss their boyfriends or girlfriends</i> | <i>T</i> | <i>F</i> |
| 7. <i>Patients often grumble or complain</i> | <i>T</i> | <i>F</i> |
| 8. <i>Patients' activities are carefully planned</i> | <i>T</i> | <i>F</i> |
| 9. <i>The patients know when doctors will be on the unit</i> | <i>T</i> | <i>F</i> |
| 10. <i>The staff very rarely punish patients by restricting them</i> | <i>T</i> | <i>F</i> |
| 11. <i>This is a lively unit</i> | <i>T</i> | <i>F</i> |
| 12. <i>The staff know what the patients want</i> | <i>T</i> | <i>F</i> |
| 13. <i>Patients say anything they want to the doctors</i> | <i>T</i> | <i>F</i> |
| 14. <i>Very few patients have any responsibility on the unit</i> | <i>T</i> | <i>F</i> |
| 15. <i>There is very little emphasis on making patients more practical</i> | <i>T</i> | <i>F</i> |
| 16. <i>Patients tell each other about their personal problems</i> | <i>T</i> | <i>F</i> |
| 17. <i>Patients often criticise or joke about the staff</i> | <i>T</i> | <i>F</i> |

- | | | |
|---|----------|----------|
| 18. <i>This is a very well organised unit</i> | <i>T</i> | <i>F</i> |
| 19. <i>Doctors don't explain what treatment is about to patients</i> | <i>T</i> | <i>F</i> |
| 20. <i>Patients may interrupt a doctor when he is talking</i> | <i>T</i> | <i>F</i> |
| 21. <i>The patients are proud of this unit</i> | <i>T</i> | <i>F</i> |
| 22. <i>Staff are interested in following up patients once they leave hospital</i> | <i>T</i> | <i>F</i> |
| 23. <i>It is hard to tell how patients are feeling on this unit</i> | <i>T</i> | <i>F</i> |
| 24. <i>Patients are expected to take leadership on the unit</i> | <i>T</i> | <i>F</i> |
| 25. <i>Patients are encouraged to plan for the future</i> | <i>T</i> | <i>F</i> |
| 26. <i>Personal problems are openly talked about</i> | <i>T</i> | <i>F</i> |
| 27. <i>Patients on this unit rarely argue</i> | <i>T</i> | <i>F</i> |
| 28. <i>The staff make sure that the unit is always neat</i> | <i>T</i> | <i>F</i> |
| 29. <i>If a patient's medicine is changed, a nurse or doctor always explains why</i> | <i>T</i> | <i>F</i> |
| 30. <i>Patients who break the unit rules are punished for it</i> | <i>T</i> | <i>F</i> |
| 31. <i>There is very little group spirit on this unit</i> | <i>T</i> | <i>F</i> |
| 32. <i>Nurses have very little time to encourage patients</i> | <i>T</i> | <i>F</i> |
| 33. <i>Patients are careful about what they say when staff are around</i> | <i>T</i> | <i>F</i> |
| 34. <i>patients here are encouraged to be independent</i> | <i>T</i> | <i>F</i> |
| 35. <i>There is very little emphasis on what patients will be doing after they leave</i> | <i>T</i> | <i>F</i> |
| 36. <i>Patients are expected to share their personal problems with each other</i> | <i>T</i> | <i>F</i> |
| 37. <i>Staff sometimes argue with each other</i> | <i>T</i> | <i>F</i> |
| 38. <i>The unit sometimes gets very messy</i> | <i>T</i> | <i>F</i> |
| 39. <i>Unit rules are clearly understood by patients</i> | <i>T</i> | <i>F</i> |
| 40. <i>If a patient argues with another patient they will get into trouble with the staff</i> | <i>T</i> | <i>F</i> |

Readiness to change

For the following four statements, RESTRICTING will be defined as “attempts to lose weight by self-imposed starvation or through severe dieting”. BINGEING will be defined as “consumption of at least 1,000 calories at one time and fear that the eating was uncontrollable”. PURGING will be defined as “any extreme weight control activity, such as self-induced vomiting, excessive exercise, use of laxatives or diuretics”.

The following **four** statements are about attitudes towards food and eating. We would like to know which statement best describes your current situation. Please circle the **ONE** statement from the four below that best describes your current situation.

1. *I am not thinking about and do not plan to stop restricting/bingeing/purging in the next six months.*
2. *I am thinking about stopping restricting/bingeing/purging in the next six months.*
3. *I intend to stop restricting/bingeing/purging in the next 30 days.*
4. *I have stopped restricting/bingeing/purging, but for fewer than six months.*

The following 8 statements describe some possible attitudes to, or behaviours related to food and eating. Please select the number FOR EACH STATEMENT that best describes your readiness to change each behaviour.

- 1 = I am not at all ready to change
- 2 = I am currently thinking about changing
- 3 = I am taking small steps toward change
- 4 = I am actively trying to change
- 5 = No longer or never was a problem for me

How ready am I to change...?

- | | | | | | |
|--|---|---|---|---|---|
| 1. <i>My preoccupation with food</i> | 1 | 2 | 3 | 4 | 5 |
| 2. <i>Dwelling on the calorie content of foods I eat</i> | 1 | 2 | 3 | 4 | 5 |
| 3. <i>Using food to avoid my feelings</i> | 1 | 2 | 3 | 4 | 5 |
| 4. <i>Trying to be thinner</i> | 1 | 2 | 3 | 4 | 5 |
| 5. <i>Eating / drinking diet foods / drinks</i> | 1 | 2 | 3 | 4 | 5 |
| 6. <i>Letting food control my life</i> | 1 | 2 | 3 | 4 | 5 |
| 7. <i>My dieting</i> | 1 | 2 | 3 | 4 | 5 |
| 8. <i>Trying to keep my stomach empty.</i> | 1 | 2 | 3 | 4 | 5 |

Satisfaction with the unit

Please answer the following questions about your overall satisfaction with your unit

(Circle one number for each question)

1. *To what extent does the unit meet your needs?*

- | | | | |
|-----------------------------|-----------------------------------|-----------------------------|-----------------------------------|
| 1 | 2 | 3 | 4 |
| None of my needs are met | Only a few of my needs are met | Most of my needs are met | Almost all of my needs are met |

2. *Does being on the unit help you to deal more effectively with your problems?*

- | | | | |
|--------------------------------------|-------------------------------|---------------------------|-------------------------------|
| 1 | 2 | 3 | 4 |
| No, it seems to make things worse | No, it really doesn't help | Yes, it helps somewhat | Yes, it helps a great deal |

3. *If a friend were in need of similar treatment, would you recommend the unit to him/her?*

- | | | | |
|--------------------|----------------|----------------|-----------------|
| 1 | 2 | 3 | 4 |
| No, definitely not | No, not really | Yes, generally | Yes, definitely |

4. *In an overall, general sense, how satisfied are you with the unit?*

- | | | | |
|--------------------|---------------------------------------|------------------|----------------|
| 1 | 2 | 3 | 4 |
| Quite dissatisfied | Indifferent or Mildly dissatisfied | Mostly satisfied | Very satisfied |

5. *Please rate how helpful or unhelpful to you the unit is overall.*

- | | | | | | | | | |
|------------------------|---|---|---|-------------------------------------|---|---|---|----------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Extremely unhelpful | | | | Neither helpful nor unhelpful | | | | Extremely helpful |

Thank you very much for taking part in this project.

Appendix 5

Excerpt from an interview transcript

Interview 16

I Can you tell me a bit about why you're here?

P Um, well I sort of, my mum sort of said I had to. [*Mm-hm*] Um well my brother sort of suggested it at first [*Your brother?*] yeah, he's 17 and then my mum and dad like said well we'll keep on trying at home sort of thing, and then I lost quite a bit of weight at a time so then dad thought it was time to do something.

I Mm-hm, mm-hm. And so how kind of did you end up coming here?

P This one? [*Mmm*] Um, 'cause my grandparents live in Buckinghamshire and my parents live in, you know and everyone else lives in North Wales, so [*Right*] we knew someone close [*Right*] so I wasn't totally isolated.

I Right. So you're quite near to your grandparents then, here? (Nods) And what's it like here?

P Um, it's a lot worse than I imagined.

I It's a lot worse?

P Yeah

I What did you imagine?

P Well I sort of just, I didn't really know what to expect. [*Mm-hm*] but I didn't realise we'd have this much like, like not time on our own sort of thing, 'cause we don't have any freedom at all.

I You don't have any freedom?

P No hardly. Well, I've come off levels now but at first it was just horrible. You just don't have any time on your own. And all control is taken away from you [*Gosh*] and that's quite annoying.

I So what's that like for you then, when that happens?

P Um frightening. [*Yeah*] I really hated it. And I'm really close to my parents so I got like really, really homesick. [*uh-huh*] But, and I thought I was getting better last week and things, and things, 'cause at first whenever I'd hear my mum's phone, no whenever I'd

hear my mum's voice on the phone I just used to cry but now I can speak to her, but um on Saturday night, I suddenly completely panicked and went in to like complete panic and then I spoke to my mum on the phone and I started like, I couldn't really breathe, I started like hyperventilating and then um I just got so shocked and I kept on...I didn't want to see myself in the mirror but I kept on going in every 5 minutes and whenever I saw myself I just burst into tears 'cause I felt so big and then um, and then I just like got so worked up that I hung up on my mum and I felt all light headed and I think I passed out, 'cause I hung up on my mum and then she rang back and I didn't hear her and then I rang back about ½ an hour later, my mum said and I thought it was only a few minutes later, [*Gosh*] so it was quite scary.

I *That does sound very frightening.*

P Yeah. It was really horrible. And it's only, it's happened twice since I've been here.

I *How long have you been here?*

P Three weeks today.

I *Right. So it sounds like it's been quite difficult for you being here.*

P I hate it, yeah.

I *You hate it. Mmm. I mean you've mentioned freedom, well a complete lack of freedom [Mmm] and what other things were worse than you expected?*

P The portion sizes. I didn't have a clue they were going to be this much. It was so frightening when I first had a plate of food in front of me [*Mmm, mmm*] and just, we seem to be eating all the time and each meal just creeps up on each other, it was just horrible.

I *Mmm...And are there any other things that?*

P Um, I used to do quite a lot of exercise and all that's been taken away from me. And now I've got to sit still the whole time and it's just really stupid.

I *Really stupid?*

P Yeah 'cause we can't do anything, like...at all. Not even allowed to stand up and it's just like...really weird [*Mmm*].

I *So how does that leave you feeling then, when you can't stand up and you have to eat big portion sizes and //*

P I feel like I'm a complete slob and I feel awful and I've already like, and I just want to lose it all as soon as I can, but then I know if I do I'll just be straight back here again. So I'm really confused about what to do.

I *That sounds, yeah, it sounds very confusing. And when you say confusing, can you...I mean, I suppose I can imagine what you mean but I'm not sure if it is exactly what you mean, so can you*

P Like in, I sort of, sort of like have 2 voices in my head and I call it like a 'He' and [A 'He'?] yeah [Uh-huh] and then, I don't know, it's just like a power and it sort of like says you know 'you can't eat, you're fat, you're ugly' whatever, and then there's another one that says um, 'come on you've got to get better, you know this is not the right thing' and they used to be balanced and now the bad one has just like completely overtaken me and since I've come here I've...got even more frightened of food. 'Cause before I used to eat little so then each meal wasn't too scary because I knew I could either be sick or you know, not eat it, but now, here we have to eat it, so each meal's just so frightening [Mmm] and it's just...and I don't know, I'm just not used to all the food and I'm just constantly bloated and things and it's just really uncomfortable...And even though I've been this weight before, not that long ago, I never felt this big [Mmm, mmm] it's really strange.

I *So something about you know, because you have to eat a lot of meals [Yeah] that are still quite large it doesn't feel so measured or balanced?*

P No not at all.

I *Mm-hm, mm-hm. And when you said it was worse, much worse than you expected, is it, you've mentioned portion sizes and freedom and we'll come back to freedom as well, um and //*

P Being homesick's a big one.

I *Being homesick.*

P Because I've never been away from home before [Right] and I'm quite dependent on my mum which is another thing they're going to try and work on here [Right].

I *So what's that been like then?*

P Really hard 'cause I'm usually with her quite a lot of the time and now, suddenly, I just felt as if like no one cared any more and they just stranded me, but they are saying you know we all love you and everything and they come and see me um whenever they can, like every weekend and just, I don't know, I suddenly feel alone and on my own and there's no one here I can really talk to [*Right*] but I found a girl um, a few, a couple of nights ago, 'cause she, she er, saw me when I just like, just like...after I'd had my panic attack and um she was really nice and I speak to her now, which is quite good.

I *On [older unit]?*

P Yeah, she's on the older one now.

I *The older one? The oldest one?*

P The young adults one

I *Oh right, so there's someone you've found [Yeah] So, that's quite interesting 'cause you're obviously with quite a few other people [Yeah] who are in the same or a similar position to you?*

P My room mate's really, really, really nice and there's a lot of them I really like, but I just didn't want any help and I wanted to do it on my own, but then she sort of like saw me and I sort of, 'cause I also don't like people helping me and I don't like people seeing me upset so I sort of just hide it all and I try to make it look as if I'm not unhappy, I try like and smile the whole time but then like when I get to bed it's just like, I just cry the whole time, so it's very hard.

I *It sounds very hard. Do you share a room?*

P Yeah, but she's asleep so she doesn't hear me.

I *I was gonna say 'cause she must, must hear. (both laugh) So that sounds like it's very difficult for you [Mmm] trying to kind of push away how unhappy it is, how unhappy you are [Yeah] Mmm, mmm. And are you able to manage that?*

P Yeah 'cause if, but sometimes I get so worked up and bottle it up so much that's what my mum said, that that's when I have my...like it works up over a week and then suddenly I like go into complete panic and, and it's only when I'm on the phone to her that I go into

panic 'casue I can't you know, be with her [*Mm-hm*] sort of thing [*Mm-hm*] it's just really hard.

I Mm-hm, mm-hm...And I suppose I'm wondering what it's like for you, 'cause you said you'd been really homesick, but what it's like being away from the rest of your family as well? 'Cause you've mentioned your mum.

P Yeah and my dad I'm pretty close to as well, I get on really well with him. And then my 3 brothers, it's been quite hard not being with them.

I Are they all older?

P No. One's 17, one's 10 and one's 4.

I Oh right, and how old are you?

P 14.

I 14. So you're number 2. [Yeah] So what is it like being away from all of them?

P Um, I'm usually quite close to them, but I always seem to miss my mum and my dad more.

I Mmm...And has it made a difference do you think, to them, with you being here?

P Yeah they said it's been horrible.

I It's been horrible for them as well?

P Yeah. They've found it really hard. But my brother's been really, really, my older brother's been really good with it, about it all and things.

I Sounds like he's been quite supportive?

P Yeah but I don't really want him to be supportive, 'cause I don't want anyone else's help (laughs) I don't like, so that's when the arguments break out.

I Uh-huh. So what...I don't know if you know, but I suppose I'm wondering what it is about getting other people's help that is difficult, or you don't want, or?

P Um, because, 'cause I've had so little control since I've been here and that's like the only thing I can control now is how much help I get, 'cause they can't do anything about that

and, I mean they can tell me to stop exercising or tell me to stop eating, tell me to eat more and things, but they can't tell me to tell them stuff, so I don't.

I Right, and is...it sounds like that's because...you want some control over something [Yeah] would that be right or have I?

P Yeah that's right. [Uh-huh] And I don't know how to tell them that 'cause sometimes I think I really do want to speak to someone, but then I just can't. I can't bring myself to do it, it's really hard.

I So what's that like for you then when you think 'I really need to talk to someone' but...I can't face it?

P Yeah. I don't know. Maybe if I did speak to someone it would be a lot better but I just can't bring myself to do it.

I Mm-hm...And do you know what it is about doing it that, that makes it so difficult?

P Um 'cause I don't really know how they'll react and [Right] and if they think I'm fine they'll let me out faster...but if they know I'm upset and struggling then they won't let me out. [Right] So...

I Something about trying to get out as quickly as you can? [Yeah] Yeah. Um...Do you think it's helpful in any way, being away from your family?

P Well I suppose it is in a way because it teaches me how to cope by myself a bit more instead of being so, relying on them all the time. But apart from that I hate it (laugh).

I Mmm. But it sounds like you think you, think that you maybe ought to or should be able to [Yeah] be on your own a bit more.

P Yeah. [mm-hm] I wish I was like more stronger but I'm just not.

I Mm-hm, mm-hm. And it sounds like something quite important to you?

P Yeah.

I Mm-hm. And does here help with that at all, or?

P Yeah 'cause you just have to cope, sort of. You don't really have a choice. [Right] You're either like...it's, 'cause, it's, 'cause I like take ages over my food, but either you scream and make a complete fit and draw attention to yourself and still eat and get the

same amount of calories or you just get on with it and no one sort of says anything to you and still get the same amount of calories, so whatever you do you have to eat, so even though it's really scary I just don't like to draw attention to myself [*Right*] so I just eat it.

I And what's that like thinking 'well I could scream, but I'm not going to'?

P I don't know. Sometimes I start like shaking 'cause I feel so angry and I just want to let it out somehow but I don't know how to. [*Mmm*] And I get, I sometimes feel overpowered by like feelings but...

I And is there anywhere here that you can take that?

P Take it out on anything?

I Take it out, or kind of go to someone and say 'I'm going to explode'.

P No.

I And do you think that's about you, or do you think there would be someone if you chose to use them?

P There probably would be someone, um, but this girl I spoke to, she's just been so nice [*Right*] so that's quite good I've found someone now.

I And is there something about her being on a different section that's helpful, or?

P No. I don't think so, but she's been here before and she knows that the first thing I want to do is just lose my weight when I get out and she said it's just not worth it and she keeps on telling me all the reasons why it's not worth it and she says at the same time she's telling me she's trying to drum it into herself too, so she's sort of helping herself by speaking and I'm sort of like, like I look at her and think 'Oh my god she's so thin' you know I want to be like her, I'm so big, and she says she feels exactly the same, so dad says, dad said to me 'doesn't that prove that you're not seeing yourself' but it doesn't really 'cause I still see myself as enormous so...

I Mmm. So it sounds like there are lots of conflicting thoughts and feelings going on. (Nods) And is that worse than when you were at home or it

P Yeah. [*it is worse*] I, I feel like I've got worse since I've come here [*Uh-huh*] and I've got even slower and slower eating, it's probably 'cause I'm not used to eating so much,

but um, I just seem to like take ages over my meal, and I couldn't do it any faster, I feel like they sort of push you a bit [*Right*] so...

I Right. And are there any other ways in which you feel you've got worse, apart from the speed of your eating?

P Um well I sort of...um, they always like comment on the way I eat too, 'cause I mash my food and chop it up and things, I just try, I don't know, the longer I take I think, you know there maybe a chance that they'd take it away (laugh) you know they never do but it's worth a try. [*Mm-hm*] So I just, I think my eating habits have got worse, in like chopping it up and things.

I Right. And what's that like for you thinking that where you've come to get better is making you not better?

P Um...I don't know really. It's a bit weird 'cause I thought as soon as I'd come here I'd be better and I'd just go out fine, but it's not like that at all. They said it's quite, it's very common for people to come back on like a second or third admission, but I don't really want to do that but I, I don't want to have anorexia but at the same time I want to be thin and that's really strange.

I Right. So that sounds like a bit of a battle.

P Yeah. And I can't win really like if I eat I feel guilty, if I don't eat I feel guilty 'cause I'm disappointing my family, and people, so I just can't really win, it's like a losing battle.

I Mmm...That sounds very difficult to cope with really. [Yeah] And are there strategies that you use to kind of get through that or?

P No, not really.

I Not really. And what's it like for you being with, I mean we've briefly touched on it, but being with other people who are in a similar position?

P It has it's good points and it has it's bad points 'cause (sigh) I have picked up habits like of the, like we all discuss like how we could hide our food and you know how we can do exercise without them finding us and you know, all those different things and you know I've picked up those different habits, and chopping up my food, I've picked up on that, and eating slower I've picked up on that, but the good points is there's finally someone, people that actually know what I'm going through, who are the same.

I Mmm. It sounds like it might be quite important? [Yeah] What does that give you then, when people are going through the same thing and you know they are?

P Well, it's a bit strange 'cause in a way it's good to think that I'm not on my own, but then again I liked being different and I was different to everyone else and I've, it's something that I achieved and other girls said this, it's something that we've, I've, you know, something that I've achieved and no one else has done it and they said you know, but we just want to get you normal, but I don't want to be normal, and then, but I'm not different here, I'm the same sort of thing as everyone else.

I So you're normal here?

P Yeah

I What's it like then not wanting to be normal, so the way you got not to be normal, is the way that you are now normal here, if that makes sense.

P It's quite hard.

I Yeah...What about it is so difficult?

P Um...I don't really know, but um, another thing that's difficult is that this is something that I've achieved and, and then the one thing I've achieved you know and I have control over has totally been taken away from me now [Mmm] and I just want one thing, to be thin, which has been taken away from me and I'm not allowed it.

I So what's that like?

P I get quite angry and it's just really, really annoying 'cause there's just people interfering, even though I do know it's for the best and they have to 'cause if they didn't then I'd just...well fade away, but I don't really care. I just want to be thin.

I You don't really care that?

P I fade away. But sometimes I think I just want to like escape or just have a shell so like no one else can see me, but you can't really do that here 'cause there's always someone with you.

I And when you say you want to escape and have a shell so that no one else can see you is that just in here, or is that generally?

- P Generally.
- I *Generally. And what would that give you? If you had that, what would that, you know, help you with?*
- P I'd decide what I want to do and when I want to do it, instead of other people interfering, even if they think they're helping, like by saying, 'Oh [names herself] you know, you're looking so much better' they think that's a really compliment, but to me that's like the worst thing they could say, so I wouldn't have people saying stuff like that.
- I *Right. It sounds a bit like what people do to try and be helpful, you find quite unhelpful [Yeah] Mm-hm, mm-hm...I suppose I was wondering, you were saying that you, the one thing that you had achieved was being thin and now that was being taken away from you...*
- P But I still don't believe I'm thin and I'm not there yet.
- I *You're not there?*
- P No.
- I *Would you ever be there?*
- P Yeah....Probably not, but (laughs)
- I *But I suppose I was wondering if, if you were in your parents' shoes, or if you were in the staffs' shoes and you could see you, what, what would you do with you?*
- P Um...
- I *That would be different or not, from what they're doing.*
- P Um, talking to me and telling me that, I don't know 'cause it must be, I know it's really hard for my parents and I always try and make it up to them by doing other things like, I like tidy the house and look after my little brothers and things, I just want to do anything to make it up to them, but I just can't do this and I think that they, my parents are being really helpful by talking to me, 'cause I always feel a lot better and I come out thinking 'o.k. I can do it' but then as soon as I have a meal then I can't do it, but the staff like, even though I don't really want the attention sometimes I think it would be nice to like be able to speak to someone, but they just don't seem to, they only focus on people who they

think are upset which is quite hard and my room mate feels the same 'cause she just hides how she feels too.

I It's interesting you say that because other people have said that as well, that unless you're screaming or crying or //

P They don't really notice you.

I They don't really notice

P But then again it's sometimes, it's a bit hard really 'cause sometimes I think ah I just don't want them to notice me anyway and if they did come I just wouldn't want to speak to them and other times I think I just wish I could speak to someone [Mmm] but I just can't [Mmm] 'cause they always, they only focus on the people who scream or who are just I don't know what.

I Mmm...And what...I suppose I'm wondering if I were here that might, I suppose make me really annoyed [Yeah] or pissed off or just like [Yeah] resentful.

P Yeah, it is quite hard but I suppose the other people who are screaming, they can't just leave them screaming.

I Mmm, mmm. What would you like f or them to do that's different?

P Just talk to me and like um just, even though it's not going to be o.k. just tell me it's o.k. 'cause then that just makes you feel better.

I Mmm. So maybe then to take notice of you even if you're not visibly distressed? [Yeah] And I'm wondering, when you're talking about people talking to you and coming and talking to you, I suppose I'm a little bit muddled because you've said that a lot of the time you don't want to talk to someone

P No I don't and I don't really want them to come to talk to me, I, I only want them when like I need them but they don't really know when they should come. I hardly, hardly ever want to speak to them but like just like the occasional time that I do and I'm just annoyed that they're not there. [Mmm] Most of the time I don't want them anyway, but it would just be nice to speak to them like sometimes.

I And how would they be able to tell, if you could have your ideal, kind of you know, that they would just know?

- P They couldn't really.
- I *They couldn't just know. [No] Mm-hm. That's quite difficult then for you*
- P Mmm. 'Cause sometimes when I'm on like the edge of crying I just pretend that I'm fine and like smile and things even though inside I feel really awful [Mmm] but I can't, I find it really hard to, like some days I can scream and kick and things, but I find it really hard to be horrible to these kind of people. I can only take it out on my parents even though I love them so much more [Mmm] I can't really seem to be able to take it out on other people like in school I never used to answer back and things I'd just take it out on my parents which is really hard for them but I just can't help it.
- I *And how does it make you feel thinking 'well I love my parents more but they're the only people I can be cross with'? Or show to that I'm //*
- P I feel, like after I've shouted at them I just feel awful and I feel really like 'why did I do that' and it's just awful, but they seem to understand each time, and they're sometimes quite glad when I do it 'cause they know that I'm letting out my anger and like that...I'm like 'I'm so sorry, I can't believe that happened' 'cause when I do should at them I feel like it's not me shouting at them it's something else and I just can't stop. [Mmm] Like another power, like it's all like 2 parts of me fighting against each other and the bad one seems to do all the bad stuff and it's just...I know it's probably something else to blame, but he just like takes over.
- I *Gosh and, and what does that feel like, having a whole part of you that you think just takes over, He just takes over?*
- P It's really scary 'cause I feel like I have no control [Mmm] like I was just, like when I had my panic attack on Saturday I was just walking round the room just like, kind of like rocking and things and I suddenly went all hot and then all cold and I had no control over what I was doing and it was just like, I don't know I was just so frightened and it was really scary [Mmm] I don't know if I should tell someone though or not, 'cause my mum was really worried that I hadn't told anyone, so she said why don't you go and speak to that other girl 'cause I said that she'd smiled at me before so I went in there and I said 'I know you don't know me' and it was like the hardest thing I've done [Mmm] so far and I was like 'I know you don't know me, but can I just talk to you' and she was just so nice and I couldn't believe it, it was really nice to speak to her.
- I *Mmm. So that sounds like you did something really brave.*

- P Yeah
- I *And what did it, I mean what kind of difference did it make? What did it make you feel having actually managed to do that and kind of plucked up all the courage?*
- P I was quite pleased to do it and then I came out feeling so much better and I thought o.k. I can do it, and I'm not alone, other people feel the same. And then again the next day, the next meal I just go back to me, to not wanting to get better. [Mmm] I'm fine when I'm not having meals, but it's just as soon as any food comes in front of me it's just horrible (laughs) [Mmm] I just hate it [Mmm] I wish I could just take a pill and then that would just
- I *A pill for all your calories? [Yeah (laughs)] Do you think that would make you feel better?*
- P Yeah then I wouldn't have to feel like I was eating...but I'm determined not to go on Jevity and I haven't tried it and I'm not going to.
- I *NG feed? [Yeah] is that, or supplement?*
- P That's in a drink.
- I *It's in a drink? [Yeah] It's not what goes through the tube?*
- P No and I don't want to do that either, 'cause then again it just draws attention to me.
- I *Mmm. It sounds like it's, something you don't really like is having attention drawn to you. [No] Mm-hm, mm-hm...And what's it like for you being away from your friends? 'Cause you know you said from your family it's horrible.*
- P Yeah, they've all been like so supportive and things but I don't know, I miss them so much and they've all just been so nice and they've written to me loads but...I'd rather be thin, I don't know, and not have them. I don't know really I do miss them loads but I've got more things to worry about, which sounds awful but there's a couple of friends that I really, really miss, like my best friend and things.
- I *When you say you'd rather be thin than have your friends, it sounds like you see it as maybe a choice between the two, you can't have both? [Yeah] Can you say a bit more about that?*

P Well, 'cause I just don't have the energy, well I do now, but I couldn't have, I just, when I was like at home I just didn't have the energy to see them and things and I was, so I just chose not to see them and then I got some more dependent on my mum and she wanted me to go out but then she didn't want me to go out because she knew that I wouldn't cope and things, so I ended up not seeing them very much in the end...which was quite hard but I didn't really mind.

I *And did they...I mean you said it was quite hard not seeing them and you didn't see them as much as maybe you'd wanted to [Mmm] but then you didn't have the energy to see them*

P And when I did see them all I wanted to do, all I thought about was going home.

I *So that sounds like another kind of conflict there?*

P Yeah. It was just like I just want to be a child the whole time but then another part of me just wants to grow up and think 'I don't need my mum, why am I doing this?'

I *Mmm...And what's that like, thinking those 2 different sides again?*

P It's sort of again the anorexia and the me, it's just

I *Is that how you see it, as being the anorexia and the you? [Yeah] As being different, or?*

P I don't know. Yeah I do see it different, but sometimes I think it's sort of my friend and if I didn't have it I'd just be totally on my own [Mmm] and other times I think...I think you know that's when I really want it and the way I have it is by not eating, but then um, if I um don't have it, there are good points about that as well but I'm a bit afraid of what will happen if I don't have it, so I'm a bit scared of um...trying it out.

I *Mmm. What, what might happen?*

P I don't know.

I *That kind of unknown [Yeah] fear. Mmm. It is a very difficult battle to fight isn't it.*

P It is, it's so weird.

I *Mmm. And you were saying that your friends have been really supportive. How, I was just wondering how they showing their support?*

P By writing me letters and things. *[Right]* But they have been supportive but none of them'll really know what it's like for me. I think at first they, some of them thought I just wanted lots of attention but now they've realised that it's not at all. Which is quite good.

I *What did it feel like then when they thought it was just attention?*

P I thought 'they can think what they want'.

I *Right, right. And were they, I mean do they treat you differently now that you're here, from the way that they treated you before?*

P Um, no they, none of them were really that surprised when I said I was coming here, but um everyone said 'oh I'm so glad, finally something's happening' sort of thing. They were sort of relieved in a way, even though I wasn't, they were.

I *So they, they kind of had your relief for you, in a way? [Yeah] Was there no bit of you that was relieved?*

P Yeah I suppose I was 'finally something's happening and I have got a chance of getting better' but since I've come in here that positive has just gone smaller and smaller.

I *Do you know what that's about, the positive having gone smaller and smaller?*

P I don't know really, but they, they said to me, like my parents and the counsellor back home said it will get worse before it gets better and I suppose this is just the getting worse. *[Mmm]* But I don't really want to get better. I just don't want to put on weight I just want to lose again.

I *So that must be really difficult for you to think like that.*

P I know. It's just really hard.

I *Is that something that the people, the other girls, share with you?*

P Yeah. They all feel pretty much the same. There's a few of them who say, like who are at their target weights say, um, it, you know of course I want to be thin and everything, but I know that if I do then I'll be back here and that's the last thing I want. I'm absolutely fed up and I just want to go back home and they sort of balance them out and realise that it's not worth it. But I just haven't got there yet. I can't really see myself getting there.

I *You can't? [No] Mm-hm. What would help you maybe to get there, do you think?*

P Um...I don't know really...um...I suppose if I wrote a list of all the good things and all the bad things I know, but mum always says I need to do that, but I never ever want to do that because I know that the good things about being anorexic are a lot smaller than the bad things, but even though there's um so many, the list goes on and on about the bad things of being anorexic and there's only a couple about the good things of being anorexic, those good things seem to completely overpower the, even like there's one good thing, there's one bad, there's one good thing about being anorexic is you know being thin and having control, is so much, like is only one of them and there's about a million bad points, but this one seems to be able to overtake all the good points [*Mmm*] all the bad points, I mean (laugh).

I What's that like though for you to have to realise that, or for you to realise that?

P Um...

I For you to know that, but still...

P It makes, because I'm with this one it means I have power sort of thing.

I You have power.

P Well not power, obviously you know not power, but I have control if I have this one. [*Right*] and these ones don't really have any control.

I And I wonder what I suppose being here then does for that?

P Um. I don't know. It doesn't really seem to help being here, I just seem to get worse.

I Get worse. Is that, you said eating habits and [Yeah] the

P And my thoughts really.

I Your thoughts?

P Like before I did want to get better and there was a part of me that really, really did want to get better and the last thing I wanted to do, well not the last thing, but I just didn't want to be anorexic any longer, but now the only thing I want to be is anorexic and lose my weight, which is a bit bad really, but...